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LOSING YOURSELF TO AIDS:
THE MEANING OF EUTHANASIA AND ASSISTED SUICIDE

by

James Vincent Lavery, B.A.(Hon), B.Sc., M.Sc.

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Institute of Medical Science/Joint Centre for Bioethics/
Collaborative Program in Bioethics
University of Toronto

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ABSTRACT

A qualitative research study was conducted with 32 people with HIV/AIDS in order to develop a theory of decision making regarding euthanasia and assisted suicide. The participants were enrollees of the HIV Ontario Observational Database (HOOD) and were contacted using a novel anonymous recruitment technique. The participants were interviewed and the audio-tapes of the interviews were transcribed and analysed using grounded theory methods in order to determine the process of decision making, factors that affect people’s decisions, and the meaning of the experience of deliberating about euthanasia and assisted suicide. The resulting theory describes a process of deliberation that involves the origin of consideration about euthanasia and assisted suicide, reflection on these options, either alone or with others, formation of specific goals and the
development of plans and strategies designed to realize the goals. The main factors that influence these deliberations are the individual's disintegration and loss of community. These factors give rise to a perceived loss of self, which in turn gives rise to existential suffering. Euthanasia and assisted suicide can be understood as means of limiting the loss of self. These findings suggest that decisions regarding euthanasia and assisted suicide are primarily metaphysical in nature, as opposed to ethical. The findings also challenge the appropriateness of the prevailing medical conception of euthanasia and assisted suicide that is apparent in existing policies and legislation.
Acknowledgements

This thesis has demanded a great deal from many people. Foremost among them is my wife Susan. She has endured enormous frustration and personal sacrifice through the course of my graduate studies. But the seemingly interminable demands of the last three and a half years in particular have precluded many opportunities for her that might otherwise have greatly enriched her life. Through it all she has been an extraordinary mother and an unquenchable source of life for our daughters, Blair and Olivia, who have blossomed as a result. Susan has also been a constant source of comfort and stability for me through a very challenging period. I owe her far more than any Ph.D. could ever provide.

This thesis could not have been written without the participants whose stories provided its substance. These thirty-one men and one woman moved me profoundly by sharing with me their most intimate and often difficult experiences in frank, gracious, and—for some—courageous accounts. If the thesis makes any worthwhile contribution to the contentious social debate regarding euthanasia and assisted suicide, it does so by way of their voices.

Peter Singer supervised this thesis, but his contribution and impact on my life have been much deeper than refining my skills as an investigator and ensuring the successful completion of this project. In every conceivable way he has been a true mentor to me, challenging and ultimately elevating my abilities far beyond what I had ever imagined was possible. He is simply the best teacher I have ever encountered, and am ever likely to encounter, and there is no way to express my profound gratitude for what he has done for me.

My mother, Winnie Lavery and my father James Lavery—who would have been very proud, had he been spared to see the occasion—created all the opportunities that have culminated in this Ph.D. Without their years of selfless work and support my life would likely have taken a very different course. They have taught me more about ethics and virtue than any University ever could. I am eternally grateful to both of them.
I have been spoiled by the extraordinary quality of the guidance I have received in preparing this thesis. My thesis committee members, Professors Bernard Dickens, Heather Maclean and Joe Boyle consistently provided insightful and incisive criticism and commentary on my work in a manner that was always deeply respectful and supportive of my own thinking and development.

I am also indebted to University of Toronto Professors Bill Harvey, Brent Kilbourne, and David Novack for their careful and thoughtful examination of my thesis. Their comments challenged me to think critically about some key aspects of the thesis—a task that has not ended with the final printing—and ultimately made the thesis richer and stronger. Professors Harvey and Kilbourne in particular helped to ensure that my oral exams were positive, constructive, experiences. As well, Dr. Robert Pearlman of the University of Washington provided a detailed review of the thesis as the External Examiner. His painstaking criticism and commentary revealed many subtle flaws in the thesis and have also been an enormous help in preparing the work for publication.

The sampling framework for the study was the HIV Ontario Observational Database (HOOD). The HOOD project has a special significance for me since I was involved from the early stages in its conceptualization and development. This thesis would not have been feasible without the HOOD database, and my involvement in the study would never have been feasible without Greg Robinson, Peggy Millson and Kira Leeb. Their unwavering support and friendship sustained me through many difficult times at HOOD and provided me the freedom I needed to complete the study. As well, James Austin, Siamak Tenzif and Nelson Maheux and the Board members of the Community Research Initiative of Toronto demonstrated enormous patience and support for my study during my brief tenure as Executive Director.

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that the study was completed successfully.

I have been extremely fortunate to have spent my entire career as a graduate student at the University of Toronto in the Institute of Medical Science (IMS) and the Joint Centre for Bioethics (JCB). At the IMS Dr. Cathy Whiteside demonstrated great confidence in me and allowed me a great deal of freedom in pursuing my Ph.D. studies and research. She was also instrumental in securing my Connaught Scholarship—the first real award I had ever won, and a great morale-booster. I am grateful for all her efforts and support over the years.

The JCB has been my real academic home since beginning my graduate studies. I cannot imagine what the experience would have been like without Rhonda Martin’s calm and patient assistance at every turn, or Margot Smith’s divine wit, or Bill Harvey’s irrepressible enthusiasm, or Peter Singer’s mind-boggling energy and clarity of thought. As well, Doug Martin, Kathy Carlin and Debbie Zinman sustained me through the years and provided me with invaluable insights, references, criticisms, arguments and humour, as did many other graduate students throughout the years.

I am grateful to the Social Sciences and Humanities Research Council for the Doctoral Fellowship that supported my Ph.D. research, and to the Canadian Foundation for AIDS Research for funding the study.

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Working Group on Euthanasia and Assisted. They taught me a great deal about the “real world” within which this thesis is situated and improved the thesis by doing so.
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CHAPTER 1

Introduction

This thesis is an example of empirical research in bioethics. It attempts to elucidate the reasons why people with HIV/AIDS decide to seek assistance in dying in the form of euthanasia or assisted suicide. Although the main objective of the thesis is to contribute to the existing knowledge of the phenomena in question, it also attempts to reflect the interdisciplinary nature of bioethics by identifying areas in which the original research findings may make a contribution in some related disciplines, e.g. law, policy and moral philosophy. As well, the findings of the thesis raise questions about concepts such as “community”, “self”, and “suffering” in relation to euthanasia and assisted suicide. These concepts have been widely explored in philosophy, psychology and sociology and the relationships between the findings and the existing accounts of these concepts have not been well developed in the thesis.

Purpose of the Study

The purpose of the original study is to develop a grounded theory of decision-making by people with HIV/AIDS regarding personal decisions for or against euthanasia or assisted suicide. The development of theory will focus on three main aspects of these phenomena: (i) the process of decision making, (ii) factors affecting the decision, and (iii) the meaning of these experiences for participants.

These procedural and substantive aspects of decision making will be explored by eliciting the personal views and experiences of people with HIV/AIDS from the following groups: (i) people who have participated in planning and/or carrying out acts of euthanasia and/or assisted suicide of others; (ii) people who have made a personal decision in favour of
euthanasia or assisted suicide for themselves; (iii) people who have made a personal decision against euthanasia or assisted suicide for themselves; and (iv) people who are undecided about euthanasia and assisted suicide for themselves. This sample should ensure that the responses used to generate theory will include a range of perspectives that adequately reflects the spectrum of views that exist in the HIV/AIDS community.

The focus on HIV/AIDS was chosen for this study since it is suspected that euthanasia and assisted suicide are widely practised within the HIV/AIDS community and therefore that it would be possible to find individuals who have actively considered euthanasia or assisted suicide as options for themselves. Furthermore, several practical mechanisms existed that greatly enhanced the feasibility of this study within the context of HIV/AIDS.

**Overview**

In general, the reasons why people decide to have euthanasia or assisted suicide are currently not well understood. This gap in knowledge makes it difficult to: (i) determine the most acceptable forms of care and/or intervention for those individuals who currently wish to have assistance in dying; (ii) assess the validity of key assumptions underlying the philosophic debate regarding the ethical acceptability of euthanasia and assisted suicide (for example, that people choose euthanasia or assisted suicide to escape uncontrollable pain and suffering); and (iii) ensure that public policy is grounded in, or at least reflective of, the values and experiences of people facing these extraordinarily difficult decisions.

The original empirical research in this thesis serves not only to enhance our knowledge of euthanasia and assisted suicide as social phenomena, but by doing so, also provides substance to the often abstract debate about the ethics of euthanasia and assisted suicide. Although the findings of this thesis do not reveal the definitive “truth” regarding the ethics of euthanasia and assisted suicide, it is reasonable to suggest that they will make a useful contribution to focussing the nature and direction of the philosophic debate on those issues and experiences.
that have the greatest significance and meaning to people actually considering these options.

This study aims to move beyond descriptions and discussions of isolated concepts by developing a theory of decision making in euthanasia and assisted suicide in HIV/AIDS that is conceptually rich and grounded in the experiences of people with HIV/AIDS. The theory reflects my account of the process of decision making, factors that affect the process, the meaning of these experiences for participants, and how they converge to shape the desire for euthanasia or assisted suicide. This approach will provide explanations of the roles and meanings of the relevant concepts, from the perspective of participants, in addition to identifying them as factors in the process. This information will be valuable in determining whether proposed legislative reform in areas such as palliative care, pain control and sedation, withholding and withdrawing life-sustaining treatment, and advance directives are likely to be adequate as alternatives to euthanasia and assisted suicide. It will also be useful for preliminary assessments of guidelines or other policy initiatives proposed in the area.

At the time that this thesis was being conceptualized (1993-4) it was still reasonable to view HIV/AIDS as a “terminal” illness, one that would invariably confront patients with the prospect of a difficult death. Ironically, during the course of development of the thesis study and the preparation of the thesis itself, the characterization of HIV/AIDS as an invariably “terminal” illness has become outdated. The advent of new drug combinations has dramatically reduced mortality rates from HIV-related disease(1) and there is reason to believe that further treatment advances may be forthcoming. These are excellent and timely advances in the lives of many people living with HIV/AIDS. Nonetheless, the prospect of a difficult death has not been completely disassociated from the experience of living with HIV/AIDS, as many of the study participants have eloquently demonstrated.

The recent developments in drug therapy may have made euthanasia and assisted suicide more remote issues for many people with HIV/AIDS than they might have been several years ago. The main implication of this development for this study relates to how these
developments may have affected the urgency and durability of people’s “decisions” to have euthanasia or assisted suicide. More specifically, it calls into questions whether reported “decisions” truly indicate a durable intention to have euthanasia or assisted suicide, or whether they simply reveal a predilection. In fact, the findings presented below help to establish a bridge between these two related positions, i.e. they help to elucidate and explain the process by which people with HIV/AIDS may move from a predilection for euthanasia and assisted suicide to the actions themselves. In this respect, the findings do further our understanding of “decision-making”, despite the fact that they do not capture people in the acts of exercising these decisions. It is also conceivable that the findings may have some applicability to other “chronic” debilitating illnesses, though this is not explicitly addressed in this thesis.

Definitions

There are 6 key terms that require definition for the purpose of this thesis: “desire to die”; “terminally ill”; “euthanasia”; “assisted suicide”; “forgoing life sustaining treatment”; and “end of life care”. The definitions used throughout the thesis are identical to, or consistent with, the definitions in the Senate Committee Report of 1995.(2)

“Desire to Die”: is a strong and durable wish for death most often demonstrated in the expressed preference or explicit request for acts and/or omissions that are known to result in death.

“Terminally Ill”: recent research confirms that it is extremely difficult prospectively to reliably identify patients as “terminally ill”, i.e. which patients will die within 6 months(3,4). The term is used in this discussion as a short-hand way of referring to those patients who have life threatening conditions and/or who have been given a specific ‘terminal’ diagnosis. The term is often misleading. For example, many AIDS patients are currently responding very well to new drug therapies and, as a result, the once uncompromisingly “terminal” nature of
AIDS is now less certain.

"Forgoing Life-Sustaining Treatment": not starting or stopping treatment that has the potential to sustain the life of a patient.

"Euthanasia": is a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person's suffering where the act is the cause of death. Euthanasia may be "voluntary", "involuntary" or "non-voluntary", depending on the competence of the recipient, whether or not the act is consistent with his/her wishes (if known), and whether or not the recipient is aware that euthanasia is to be performed on her/him.

"Assisted Suicide": is the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both. In 'physician-assisted suicide', a physician provides the assistance.

"End of Life Care": is any kind of care provided to terminally ill patients.

Organization of the Thesis

The thesis is divided into 10 main chapters. This first chapter provides an overview of the thesis. Chapter 2 provides a review of the literature regarding empirical research in euthanasia and assisted suicide. This Chapter begins to examine and highlight areas in which empirical research has provided critical fuel to the debate and explores some of the shortcomings in the empirical research to date. In doing so, it provides an account of some of the specific questions about euthanasia and assisted suicide that remain unanswered and raises questions about the validity of some of the assumptions described later in Chapter 4. As well, Chapter 2 provides an overview of some of the relevant aspects of living with HIV/AIDS as an individual, and at a broader, societal level, that shape the context within which people with
HIV/AIDS consider and make decisions to seek assistance in dying. Chapter 2 is adapted from a paper that we published in 1997 in the Canadian Medical Association Journal on Euthanasia and Assisted Suicide for clinicians(5).

Chapter 3 is a review of the literature on the desire to die in terminal illness. Although most of the findings relate to patients with conditions other than HIV/AIDS, the concepts and ideas that emerge from the evidence provide an excellent initial framework for the consideration of the stories and experiences of the study participants. Many of the ideas and concepts found in Chapters 2 and 3 are echoed in the participants' accounts in the study findings in Chapters 7, 8 and 9. Chapters 2 and 3 also serve to highlight some of the gaps in knowledge in end of life care and illustrate the inadequacy of many of the processes in place to care for terminally ill patients. Many of these issues are also echoed in Chapters 7, 8 and 9. Chapter 3 is adapted from a Synthesis of Evidence that I did under contract with Health Canada in conjunction with Dr. Sam Shortt, Director of Queen’s Health Policy Research Unit.

Chapter 4 provides an overview of the debate over the ethical acceptability of euthanasia and assisted suicide, highlighting some key aspects of the philosophic, legal and policy literature. Some of its content is also drawn from our euthanasia paper described above(5), and from an editorial on the U.S. Supreme Court decisions in 1997(6). The aim is to provide readers with a balanced account of the intellectual context within which the thesis study is situated. This Chapter also highlights some of the common assumptions that shape conventional thinking about the ethical acceptability of euthanasia and assisted suicide.

Chapters 5 through 9 comprise the original research portion of the thesis. Chapter 5 describes the purpose of the research and the methods employed. Chapter 6 provides a detailed account of the ethical and legal issues that had to be addressed in conducting this study and the process by which the research ethics review was conducted. This chapter outlines a model for research involving euthanasia and assisted suicide (which are currently illegal activities in
Canada) that allows for rich detailed personal accounts of those facing these decisions, while maintaining anonymity and respecting their privacy. Chapter 7 is the first of three chapters that present the results of the study. It begins with a description of the characteristics of the participants and then provides a detailed description of the process by which people with HIV/AIDS make decisions regarding euthanasia or assisted suicide. Chapter 8 provides a focussed account of the main factors that influence people in their process of deliberations about euthanasia and assisted suicide. And Chapter 9 describes the core idea emerging from the study, namely, that euthanasia and assisted suicide represent means by which people with HIV/AIDS limit the existential suffering that accompanies their progressive disintegration and loss of self.

Finally, Chapter 10 provides a discussion of the study findings with respect to the question that the study aimed to address, i.e. how do people with HIV/AIDS make decisions to have euthanasia or assisted suicide. This Chapter attempts to tie the results of the study to some of the key questions and assumptions facing policy makers in Canada and in countless other jurisdictions worldwide. The main limitations of the study are also reported in Chapter 10.
CHAPTER 2

Empirical Studies of Euthanasia and Assisted Suicide

Overview

In 1995, in a commentary article in the Journal of Clinical Ethics, Ezekiel Emanuel described the state of the empirical evidence regarding euthanasia and assisted suicide at the time(7). Emanuel’s description suggests a body of evidence that is remarkably one-dimensional, reflecting, predominantly, public and professional attitudes and opinions toward the acceptability of euthanasia and assisted suicide, and—with few exceptions—virtually ignoring the perspective of people who are actually considering, deciding about, and carrying out euthanasia and assisted suicide.

In Chapter 6, I suggest that this gap in knowledge reflects the fact that research on euthanasia and assisted suicide is fraught with legal and ethical problems that have discouraged many researchers from working in this area. As well, the questions that are most in need of attention, such as why people decide to have euthanasia or assisted suicide, require research methods (e.g. qualitative methods) that may exacerbate the existing legal and ethical problems in that they require closer contact with participants and richer accounts of their experiences than the more common quantitative methods. In other words, they make it more difficult for researchers to protect themselves from the consequences of having special knowledge of identifiable individuals’ involvement in criminal activities. Chapter 6 offers a modest remedy for this complex problem.

Since Emanuel’s paper in 1995 there have been several important new studies that have furthered our understanding of euthanasia and assisted suicide. But a recent review of the empirical literature by Quill(8) illustrates convincingly that the perspective and experiences of
the people most closely affected by euthanasia and assisted suicide, i.e. those who desire and seek them, have not found a significant place in our conceptualization of these phenomena. Quill’s review of the empirical data is instructive for understanding the objectives and importance of the study described in Chapters 5-9.

In an attempt to highlight areas where there are convergent views regarding euthanasia on both sides of the social debate, Quill presents a taxonomy of findings that does not include the experiences of individuals considering euthanasia or assisted suicide, and only mentions in passing the factors that may motivate them in these pursuits. He then re-visits a list of the same assumptions that have guided the debate for years (these are outlined in detail in Chapter 4). The fact that many of these assumptions are now well supported in evidence (others have not been so well supported) does not, in itself, further our knowledge or understanding of these phenomena. The question “why do people decide to have euthanasia or assisted suicide” is still valid and important, despite the detailed improvements in knowledge within the specific areas of the prevailing framework of understanding.

This conceptual entrenchment is the point of departure for the original research that follows. In particular, it is the lack of synthesis among the various components of the empirical literature that appears to be most badly lacking. Aside from the literature on suicide and parasuicide(9), which is instructive, but which is likely to also be limited in its ability to explain euthanasia and assisted suicide, particularly in terminal illness or in the context of life-threatening disease states like HIV/AIDS, we cannot even adjudicate between competing theories or explanatory accounts of why euthanasia and assisted suicide happen; these theories do not exist. As a result, policy discussions and empirical studies of euthanasia and assisted suicide are conducted in a theoretical vacuum.

In Chapters 7-9, I propose a more robust framework for understanding euthanasia and assisted suicide that incorporates the experiences of people with HIV/AIDS who are deliberating about euthanasia and assisted suicide as options for themselves. The framework
includes a number of factors, such as the role of community and the process of disintegration that are not thoroughly explicated in the existing literature.

Rather than duplicate other existing reviews of the empirical literature, I will use this chapter to describe some of the main strengths and weaknesses of the existing empirical literature. The chapter examines several of the key areas of investigation related to euthanasia and assisted suicide, including their prevalence within the HIV/AIDS community, and concludes with an account of the main gaps in knowledge.

**Surveys of Physicians’ Attitudes and Practices**

Because euthanasia and assisted suicide are prohibited in most jurisdictions, the research designs and techniques usually employed by observational epidemiologists are generally not applicable for these phenomena. As a result, estimates of the incidence of euthanasia and assisted suicide must be obtained indirectly. The most common approach to obtaining these data has been through survey questionnaires that document requests to physicians and their willingness to accede to these requests.

In Canada, a recent survey by Kinsella and Verhoef has indicated that 24% of Canadian physicians would be willing to practice euthanasia and 23% assisted suicide if they were legalized(10). These are the only national data available for Canada. However, there have been other studies that provide insights into attitudes and practices in individual provinces.

In Manitoba, for example, a study performed for the Manitoba Association for Rights and Liberties found that 16% of Manitoba physicians had been asked by a patient to “shorten her or his life through assisted suicide or euthanasia”, and that 14% of the same sample “ha[d] facilitated a patient’s request to shorten her or his life, by way of assisted suicide or euthanasia.”(11).
A follow-up survey of physicians in Alberta in 1994 (12) illustrated a decrease in support since the initial survey of attitudes in 1991 (13, 14). Only 15% of responding physicians in 1994 reported that they would practice active euthanasia if it were legalized, down from 29% in 1991. And although 50% of respondents in the 1991 survey had indicated that they would practice active euthanasia if it were legalized, this proportion dropped to 37% in the 1994 survey. A more recent survey of Alberta physicians found that 60% to 80% opposed the legalization of euthanasia and assisted suicide, a number similar to the 1994 survey by Kinsella and Verhoef (15).

A recent survey of 3,102 physicians from 10 medical specialties across the United States indicated that 18.3% of respondents had received a request from a patient for assistance with suicide and 11.1% had received a request for a lethal injection. Sixteen percent of physicians who had received a request for a lethal prescription (or 3.3% of the entire sample) reported that they had written a prescription for a lethal dose of medication (median 2 prescriptions, range 1-25). All respondents were asked if they had ever given a patient a lethal injection and 4.7% reported that they had (median 2, range 1-150) (16).

Surveys of physicians in individual U.S. states have demonstrated varying rates of participation in euthanasia and assisted suicide (17). Ironically, a survey of Oregon physicians conducted prior to the enactment of that state’s Death With Dignity Act indicates that 21% of physicians have received requests for assisted suicide and only 7% have complied (18), a proportion that is lower than most other reported rates of participation. In Michigan, where Dr. Jack Kevorkian has successfully evaded conviction for his participation in more than 100 highly publicized assisted suicides, 56% of physicians support the legalization of assisted suicide, while 37% prefer an explicit ban (there is currently no explicit statute addressing assisted suicide in the state of Michigan) (19). The willingness to perform euthanasia appears to be affected by individual patient characteristics and by physician specialty and religion (20).

Some data suggest higher rates of requests among U.S. oncologists. One study documented
that 57.2% of New England oncologists had received a request for either euthanasia or assisted suicide and that 13.5% of respondents had assisted a suicide and 1.8% had performed euthanasia(21). Another study of oncologists in Michigan indicates that approximately 40% had received a request for either euthanasia or assisted suicide and that 18% had assisted a suicide and 4% had performed euthanasia(22).

In Britain, a survey of 273 National Health Service physicians conducted in 1992-3 revealed that 124 (45%) had been asked by patients for active euthanasia. Of the 124 who had been asked for euthanasia 119 responded to the question of whether or not they had ever acceded to a patient’s request. Of these, 38 (32%) had performed euthanasia(23).

Although Australia’s Northern Territory was the first jurisdiction to enact legislation to legalize assisted suicide, only four patients died under its provisions before the law was repealed by an act of the Australian Parliament. As a result, the Northern Territory experience has to date contributed very little to our knowledge of the epidemiology of assisted suicide.

In an Australian survey, almost half of the responding physicians in New South Wales had been asked by patients to perform euthanasia. Of these, 28% had complied. Only 7% of physicians who had been asked to assist in suicide had complied(24). A more recent survey designed to allow comparison with data from the Netherlands revealed that 1.8% of all Australian deaths in 1995 involved voluntary euthanasia, 3.5% of all deaths involved non-voluntary euthanasia (i.e. administering a lethal dose of drug without the patient’s request), 24.7% of all deaths involved a decision to forgo life-sustaining treatment, where the decision involved the explicit intention to hasten the patient’s death, 24.4% involved a decision to alleviate pain with large doses of opioids, in the knowledge or belief that this would probably or certainly hasten the patient’s death, but did not involve the explicit intention to cause the patient’s death, while an additional 6.5% did have this explicit intention(25). The Australian data provide an interesting comparison with the available data from the Netherlands, where
the liberal public policy on euthanasia and assisted suicide has allowed for some comprehensive epidemiological research.

Two main studies have provided a perspective on the Dutch experience, first in 1990, and then again in 1995-96(26,27). The overall incidence of voluntary euthanasia rose from 1.9% in 1990 to 2.6% from 1990-1995, while the incidence of non-voluntary euthanasia dropped from 0.8% to 0.7%. Reports of forgoing treatment rose from 17.9% to 20.2% of all deaths, and the use of life-shortening doses of opioids increased from 18.8% to 19.1%. A 1996 study of physicians' compliance with notification procedures for euthanasia and assisted suicide in the Netherlands demonstrated that about 41% of all cases of euthanasia and physician-assisted suicide were reported(28).

There has been a long-standing debate about the meaning and significance of the Dutch data. The substance of the debate was summarized in an editorial in the New England Journal of Medicine, in which Journal editor Dr. Marcia Angell argued that the relative stability of the Dutch data between 1990 and 1996 demonstrates that these practices do not represent a threat to the basic fabric of society (as some would suggest) and do not suggest an inevitable decline into higher rates of non-voluntary and involuntary euthanasia(29). In a rebuttal in The Journal of the American Medical Association Dr. Herbert Hendin argued that the reported rates of life-ending acts without the explicit request of patients already constitute an erosion of medical standards in the care of the terminally ill in the Netherlands(30).

A recent survey of Massachusetts physicians explored the moral reasoning of physicians in cases where different forms of suffering were involved. Physicians were asked about the appropriateness of euthanasia and assisted suicide for two patients with metastatic cancer whose circumstances were identical except that one patient had extreme physical pain and was also experiencing considerable anguish and despair ("non-physical suffering"), whereas the other had only extreme "non-physical suffering". Twenty-six percent and 13% of physicians reported that assisted suicide and euthanasia, respectively, were appropriate for
the patient with "non-physical" suffering only(31). This study is timely given the 1994 Dutch Supreme Court decision that explicitly recognized suffering that is not caused by "somatic disease"(32) as legitimate grounds for euthanasia in some circumstances.

Overall, the available epidemiological data permit the following general conclusions. First, euthanasia and assisted suicide (particularly physician-assisted suicide) are occurring, even in jurisdictions in which they are illegal. Second, they are occurring at significant rates. Third, despite the demonstration of stability in incidence in the Dutch data, these practices are not limited to competent patients who make a clear and durable request in the context of intractable suffering in terminal illness. And finally, these data demonstrate that a significant proportion of physicians support euthanasia and assisted suicide in principle and in practice, despite legal prohibitions in most jurisdictions.

Public Opinion

Public opinion polls play an important role in documenting and shaping the popular disposition toward euthanasia and assisted suicide. They have also been criticized for being vague, ambiguous and, therefore, misleading, often suggesting greater public support than may actual exist(33). In fact, some of these effects have been well documented within the context of euthanasia and assisted suicide(34).

For example, in a poll conducted by Roper Organization for the Euthanasia Research and Guidance Organization, the specific wording of the questions produced dramatic differences in response. When 1000 randomly selected people were asked: "Would you vote for or against a law that allowed a terminally ill person to choose euthanasia rather than prolong life?", 55% responded “for”, 27% “against”, 12% “depends” and 6% “don’t know”. When another 1000 randomly selected people were asked: "Would you vote for or against a law that allowed a terminally ill patient to choose to die with dignity rather than prolong life”, 65% responded “for”, 20% “against”, 11% “depends” and 4% “don’t know”(35).
In the same survey, substituting “physician’s aid-in-dying” for “physician-assisted suicide” produced a 7% difference (higher) in “for” votes and a 7% difference (lower) in “against” votes. An almost identical difference also occurred between “by way of a medical procedure” (higher) and “by way of a lethal injection” (lower).

A similar poll conducted for the U.S. National Conference of Catholic Bishops in 1994 asked two groups of 500 randomly selected people if they “favour a law allowing terminally ill patients to obtain” either “a physician’s prescription for lethal drugs to end life”, or “physician-assisted suicide”. Forty-six percent of respondents voted in favour of “physician-assisted suicide”, while only 43% voted in favour of “a physician’s prescription for lethal drugs to end life”(36). These differences, attributable to wording in these polls, are particularly interesting in light of the 51%-to-49% margin of victory by which the Oregon Death With Dignity Act first became law by a vote in a referendum.

In the Netherlands, a series of public opinion polls has enabled researchers to map changes in public opinion regarding the acceptability of euthanasia from 1966 to 1991. In 1966, nearly half of all respondents said that a physician should not give a lethal injection “to a patient who asks to put an end to his [sic] suffering”. Only 4 years later in 1970, less than 25% of the respondents adhered to this position. The percentage not supporting active euthanasia continued to decrease to 9% in 1991(37).

In the United States, a comprehensive survey of public opinion was conducted in 1991. This project also involved the review of 20 national opinion surveys conducted between 1950 and 1991(38). The survey and historical analysis revealed that public support for legalizing euthanasia and other means of patient self-determination has increased over time. In 1950, only 34% of Americans thought physicians should be allowed to end the lives of patients with incurable diseases if they and their families requested it. By 1977 this figure had risen to 60% and has remained stable since then, ending at 63% in 1991.
The survey showed that age, religion and race played an important role in shaping people's attitudes toward legalizing euthanasia, with younger adults, i.e. aged 18-34, Catholics (perhaps surprisingly), and whites being more likely to support legalization. However, the main reason why Americans would consider euthanasia or assisted suicide, reported by 47% of respondents, is a fear of being a burden on the family, a finding that is echoed in other studies(39,40,41).

Two separate Canadian studies have demonstrated the effect of context on public opinion regarding euthanasia and assisted suicide(42,43). In one of these studies, active euthanasia for patients experiencing severe pain and terminal illness was supported by 65% of respondents. Whereas, for an elderly disabled person who feels he or she is a burden on relatives, it was opposed by 65%. Euthanasia for a patient with chronic depression resistant to treatment was opposed by 75%, while 83% opposed euthanasia for an elderly person who is no longer satisfied with life and who has various minor ailments(41).

Public opinion polls show an increasingly liberal public disposition toward euthanasia over the past 20 years. However, the public opinion appears to be highly sensitive to the effects of wording and context in the questions asked in the polls. It is clear that opinion polls may be manipulated to alter public opinion for political purposes, suggesting that their role in shaping our understanding of euthanasia and assisted suicide should be better scrutinized.

**Patient Perspectives**

Although there are no studies that explicitly examine the reasons and process by which individual patients come to desire euthanasia or assisted suicide, there have been some studies that provide some useful insights on patients' perspective on euthanasia and assisted suicide. In a recent study, more than a quarter of 155 oncology patients from 3 teaching hospitals in Boston had seriously thought about euthanasia or physician-assisted suicide, and nearly 12% had seriously discussed these interventions with physicians or others(21).
In another sample of 100 patients hospitalized in Australia for treatment of cancer, 1/3 anticipated eventually taking some steps to end their lives. Surprisingly, sicker patients expressed interest in euthanasia and assisted suicide less frequently than their relatively well counterparts. Although 70 patients reported that they were opposed to suicide, 4 of these patients were still very interested in euthanasia. They thought of suicide as cowardly, whereas euthanasia was viewed as “an act of active treatment”(44).

Jacobson et al. surveyed survivors of terminally ill patients who were listed as informants on death certificates in Utah. Among their results was the finding that those who were reported as dissatisfied with their care were no more likely to want euthanasia or assisted suicide than those who were satisfied with their care. Furthermore, approximately 90% of patients who would have wanted euthanasia or assisted suicide were satisfied with their comfort care. Marital status was also an important factor, with patients who were divorced or widowed being significantly more interested in euthanasia and assisted suicide(45). Although there are some important limitations in the Jacobson study, the findings raise some difficult questions about certain fundamental assumptions underlying arguments in favour of euthanasia and assisted suicide. Emanuel suggests that Jacobson’s findings elevate issues such as social isolation, loneliness and hopelessness and desire not to be a burden on others to the level of factors requiring further investigation(7).

The Jacobson study is consistent with other research that suggests that requests for euthanasia and assisted suicide do not arise exclusively out of a desire to avoid pain and suffering. Clinical depression(46), desire to maintain personal control(47), fear of being dependent on others(15), and concern about being a burden on loved ones(19) have all been reported as reasons underlying requests for euthanasia and assisted suicide. Although these studies provide some preliminary evidence that these factors may play a role in shaping decisions to have euthanasia or assisted suicide, they fail to explain how they might do so in practice.
Determining how these various factors might function in practice, i.e. what they mean to individuals and how they function to shape their decisions concerning euthanasia and assisted suicide, is a central aim of the original research described in Chapters 5-9. The study findings reported in Chapters 7-9 provide an explanatory account of how these factors function in individual decision making that has until now been absent from the empirical literature.

**Euthanasia and Assisted Suicide in HIV/AIDS**

The following review of the literature regarding euthanasia and assisted suicide in HIV/AIDS suggests that these practices may have a special relevance to the HIV/AIDS community compared to the general population. With respect to the study described in Chapter 5 this brief review provides an overview of the state of knowledge about euthanasia and assisted suicide in HIV/AIDS, while the findings in Chapters 7-9 begin to provide a more detailed account of the meaning of euthanasia and assisted suicide to some people with HIV/AIDS, i.e. the study participants.

There is a growing body of evidence to suggest that living with HIV/AIDS can be an extraordinarily trying and complex experience. The evidence—summarized below—reflects the fact that living with HIV/AIDS is dramatically unlike any other experience of disease and that the mainstream societal response to HIV/AIDS, and to individuals with HIV/AIDS, contributes as much to individual misery and destruction as does the disease itself. This appears to be particularly true among gay men, who still make up the vast majority of people living with HIV/AIDS. Steven Schwartzberg describes the scope of the challenge for gay men as follows:

*AIDS is much more than a health crisis. For gay men, it has unleashed a crisis of meaning. With so much loss and grief in its wake, so many lives affected in wrenching and unexpected ways, AIDS has obliterated many people’s prior beliefs of the world as meaningful. In its enormity, intensity, and relentlessness, AIDS cuts to the very heart of how people find meaning in*
Another account, this one a guest editorial in POZ magazine, a publication devoted to people living with HIV/AIDS, describes the author’s “relief” at being diagnosed with HIV:

And so I got HIV, just as I'd wanted. I laughed when I was told. It was such a relief. Everything fell into place. The future was clear; there was no need to worry about a career or old age. My marginalization and self-image were distilled, purified. An HIV community materialized where the mythical gay one never had. Gay men did have something in common, after all. My death would be painful, like my life. Somehow, this seemed heroic. It was a ticket to spirituality. At a time when I felt little, a virus gave me so much to feel. (49)

A recent series of case studies in Los Angeles and New York City revealed that people with HIV/AIDS frequently withdraw and isolate themselves around the time of their death. This self-initiated social isolation has been attributed to a heightened sensitivity to other people's reactions and a genuine fear of rejection (50). Although this characterization is not likely to be generalizable to all people with HIV/AIDS, an impressive array of studies have demonstrated similar findings.

For example, a sociological study of living with AIDS describes how people with AIDS avoid or reduce the effects of social stigma by concealing their illness, changing their social networks, educating others about HIV/AIDS, and using bravado to convince others that they are still functioning normally, despite the presence of HIV/AIDS in their lives (51). Many other studies document similar patterns of isolation, estrangement, alienation and grief in people with HIV/AIDS (52, 53, 54, 55, 56) and their caregivers (57, 58, 59, 60).

There have also been many reports of increased incidence of psychiatric symptoms among people with HIV/AIDS (61, 62, 63, 64, 65). The proportion of people living with HIV/AIDS who have considered asking for assistance to hasten death has been estimated at 33%, significantly more than seronegative controls 3% (66). In the Netherlands an estimated 50%
of people with AIDS make the necessary arrangements for a possible death by euthanasia, and euthanasia is performed in approximately 50% of those cases (i.e. approximately 25% of people living with HIV/AIDS) (67), which is virtually identical to another estimate which places the incidence at 26% (68). When decisions to forgo life-sustaining treatment were also included with euthanasia and assisted suicide this accounted for an estimated 35% of all deaths from HIV/AIDS between 1984 and 1995 (69). In another study of three hundred seventy-eight ambulatory HIV-infected patients from New York City, 90% of whom met the criteria of the Centres for Disease Control for AIDS, 55% acknowledged considering physician-assisted suicide as an option for themselves (70).

The heightened interest in euthanasia and assisted suicide among people with HIV/AIDS is consistent with studies that have suggested an increased risk of suicide for persons with HIV/AIDS (71,72,73). One report places the risk of suicide for men with HIV/AIDS at 7.4 times higher than for demographically similar HIV-negative men in the general population (74).

In a Canadian study, Ogden conducted interviews with 18 persons with HIV/AIDS and 17 individuals who had been involved with a total of 34 acts of euthanasia or assisted suicide of people with HIV/AIDS. The study provides a description of participants, their attitudes toward euthanasia and assisted suicide, and documents the views of the participants regarding issues such as control, suffering, fear, and stigmatization, thus providing one of the first qualitative accounts of these phenomena (47). For example, 83% of the participants reported that euthanasia or assisted suicide were options for them personally and within this group 53% had already taken steps to plan their euthanasia or assisted suicide. In general, these plans were developed cooperatively with friends, family members, and physicians.

Although Ogden's study is an important landmark in research on euthanasia and assisted suicide (see also the account of the legal problems encountered by Ogden in conducting his study in Chapter 6) in that it successfully employed qualitative research methods to gain a
richer account of individuals' experiences, the study falls short of providing an account of the personal meaning of euthanasia and assisted suicide for the study participants or a coherent explanatory account of why they desired euthanasia or assisted suicide.

In a survey of HIV physicians in San Francisco in 1992, 28% of respondents reported that they would be likely or very likely to grant the request of a hypothetical patient with AIDS (presented as a case vignette) for assisted suicide(75). In a follow up study in 1997, the number of physicians reporting that they would be likely or very likely to grant the request had increased to 48%. As well, 53% of respondents in the 1997 survey reported that they had provided real AIDS patients assistance in suicide at least once (median 1, range 0-100)(76).

Another study of caregiving partners of gay men with AIDS documented that 12% of participants had increased the dose of medications immediately before death with the intention to hasten death(77).

These findings paint a portrait of life with HIV as socially complex and fraught with a variety of physical, emotional and psychological challenges. Although great care must be taken to avoid conclusions about any individual living with HIV based on these data, it appears reasonable to suspect that some of the problems faced by people with HIV/AIDS outlined in the summary above will be involved in the lives of those who self-select for assisted suicide or euthanasia. This same concern regarding generalizability is relevant to the study described in this thesis and is discussed in detail in Chapter 10, in which the study's limitations are discussed in detail.

The findings described in this chapter demonstrate that, despite a considerable body of research on euthanasia and assisted suicide, our understanding of why people desire and decide upon these options for themselves is still in its infancy. In particular, in the context of euthanasia and assisted suicide there are no studies examining factors and circumstances that give rise to the desire to die, though there are many studies that address this issue in other
contexts, e.g. forgoing life-sustaining treatments in terminal illness. Therefore, before reviewing the ethical, legal and policy issues associated with euthanasia and assisted suicide I will review the literature related to the desire to die in the context of terminal illness with the aim of identifying factors and circumstances that may also be generalizable to the context of euthanasia and assisted suicide.
CHAPTER 3

The Desire for Death in Terminal Illness

This chapter provides a review of the literature regarding the desire to die in terminal illness. This aspect of the literature review was undertaken in an attempt to strengthen the main assertion of the thesis, namely that we do not yet know why people decide to end their lives by euthanasia or assisted suicide, despite some compelling clues. An examination of the closely-related actions of forgoing life-sustaining treatment in terminal illness provides some valuable insights about the factors and circumstances that give rise to the desire to die in this context and serve to enhance the plausibility of the study findings in Chapters 7-9.

In approaching the literature it was assumed that the desire to die, or hasten death, could be manifest either in decisions to forgo life-sustaining treatment, or to have assistance to deliberately bring about death. Clearly, the desire to die may also be manifest in suicide or attempted suicide. These acts have important legal and philosophic differences, and it is highly likely that they are also perceived differently and have different meaning to the individuals involved. For the sake of clarity and to ensure a manageable volume of material, the examination of the literature focussed primarily on forgoing life-sustaining treatment and requests for euthanasia and assisted suicide.

This chapter is organized into three main sections, first an overview of the desire to die in terminal illness, including its relevance to institutional and public policy and a brief account of its incidence. The second section provides a summary of the literature with special attention to the factors and circumstances that appear to give rise to the desire to die, and the third section summarizes these factors and their potential relationship to euthanasia and assisted suicide.
Overview

The bulk of the available evidence about the desire to die in terminal illness stems from the clinical perspective, and/or from clinical settings, and implies a causal relationship between the quality of end of life care for terminally ill patients and their desire to die, or to hasten their death(78,79). These associations are reinforced by the fact that the incidence of the desire to die, or to hasten death, appears to be alarmingly high in terminally ill patients(46). Yet despite the compelling logical and anecdotal case for the association, the evidence for why some terminally ill patients desire to die, or to hasten death, is still sparse and fragmentary. The state of the evidence mirrors the complex nature of research in this area. As is the case for euthanasia and assisted suicide, the necessary studies are fraught with ethical and legal obstacles (see Chapter 6) and a daunting array of conceptual and methodological challenges(7).

At the institutional level, although the right to refuse treatment has been clearly enshrined in case law and is now captured in legislation in most jurisdictions in North America, the development of institutional policies to reflect and facilitate these legal rights has lagged far behind. Although about half of Canadian public general hospitals surveyed in 1994 had do-not-resuscitate (DNR) policies, few had policies regarding other life-sustaining treatments or advance directives(80). Likewise, a similar study of long-term care facilities in Canada revealed that only one third had policies on life-sustaining treatments and advance directives(81), despite the obvious relevance of these policies in this context.

Similarly, at the public policy level, all aspects of end of life care (including forgoing treatments) have achieved a remarkably low profile. The recent recommendations of the National Forum on Health failed to identify end of life care as a priority(82), despite the much publicized concerns regarding our ability to respond adequately and appropriately to the health care needs of the rapidly expanding elderly population in Canada, and a growing urgency internationally to improve the quality of care for the dying(83,84). This failure to
identify the health care needs of the dying is consistent with several sociological perspectives on death in modern society(85), which emphasize that we treat death as an aberrant event, which is therefore highly privatized and excluded from public discourse, rather than being dealt with more openly as an integral part of the human condition(86). This is an important aspect of the overall framing of the desire to die (and euthanasia and assisted suicide), i.e. whatever its root causes, it occurs within a context that is generally inhospitable to death in any form.

The Special Senate Committee Report on Euthanasia and Assisted Suicide(2) made a number of recommendations regarding euthanasia and assisted suicide and related issues in 1995. These recommendations focussed on: enhancing training and education for health care professionals, restructuring, standardizing, and delivering specific health services, such as palliative care, pain control and sedation; and amending, and thereby clarifying, the Criminal Code in order to remove ambiguity about the circumstances in which forgoing life-sustaining treatment is legally acceptable. The Senate Committee's recommendations have not been reflected to any meaningful extent in changes to the practices and policies that the Report addressed, a point that was illustrated dramatically in some recent high profile court cases involving assisted suicide and euthanasia, most notably the case of Dr. Nancy Morrison in Halifax(87).

The Nature and Incidence of the Desire to Die in Terminal Illness

It is clear that the experience of a terminal illness can have profound effects on both patients and their caregivers(88). Although terminally ill patients often hope that death will come quickly, this does not usually reflect a sustained desire for suicide or euthanasia(46,89). Thoughts about accelerating death are often related to: the adequacy of symptom control; difficulties in the patient's relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety, organic mental disorders, and personality disorders; and the patient's personal orientation to the meaning of life and suffering(90).
This personal perspective has been vividly represented in a study in which a diverse sample of terminally ill patients and well adults were asked to describe states that, for them, would be worse than death. These descriptions reflected a fear of, and desire to avoid, physical and mental deterioration, discomfort, dependency on machines or technology or other life-sustaining treatments, being a burden on others, and loss of the ability to communicate or participate meaningfully in life. In this sample, the well adults’ descriptions did not differ substantially from those of the terminally ill patients(40).

The desire for an early death has been documented in several studies, perhaps most notably in a study of 3,696 relatives of people who died in Britain in 1990, and whose death certificates were drawn in a random sample. Respondents reported that about a quarter of the people who died expressed the view that an earlier death would have been preferable and that 3.6% had asked for euthanasia at some point in the last year of life(41).

Although the act of forgoing life-sustaining treatment is generally thought to be a direct manifestation of the desire to die, or the desire to hasten death, great care must be taken not to assume that all cases of forgoing life sustaining treatment by competent patients are primarily demonstrations of a desire to die. It is clearly possible and logically consistent to forgo life sustaining treatment and yet not hold a desire to die as the principal motivation(6). However, the circumstances under which patients decide to forgo life-sustaining treatment may prove to be instructive in the attempt to understand the origins of the desire to die in terminally ill patients.

The process of forgoing life-sustaining treatment was studied by reviewing the charts of all patients who died at the University of Minnesota Hospital, a 586-bed tertiary care university hospital, during a 2-month period. A total of 52 of 70 patients (74%) who died had some intervention withheld or withdrawn before death. Forty of the 52 (77%) patients who died, had made Do Not Resuscitate (DNR) orders and had forgone mechanical ventilation in addition to other interventions such as vasopressors, antiarhythmics, dialysis or surgery.
Those patients in whom treatment was forgone were more likely to have an underlying malignancy or impaired mental status and longer hospital stays. Thirty-two of 52 patients (62%) who declined some treatment were in an Intensive Care Unit (ICU); 26 of 52 patients (50%) required mechanical ventilation. On average, 5.4 separate interventions were forgone per patient. Resuscitation and/or endotracheal intubation were generally the first measures withheld. Once a patient required a ventilator, the decision to withdraw it came late in the decision making process(91). In a more recent study at the same institution, 229 of 274 patients (84%) who died had some intervention forgone before death(92).

In an early study (1988), 26/1766 (1.5%) of chronic dialysis patients, followed prospectively, made decisions to stop dialysis that resulted in death, although there was no technical dialysis complication or new medical complication. This amounted to 26/704 (4%) of all deaths in the cohort. Stopping dialysis was three times more common in patients receiving dialysis at home (3.0%) than in those who received their treatment in the clinical setting (1.1%)(93).

Factors that Appear to Give Rise to the Desire to Die in Terminal Illness

There is no single factor or set of circumstances that can be said in advance to give rise to a desire to die. In the context of terminal illness, the desire to die appears to be associated with a complex array of factors or circumstances. One approach to categorizing these factors is to distinguish between those factors that arise from, or are most closely associated with, medical or health services interventions (clinical factors), and those that are not. In fact, it appears that most of the non-clinical factors can be characterized as “existential”, having to do with the way that each individual ascribes personal meaning to certain symbols, acts, processes, circumstances and relationships in her/his life. These ascribed meanings determine, to a large extent, the way the individual considers and makes specific decisions. It is also becoming clear that these “existential” factors play at least as important a role--if not more important--as the clinical factors.
Clinical Factors

The Influence of the Clinical Context

Very little is known about what aspects of the clinical experience may influence end of life decisions. Some recent studies have begun to offer insights into this question. A study of 1,676 patients hospitalized with serious illnesses in five geographically diverse academic acute-care medical centres in the United States, attempted to identify factors associated with a preference to forgo cardiopulmonary resuscitation (CPR). Twenty-eight percent of patients did not want CPR. These patients were older, more functionally impaired, and had a worse perception of their prognosis than those patients who wanted CPR. They also had a higher mortality at 2 and 6 months following entry into the study than those patients who wanted CPR (94).

To determine whether or not preferences for or against CPR were stable over time, a follow-up study with 1,590 patients from the same patient cohort described above examined the stability of the preference for or against CPR over 2 months. Of the 1,590 patients analysed, more than two thirds preferred CPR for cardiac arrest and 80% had stable preferences over 2 months. Patients who initially decided to forgo CPR in the event of a heart attack, but who had changed to prefer CPR at follow-up, tended to be younger, male, had less depression at baseline, had greater improvement in depression between interviews, and had an initial admission diagnosis of acute respiratory failure or multiorgan system failure. Patients in this group who had substantial improvements in their depression score between interviews were more than 5 times as likely to change preference to CPR than were patients with substantial worsening in depression score (95).

These preliminary findings suggest that age, diagnosis, and perception of prognosis (which may also be associated with diagnosis and the way this is presented to patients) and depression may be important factors in decisions to forgo life-sustaining treatment.
Role and Influence of Health Care Providers

It is clear that patient preferences and clinical circumstances alone do not determine how decisions to forgo are made. Although most discussions and investigations of forgoing life-sustaining treatments focus on the appropriateness of this practice for patients in any given diagnostic and prognostic group, recent evidence has begun to suggest that the values and attitudes of care providers may also have an influence on the nature of these decisions(96).

In a survey of 862 Pennsylvania internists, physicians were more willing to withdraw life support if they were young, practised in a tertiary care setting, or spent more time in clinical practice. A greater willingness to withdraw is also associated with a reported higher frequency of withdrawal. They were less willing to withdraw life-sustaining treatment if they were Catholic or Jewish. Physicians reported a higher frequency of actually withdrawing life support if they were young, had more contact with ICU patients, spent more time in clinical practice, or were specialists. Physicians with a greater willingness to withdraw were more likely to report having done so(97).

A study done in the early 1990s illustrated an important trend in the practice of forgoing life-sustaining treatment. Recommendations from physicians to withhold or withdraw life support preceded 179 of 200 deaths (90%) in 1992 and 1993, compared with 114 of 224 deaths (51%) in 1987 and 1988. Cardiopulmonary resuscitation was initiated in 10% of deaths in 1992 and 1993 as compared with 49% in 1987 and 1988(98).

These two studies suggest that there has been a cultural shift--perhaps influenced by several high profile court cases involving the withdrawal of life-sustaining treatment--in the last 10 years(99). The findings would suggest the gradual normalization of withdrawal practices, though the findings regarding the influence of physician preferences still raise the spectre of inappropriate withdrawal in some cases. This concern regarding the appropriate provision of all aspects of end of life care is illustrated in a survey of 1,361 Canadian ICU clinicians,
including 149 attending staff, 142 house staff, and 1,070 nurses in 37 Canadian university-affiliated hospitals. The study uncovered extreme variability in the selection of the appropriate level of care for patients in 12 clinical scenarios. In choosing the level of care appropriate for the patient scenarios, the same option was chosen by more than 50% of respondents in only one of 12 scenarios. Respondent characteristics affecting choices included the number of years since graduation, the city and province in which they worked, the number of beds in their ICU, and their assessment of the likelihood that they would withdraw life support in comparison with their colleagues(100).

Some evidence has emerged regarding physician preferences in the withdrawal of life-sustaining treatment. In general, the physicians studied prefer to withdraw forms of life support that are scarce, expensive, invasive, artificial, unnatural, emotionally taxing, high technology, and rapidly fatal when withdrawn. They prefer not to withdraw forms of therapy that require continuous rather than intermittent administration, and forms of therapy that cause pain when withdrawn(101).

A survey of 481 American internists provided a specific list of their preferences for treatments to withdraw. From most likely to least likely the order is: blood products, haemodialysis, intravenous vasopressors, total parenteral nutrition, antibiotics, mechanical ventilation, tube feedings, and intravenous fluids. This list appears to be reasonably consistent with the list of criteria provided above. Four biases in decision making were also identified in this survey. Physicians prefer to withdraw forms of therapy supporting organs that failed for natural rather than iatrogenic reasons, to withdraw recently instituted rather than longstanding interventions, to withdraw forms of therapy resulting in immediate death rather than delayed death, and to withdraw forms of therapy resulting in delayed death when confronted with diagnostic uncertainty(102).

These findings reinforce the emotional and psychological complexity of physicians' role in the withdrawal of life-sustaining treatment and may begin to provide clues as to specific targets.
for physician training (including, perhaps, practice guidelines) and education and professional support. The findings also reinforce the need for diligence and honest self-assessment by physicians in all aspects of withdrawing life-sustaining treatments so as not to unduly influence patients’ decisions according to their own biases.

In addition to variability in physicians’ preferences for withdrawing life-sustaining treatment, there is also evidence of great variability in the communication skills of physicians in this same context. Poor communications could inadvertently frame momentous life decisions inappropriately for terminally ill patients.

In an observational study of how 31 medical residents discuss do-not-resuscitate (DNR) orders with patients, the physicians often did not provide essential information about cardiopulmonary resuscitation (CPR). While all the physicians mentioned mechanical ventilation, only 55% mentioned chest compressions and 32% mentioned intensive care. Only 13% of the physicians mentioned the patient’s likelihood of survival after CPR, and no physician used a numerical estimate. The discussions lasted a median of 10 minutes and were dominated in speaking time by the physicians. The physicians initiated discussions about the patients' personal values and goals of care in only 10% of the cases, and missed opportunities to do so (103). These findings indicate that physicians are not well attuned to the concerns and desires of patients, who express strong feelings about having straightforward and honest end-of-life discussions early in the course of their illness. Patients also appear to be less concerned than the physicians about damaging hope. Patients want their physicians to play central roles in discussions and they desire information focusing more on expected outcomes than on medical processes (104).

Similarly, families of patients who died in the intensive care unit following the withdrawal of treatment identified selected physician and nursing behaviours as helpful, and others that increased their burden. Helpful behaviours included: encouraging advanced planning, timely communication, clarification of families' roles, facilitating family consensus, and
accommodating family's grief. Behaviours that made families feel excluded or increased their burden included postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the full burden of decision making on one person, withdrawing from the family, and defining death as a failure(105). Although the precise significance of these behaviours and shortcomings in communication for decisions to forgo treatment is not clear, it is readily apparent that they contribute profoundly to shaping the experience of patients and their families.

In a nationwide study of decisions concerning the end of life in general practice in the Netherlands, general practitioners made fewer decisions about euthanasia, assisted suicide and forgoing life-sustaining treatment than hospital doctors and doctors in nursing homes (34%, 40%, and 56% of all dying patients, respectively). Specifically, decisions to forgo treatment were made less often, older general practitioners discussed such decisions less often with their patients, and colleagues were consulted more often if the general practitioner worked in group practice(106).

In a random sample of Dutch doctors, the 52% who at one time or another had performed euthanasia were asked whether their personal practices conform with the required guidelines. A total of 12% of the 52% of the doctors had performed euthanasia or assisted a suicide without having had any kind of consultation or discussion with a colleague, a nurse or any other health care professional; 26% had not issued a certificate testifying to death from natural causes(107).

**The Influence of Pain and Symptom Management**

Pain is common among severely ill hospitalized patients. Nearly 50% of 5,176 patients from the SUPPORT cohort reported pain during their hospitalization. Nearly 15% reported extremely severe pain or moderately severe pain occurring at least half of the time, and nearly 15% of those patients with pain were dissatisfied with its control. Older and sicker patients
reported less pain, while patients with more dependencies in activities of daily living, more co-morbid conditions, more depression, more anxiety, and poor quality of life reported more pain. Dissatisfaction with pain control was more likely among patients with more severe pain, greater anxiety, depression, and alteration of mental status, and lower reported income. Level of pain in this patient population appears to also be associated with reports of pain 2 and 6 months after hospitalization(108).

The experience of pain can be extremely disabling. In a survey of 438 ambulatory AIDS patients recruited from health care facilities in New York City, more than 60% of the patients reported 'frequent or persistent pain' during the 2 weeks preceding the study. The presence of pain and increasing pain intensity were significantly associated with greater impairment in functional ability and physical symptom distress(109). As well, in this same patient sample, there were significant associations between the presence and intensity of pain and scores on the measures of psychological distress, depression, hopelessness, and quality of life. The perceived adequacy of social support was also significantly associated with lower levels of psychological distress and depression, and better quality of life(110). In another cohort of AIDS patients, interest in physician-assisted suicide was not related to severity of pain, pain-related functional impairment, physical symptoms, or extent of HIV disease(70). There is known to be significant under-treatment of pain in ambulatory AIDS patients(111).

A central assumption in the long-standing debate about euthanasia and assisted suicide is that the desire to die arises in response to pain and suffering (and presumably the concomitant effects described above) and that, if pain and suffering were to be well controlled, requests for euthanasia and assisted suicide and other manifestations of the desire to die would be irrelevant. However, some recent findings have called the validity of this assumption into question(112).

In a study of 155 oncology patients from 3 University hospitals in Boston, patients who reported that they had experienced significant pain within the previous 24 hours were more
likely to find euthanasia or physician-assisted suicide unacceptable(21). Data from other studies have also undermined the validity of the longstanding assumption that requests for euthanasia and assisted suicide usually stem from unbearable pain(26,70,107).

As well, a study of informants for people who had died in Utah found that approximately 16% would have wanted some form of assistance in dying if it were offered. Those persons who were reported as dissatisfied with their comfort measures were no more likely to want assistance than those who were satisfied, and as many as 90% of individuals who would have wanted assistance were satisfied with their comfort care(45). These findings are particularly interesting when compared to the attitudes of a sample of cancer patients, for whom pain, or fear of pain, was the most commonly cited reason for considering euthanasia or assisted suicide(44). The apparent discrepancy raises questions about whether there are strong expectation effects at play in the desire to die, or to hasten death, and if so, what implications this might have in end of life care and public policy regarding euthanasia and assisted suicide.

In light of the widespread belief that physicians lack the appropriate skills and training to deal effectively with pain at the end of life(113), it seems reasonable to assume that pain and its many associated debilities could contribute to the desire to die, or hasten death in terminal illness, but that it might not be sufficient in itself to assure requests for euthanasia or assisted suicide, or decisions to forgo life-sustaining treatment.

_The Influence of Depression and Other Psychiatric Conditions_

In a landmark study of 44 terminally ill patients, 34 had never wished death to come early. Of the remainder, three were or had been suicidal and seven more had desired early death. All 10 patients who had desired death were found to be suffering from clinical depressive illness(89). A more recent study of 200 terminally ill patients produced similar findings. Although occasional wishes that death would come soon were common (reported by 44.5% of the patients), only 17 (8.5%) of these individuals acknowledged a serious and pervasive desire to
die. The desire for death was correlated with ratings of pain and low family support but most significantly with measures of depression. The prevalence of diagnosed depressive syndromes was 58.8% among patients with a desire to die and 7.7% among patients without such a desire. Moreover, 2 week follow-ups with 6 patients revealed that depression scores had decreased in 4 of the 6 and their desire to die had decreased during the 2-week interval(46).

The evidence of an association between depression and the desire to die is now compelling. Cancer patients with depression and psychological distress were significantly more likely to have seriously discussed euthanasia, hoarded drugs, or read Final Exit(21). In a sample of 378 ambulatory HIV patients, 90% of whom had AIDS, 208 (55%) acknowledged considering physician-assisted suicide as an option for themselves. The strongest predictors of interest in physician-assisted suicide were high scores on measures of psychological distress (depression, hopelessness, suicidal ideation, overall psychological distress) and experience with terminal illness in a family member or friend(70). Depressed mood is known to affect care preferences in patients with AIDS(114) and give rise to requests for euthanasia and assisted suicide in terminal illness(115,116).

The greatest single reservoir of clinical depression, and perhaps the most critical with respect to the desire to die, is in the elderly. This is particularly important given the tendency of some older patients with clinically significant depression to under-report their symptoms(117). The co-morbidity of depression and medical illness likely has a tremendous impact on both health and health care delivery for older adults(118,119,120,121,122). During the terminal phase of illness, many geriatric patients develop psychiatric complications that subsequently have profound effects on their quality of life(123). However, it is also known that treating depression can change elderly patients’ preferences for(124), and attitudes toward(125), life-sustaining treatments.
Existential Factors

The majority of writings and studies on euthanasia, assisted suicide and forgoing life-sustaining treatment focus on clinical aspects of patients' experience. But increasingly, evidence is emerging that suggests that other dimensions of terminal illness, such as its challenges to personal integrity and identity play at least as important a role as the clinical determinants of the desire to die(40).

'Existential' factors are those that have direct relevance to the individual's personal system of meaning and identity. For example, religious beliefs, or the meaning and importance of close personal relationships are existential concerns for the purposes of this thesis. Not surprisingly, the evidence regarding the influence of existential factors on the desire to die is limited, though several important insights are emerging from the literature.

A study of attitudes toward euthanasia and abortion in 168 Australian adults (68 men, 100 women) indicated that level of conservatism was the most consistent predictor of attitudes, whereas religiosity was found significantly to predict attitudes toward abortion only(126). However, several other studies have found clearer associations. One study reported that people with HIV/AIDS who attend church regularly were less likely to consider euthanasia than those who didn't (though there were no significant differences between people from different religions)(70). Another study of cancer patients found that Catholics were least likely to find euthanasia or assisted suicide acceptable(21).

A survey of physicians, nurses and social workers also found a strong negative correlation between level of religious belief and willingness to endorse assisted suicide(127). Terminally ill patients have also identified religious faith as an important factor in decision making about euthanasia and assisted suicide(44).

These findings appear to be consistent with data from a general social survey in the United
States that showed that opposition to euthanasia is strongest among the more fundamentalist religious groups, those with conservative personal moral codes, and those who oppose abortion. Religious conservatism, personal moral legalism, and intolerance of "deviant" beliefs appear to constitute a general "life-intervention attitude", which is the main direct predictor of attitudes toward euthanasia.(128).

Another theme that is frequently associated with the desire to die is the fear of being a burden on others. This idea is now common in the literature(26,40,66), but it is still not clear whether fear of being a burden on others is, in itself, a powerful enough motivator to justify a decision to have euthanasia or assisted suicide in the absence of other contributing factors.

Closely tied to the fear of being a burden on others is the fear of losing dignity in the course of a terminal illness. Although the term 'dignity' has various meanings and applications(129,130,131), it is clear that terminally ill patients consider dignity to be an essential measure of their self-worth and personal identity(26,40,66) and probably a measure of disease progression and functional decline.

For people with HIV/AIDS, concerns with dignity and deliberations about euthanasia and assisted suicide often occur against a backdrop of stigmatization and discrimination. These broader social pressures and the feelings they often engender in people with HIV/AIDS must be considered in any account of why people with HIV/AIDS may desire to die, or to hasten death(49,51).

**Summary and Relevance to Euthanasia and Assisted Suicide**

These findings have established that our understanding of the desire to die, or to hasten death, in terminally ill patients is still in its infancy. Certain factors affect the desire to die. Some of these are "clinical factors", while others are not ("existential factors"). Clinical factors include pain and discomfort associated with the physical body, and depression
(though depression likely has an important existential dimension as well), while existential factors include issues of fundamental identity, personal meaning and dignity. These factors appear to function cumulatively to give rise to or reinforce the desire to die, whereas the absence of any specific factor(s) may be sufficient to temper, defer, or reverse the desire to die. Elderly terminally ill patients are likely to experience many of these factors. Doctors and other health care professionals can influence the desire to die by their personal biases, by the quality of end of life care that they provide, and by the quality of their communications with patients.

These findings are similar conceptually to those of the literature review of empirical studies of euthanasia and assisted suicide reported in Chapter 2. Nothing about the findings suggests that these factors or similar ones could not also be relevant to decision making regarding euthanasia or assisted suicide. In fact, it is likely that differences between the desire to die in terminal illness and decision making regarding euthanasia and assisted suicide may only be identified by more elaborate accounts of both processes. Therefore, despite the general similarities between the two contexts, the review of the desire to die literature reinforces the notion that we do not yet understand precisely how these various factors interact to give rise to the desire to die. These findings add weight to the rationale for the study described in Chapter 1, i.e. that we do not yet understand the precise reasons why people end their lives by euthanasia or assisted suicide.
CHAPTER 4

Ethical, Legal and Policy Issues Related to Euthanasia and Assisted Suicide

In this chapter I will review some of the main ethical, legal and policy issues associated with euthanasia and assisted suicide with the aim of describing the context within which the thesis is situated. In doing so, I will also attempt to identify aspects of these issues for which the empirical findings in Chapters 7-9 may prove useful. The chapter is organized into three main sections that provide accounts of the important current issues in ethics, law and policy of euthanasia and assisted suicide, respectively.

There is increasing pressure to resolve the question of whether doctors, and/or other health professionals, should participate in intentionally bringing about the deaths of their patients and whether these practices should be embraced by society as a whole. Many argue that these practices should not be the exclusive domain of physicians and/or other health professionals, but should be accepted more broadly in society. Whatever the scope, these questions require careful consideration of the relevant ethics, law, and public policy implications.

Ethics

There is considerable disagreement about whether euthanasia and assisted suicide are ethically distinct from decisions to forgo life-sustaining treatments (132,133,134,135,136,137,138,139,140). At the heart of the debate is the ethical significance given to the intentions of those performing these various acts (141,142). Supporters of euthanasia and assisted suicide reject the ethical distinction between those acts and acts of foregoing life-sustaining treatment. They claim, instead, that all are examples of patients making autonomous choices about the time and manner of their own death (133).
Opponents of euthanasia and assisted suicide claim that death is a predictable consequence of the morally justified withdrawal of life-sustaining treatments only in cases where there is a fatal underlying condition, and that it is the condition, not the action of withdrawing the treatments, that causes death(143). A physician who performs euthanasia or assists in a suicide, on the other hand, has the death of the patient as his/her primary objective.

Although opponents of euthanasia and assisted suicide recognize the importance of self-determination, they argue that individual autonomy has limits and the right to self-determination should not be given ultimate standing in social policy regarding euthanasia and assisted suicide(144).

Supporters of euthanasia and assisted suicide also believe that these acts benefit terminally ill patients by relieving their suffering(145), while opponents argue that the compassionate grounds of the endorsement cannot ensure that euthanasia will be limited to those individuals who request it voluntarily(146). As well, opponents are concerned about how endorsing euthanasia might contribute to an increasingly casual attitude toward private killing in society(147).

Most commentators make no formal ethical distinction between euthanasia and assisted suicide, since in both cases the person performing the euthanasia or assisting the suicide deliberately facilitates the patient's death. However, concerns have been expressed about the risk of error, coercion or abuse that could result if physicians become the final agents in voluntary euthanasia(148). At the root of this concern is the potentially destructive effect on the professional role and integrity of physicians. As a result, there is also disagreement about whether or not euthanasia and assisted suicide should rightly be considered "medical" procedures(149,150).

Although no empirical study can determine whether or not euthanasia and assisted suicide are ethically acceptable, it is clear from the preceding literature reviews that our knowledge of
these phenomena is not complete. Yet the ethical and philosophic arguments imply certain assumptions, particularly regarding the motivation of those availing themselves of euthanasia or assisted suicide and those providing assistance. Hoffmaster has suggested that the kinds of reasoning applied to "moral" decision making by philosophers may not bear much resemblance to how people approach and understand these decisions in real life.

*They know they have a hard, perhaps tragic, decision to make, and they want to do the best or the right thing (not the morally right thing). They agonize over these decisions, but they do not ask themselves whether a proposed course of action would be immoral or irrational, or whether a reason that appears persuasive to them is really a valid moral reason. The philosophical desire to portray such decisions as exclusively and prototypically moral is not faithful to the phenomena.* (151)

In line with Hoffmaster's reasoning, the findings in Chapters 7-8 offer some potentially useful insights into how people with HIV/AIDS approach decisions about euthanasia and assisted suicide and what these decisions mean to them. The relevance of these findings to the ethics of the debate is discussed in more detail in Chapter 10.

**Law**

**Canadian Legislation**

The *Criminal Code* of Canada prohibits euthanasia under the homicide provisions, particularly those regarding murder, and makes counselling a person to commit suicide or aiding a suicide punishable offences. The consent of the person whose death is intended does not alter the criminal nature of these acts(152).
In 1993, the Supreme Court of Canada dismissed an application (by a 5-4 margin) by Sue Rodriguez, a 42 year old mother with amyotrophic lateral sclerosis for a declaration that the Criminal Code prohibition against aiding or abetting suicide is unconstitutional. Rodriguez claimed that Section 241(b) violated her rights under the Charter of Rights and Freedoms to liberty and security of the person, to freedom from cruel and unusual treatment, and to freedom from discrimination on grounds of disability, since the option of attempting suicide is legally available to non-disabled members of the public(136).

Like the U.S. Supreme Court, the Supreme Court of Canada held in Rodriguez that the Canadian Charter of Rights and Freedoms' guarantee of security of the person does not extend to assisted suicide. However, unlike the U.S. Supreme Court, four of nine justices dissented. They found that Rodriguez was discriminated against on grounds of disability, in violation of Section 15(1) of the Charter, because the option of attempting suicide, which is legally available to anyone, was not available to her because she was physically unable to commit suicide. The majority (of 5 judges) felt that even if she was discriminated against, the discrimination was deemed to be within the reasonable limits that could be imposed in a free and democratic society.

Although the Criminal Code is a federal matter in Canada, the administration of the criminal law falls under provincial jurisdiction. This has allowed the province of British Columbia (Sue Rodriguez's home province) to introduce guidelines that provide Crown prosecutors some discretion over laying charges in individual cases involving euthanasia and assisted suicide(153).

Despite the reaffirmation by the Court in Rodriguez that assisting in the suicide of another person is appropriately viewed as a criminal activity, there has been a clear trend toward leniency at sentencing for those individuals, some of them doctors, convicted of relevant
This trend was interrupted recently, with the conviction of Dr. Maurice Genereux, a Toronto primary care physician specializing in the care of people with HIV/AIDS who became the first Canadian physician to be charged with aiding a suicide under Section 241(b) of the Criminal Code. Dr. Genereux was convicted on a plea of guilty on two counts of criminal negligence causing death. He was investigated following a complaint by the lover of one of Dr. Genereux’s patients who had died of an overdose of secanol, that Dr. Genereux was prescribing the drug indiscriminately, and on the discovery that Dr. Genereux had falsified the patient’s death record.

Shortly after the Genereux trial began, Dr. Nancy Morrisson of Halifax was arrested and charged with first degree murder in the death of Mr. Paul Mills, a cancer patient at Queen Elizabeth II hospital in Halifax. Morrisson allegedly injected Mills with potassium chloride in response to his breathlessness, pain and anxiety moments after withdrawing the mechanical ventilator that he required to breathe. The case appeared to be closed in February 1998 when the presiding judge decided at a preliminary hearing that there was insufficient evidence to put Morrisson on trial. Recently, however, a Crown attorney in Halifax has petitioned the Nova Scotia Supreme Court to quash the judge’s decision and clear the way to bring Morrisson to trial.

Other Jurisdictions

On September 22, 1996, a cancer patient in Australia’s Northern Territory became the first person in the world to receive assistance from a physician to commit suicide under specific legislation. The Rights of the Terminally Ill Act 1995 allowed physicians to prescribe and administer lethal doses of drugs to patients who were (a) at least 18 years of age, (b) terminally ill, (c) experiencing severe pain or suffering, and (d) where procedures had determined that the patient’s request was competently made and durable. In early 1997,
after only 4 patients had died under the provisions of the law, it was declared unlawful by the Federal Parliament of Australia and withdrawn(160).

In the Netherlands, a series of judicial decisions has made euthanasia permissible since the 1970s, despite the fact that it is still officially a criminal offence. Official guidelines were prepared by the Royal Dutch Medical Association in 1984, and these were endorsed by a government commission the following year. In 1993, the Dutch parliament wrote a provision into the Burial Act stating that acts of euthanasia should not be prosecuted as long as the Guidelines were adhered to(161).

Several legislative initiatives in the United States have either been narrowly defeated (162), or have met with a constitutional challenge (163). In 1995, two United States Federal Appeals Courts (9th Circuit and 2nd Circuit) independently struck down Washington and New York state laws prohibiting assisted suicide and ruled that there is a constitutionally protected right to choose the time and manner of one's death, and that this right includes seeking assistance in committing suicide (133,134).

These decisions have been strongly criticized for their lack of appreciation of the complexity of the problems, particularly in clinical settings (164), and for their apparent inconsistency with important related jurisprudence (140,165).

In the fall of 1996 the U.S. Supreme Court began to hear arguments in appeals of both cases. On June 26, 1997, the Court ruled in 2 unanimous decisions that there is no constitutionally protected right to assisted suicide (166,167), overturning both the 2nd and 9th Circuit Court rulings and rejecting two key arguments. First, the Supreme Court rejected the argument that the right to liberty guaranteed by the due-process clause of the fourteenth amendment to the U.S. Constitution includes the right to seek the assistance of a physician to commit suicide. The Court has previously assumed that the right to liberty includes decisions to forgo life-sustaining treatment. However, in these most recent decisions it drew a clear distinction
between forgoing life-sustaining treatment, which was consistent with “the common-law rule that forced medication was a battery and the long legal tradition protecting the decision to refuse unwanted medical treatment”, and assisted suicide, which “may be just as personal and profound as the decision to refuse unwanted medical treatment...[but] has never enjoyed similar legal protection.”(166). The Court found that “[t]he distinction between letting a patient die and making that patient die is important, logical, rational, and well established” and is “widely recognized and endorsed in the medical profession, the state courts, and the overwhelming majority of state legislatures.”(167)

Second, the Supreme Court rejected the argument that laws prohibiting assisted suicide violate the right to equal protection of the laws guaranteed by the Fourteenth amendment, i.e. that states must treat like cases alike. Specifically, the Court rejected the Appellate Court’s ruling that decisions to forgo treatment (which are legally permissible) are the same as assisted suicide and so should also be legally permissible. Instead, the Court ruled that permitting decisions to forgo treatment while prohibiting assisted suicide does not “[treat] anyone differently from anyone else, or [draw] distinctions between persons. Everyone, regardless of physical condition, is entitled, if competent, to refuse unwanted life-saving medical treatment; no one is permitted to assist a suicide.”(167)

Aside from determining the constitutionality of existing laws prohibiting assisted suicide, the Supreme Court also introduced two important substantive twists into the on-going debate on the ethical acceptability of assisted suicide and euthanasia. First, the Court effectively required all states to ensure that their citizens have unobstructed access to palliative care(168), a requirement that could result in challenges to the constitutionality of some existing legislation governing the delivery of health care services in the United States. And, in a related aspect of the decision, the Court ruled that if a right to assisted suicide arises from the need to relieve patients’ suffering, then the legally available alternative of terminal sedation made this right unnecessary(169).
The Supreme Court’s decisions do not resolve the ethical or legal debate about euthanasia and assisted suicide. Instead, the Court has returned these issues to the state legislatures, reflecting the reluctance of the Supreme Court justices to substitute their views for the democratic will of the people. The Court said simply that two state laws prohibiting assisted suicide withstood constitutional challenge, not that assisted suicide itself is or should be illegal. Therefore, these Supreme Court decisions do not prevent a state legislature from legalizing euthanasia or assisted suicide.

In fact, in November 1997, only months after the Supreme Court’s decisions, residents of Oregon voted for a second time on that state’s controversial Death With Dignity Act, which was passed by a 51%-to-49% margin in a 1994 referendum but never implemented because of legal challenges(170). In this second referendum, the Death With Dignity Act was passed by a 60%-to-40% margin, making assisted suicide legally permissible in Oregon.

Surprisingly, the response by Oregonians seeking assisted suicide has been extremely slow. This has been attributed in part to the threat of close scrutiny of physicians’ activities by the Drug Enforcement Agency under a proposed law that is currently before the U.S. Congress(171,172).

Policy

There are many types of policy that affect the way euthanasia and/or assisted suicide may be received in Canada and elsewhere. Although the existing legislative prohibitions anchor these policies, they are by no means exhaustive of them. Other government, institutional and professional policies govern how euthanasia and assisted suicide are handled even in advance of any encounters with the law. For example, the B.C. Crown Prosecutor’s guidelines, described above, provide for some prosecutorial discretion in cases involving euthanasia and assisted suicide despite their prohibition in the Criminal Code, whereas the Canadian Medical Association’s policy on euthanasia and assisted suicide(173) defines the Association’s
expectation of what constitutes a fitting response of its members when faced with requests for euthanasia and assisted suicide. The Guidelines on Palliative Care developed by the Office of the Chief Coroner of Ontario assists Coroners in determining when a death should be accepted as having resulted from appropriate palliative care, and when it should be pursued as a case of euthanasia or assisted suicide.

Another less visible—but no less important aspect of public policy—is the manner in which research on euthanasia and assisted suicide is supported and facilitated in Canada. Although the Senate Committee report recommends “research be undertaken into how many are requesting assisted suicide, why it is being requested, and whether there are any alternatives that might be acceptable to those who are making the requests(2). The reality for Canadian researchers is that rigorous investigations of these questions are impeded by the myriad ethical and legal obstacles (these are discussed in detail in Chapter 6), and the painfully slow pace at which these studies are often completed (for example, the study reported in Chapters 5-9 took almost three years to complete), which is potentially incompatible with the rate of publication required for advancement in academic positions.

In 1995, The Special Senate Committee on Euthanasia and Assisted Suicide issued a report on the legal, social and ethical issues relating to euthanasia and assisted suicide(2). Like the Law Reform Commission’s report before it(174) the Senate Report suggested several clarifications to the Criminal Code in order to remove ambiguity about the legal acceptability of forgoing life-sustaining treatment. Unlike the Law Reform Commission before it, a majority of the Senate Committee recommended amendments to the criminal code that would provide for less severe penalties for non-voluntary euthanasia in which there was “an essential element of compassion or mercy”, and for voluntary euthanasia under similar circumstances. The Senate Committee recommended that no amendments be made to the offence of counselling suicide under subsections 241 (a) and (b) of the Criminal Code.

The Special Senate Committee’s recommendations were meant primarily as a guide to be
used by parliament for any endeavour aimed at altering existing legislative policy regarding euthanasia and assisted suicide (and forgoing life-sustaining treatment, which is already legal). Although the writing and/or amending of legislation is one key element in public policy with respect to euthanasia and assisted suicide, it is not the only element. In fact, although it is often claimed that the government is not pursuing any policy in this area a careful examination of the Law Reform Commission and Special Senate Committee Reports reveals that the decision not to pursue any specific legislative policy regarding euthanasia and assisted suicide is, in fact, a reasoned approach to the public management of these contentious issues. It is important to compare euthanasia and assisted suicide with other related areas in which there is no explicit policy, such as abortion.

The legal developments described earlier in this chapter have had an enormous influence on thinking regarding public policy for euthanasia and assisted suicide. In fact, the vast majority of discussions about policy in these areas appear to revolve around the very issues that are played out in detail in these legal cases.

These issues include the nature of individual rights and freedoms in this context (175,176,177,178,179), the constitutionality of laws prohibiting euthanasia or assisted suicide(140,165,168,169), the nature and relevance of distinctions between palliative measures, forgoing treatment and euthanasia and assisted suicide(164,180,181,182,183,184), and the appropriate response of organized medicine in terms of its responsibilities to provide high quality care for dying patients(185,186,187,188,189,190,191,192,193,194) or to embrace euthanasia and assisted suicide as appropriate medical interventions(145,148,150,195,196,197). Though fascinating and important, these discussions provide little sense of progress toward a different way of understanding and/or approaching euthanasia and assisted suicide.

Another aspect of the debate that receives far less attention, is no less significant, and holds some promise of expanding the way we understand and interact with euthanasia and assisted
suicide, is the nature of the social response to euthanasia and assisted suicide and its impact on those individuals considering these options. Evidence has begun to suggest (including the findings of the study described in Chapter 5) that this sociological perspective may be particularly important for understanding and responding constructively to marginalised groups in society, such as the poor (198, 199) people with HIV/AIDS (47, 68, 69, 200), cultural or ethnic minorities (201, 202, 203), and possibly also women (204, 205).

A central aim of this thesis is to provide an account of the social process of decision making regarding euthanasia and assisted suicide (by people with HIV/AIDS), with a view to embellishing our current language and conceptual frameworks for these phenomena. (These issues are explored in greater detail in Chapters 7-8).

Summary

The long-standing debate about the ethical and legal acceptability of euthanasia and assisted suicide has given rise to a rich palate of ideas that has shaped the way we approach and understand euthanasia and assisted suicide at various levels in society. Although the debate has been—and remains—central to the on-going process of evaluating the appropriateness of the public response to euthanasia and assisted suicide, it has remained remarkably unencumbered by accounts of the experiences of people facing these decisions. In the following chapters, I will describe a qualitative study that aims to expand the role of these experiences in the public debate. The relevance of the findings for the ethical, legal and policy aspects of the debate are described in detail in Chapter 10.
CHAPTER 5

Methods

Introduction

In the previous three chapters I have introduced the study described in this and the following three chapters. In Chapter 1 I explained the purpose of the study. In Chapters 2 and 3 I have tried to provide a description of the background for the study and an account of its significance by reviewing the state of knowledge regarding euthanasia and assisted suicide—particularly as they relate to HIV/AIDS—and the desire to die in terminal illness, and by identifying ways in which the study findings may represent a useful contribution to the existing knowledge.

In this chapter I will review the study methods in detail. The chapter is organized into subsections on Design, the Research Setting, Sampling, Sample Size, Data Collection, Data Analysis, and Legal and Ethical Issues, respectively.

Design

The central aim of the proposed study is to document the experiences of people with HIV/AIDS with decision making regarding euthanasia and assisted suicide. There are two main facets to these experiences: (1) what actually happens, i.e. an account of the process of decision making; and (2) what is the meaning of the experiences, and the specific components of the experiences, for participants, and how does the meaning influence what they do?

These questions are most appropriately addressed using a Grounded Theory approach (206, 207). Grounded Theory is a qualitative research method whose principle aim is
to facilitate the "discovery of theory from data systematically obtained from social research." (208) The method is particularly well suited to the investigation of complex social processes.

A qualitative research design was chosen over some of the more common research designs that have been applied to euthanasia and assisted suicide, such as surveys, because it was thought that these methods had not been sufficiently productive in terms of revealing why people decide to have euthanasia and assisted suicide. Because they ask only a limited set of questions in one specific way, they reveal little of the highly personal meaning of these experiences to the respondents, nor the richness of these experiences. Like surveys, qualitative research methods aim to discover patterns and similarities within a sample. But unlike surveys, qualitative methods are designed so that these patterns are sought from within the participants' own account of the phenomena, not an account imposed on them by the investigators (though this is a concern in qualitative research as well—see the discussion of the initial conceptual framework below).

Another shortcoming of surveys to date is that they have contributed little to our understanding of what actually happens in practice, i.e. what gives rise to considerations about euthanasia and assisted suicide and the process by which people make their decisions. Even the few qualitative studies that have been done in the area (40, 45, 47), though helpful in providing a richer account of the phenomena, have been largely descriptive and have revealed little of the complex motivating forces that bring people to decisions regarding euthanasia and assisted suicide. Therefore, the decision to use a Grounded Theory method involved a choice among qualitative methods as well.

The decision to use Grounded Theory was made for two main reasons. First, because the method offers explicit procedures aimed at providing a thorough account of the social process (in this case decisions making about euthanasia and assisted suicide in people with HIV/AIDS) as it relates to, and is shaped by, its meaning(s) to participants. And second,
because the method generates a theory, or explanatory account, of the phenomena in question. As was discussed in Chapters 2 and 3, there are currently no theories of euthanasia or assisted suicide. This means that the existing empirical evidence regarding euthanasia and assisted suicide is not well integrated into a coherent explanatory account of the phenomenon. Morse has described one of the roles of theory in research as “a summary of knowledge to date that organizes ideas, delineates variables, and identifies the relationship between those variables so that the framework guides the process of data collection and analysis” (209). It is hoped that the Grounded Theory generated in this study can provide at least part of this suggested function.

The Research Setting

In the spring of 1995 I was working on the development of a population-based database for HIV/AIDS related research in Ontario, the HIV Ontario Observational Database (HOOD). The HOOD is unusual among epidemiological databases in that it utilizes a completely voluntary enrolment model. One feature of the enrolment procedures in particular provided the impetus for a study of enrollees’ experiences regarding euthanasia and assisted suicide. Once prospective participants have consented to enrol in the HOOD, they are given an opportunity to indicate whether or not they wish to be contacted at a later date, by their enrolling physician, to participate in future HIV/AIDS related studies. This feature makes the HOOD database a powerful and flexible sampling frame (see discussion under Sampling below).

Participants’ experience with the study began when they were approached by their physicians and provided with the study information and a number at which they could reach me to arrange an interview (see Patient Information Package, Appendix A). In many cases, the physicians had a brief discussion with the participants about the study (this was later recounted to me by the participants), in some cases because of a past history and/or a present experience of depression. Physicians were asked to screen patients who were suicidal, or
imminently suicidal, and some chose to explore the patient’s mindset before informing them of the study (see Appendix B for a copy of the letter to participating physicians).

The study interviews took place in one of several interview rooms that had been made available to me for the study, at the participating clinics: the Medical Outpatient Clinic at Sunnybrook Health Sciences Centre; The Wellesley Health Centre; and The Immunodeficiency Clinic at the Toronto Hospital.

**Sampling**

Following the ethics approval of all study documents (see discussion below) information packages were distributed to all HOOD enrollees in the participating clinics who had indicated that they wished to be contacted by their physician about non-clinical trial studies related to HIV/AIDS. Each HOOD enrollee has a set of unique identifiers that allow HOOD staff members to differentiate among individual enrollees for data management purposes, without knowing the identity of any individuals. These identifiers are part of a more elaborate strategy to protect the confidentiality of HOOD enrollees and the security of HOOD data.

Initially, in October 1996, unique identifiers for the 320 eligible HOOD enrollees were generated from the main HOOD database and forwarded to the participating clinics, where the clinic staff matched the unique identifier with the patient’s name. Almost a year later, in September 1997, unique identifiers for another 366 eligible patients were generated and forwarded to the participating clinics, for a total of 686 eligible patients who represented all eligible HOOD patients between October 1996 and September 1997. The second list was used because of a slower than expected response to the first distribution of patient information packages. The list containing both the HOOD identifiers and the patients’ names

\[ \text{1Several interviews were held at undisclosed locations that were selected by the study participants either for their convenience, out of concern for confidentiality, or in the case of quite advanced illness in the case of one participant.} \]
is kept in the clinics at the same level of security as all patient chart information. This list is used by the clinic staff to facilitate all approved HOOD research. The patient information materials were packaged in an unmarked envelope, were placed in the charts of the eligible patients by clinic staff and were distributed to the patients by the physician.

Once the patients had received and read the study information, they were free to decide whether or not to contact me to arrange an interview. No one at the clinic or at HOOD knew whether or not any specific patient had called to arrange an interview. Patients were given a cellular phone number. I carried this phone during business hours for the duration of the study. The phone system (Bell Mobility) does not keep records of in-coming calls, which added one additional level of security in that it would be impossible to trace calls from participants. The phone does not have a call-display function.

When patients called, I reviewed the main risks of participating in the study with them, as outlined in the information sheets. I then explained the nature and processes of the study, reminded them that they were under no obligation to participate, that they should use a pseudonym at all times during the study to ensure anonymity, that all tapes will be transcribed and destroyed and that any identifying information will be removed from the transcript, and that they may choose to end their participation in the study at any time. I then asked whether they had any questions they would like me to answer, and finally I asked if they would like to arrange an interview. Patients were given the option of meeting at one of the rooms available to me, or at a place of their choosing, so long as it did not present a security threat to me.

In total, 37 calls were received between November 1996 and June 1998. Of these, 2 interviews were booked but the participants did not show up for the interview, 2 callers were not sure whether or not to agree to be interviewed and ultimately chose not to be, and I missed one interview that could not be rescheduled. In total, 32 interviews were completed.
Sample Size

The standard approach to determining the appropriate sample size for a Grounded Theory study is to stop recruitment when new data do not add to the properties or dimensions of categories in the developing theory(208). At the most basic level, this “saturation” effect is well known to qualitative researchers. However, Glaser and Strauss’s requirements—outlined above—if taken literally, provide an extremely stringent measure of sampling sufficiency. It is doubtful that the vast majority of published studies using any qualitative research methods achieve this goal.

Sampling was limited in two ways in this study. Both limitations were a result of the passive stance to recruitment that was required by the Research Ethics Boards that approved the study. These requirements were due to the potential legal implications of the study (see Chapter 5 for a complete discussion of the ethical and legal issues encountered in the study). First, the study procedures limited me to non-theoretical sampling only. In other words, as theoretical questions arose from the analysis of new data, I was unable to follow up with purposive sampling aimed at clarifying or elaborating on the specific concept, category, property or dimension of interest at the time. Instead, these were explored with subsequent participants without specifically seeking out participants who might be particularly well situated to provide insights on these matters (as is done in purposive or theoretical sampling). Second, the passive recruitment method made it impossible for me to recruit participants within the approved study protocol beyond those who actually called. The final result was that only 32 participants were recruited over an 18 month period. There were several opportunities to recruit participants during the course of the study through other connections within the HIV/AIDS community, but these were forgone.

The final sample of 32 participants might best be characterized as a “convenience” sample. However, the sample may be better representative of the population in question, i.e. those people with HIV/AIDS who consider, deliberate about, or make decisions about euthanasia
and assisted suicide, than typical convenience samples. This is because euthanasia and assisted suicide, unlike diseases or genetic pre-dispositions, are self-selected activities. There is reason to believe that the topic of the study acted as a powerful selection mechanism for those individuals who may also "self-select" for euthanasia or assisted suicide. Most participants reported that they had participated in the study because of a personal interest in (for many, though not all, this was also a strong conviction in favour of) euthanasia and assisted suicide, and the vast majority of participants had clearly thought deeply about these issues from a personal perspective.

The sample of 32 people with HIV/AIDS provided a rich data set that provided adequate data in most of the categories of the theory. In some cases, for example the role of gender, there were aspects of the theory that could not be explored in sufficient detail due to limited variability with respect to the category. Only one of the 32 participants in the sample was female(3%), whereas 11% of those people with HIV/AIDS enrolled in the HOOD database are women(210). Overall, however, the sample provided sufficient variability to allow for a rich theoretical account.

**Data Collection**

**Data**

The source of data for this study was the verbatim transcripts of 32 individual participant interviews, totalling approximately 600 transcribed pages. These were transcribed from tape-recorded, face to face interviews. Initially the interviews were loosely structured around the conceptual framework described above. The transcripts were saved as text files and imported into ATLAS/ti, the qualitative research software used to facilitate the analysis. Within ATLAS/ti, each transcript was stored under its corresponding unique identifier as a "primary text document" from which all quotes are drawn and to which all further steps in the analysis referred (see Data Analysis, below).
The Interviews

Upon meeting the participants, and prior to the interviews beginning, I once again explained the main risks and procedures involved in the study and asked the person whether she/he was willing to consent to participate. The participants were not asked to sign a consent form, in order to ensure that no names were recorded, but rather were asked to state their consent on the tape, for the transcript record. The interviews ranged in length from 40 minutes to 120 minutes. Following the interview, participants were given an opportunity to ask any questions about the study and/or their participation in the study. All participants were given a $20 stipend to cover personal expenses incurred through their participation.

The data collection occurred in two steps. First, At the beginning of each interview, the participants were asked a series of questions about their demographic and health status information (see Appendix C for the demographic questionnaire). I asked the participants each question and recorded their answers onto a separate data sheet. These sheets were then coded with the participant’s unique identifier so that their data could be linked to their transcript. These data were then entered into a data file in SPSS for subsequent analysis.

The second step in data collection was the interview itself. I began the interview by explaining—for the third time (i.e. first in the information packages, second when the participant phoned to arrange an interview)—the risks of participating in the study and discussing any concerns the participant may have had. At this point I also informed the participant that he/she was free to stop the interview at any time. Once any concerns had been discussed to the satisfaction of the participant, I said that I would ask her/him, for the record, to consent to participate when I turned on the tape recorder. I then turned on the tape recorder and said that we had discussed the main risks of participating in the study and asked the participant if she/he consented to participate in the study.

Once the participants had given their consent to continue the interview, I asked two questions
that were designed to bring the interview to a focus on euthanasia and assisted suicide. First, I asked participants why they had decided to participate in the study, and second, I asked them how they would define euthanasia and assisted suicide. Once these initial questions had been asked and answered I followed two parallel tracks in terms of guiding the process of the main body of the interview: (i) the participants’ responses to the demographic and health status questions; and (ii) a conceptual framework developed in the initial phase of the study development (see Data Analysis, below). The passages below are examples of how I asked these questions. The examples are taken from the verbatim transcripts.

O.K. Uhmm, now you’ve said that even before your diagnosis in 1986 you felt strongly about this [euthanasia], could you tell me a little bit more about where that feeling came from?

O.K. let me just follow up on two things, then. I want to ask you a little bit about the discussions with your family, but before I do that, could you tell me what it is that the drugs are doing? It seems obvious in one sense, but I’d just like you to tell me why it is right now that you don’t feel that you need to do this [euthanasia or assisted suicide].

So was there, what affect did that that sort of framing [the way HIV diagnosis was delivered by participant’s doctor] then have on on the way you were thinking about just your life, in general, at that point?

Right. Okay. Okay that’s great then that’s that helps just sort of set the set the tone. Okay, uhmm the uhmm what I’d like to start off with then is just to ask you about you’re your decision. Uhm you said that uhmm that you’re undecided at this point but that you’ve started to to think about this. Could you just, you know, tell me about that generally?

Data Analysis

An initial conceptual framework was developed in order to guide the initial interviews. This conceptual framework is derived both from the preliminary studies of our research group and
an initial review of the literature on euthanasia and assisted suicide that was performed as one of the initial steps in the development of study protocol.

**Preliminary Studies of Our Research Group**

At the time the study was being developed, our research group was in the process of completing a study on advance care planning in patients undergoing renal dialysis (211). One of the findings of that study was that even those people who wanted to talk about advance care planning with their loved ones could be thwarted in their efforts if the person with whom they were trying to discuss these issues was uncomfortable, in any way, with the topic of death and dying. In other words, the stance of this person toward to subject matter of the discussions had a profound effect in determining whether or not the patient successfully completed his/her advance care planning, or whether the process simply stopped at that point (which was the case for many participants).

In beginning to design the present study, this concept of others influencing patients' decisions was thought to be potentially important in decision making regarding euthanasia and assisted suicide, though the initial searches yielded no published data on this. As well, the advance care planning study illustrated the profound discomfort that some people experience in even talking about their loved one’s death or dying process. It was unclear at the time how this might be reflected in decision making regarding euthanasia and assisted suicide in HIV/AIDS, but it was felt to be an important contextual issue to explore in the study.

**Initial Review of the Literature**

The initial literature review uncovered empirical and philosophic literature regarding euthanasia and assisted suicide. It resulted in the identification of a set of prominent concepts. These concepts were used as a way of organizing some of the main ideas in the literature and provided a schematic guide with which to begin the study interviews. The conceptual
framework that was used to initiate the study bears little resemblance to the literature reviews that are described in Chapters 2 and 3. These represent a much more thorough and detailed exploration of the literature, including the sociological and psychological literature, and explicitly emphasize the factors that were thought to influence people's decisions, the process through which decisions are made and euthanasia and assisted suicide are carried out, and the inter-relationship between the factors and the process. These reviews were conducted once the main concepts and categories had already been discovered in the current study.

The role of initial, guiding conceptual frameworks is contested in qualitative research. Although it is considered unreasonable for qualitative researchers to begin their investigations of complex phenomena without some sense of the main concepts and issues that they may encounter in their studies, it is widely known that well developed conceptual frameworks can constitute a real threat to validity. Researchers often use these frameworks to organize data into pre-selected categories, which serves merely to confirm the researcher's perspective and hinder real discovery(209).

Therefore, in beginning this study I chose to familiarize myself with some of the main ideas in the literature and to keep these ideas on hand as a schematic outline for an interview in the event that participants had little to offer (in fact, this never happened). I also used this framework as a guide to help me to probe and prompt participants, particularly with respect to the inter-relationships between and among their own concepts and those of the initial conceptual framework. For example, when participants mentioned the concept of 'dignity' I asked them what the concept meant to them and tried to ask them questions that would let me hear their own perspective on various aspects of the concept, so as to avoid implicitly seeking their agreement with a pre-conceived idea about the concept. For example, I asked several participants why they thought it was undignified for someone else to clean them if they became incontinent (the philosophic literature offers many perspectives on this issue). These uses of the literature and previous findings are consistent with those suggested by Strauss and Corbin(206). In particular, they suggest that investigators have some "theoretical
sensitivity" when beginning any investigation and that the literature and previous research findings are appropriate sources for a useful set of sensitizing concepts.

These concepts included the following:

**Autonomy.** Although autonomy has been described in various ways, it is autonomy as the right of individuals to determine the events and course of their own lives that appears to be most relevant to the debate about euthanasia and assisted suicide. Empirically, the importance of the concept of autonomy is demonstrated in findings such as those of Ogden that suggest that maintaining control over the dying process is a high priority for people with HIV/AIDS(47). However, the prominence of autonomy, both as an explanation of, and justification for, euthanasia and assisted suicide and other activities related to health care decision making has recently been called into question. For example, a recent study by our research team in dialysis showed that both control and relieving the burden on loved ones were important goals of advance care planning(211). These findings raise questions about what autonomy means to people with HIV/AIDS in the context of decisions making regarding euthanasia and assisted suicide.

**Role of Others.** In our study of the social process of advance care planning in dialysis(211) none of the participants whose friends or loved ones gave a neutral or negative response to the idea of living wills, or the notion of discussing matters surrounding death and dying, went on to complete a written advance directive. Whereas, a third of the individuals who reported a positive response from friends or loved ones went on to complete a written advance directive, a higher proportion than that reported for the general public(212).

Three specific themes regarding the role of others emerged as important mediators of decision making in the dialysis study: the attitudes and opinions of others; past personal experiences with death and dying; and the desire to relieve loved ones of the burden of making difficult life and death decisions on their behalf in the event that they became
incapable. In the dialysis study, and in a subsequent study with people with HIV/AIDS(213), past experience with severe illness, either a personal experience, or the experience of someone close, had a clear influence on decisions in favour of forgoing life-sustaining treatment. This theme was expected to be relevant to euthanasia and assisted suicide in HIV/AIDS, particularly in the gay community, where people with HIV/AIDS are likely to have experienced the deaths, and perhaps assisted with the deaths, of a number of friends/partners.

As well Dr. David Roy, in his testimony before the Special Senate Committee, suggests that rejection by others may play an important role in shaping decisions regarding euthanasia and assisted suicide for people with HIV/AIDS: "I have seen that, particularly with respect to AIDS patients who have been totally abandoned by their parents, brothers and sisters and by their lovers, in a state of total isolation, cut off from every source of love and affection, they would see death as the only liberation open to them. In these circumstances, subtle pressure could bring people to request immediate, rapid, painless death, when what they want is close and powerful support and love."(2(pp.56-57))

*Dignity.* Dignity is a term that has been used extensively in the titles of organizations(214), titles of legislation(215,216,217), the medical literature(218,219,220), and even in Supreme Court decisions pertaining to euthanasia and assisted suicide(136). What is most compelling is the way that the term, though vague, has come to be accepted as an abstract standard of how terminally ill patients are expected to die. For example, in his study of patient attitudes to euthanasia and assisted suicide in the Netherlands, van der Maas found that 57% of patients surveyed cited "loss of dignity", and 46% cited "not dying in a dignified way" as reasons behind their requests for euthanasia or assisted suicide(221). These patients equated these reasons with "unworthy" dying(222), though no further explanation is offered.

Similarly, reports of humiliation, shame, and embarrassment by people with HIV/AIDS(8) and reports of experiences of stigmatization and discrimination, even from within the gay
community(47), are already part of the prevailing culture of AIDS. These ideas raised questions in my mind about the societal expectations of the behaviour of dying persons, expectations of care givers, the role of discrimination and stigmatization, and the origins and implications for people with HIV/AIDS of feelings of shame, humiliation and embarrassment in the face of the dying and death.

**Suffering.** Several commentators have explored the complexity of the phenomenon of suffering, particularly as it relates to dying and terminal care(223,224). However, the specific nature of suffering that patients are presumably aiming to avoid by requests for euthanasia or assisted suicide has not been well characterized. In particular, the relationship between the mental and physical components of suffering is poorly understood. Several studies have demonstrated a strong correlation with depression and desire to die(125,225). One study demonstrated that this correlation was even stronger than that between physical pain and the desire to die(46). This relationship between depression and desire to die has also been demonstrated specifically in people with HIV/AIDS(114). These findings directed me to be sensitive to how participants perceived suffering associated with dying from AIDS, whether there are discernable 'mental' and physical components of suffering, experiences of loneliness, abandonment, and perceived quality of life and how they might affect decisions regarding euthanasia and assisted suicide.

**Care.** It has been argued that the widespread availability of excellent palliative care would render euthanasia and assisted suicide unnecessary. Much has been written already about the inadequacies of our existing caring institutions(188,196). It is also known that physicians are, in general, inadequately trained(226), and generally ineffective in pain management(113) and terminal care(226). As euthanasia and assisted suicide are, almost by definition, acts intended to avoid continued 'care' interactions—both formal and informal—it was expected that an exploration of the experiences of people with HIV/AIDS with these care institutions might illuminate discrepancies between the way care is delivered and the needs and expectations of people with HIV/AIDS.
As the data collection and analysis proceeded, the interviews became more solidly based in the participants' own concepts, while the initial concepts took on a secondary importance. This does not mean, however, that the initial framework was irrelevant, but rather that the participants had sufficient insights that were not reflected in the initial concepts (or not adequately reflected) to ground a developing theory. With a few exceptions that resulted from back-to-back interview scheduling, or back-logs with data transcription, I used the developing theory to guide each subsequent interview. Nearer to the end of the study, beginning approximately with the 25th interview, I began to take some time at the end of each interview to present the participants with some of the main concepts emerging from the analysis and ask them whether or not these concepts made sense to them and whether they were reflected in their own personal experience.

The Role of the Investigator

As the investigator in this study I had no prior knowledge of any of the participants and none of them knew me. As a non-clinician, there was no real concern about crossing into the role of a counsellor or diagnostician, though I found myself, on occasion, trying to clarify glaring misconceptions about the availability of services or other matters that could potentially have had a bearing on the participants' well being. For example, one participant was under the impression that all deaths from AIDS were necessarily filled with unremitting pain. I broke out of the role of investigator briefly and told the participant that this was not true, but that we still had a long way to go in terms of ensuring access and consistently high quality pain control. None of these issues had any bearing on the immediate health or well being of the participants, and in all cases I urged the participants to consult with their doctors or clinic staff if they had any specific questions or concerns.

One of the complicated aspects of my role as a data collector and analyst was trying to minimize the influence of my own personal ideas about euthanasia and assisted suicide and the constraints of some of the main theoretical questions that had given rise to the idea for
the study in the first place (see the discussion of the initial conceptual framework above).

Having been interested in euthanasia and assisted suicide for some time, and having worked in HIV/AIDS research for a short time (at that time) I was concerned on two broad grounds: (i) that decisions to have euthanasia or assisted suicide may be influenced by others, particularly others who might subtly or not so subtly encourage these options; and (ii) that the prevailing negative attitudes in society about AIDS and homosexuality, in particular, might provide an ironically tolerant context for such coercive actions.

Fortunately, both processes were greatly simplified early on in the study interviews, when it became readily apparent that none of the participants was experiencing anything like this type of coercive influence. Though there were discernable influences within individual relationships and among groups, these were subtle and not easily identifiable at the outset, i.e. they appeared to be good subject matter for a qualitative study, requiring some labour and analysis to understand.

Although I do not hold a dogmatic view toward euthanasia and assisted suicide, I am not a ready supporter of public policy that simplifies access to these options. In the context of HIV/AIDS my main fears surround our failure as a society to make a comfortable place for many of the people most affected by HIV/AIDS, as well as the consequences of eroding the symbolic prohibition against killing that must play some fundamental role in the order of a decent society. My personal experience with suffering and marginalization are negligible, but my experience working with the AIDS community has been extremely illuminating in terms of my awareness of the breadth and depth of the discrimination and alienation experienced by people with HIV/AIDS. Although my fundamental views have changed little through the course of this investigation (in some ways they have been reinforced), my appreciation of the extent to which many people with HIV/AIDS have experienced horrible deaths, and of their genuine desire to avoid a horrible death for themselves has been greatly enhanced. As well, my appreciation for the complexity of the lives of many of the participants has left me with a deep rooted admiration for the way they conduct themselves in the face of their many
personal and political struggles.

Analytic Process

The analysis of the data followed the methods described by Strauss and Corbin (206), though the initial discussions of theory and constant comparative method in Glaser and Strauss's *The Discovery of Grounded Theory* (208) were also referred to extensively. The analytic approach involves three main steps: (i) open coding, the process of breaking down, examining, comparing, conceptualizing, and categorizing data; (ii) axial coding, the process of re-assembling data into groupings of categories based on relationships discovered in the data; (iii) selective coding, the process of identifying and developing the central phenomenon as indicated by the data.

For example, one participant talked about people dying slowly, "a little piece at a time". In open coding, I identified this discrete passage of text as being indicative of a specific code or concept that I called 'disintegration'. In axial coding, after more than 200 individual codes had been identified in the transcripts, I began to subsume a number of these codes into the developing category called disintegration. These codes included 'duration of illness', 'symptoms', 'onset of symptoms', 'physical activity', 'quality of life', 'reliance on life-sustaining treatment', 'slow disintegration', 'the bottom line', and others. These additional codes (i.e. the data represented by the codes) contributed to the development of the properties and dimensions of the category by demonstrating that disintegration has the following properties: duration, pace, functional effect, and extent (in Chapter 7 I provide a more thorough account of the category of disintegration).

In Grounded Theory, the main tool for developing the specific properties and dimensions of the categories, is the "paradigm model", a structured account of the relationships discovered between and among categories of data. This is a heuristic device that encourages the analyst to identify and account for the causal conditions associated with the specific category or
phenomenon, the context and conditions under which the category relates to other categories and the broader theory, and any actions or interventions that may affect any specific consequences associated with the specific category (206).

The analysis for this study was performed using ATLAS/ti v. 4.1. This is qualitative research analysis software that was initially designed to facilitate the analytic procedures of Grounded Theory. By combining powerful text analysis capabilities with a sophisticated visual model-building interface, it allows for elaborate graphical depictions of categories using the basic structure of the paradigm model and greatly simplifies the process of integrating each category into the overall theory, a task that is both labour-intensive and cumbersome in the absence of these tools. I have utilized the basic structure of the paradigm model as a conceptual data management tool to ensure the adequate conceptual and mechanistic development of each category and to guide the development of theory.

The process of open and axial coding involves making comparisons among the many various instances of a given code or developing category found in discrete selections of data. These comparisons form the analytic basis for the identification and specification of the properties and dimensions of categories (206). The process of grounded theory analysis is often referred to as the ‘constant comparative method’.

During the process of open and axial coding, I began to explore various alternative conceptualizations of the core meaning of the data, i.e. I began the process of selective coding, though this was not complete until after the first draft of this thesis was scrutinized. In terms of the grounded theory method, there are stylistic differences in the way that even Glaser and Strauss (who initially introduced grounded theory) recommend pursuing the intellectual process of selective coding. Strauss was said to interrogate the data through a series of theoretical questions suggested by the data, whereas Glaser is said to take a more inductive approach, whose point of departure is the question “what is going on with this data?” (227), with a view to allowing the theory to “emerge”.

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My general approach to selective coding, and the approach that I took in this study, is more in line with Strauss's tendency to interrogate the data with theoretical questions, though Glaser's notion of the theory "emerging" from the data seems to me to accurately reflect the process whereby initial questions of the data—which appear to be largely unfruitful in eliciting theory—gradually evolve into a more focused and refined stance with respect to the data and give rise to a much more limited range of viable options for a selective code that best fits the data. Once the open and axial coding were complete in this study, the process of selective coding described above led me to conclude that the central meaning of the study was that the disintegration of AIDS can ultimately result in a sense of loss of self, and it is this experience—and even the fear of it—that leads some people with HIV/AIDS to decide to have euthanasia or assisted suicide. This account is developed in more detail in Chapter 8.

**Ethical and Legal Issues**

The study was reviewed by independent Research Ethics (and Research Review) Boards at all participating institutions, including The University of Toronto Human Subjects Research Ethics Review Panel and the HOOD Research Review Committee. Chapter 5 provides a detailed account of the research ethics review process (see Appendix D for the notifications of approval from the participating Research Ethics Boards). In the study individuals were interviewed about personal experiences, some of which may have involved illegal activities. There were three major ethical issues related to the design and methods of the study: the risk of identification and legal repercussions, the risk of emotional harm to participants, and the nature of the consultation with the HIV/AIDS community. In Chapter 6 I explore these issues in detail and provide a thorough account of how each was managed along with an account of the process by which the study was reviewed by the Research Ethics Boards at the participating institutions.
Chapter 6

Ethical and Legal Issues

A serious discussion of physician-assisted death for persons with AIDS has begun in our nation. But we have developed a pseudo-dialogue rather than an authentic one....The subjects (or objects) have been left out; their voices unheard....Are we resisting doing the necessary research because it will be difficult? Is any serious research easy?(200)

In Chapter 2, I presented a summary of the growing body of empirical evidence regarding euthanasia and assisted suicide. Most of these studies have employed surveys of public opinion, and physicians’ attitudes and opinions. There remains a gap in the literature, however, regarding the personal experiences of those individuals considering and requesting these interventions(7), despite the fact that some of the few available studies challenge the notion that terminally ill patients desire euthanasia or assisted suicide largely in response to pain and physical suffering(21,47). Empirical evidence of these experiences is essential to understand what actually happens and why. Yet the question: Why do people desire or request euthanasia or assisted suicide? has received very little direct attention in empirical studies. Intuitively, this seems remarkable, but there are two good reasons why it has not.

First, because of their current legal status, any study involving people’s experiences with euthanasia and assisted suicide entails a number of complex legal and ethical issues that must be addressed. These include the risk of legal consequences for participants, third parties and investigators, the emotional nature of the subject matter including complications associated with active depression, and the broader implications of working closely with participants from an identifiable community. Although these issues are common to all studies involving euthanasia and assisted suicide, they may be particularly salient in qualitative studies that involve face-to-face interactions between participants and investigators, and which entrust
investigators to fairly and accurately represent the personal “stories” of participants.

Second, because of the complexity of these issues, the ambiguity about the legal obligations of investigators working in these areas, and the scarcity of previous research, the process of designing studies that are ethical and legal and having these approved by the necessary Research Ethics Boards may be complex and lengthy.

This chapter has two aims. First, to describe the ethical and legal problems that were encountered during the process of designing and implementing the original study of decision making regarding euthanasia and assisted suicide in people with HIV/AIDS described in Chapters 5-9 and the approach taken to address them. And second, to describe the process of research ethics review and its contribution to the way the ethical and legal issues were managed in the study. The description of how this study was designed and conducted is important because it illustrates how the ethical and legal problems that currently constrain research in euthanasia and assisted suicide can be addressed successfully.

Although there have been many calls for further research in this area(2,228), to my knowledge there are no published descriptions of how ethical and legal issues should be addressed in empirical research in euthanasia and assisted suicide. The description of how these problems were addressed in this study may assist other investigators in designing subsequent studies and may also be instructive for Research Ethics Boards, which are likely to have limited experience in reviewing this type of proposal.

Ethical and Legal Concerns in Empirical Research on Euthanasia and Assisted Suicide

Risk of Identification and Legal Repercussions

Euthanasia and assisted suicide are currently illegal activities in Canada and in most
jurisdictions in the United States. As a result, any investigation of people’s experiences with euthanasia and assisted suicide entails some risk that participants, investigators and, potentially, third parties (i.e. others, such as doctors, who may be implicated in illegal activities by study participants) could be identified against their will, compelled to give evidence or surrender study data to a legal inquiry, or charged with a criminal offence. If an individual is charged, the evidence contained in the study data may increase the likelihood that she/he is prosecuted successfully.

These risks are not merely hypothetical. In 1993, in a study of euthanasia and assisted suicide in people with HIV/AIDS in Vancouver, Russell Ogden was called to testify and surrender study data to a coroner’s inquest of a suspicious death. Ogden refused to surrender his data, claiming that such an action would be detrimental to all social research that requires special disclosures in confidence(229). Although Ogden prevailed in the coroner’s court, in that he was not compelled to surrender his data, this decision does not constitute a legal precedent and, therefore, does not confer any protection on future researchers engaged in similar activities(230).

In the United States, the Federal Public Health Service Act(231) provides for certificates of confidentiality, which protect against compelled disclosure of identifying information about participants in biomedical, behavioural, clinical and other research. Several states have enacted similar laws(232). Although these laws address the main concerns encountered by investigators researching euthanasia and assisted suicide, they may not provide sufficient protection for research participants in every circumstance.

For example, the certificates do not necessarily protect participants from discretionary, voluntary disclosures by investigators, as in the case in which the investigator feels a legal and perhaps moral duty to disclose a reported illegal activity to the authorities. As well, because neither suicide, nor attempting suicide, is illegal in the United States or Canada (though a person may be found guilty as an accessory to a third party’s offence under S. 241 of the
Criminal Code of Canada), the risks of compelled disclosure are likely to be borne by third parties such as friends, family and physicians who might be harmed by the disclosure. Because the central issue is the protection of research data, the law provides no specific protection for these people. The new Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans does not explicitly address this issue (233).

A recent decision by the European Court of Human Rights upheld the right of a British journalist to withhold the identity of his informant and personal notes that may have assisted the authorities to identify the informant, despite a ruling by the House of Lords that disclosure of the informant's identity was "in the interests of justice" (234). The implication of this decision for social researchers is not clear, but a vigorous debate on the issue of continues (235, 236).

In light of the uncertainty regarding the rights of social researchers to withhold the identity of their informants and personal notes or data that may aid in identification of informants, an ethical study of people's experiences with euthanasia and assisted suicide must adequately address these legal risks for the study participants and third parties.

In addressing the risk of identification and legal repercussions, I chose to place the emphasis on two aspects of the research design: (i) developing mechanisms to ensure anonymity; and (ii) the adequate disclosure of residual risks to prospective. I saw this approach as a viable way to address some of the problems that had been encountered by Ogden in his study of euthanasia and assisted suicide in people with HIV/AIDS in Vancouver participants (237) (see a more detailed description in Chapter 2).

In Ogden's study the investigator was subpoenaed by a coroner's inquest and compelled to surrender his study data into evidence. The investigator's refusal to surrender his data and his subsequent release from this obligation by the presiding coroner have contributed to an expectation within the HIV/AIDS community that researchers will promise not to surrender
their study data in the face of a court order to do so.

This approach is problematic for several reasons. First, the result of the coroner's inquest in the Ogden case does not constitute a legal precedent and, therefore, does not provide any legal protection or privilege for researchers with respect to legally withholding study data under a court order. As well, there is no mechanism in Canadian law that provides the equivalent protection as certificates of confidentiality and similar mechanisms in the United States. As a result, any promise to participants that their data will not be surrendered to the authorities may turn out not to be tenable. For example, if study data were subpoenaed and the investigators refused to surrender the data, a judge could simply find the investigators in contempt of court and conceivably order the seizure of the study data. In this event, the real tragedy—and potential source of further liability for the investigators—would be that participants had not been adequately informed about the foreseeable risk of these occurrences.

**Anonymity**

Anonymity is a crucial feature of research involving criminal activities, since it provides study participants, and others who may otherwise be identifiable, some degree of protection from being identified to third parties, and provides the investigators some legitimate insulation from obligations to report criminal activities to the authorities (i.e. with an anonymous contact, the investigator genuinely does not know who has allegedly committed any offence that may be described by a participant). Since researchers (HOOD staff included) do not have access to the names of any HOOD enrolees, the sampling frame feature of HOOD was seen

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2It is worth noting here that Ogden and I have discussed our respective strategies thoroughly over the past three years and that our differences arise ultimately in our interpretations of the place of social research in society and the freedom that should be afforded researchers to carry out their investigations. Ogden holds a more absolute position than I do on the rights of researchers to protect research data. In his view, any coercive measures that require disclosure of confidential data are unacceptable because they undermine the integrity of social research, whereas I believe that adequate disclosure of research risks to participants is a reasonable way to protect them and the integrity of social research.
as an ideal means of making anonymous contact with potential participants.

The participants' information package included a separate sheet that provided information about how the person could reach me to arrange an interview. The sheet provided a phone number for a cellular phone that I carried during set hours. The sheet also explained that the cellular phone was used because this phone system does not keep a record of incoming phone calls and, therefore, it would be impossible for the authorities to trace callers through phone records if these records were to be subpoenaed as part of an investigation. The information sheet requested that callers use a pseudonym if they called to arrange an interview in order to maintain anonymity.

Finally, a potential conflict existed between the requirements of scientific integrity and protection of anonymity. Although the transcripts of the participant interviews were 'cleaned' of any individuals' names, place names and other potentially identifying material, it was felt by some Research Ethics Board members that the audio tapes could still be a potential source of identification of individual participants through voice analysis. Therefore, it was proposed that the tapes be destroyed after transcription to defend against this possible means of identifying participants. However, the destruction of primary data is a highly irregular and controversial practice and places investigators in a very weak position in the face of challenges regarding the authenticity of the study data, i.e. to defend their scientific integrity. Therefore, a mechanism was sought that would remove the possible means of identifying participants and still ensure a reasonable defense in the face of potential allegations of fabrication of data.

The specific solution is currently being worked out. It is likely (though at the time of writing not definite) that the Office of Research Services at the University of Toronto will provide some assistance in locating a credible independent auditor who will sample the audio tapes and transcripts and make a determination as to their authenticity. The auditor's conclusion would then become part of the record of the study and would provide a reasonable response.
to any allegations of data fabrication.

**Disclosure of Residual Risks**

In the initial information sheet the risks associated with legal investigations are explained in detail, including a description of the fact that the investigators have no legal privilege with respect to withholding study data. At two subsequent points, first during the initial phone contact, and second before the interview, participants are informed of the residual risk of being identified. That is, despite the best efforts to design the study in a way that minimizes the risk of identification, it is still possible that the data could be subpoenaed as part of a legal proceeding and transcripts used in an attempt to establish the identity of one of the participants.

**Risk of Emotional Harm**

A second ethical issue is the participants' willingness and ability to discuss a difficult and highly personal, and potentially upsetting topic like euthanasia and assisted suicide. In some cases, participants' personal experiences may include participation in an assisted suicide. These experiences can be extremely disturbing and traumatic. The risk associated with this type of discussion is that participants may be upset, or that the discussion itself may contribute to the participant's desire to end his/her life. The latter, more extreme, outcome is a particularly pressing concern in the presence of active depression.

The association of depression and suicidal ideation is well known, and there have also been several reports of a close association between requests for assistance in dying and active depression(46,70). The challenge is to ensure that those participants who are most likely to have special knowledge of the phenomena of interest are included in the study while minimizing the risk of emotional harm and/or suicide, and to have a reliable strategy in place to deal with an actively suicidal individual should this become apparent through the course of
the interview.

To address this problem, the participating clinic physicians agreed to perform a pre-distribution screening of the eligible patients to exclude those that they felt were actively depressed, suicidal, or imminently suicidal. Although it has not been possible to determine the actual number of patients excluded on these grounds, several of the participating physicians have estimated that fewer than 10% of the 686 eligible patients were excluded.

I also consulted with a local psychiatrist specializing in the treatment of people with HIV/AIDS and sought advice regarding subtle signs of distress and discomfort that might assist me in the conduct of the interviews. Each participant was also offered a sheet containing contact numbers for all the participating hospital based clinics and emergency services in the event that they should feel upset or in need of attention following the interview.

The information sheet informed recipients that the packages were distributed solely on the basis of their enrolment in HOOD and their prior authorization to inform them of future studies, and that no health related criteria were used to target the distribution. The information sheet also contained a clear statement that the investigators would like to interview individuals who had decided in favour of euthanasia or assisted suicide, those who had decided against these, and those who are, as yet, undecided. These statements were intended to minimize patients' feelings of anxiety over receiving any material about euthanasia or assisted suicide from their caregivers. The method of distribution of the information sheets also ensured that no one knew whether or not any individual patient had chosen to call me to participate in the study. This was important as a means of ensuring participants that their care would not be affected in any way by their decision to participate or not participate in the study.

As a procedural safeguard, all prospective participants were given three separate
opportunities to make a voluntary decision not to participate, once upon receipt of the
information sheet, once during the initial phone conversation, and once during the consent
process before the interview. In addition, all prospective participants were informed that they
were free to withdraw themselves and their interview data from the study at any time, up until
the time of publication of the study.

In the final act of the consent process, I stated that we (the prospective participant and I)
have just reviewed the risks of participating in the study and discussed any questions raised. I
then asked if the prospective participant consented to participate in the study. This exchange
was captured on tape, in lieu of a signed consent, as a way to authenticate the consent
without compromising the anonymous nature of the interview.

Process of Consultation with the HIV/AIDS Community

A third ethical issue involves the nature of the population from which the individual
participants are recruited and the obligations the investigators have to this population as a
community. Euthanasia and assisted suicide are often associated with people who are
extremely sick and terminally ill. This latter group of patients is often characterized as
"vulnerable" by individuals and committees engaged in research ethics review. Levine has
defined as vulnerable "those who are relatively (or absolutely) incapable of protecting their
own interests. More formally, they have insufficient power, prowess, intelligence, resources,
strength, or other needed attributes to protect their own interests through negotiations for
informed consent."(238)

Any ethical study of euthanasia and assisted suicide must acknowledge the potential of
vulnerability and ensure that the study procedures do not capitalize on or increase the
vulnerability of the population. However, it is also important not to incorrectly characterize a
population as vulnerable, as this can result in the unjust exclusion from the research of the
most appropriate participants(238). To the degree possible, an ethical study should consult
with and seek guidance from the community of interest before making judgements of vulnerability, and in many other aspects of the study design, implementation, analysis and dissemination(239).

The HIV/AIDS community was instrumental in determining the shape of the current study in two ways: (i) as partners in the development of HOOD procedures and policies in general; and (ii) as representatives on the various committees charged with assessing the scientific and ethical acceptability of the study (see discussion below).

The input of representatives from the HIV/AIDS community had a crucial role in determining the procedures and policies of HOOD, in particular, the stringent standards regarding participant confidentiality and data security. The voluntary enrolment model and specific aspects of the consent process were adopted in cooperation with and in response to the clear demands of the HIV/AIDS community.

The representatives of the HIV/AIDS community on the various review committees expressed several concerns about the study. The most challenging concerns involved the fear of misrepresentation, by me, of the study participants' experiences. This sentiment—expressed by a small minority of the HIV/AIDS community members—arose in response to the disclosure to the panel (and in advance to the agency that funded the study, the Canadian Foundation for AIDS Research) that I was not a strong supporter of euthanasia or assisted suicide. A fruitful discussion ensued during which I tried to focus the committee on the purpose of the study, namely decision making regarding euthanasia and assisted suicide, and the fact that the proposed method provided a means to bring the personal stories of people with HIV/AIDS to bear on the broader debate regarding euthanasia and assisted suicide. Furthermore, it was argued that the study results could conceivably be used by both supporters and opponents of euthanasia and assisted suicide and that, by itself, should not prevent the study from taking place.
Another difficult issue involved the role of the community in reviewing the study results in advance of their publication and dissemination. In particular, I was asked whether I was willing to provide the community with an opportunity to dissent from the findings if they do not accurately reflect the community's position. This issue was addressed procedurally. I proposed that the study results would be presented to the community, in several separate forums, and the feedback of community participants elicited in some manner that could be included into a final report of the results. Difficult questions arose regarding the nature of dissent from research findings that are based on the experiences of individuals with HIV, and conceptual and methodological issues about whether there was, in fact, a coherent community position regarding euthanasia and assisted suicide, and how representation of the community should be managed in any forum involving feedback regarding the study results.

At the time of writing, plans are being made to present the study findings at the participating HIV/AIDS outpatient clinics and to post notices to encourage community members to attend these sessions. At these sessions I will invite feedback and will incorporate this feedback into any subsequent publications.

One final issue concerned the dissemination of the research findings within the HIV/AIDS community. This issue has been dealt with previously at the HOOD and a mechanism has been established to distribute results of studies to AIDS organizations throughout the province of Ontario. As well, it is expected that at the time the study is completed a HOOD Web site will be operational on which the study, or some summary of results, will be available. The Joint Centre for Bioethics already has a Web site and the study results, or some summary of the results may also be available through it.

**Balancing Confidentiality with Concerns Regarding Scientific Integrity**

During the process of research ethics review the issue of scientific integrity was discussed, specifically, how charges of data fabrication might be responded to after the original taped
recordings of the interviews had been destroyed. However, the study was approved by all participating Research Ethics Boards without a specific strategy being selected. As a result, the study protocol, as approved, stipulated that the tapes would be destroyed immediately after the tapes had been transcribed.

Although the protocol was clear, I experienced some strong reservations when it came time to destroy the tapes, since we had not arrived at a satisfactory solution regarding potential challenges to scientific integrity. My decision at the time was to re-locate the tapes to a more secure storage facility (within the jurisdiction) and to delay their destruction of all the tapes until a satisfactory solution could be found with respect to the issue of scientific integrity.

In consultation with my supervisor Dr. Peter Singer and committee member Professor Bernard Dickens, who is also the Chair of the University of Toronto Committee on the Use of Human Subjects in Research, we explored a number of possible solutions to balance the twin issues of confidentiality and scientific integrity. We were assisted in this process by Ms. Susan Pilon, Director of the Office of Research Services at the University of Toronto, and a staff member of that department, Ms. Robyn Penslar, a lawyer with expertise in issues regarding scientific integrity. We ultimately arrived at an innovative solution. We decided to invoke the University of Toronto Faculty of Medicine’s policy regarding Academic Misconduct prospectively, in a protective stance against potential challenges of data fabrication. This policy has the distinct advantage of addressing both issues of confidentiality and misconduct, which also ensured that the process of authentication of the data was consistent with accepted principles of confidentiality.

After consultation with Dr. Mel Silverman, Chair of the Institute of Medical Science at the University of Toronto (my graduate department) it was decided that an authentication committee would be struck consisting of Dr. Silverman as Chair, and a member external to the University suggested by the Director of the Office of Research Services from an existing list of external reviewers. I would be required to appear before this committee with the
original tapes and transcripts and instructed to demonstrate the authenticity of transcripts and/or direct quotations from my thesis by playing the corresponding section of the original tape. The tape machine is equipped with a play-back speed control which allows for the distortion of the voices, hence ensuring that no one will recognize the voice of a given participant. As well, I will be present to play all tapes to ensure that any sections of the tapes that contain potentially identifying information are not heard by the committee. This process was also used to ensure confidentiality during data authenticity by Dr. Peter Singer in the normal course of Ph.D. supervision.

At the time of writing, the committee has been struck and a date is being selected to perform the final data authentication. The tapes will be destroyed in the presence of the committee members.

The Process of Research Ethics Review

The process of research ethics review and community consultation took nine months and involved reviews by eight separate committees. Ultimately the study was approved by seven of the eight committees. The study was not allowed to proceed at one institution. The reasons for the refusal at this institution are described in detail below.

The University

The study was reviewed by the Human Subjects Review panel at the University of Toronto. At the University, individual panels are struck for each protocol submitted for review. When it is deemed necessary by the panellists, a meeting is arranged and the investigators are invited to respond to questions and concerns about ethical issues associated with the proposed research. Such a meeting was convened for this study. The panel consisted of a lawyer, a criminologist, and a representative from the HIV/AIDS community. The meeting was chaired by the Director of Research Services.
The main concerns expressed during this meeting were about the nature of the anonymous contact and potential problems associated with my ability to recognize participants after interviewing them, practical issues regarding the extent to which transcripts could be "cleaned" of identifying names and remarks, the nature of cellular phone records, the destruction of the tapes, and questions about the suitability of the proposed methodological approach.

The community representative raised questions regarding the extent to which the HIV/AIDS community could expect to be involved with the study beyond participation in the interviews and what plans I had to disseminate the study results within the HIV/AIDS community. These issues are addressed above under Role of the Community.

The HOOD

The study proposal was submitted for review to the HOOD Research Review Committee (RRC). This committee reviews all proposals for research utilizing the HOOD database. This study utilized the database as a sampling frame only. The protocol did not call for the use of any data contained in the database. At the time, the committee was made up of two physician-researchers and two representatives of the HIV/AIDS community, one of whom was the Chair of the committee and also a member of the HOOD Executive Committee (HEC). The HEC is the main policy setting body for the HOOD. A majority of its membership (50% + 1) is from the HIV/AIDS community, elected by the Ontario AIDS Network, a provincial association of AIDS service organizations. The remainder of the HEC members are elected from provincial HIV clinic directors and coordinators, HIV primary care physicians and the University of Toronto.

The RRC reviewed the proposal and provided feedback. The main issue raised by the committee was of the risk of potential harm to physicians who may be implicated by patients as collaborators in acts of euthanasia or assisted suicide and who may, ultimately, be
identifiable through interview transcripts. This issue was complicated, in the eyes of the committee members, by the fact that the physicians had no power to consent to participate, or withhold their consent to participate in the study.

I responded to the RRC's concern about the physicians' involvement in the following way. First, euthanasia and assisted suicide are illegal activities in Canada and therefore physicians involve themselves in these activities at their own peril. Second, I argued that such an important research question should not be obstructed because of concerns about risks that only accrue to physicians if they are already engaging in illegal activities. Third, I argued that it was extremely unlikely that a prosecutor would pursue charges under the Criminal Code based solely on evidence acquired through study transcripts that had been "cleaned" of any identifying names and remarks. Assuming this is true, I argued that the transcripts could, at worst, increase the likelihood of a successful prosecution by providing corroboration of other evidence.

The RRC deferred the final decision regarding the approval of the study to the HEC, informing that committee that it found the study to be scientifically acceptable but that there were still questions about whether the study fell within the scope of values articulated in the policies of the HOOD. Ultimately, the HEC approved the study after a lengthy discussion of the study vis-a-vis the core values of the HOOD. At the time, I was a HOOD staff member, and was excluded from the discussion of the study by the HEC.

The Research Ethics Boards of the Institutions of the Participating HIV Clinics

The study proposal was submitted to four separate hospital Research Ethics Boards (REB). At one institution it was also necessary to gain the approval of a separate HIV Community Advisory Panel before final approval could be given by the hospital REB. The community advisory panel consists of approximately 20 representatives from the HIV/AIDS community and the hospital's HIV program. The panel invited me to respond to questions and concerns
at two separate meetings before reaching a decision. The concerns of the community and my responses are summarized under the Role of the Community, above.

All but one of the REBs approved the study, some with minor modifications. At the time of the reviews I was a member of one of the REBs. I was not present at the meeting of this REB during deliberations and decisions about the approval of the study. One of the REBs did not approve the study. Its reasons are summarized under The Dissenting Voice below.

The Dissenting Voice

One REB did not approve the study, stating that "While the committee was particularly impressed with the value of exploring end-of-life decision making, it felt strongly that this study did not represent an ethical method of achieving that end and other methods should be sought." Specifically, the REB identified three main points of objection to the study and/or its specific design. First, it identified "those who live with a terminal disease" as "a particularly vulnerable group". Second, it suggested that attempts to screen and exclude individuals with active depression or those who are imminently suicidal would not "alleviate the more fundamental aspects of their vulnerability." Third, the REB was also "struck by the lack of perspective in the study of alternate end-of-life care presented to people with HIV/AIDS", despite the fact that the purpose of the study was to examine decision making for or against euthanasia and assisted suicide specifically, and the proposal explicitly acknowledged—in a section entitled "Care"—the importance of understanding people's experiences and attitudes regarding different types of care and the process of being cared for by others.

The central concern of the dissenting REB regarding the vulnerability of the population appears to be at odds with several commentators on research ethics, including a Draft of the Canadian Tri-Council Code of Conduct for research involving humans that was current at the time of its review. It stated that:
Researchers and REBs must avoid the exclusion of potentially disadvantaged groups of individuals from participating in research where such exclusion has adverse implications for scientific validity and/or when it unfairly excludes members of those groups from the benefits of research. (Draft Tri-Council Code, Article 12.2)(239).

Levine also warns that determinations of vulnerability must be made prudently:

It is easy to identify too many persons as vulnerable and to apply procedures designed to protect the interests of vulnerable persons too extensively. Some judgment is required. In each case it is worthwhile to reflect on the implications of labelling persons as vulnerable. Are we being disrespectful of persons by repudiating their authority to live according to their considered judgments? Are we inappropriately stigmatizing groups of people as being unable to take care of themselves?(238(p. 73))

After a nine month period of research ethics review, I decided not to pursue the recruitment of participants at the dissenting institution, despite disagreement with the substance of the arguments underlying the refusal.

Summary

I have described the main methodological, ethical and legal obstacles encountered in an empirical study of the question: Why, or under what conditions do people desire, or make decisions for euthanasia or assisted suicide? Notwithstanding the objections of the single dissenting REB, described above, I believe that the study adequately addresses each of the obstacles described while answering the research question directly. I believe that this study represents an important advance in the existing empirical research on euthanasia and assisted suicide and believe that the results further our understanding of these phenomena from the perspective of the individuals who are personally faced with decisions regarding them.
CHAPTER 7

Results: The Process of Deliberation

Overview

One of the key findings of this study became apparent very early on in the process of data collection and analysis. Although the study had specifically focussed on decision making, it was clear that none of the study participants had actually made a decision to have euthanasia or assisted suicide (though 63% reported that they had—see below), in many cases despite their forcefully stated support for euthanasia and assisted suicide in principle. In fact, the data suggested that participants were engaged in an on-going process of deliberation regarding whether or not euthanasia or assisted suicide would be an appropriate choice for them and that even the sickest participants and most vociferous proponents of liberalizing access to euthanasia and assisted suicide had not reached an irreversible conclusion in favour of euthanasia or assisted suicide.

In this chapter, I will present a description of the overall process of these deliberations and provide support for my account of the process using direct quotes from study participants and detailed accounts of my interpretations, where warranted. The aim of this chapter is to sketch the overall shape of the phenomenon of deliberation regarding euthanasia and assisted suicide from the perspective of people with HIV/AIDS (i.e. the ‘process’ component of the theory). In Chapter 8 I will describe some of the key factors that appear to influence the desire to die, i.e. the desire for euthanasia and assisted suicide. And in Chapter 9 I will present my interpretation of the meaning and importance of the process and factors in the lives of the study participants (i.e. the ‘meaning’ component of the theory).

Before presenting the process of deliberation I will describe the characteristics of the study
participants.

Participant Characteristics

General Characteristics

In total, 32 people took part in the study, 31 males and 1 female. At the time of the interview, 20 participants (63%) reported that they had made a decision to have euthanasia or assisted suicide, 3 participants (9%) reported that they had made a decision not to have euthanasia or assisted suicide, and 9 participants (28%) were undecided. The median age of the participants was 39. Seventy-five percent of the participants had at least some post-secondary education. Half of the participants reported having a specific religious affiliation, though slightly more than half said they were not at all religious. See Table 1.

| Table 1.—Participant Characteristics (General) |
|-----------------------------|----------------|
| Age                        | median=39, range (30-66) |
| Gender                     |                          |
| Male                       | 31 (97%)                |
| Female                     | 1 (3%)                  |
| Education                  |                          |
| Less than complete high school | 1 (3%)               |
| Complete High School       | 7 (22%)                 |
| Incomplete Post Secondary  | 6 (19%)                 |
| Community College          | 7 (22%)                 |
| Undergraduate University   | 7 (22%)                 |
| Graduate University        | 4 (13%)                 |

3Technically, this number represents a response rate of approximately 5%, although the rationale for reporting response rates, i.e. to provide insights regarding the representativeness of the respondents with respect to the overall sample, is not applicable in the qualitative research design described.
Table 1.—Participant Characteristics (General)—Continued

<table>
<thead>
<tr>
<th>Religious Affiliation</th>
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<tbody>
<tr>
<td>Yes</td>
<td>16 (50%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16 (50%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religiosity</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Not at all religious</td>
<td>18 (56%)</td>
<td></td>
</tr>
<tr>
<td>Not very religious</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Somewhat religious</td>
<td>6 (19%)</td>
<td></td>
</tr>
<tr>
<td>Very religious</td>
<td>3 (9%)</td>
<td></td>
</tr>
<tr>
<td>Extremely religious</td>
<td>5 (16%)</td>
<td></td>
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</tbody>
</table>

Employment and Financial Profile

One quarter of the participants were working at the time they were interviewed. Of those who were not working, 3 had retired and two were actively looking for work. Sixty-three percent of participants considered themselves to be financially secure and 44% had life insurance. Forty-four percent of participants reported being active in an AIDS Service Organization. See Table 2.

Table 2.—Employment and Financial Profile

<table>
<thead>
<tr>
<th>Currently Working</th>
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<tbody>
<tr>
<td>Yes</td>
<td>8 (25%)</td>
<td></td>
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<tr>
<td>No</td>
<td>24 (75%)</td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Currently Looking for Work</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Applicable (Working, Retired)</td>
<td>11 (34%)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2 (6%)</td>
<td></td>
</tr>
<tr>
<td>No (On disability)</td>
<td>19 (59%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Financially Secure</th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>Yes</td>
<td>20 (63%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>11 (34%)</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>1 (3%)</td>
<td></td>
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</tbody>
</table>
Table 2. Employment and Financial Profile—Continued

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Life Insurance</td>
<td>14 (44%)</td>
<td>18 (56%)</td>
</tr>
<tr>
<td>Active in an AIDS Service Organization</td>
<td>14 (44%)</td>
<td>18 (56%)</td>
</tr>
</tbody>
</table>

Relationship and Community

Half of the participants, 16/32 had a partner or spouse. Of these 16, 4 reported that their partner also had HIV and one person told me that neither he nor his partner knew if his partner had HIV. For the 16 participants who had a partner, 4 reported that their partner shared their views on euthanasia and assisted suicide, while the same number did not. However, 8 participants reported that they were unsure about their partner’s views on euthanasia and assisted suicide. Ninety-four percent of participants had lost friends or loved ones to AIDS (median=6) and 53% had cared for friends or loved ones when they were dying. See Table 3.

Table 3.—Relationship and Community

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner/Spouse</td>
<td>16 (50%)</td>
<td>16 (50%)</td>
</tr>
<tr>
<td>Partner HIV+ (N=16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4 (25%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>11 (69%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (6%)</td>
<td></td>
</tr>
</tbody>
</table>
Health Status

All study participants are living with HIV. Ninety-four percent of the participants (including the 1 woman) acquired HIV through sex with men. The median low CD4 count was 139 while the median high count was 230. Seventy-eight percent of the participants were on new combination anti-HIV drugs, including protease inhibitors.

Table 3.—Relationship and Community—Continued

<table>
<thead>
<tr>
<th>Partner Same Attitude Towards E/AS (N=16)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4 (25%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4 (25%)</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>8 (50%)</td>
<td></td>
</tr>
</tbody>
</table>

Lost Friends to AIDS

| Yes     | 30 (94%) |
| No      | 2 (6%)   |

Number of Friends Median=6, (1-100)

Participated in Care of Dying Friends

<table>
<thead>
<tr>
<th>Not Applicable</th>
<th>2 (6%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17 (53%)</td>
</tr>
<tr>
<td>No</td>
<td>13 (41%)</td>
</tr>
</tbody>
</table>

Table 4.—Health Status

<table>
<thead>
<tr>
<th>Mode of Infection</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex With Men</td>
<td>30 (94%)</td>
<td></td>
</tr>
<tr>
<td>IDU</td>
<td>1 (3%)</td>
<td></td>
</tr>
<tr>
<td>Tattoo</td>
<td>1 (3%)</td>
<td></td>
</tr>
</tbody>
</table>

CD4

| Low    | Median=139, (0-563) |
| Hi     | Median=230, (5-863)  |

90
Forty-one percent were asymptomatic, 19% had at one time had a non-AIDS-defining illness, while 41% had had an AIDS-defining illness (i.e. they had AIDS). Thirty-four percent had been hospitalized for an HIV-related reason. Half the participants had been given a diagnosis of depression at some point. In 62% of these participants the diagnosis of depression preceded their diagnosis with HIV. See Table 4.

**Euthanasia and Assisted Suicide**

Sixty-three percent of participants reported that they had made a decision to have euthanasia or assisted suicide, though during the interviews it became clear that for most—if not all—participants this decision was contingent on a number of factors.

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4This taxonomy is taken from the Centres for Disease Control (U.S.) criteria for AIDS.
### Table 5.—Euthanasia and Assisted Suicide

<table>
<thead>
<tr>
<th>Decision</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i.e. reported in response to the following question: “at this time have you made a decision to have euthanasia or assisted suicide (“yes”), to not have euthanasia or assisted suicide (“no”), or are you undecided?)</td>
<td>20 (63%)</td>
<td>3 (9%)</td>
<td>9 (28%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discussion with Doctor</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16 (50%)</td>
<td>16 (50%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Asked Doctor to Assist (N=16)</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5 (31%)</td>
<td>11 (69%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Doctors Willing to Assist (N=5)</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2 (6%)</td>
<td>3 (9%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participated in Euthanasia or Assisted Suicide</th>
<th>Yes</th>
<th>No</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6 (19%)</td>
<td>26 (81%)</td>
<td></td>
</tr>
</tbody>
</table>

Half of the participants had discussed euthanasia or assisted suicide with a doctor and of these participants 5 had explicitly asked the doctor to assist them. In two of these cases the participants reported that the doctor was willing to provide assistance. Six participants (19%) reported that they had participated in euthanasia or assisted suicide. See Table 5.

### A Process of Deliberation

The data suggest that deliberation about euthanasia and assisted suicide, though varied in

---

5Three participants reported having participated in euthanasia (from 1 to 3 times each) and another three participants reported having participated in assisted suicide (from 1 to 2 times each).
intensity and duration, is a common experience among study participants, even with the somewhat improved prospects for long-term survival offered by the introduction of potent new drug "cocktails". To be sure, the fact that it appears to be a common experience, does not suggest that all people with HIV/AIDS are consumed by thoughts of euthanasia and assisted suicide. Rather, it appears that even among the few participants who believed that access to euthanasia and assisted suicide should not be liberalized, i.e. the participants who might reasonably be considered least likely to carry out euthanasia or assisted suicide, there was a general awareness of these options and at least some passing thoughts as to their potential appropriateness. In some cases the "passing thoughts" amounted to re-evaluation of their stance toward euthanasia and assisted suicide, i.e. some participants who said that euthanasia and assisted suicide were "wrong", could not certainly rule out that they might resort to them if their life circumstances became completely unbearable. The majority of gay men in the sample acknowledged that euthanasia was part of the overall landscape in the lives of gay men living with AIDS, an observation that is consistent with a number of empirical findings (see Chapter 2).

One of the initial theoretical questions that gave rise to the study concerned the role of others in potentially influencing the way decisions are made regarding euthanasia and assisted suicide. This concern arose from our previous work in advance care planning with people receiving renal dialysis. For those patients, the willingness (or not) of loved ones to discuss death and preparation for death had a powerful impact on their ability to carry out advance care planning, often resulting in proxy decision makers who were poorly prepared to make decisions on behalf of the patients(211). The concern for how decisions might be influenced directly by the pressure or influences of others appears not to play as clear a role in the deliberations of the study participants, though "community", i.e. the availability of close personal relationships does appear to play an important role in these deliberations (see Chapter 8). The remainder of this chapter will provide a detailed account of the various categories in the process of deliberation about euthanasia and assisted suicide and their inter-relationships.
Origins of Deliberations

Deliberation about euthanasia and assisted suicide seldom follows a specific precipitating event, though it can. In this case, for example, the participant’s personal deliberations about euthanasia and assisted suicide began with an early life event in which a close friend and mentor died a “ghastly, grizzly death” from respiratory failure.

My feelings at the time were incredible anger at society that we were not allowed to do what this woman wanted, which was to end her misery...6

Most often, deliberations about euthanasia and assisted suicide originate with some signs or symptoms of disease progression, i.e. some impetus for thinking about death from HIV/AIDS (this can also be at diagnosis). But the extent that these initial thoughts are fostered and explored is a function of many individual factors, the most important of which is the mind-set of the individual. By mind-set, I mean the overall frame of mind that the individual is in at the time when she or he is first confronted with thoughts of dying of AIDS, and the individual’s working palate of ideas and values, specifically as they relate to self-identity7. For example,

I6 OK. Now, you.... if I’m right, you said that you became an injection drug user after your diagnosis with HIV.....

6Because of the potential legal implications described in detail in Chapter 6, I have chosen not to identify the individual quotes with the unique identifiers of the participants, as is the convention in qualitative research involving interview quotes. The selected quotes that follow in the body of the findings represent the voices of 25 of the 32 participants. Several participants contributed more than one quote. The quotes were selected for their representativeness of the concepts that they are intended to illustrate. There was no attempt made to omit data from any individual, though it is inevitable that some unique perspectives are lost in the attempt to summarize from the extensive primary data.

7In the process described below, mind-set may also be understood to reflect the extent to which participants consider the self to be intact or threatened or compromised. As such, it plays a key role in determining participants’ approach at each step in the process. This is illustrated in Figure 1 on page 130.

8This is the first point in the presentation of the data that the designations “I” and “P” are used. I use these designations to refer to the voices of the interviewer and participant, respectively, in quotes that involve dialogue. I will use these designations from this point forward in the thesis.
yes... after my diagnosis with HIV; after my ah... just shortly before
my diagnosis with full-blown AIDS. And it was after I met this man.
He was clean and sober, when I met him. And soon afterwards, we
started IV drug use. And in large part because I was given a matter of
months to live. And he felt that his time was up. He was HIV positive,
though asymptomatic. And after my first bout of PCP, ah... they...you
know, they didn’t ex....wanted me to think about a palliative care, at
that point. And I said: I’m just going to go home and sh-shoot my
brains up.... And, you know, here is, it’s 2 ½ years later. So....that’s
often medical predictions. Or, when you realise that, I mean they
didn’t give you a specific time. But when they’re suggesting home
hospice, or transferring you to the palliative care unit, you know that
they do not expect you to live. And so, you go: What the Hell. Went
home and I became totally obsessed with using IV drugs. And then
you end up living, and you’re so far gone on the drugs, themselves.

Now, the.... I guess what I’d just like to ask you a little bit more is that
transition, if you like, to drug use. Could you help me understand that
a little bit better...that-that whole process?

Ah....I’ve used street drugs since I was 12 years old...so 27 years. I’ve
never used intravenous drugs, before. And it was just... And since my
partner was very shortly...it hadn’t been long that he’d been clean
and sober, just from IV drug use. He still uses other street drugs... or
use street drugs. Simply orally, or needily...? ah..... sounds like a bad
Country Western singer......needily. OK. And so I am actually the one
that insisted that I would like to do this before I died. If it was
supposed to be-supposed to be such a thrill, such a kick, then what
difference does it make. I... and they’re expecting... and I’m but really
buying into the fact that I would be dead in a matter of months. So...
what in the hell difference does it make? Let’s go up here, all the
bang for your buck. Yeah....

Ok. And do you-has your view changed about that, now?

Which...aspect....?

Well, you said, sort of: What the hell.....

Oh yes, my view has definitely changed. Particularly after the death
of my partner. I have since used IV drugs only twice in the last....9
months. He died last June. I went on a binge, for the-the rest of that
month of June, and July... And then said either take your own life—I was about to give my own name—I take your life, or deal with it.... which is my basic philosophy. Slash your wrists, or deal with it. Both are acceptable choices. And I chose to—to deal with it. Like, I couldn’t continue at that consumption level, because it would kill me. There was—there were several over-doses, in the time shortly after his death, on my part. I believe that be the correct term: over-dose. Unsuccessful....it wasn’t -it wasn’t attempting to take my own life. But I certainly over-dosed.

Compare this quote to the following, more positive mindset:

*At this point in time, for myself, I am facing the disease as a challenge, every day is a new challenge to see how much I can accomplish, to see how much I can manage to help make things easier for other people*

It is clear, from the preceding sections, that mind-set is determined to some extent by the individual’s disintegration and by the nature of her/his personality and personal experience and available community. Disintegration leads to dependency and suffering. One of the key concerns of participants with respect to dependency was of being a burden on others. In fact, the fear of being a burden on others is one mind-set that, when confronted with a precipitating event like an HIV diagnosis, or the progression of symptoms, can constitute an origin of deliberations, i.e. it can give rise to active consideration of euthanasia and assisted suicide.

*I have even gone through bouts of feeling like a burden to my doctors, feeling like a burden to my family, to my siblings, to my friends, to my partner, particularly to my partner, uhm, and it’s a very, very, very hard feeling to work yourself through, and you need the people who are around you who are around you to support you to help you work your way through. However, when things have reached a level of desperation, that they have with many of the people who I work with, there’s no turning around that feeling.*
I watched my mother care for my grandmother, with Alzheimer's and as a result of that I thought: if there was a similar situation... OK If I knew I was at that type of a state, that I couldn't function as I am now, I don't know if I'd want to continue living... and be the burden that it is on everybody else. Not just the physical burden, caring for the people. It would just... mentally and emotionally: how exhausting it is. And, in the sense of... just... As it does with Alzheimer's, you can live an incredibly long time with that... And it just... It's a very slow, progressive thing, where you just get worse, and worse and worse. And it can go on for years and years and years. And I don't know if I'd want to do that to someone else..... Especially because there's no hope of correcting it.

Another route into active consideration of euthanasia and assisted suicide appears to stem from suffering, particularly existential suffering. One of the results of existential suffering, particularly for protracted periods, is feelings of hopelessness.

Well, right now I get general pain; and... it bothers me. And... but last year, around Christmas time I was VERY sick, and I was losing weight... and I just felt the hopelessness... like, I don't want to go on.... I don't want to feel this anymore.

There does not appear to be any common starting point for active consideration of euthanasia or assisted suicide. For most participants, it appears that the origins lie in quiet reflection or introspection, following some of the triggers outlined above. Many participants told me that they have very few opportunities to discuss these issues openly and some told me that they weren't concerned about becoming upset during the interview, since they were "ready" to talk about euthanasia and assisted suicide now, suggesting a possibly long process between the initial thoughts on euthanasia or assisted suicide and more focussed deliberations about them.
Active Consideration of Euthanasia and Assisted Suicide

Active consideration of euthanasia and assisted suicide does not appear to follow any discernable pattern, though there are some common features. In general, active consideration is either solitary, i.e. it involves reflection and introspection on the part of the individual, but does not include discussions or sharing of information, attitudes, or feelings with other people, or it involves solitary reflection in conjunction with communal explorations.

**Solitary**

There are several ways in which participants described their solitary consideration of euthanasia and assisted suicide. One common approach was through the assessment of the experiences of others. For example,

**P** My decision was, is that if I became at a place in my life, was unable to care for myself, and I was really a burden, to those who assist me, I would chose not to want to continue my life.

**I** OK. Then can you tell me a bit more about what you mean by “being a burden on others...”?

**P** Being a burden, I mean obviously in the sense of being physically ill, and having to be assisted. Which is a lingering. A linger, that knows difficult of...of.. There’s no possible medical way that they could revert me back to a status where I would have a quality of life, and the present to confirm it with.

**I** OK. And how is that a burden?...on other people?

**P** I’ve seen it in a lot of friends: who just get burnt out....waiting for the end to have to... I mean for their friend to depart. Whereas opposed to having that happen, and what it does to them. And it builds... I’ve seen how it builds a little bit of resentment against the person themselves. I don’t want to be in that position....The decision I made, I made prior to that [to Grandmother having Alzheimer's and being cared for at home by his mother]. And that...and that just confirmed what I always had made.
I, I know a...a.... friend of mine had a friend who, you know, it was his time. And he said: "I'm finished now..." more or less. And he had decided that, you know, just took the ah...cocktail, and... good night. You know, it was quite painless. You know, just go to sleep kind of thing.

Although participants did not always appear to be consciously aware of their thinking about euthanasia and assisted suicide, i.e. of the kinds of conscious steps taken, approaches and time frame during which these thoughts occur, their stories make it clear that many participants had thought deeply about these issues, likely as part of the overall context of living with HIV/AIDS. Participants may not have spoken much about the process of solitary consideration of euthanasia and assisted suicide because they do not appear to view the act as very remarkable, in the context of living with HIV/AIDS.

Communal

The point at which solitary consideration becomes communal was not clearly reflected in the data, though it appears—not surprisingly—that the availability of a receptive community facilitates the transition. It is also possible that the transition from solitary to communal consideration of euthanasia and assisted suicide plays a role in fortifying the individual's community, i.e. through the sheer gravity of the issue and the obvious need for others to provide strong support, whatever the individual's stance toward euthanasia and assisted suicide. Most of the communal consideration involved discussions with partners, family, friends and other loved ones. The goals of these discussions were not always clear, but participants appear to accept these discussions as self-evidently valuable. For example,

I: you were saying that your....that you think your attitude and your partner's attitude are quite similar
P: yeah.
I: Have you had discussions about..
P: yes... assisted suicide?
Could you tell me a little bit about those discussions?

My partner had lost his partner. And so... And him and his partner had also... they had discussed in depth... Because, unfortunately a lot of his illness that finally took his life, were the long, lingering types. So... and as a result, they had already discussed about, you know like what if... what if... what if....and it never happened. But at least the conversations come in place, there. They wanted to decide to do it. It it wouldn't be like you were taking somebody who was very ill, and wasn't mentally or emotionally competent to make decisions. All this stuff had been discussed before. And that's the same thing I wanted to do, this time around. That... get everything up on the table; have everything understood. So if they were down the road.... The subject comes up again for serious discussion, like for making a decision or things, at least you know that...the ground work was already laid, long before. It was not just... It wouldn't be...ever be taken.... I wouldn't want a family member, or another close friend, to say: "Well, I don't think that was the right decision." The ground work's already been laid with everyone.... From day one, on. So, it's not to be ever considered a spur of the moment decision.

In many cases, these discussions had been occurring over a period of months or years. For example.

And could you describe a little bit your role... in the assisted suicide?

My role was to-- was to help him. And it meant to.... he went to swallow the pills. But when he lost that ability, within a matter of 3 or 4 days, then he panicked. And I said: Don't worry. And I was able to, you know, to contact the people that I knew. And was able to, basically, barter. I bartered pills for-for liquid (morphine), and with a little added extra of money. Yeh.....

OK. And then what happened, once you got the drug?

Ah.... I gave-gave him an overdose. Ah..... he went into unconsciousness. And was dead within 6 hours.

OK. Could you tell me about the discussion....that you had... did

I had the discussion with ah... with my friend... Can I use names?
No, you don't have to. It's better if you don't...

Ok. .....with him..... We had the discussion. And that-that was his choice. He wanted to be the one to determine when he dies, and not-not a disease.

And was there..... was there any other... Well did this just happen, say on one occasion, the discussion?..... Or....

No, no. The discussion had been on-going for years, even before diagnosis.

OK. So could you tell me a bit more, then, about the substance of the discussion.....then, if it had been going on for years?

Basically, that we ha--we have the right to decide when and how ah....our end is to come. And, we both agreed, and I support, that if not for psychiatric reasons, that that's not a good reason.... because there's enough anti-depressants and anxiolytics, and medications out there to deal with those. But for physical reasons, certainly. We almost have a responsibility to ourselves, to our families, to the health care system, to not prolong grief.... and prolong the pain of having someone that's, basically, they're dying..... is part of the grieving process for others. And it.... it's no need to be dragged out for many weeks, and many months, and possibly even years. And when there's no quality of life for the person, and they indicate it in some way: that it's.... this is the time. Ah... then hopefully, they are able to carry it out...carry out their wishes.

Would you say, then, when it got to that point for your friend that....would you say that you-that you felt that you needed to explore these things, in great detail? Or ...

No...no. Because we had discussed it over a period of number of years. And it... you just... And we had talked about it.....just...we reminded each other of our, sort of, commitment.... before I-I assisted him.... when he was still able to speak. Which is, you know, a week or 2 before that.

Several participants had also completed a Living Will and some had held meetings or gatherings of loved ones to discuss their wishes for end of life care.
I have had it put right into my Living Will that when I reach that point there is to be no assistance given to me whatsoever, by way of life support, breathing support or anything else, I am to be let go. My family is all of the same belief and they all wish the same things for themselves. It's very unfortunate in this day and age with the recognition of the disease and the experience that we have of the various terminal diseases that we can't grasp the concept that there does come a time when the person just isn't there any longer. There is just shell left there. There may be some of the person left there, but what the person inside is begging for is: "please, let me go".

This passage also provides a good example of the kind of ambiguity that characterizes some of the discussions with participants. Although the participant above had been arguing strongly for euthanasia and assisted suicide, his comments above do not mention these activities. Instead, he describes a desire for forgoing all life-sustaining treatment, a practice that is currently legal in Canada. This ambiguity may be indicative of a lack of conceptual clarity among participants, particularly in making distinctions between euthanasia, assisted suicide and forgoing treatment. However, it may also reveal participants' acceptance of the equivalence of euthanasia and assisted suicide and forgoing life-sustaining treatments. This ambiguity is reflected in some of the definitions of euthanasia that participants offered me on request. For example, one participant defined euthanasia and assisted suicide in the following way:

I think euthanasia, though obviously you can do it yourself, basically, there has to be no contact with anybody in order for euthanasia to be involved. So whatever, that could be your own undertaking without anybody's assistance. Now of course when you use the word "assisted" and you put it in front of suicide, that's definitely, you know, assisted, uhm....you know, uhm....suicide...it's not like you're totally involved in it.....unless, uhm, maybe the definition is it can't really be assisted suicide because it's, you know, if the person isn't, whatever, administering the pills or drugs or whatever the case, and the other person is the one that's taking them that somehow they assisted them with providing them with the medication and whatever, you know....I don't think there's much of a difference between the
Overall, the process of deliberation does not appear to have a set format. Rather, euthanasia and assisted suicide appear to be accepted as part of the milieu for people living with HIV/AIDS and managed along-side all the other uncertainties. It is likely that the advent of new drug combinations during the development and conduct of the study made considerations of euthanasia and assisted suicide seem more hypothetical for most participants than they may have been otherwise. Either way, the deliberations—whatever their particular format—appear to have the overall effect of moving the participants in their thinking from the realm of the purely hypothetical to the concrete and practical. The nature and extent of the deliberations likely affects the rate and thoroughness of this transition.

Goals

Part of this transition appears to involve the formulation or articulation of broadly framed goals. These goals appear to function like beacons or targets for people, giving them a way of guiding their thinking and preparations. Most often, these goals are stated in the form of familiar and general concepts such as dignity, quality of life, quality of death and the point beyond which the individual does not wish to exist. This finding is important in that it demonstrates that people with HIV/AIDS who think about euthanasia and assisted suicide are not eager to kill themselves. Rather, they seek control and reassurance about their own deaths and see euthanasia and assisted suicide more as management strategies for death than as compelling goals in themselves. For example:

I'd like to go naturally, no tubes etcetera

I really want the choice in my ending my life to be my choice and not someone else's

If I was in a position where I could not function mentally at full capacity, and
physically with any significant capacity, then I wouldn’t want to exist, I
wouldn’t want to just be kept alive for the sake of keeping me alive. Life is all
about living it, and you know, if I can’t use my brain, or if I’m in such
discomfort that I can’t focus on the things I want to do—regardless of what
those things are, then I don’t see a point in continuing to exist........That’s
why we exist, is to flourish and to build upon what we are, to help ourselves
evolve. And if our capability to do that has been removed, then we need to...I
don’t see a purpose in continuing.

Plans and Strategies

Once these general goals have been identified, then specific plans and strategies for achieving
them may be designed and implemented. It is important to note, however, that the distinction
between goals and specific plans may not be as clearly demarcated for participants as is
represented here. The distinction is important, however, in the overall theory, in that the
broad goals—even if not understood by participants as goals—appear to shape the specific
plans.

For a few participants, the transition from origins of active consideration of euthanasia and
assisted suicide to plans and strategies was extremely fluid. For these participants, their level
of involvement and specific status within their own community meant that they were
“plugged in” to networks whose aim was to facilitate euthanasia and assisted suicide.
Acquaintance with such a network simplifies access to drugs and support for euthanasia and
assisted suicide, and also results in the individuals themselves having a more active, i.e.
participatory role. These networks are seen by these participants as strong and dynamic
elements of the broader HIV/AIDS and gay communities, and illustrate that their transition
through this process of deliberation was strongly mediated by community.

For example,

\[ P \quad \text{It would be more a decision of euthanasia, I’d see it, rather than} \]
assisted suicide. I hopefully will be able to do it on my own. And, ah... I've spoken with doctors. And I certainly have enough medication on hand to be able to carry that out. Whether it’s through orally or IV.

I  OK. And you would see that as euthanasia, if you're doing that on your own?

P  Yes. Yes. But there are people that of--that would offer to-to help me, if I was unable. They would ...(name) said they’d prop me up, and-and throw me against the wall, kind of thing. So the syringe–so the plunger would go down. But they wouldn't actually be the ones doing it, you know..... I guess that's assisted.

I  OK, now in terms of the medication: Is that the route that you would take?

P  Yes...yes....yes. Definitely not a violent. It would be a drug-a drug overdose, yes.

I  And do you have some thoughts about how... what that- what kind of medications it would be?

P  Oh, yes. I-I have lots of ah.... (Nosenon) which is an anti-psychotic; (Digoxin) ah.... (Amytriptil) tons of (Amytriptilene) and (Morphine).

I  OK. And how did you acquire the medication?

P  Ah, acquired almost all of these medications from people who had previously taken their own lives. And it’s standardly done: that when someone dies, people look...first thing they go through in the-in someone’s apartment is... go through their medicine cabinet, and take what drugs can be used ah... for assisted suicide or euthanasia, as well as for those who don't have the money to pay for medications... if there's certain things that are not on the formulary. And that's standardly done.

I  And when you say "...that's standardly done..." is there some sort of, you know, “network”, or...

P  Ahhhh..... everybody sort of has a personal network.

I  OK. Could you tell me a bit about .... Did you have an involvement with a group, like a network like this...?

P  Ahhhhh

I  I don't wanna put words in your mouth, call it a “network”.... I just

P  No...no. In regards to assisted suicide /euthanasia? No... other than
I’ve received them from people before their point of death... because they had an excess of what they needed. And these are the drugs that I have used to assist someone in taking their own life.

Most participants did not have firm plans and strategies for euthanasia or assisted suicide, though some had stockpiles of medication and others had had discussions with doctors about euthanasia and assisted suicide. One participant, who was a health care professional, was thoroughly prepared in the event that he should decide to end his own life. His presents an interesting case, because he was able to acquire all the necessary drugs and tools he would need to commit suicide himself, without any assistance, i.e. his activities, if followed through, would not constitute assisted suicide and would not be illegal.

I Ideally it would be nice to have a big line of coke, an IV, some sodium pentathol, some pavulon, some morphine and some valium, do the line of coke, smoke a joint, start the IV, give yourself the morphine, give yourself the valium, and have the pavulon and sodium pentathol in the IV and go out that way. But not everyone has that at home, not even a few dozen secanol, people don’t usually have at home, so you think of other ways you’re going to do it at home.

The participant confided in me that he, in fact, had all the resources to die the way he had described.

Summary

The process of deliberation occurs over time from the origin of active consideration, i.e. the first thoughts and feelings about euthanasia and assisted suicide, likely to the point at which the individual acts upon his or her decision to have euthanasia or assisted suicide (though there were no data that directly support this conclusion), or until death, or some positive changes in health status. The process of disintegration experienced by the individual and the community of personal relationships and resources available to him/her contribute to the
individual's mind-set. A positive mind-set is important in determining the manner in which individuals consider euthanasia and assisted suicide, which may be either solitary or communal, or a combination of both. The deliberations give rise to broad, and often not explicit, goals. Plans and strategies are then developed and refined through continued deliberations and the continual influences of disintegration and community. These plans and strategies may or may not culminate in euthanasia or assisted suicide.
Chapter 8

Results: Factors Affecting Deliberations

In order to fully understand the process of deliberation about euthanasia and assisted suicide described in Chapter 7, it is necessary to gain some insights into the theoretical categories I have called “Disintegration” and “Community”. These two categories form the central scaffold of the theory and frame deliberations with respect to the health status, perceived health status, and perceived trajectory of changes in health status of the individual on the one hand, and the web of human relationships and resources that are available within the context of these relationships, on the other. Both categories are complex and appear to function across the temporal sequence to continually shape, or provide referents for, deliberations and/or the formation of goals, and plans or strategies.

Disintegration

The initial concept of disintegration (i.e. the code assigned in the process of open coding) came from the following quote from a study participant:

You know you don’t want to die slowly on a ventilator yourself and die little piece by little piece. Stuff like that, and go slowly like that.

The main properties of disintegration are duration, pace, functional effect, and extent. Disintegration can be temporary and reversible, and therefore not perceived by the individual as threatening to life or identity, whereas the longer lasting the disintegration the more powerful these threats appear to be (i.e. these issues are about duration). As well, although, theoretically, disintegration may be rapid, participants’ concerns seem to suggest that its slow, lingering nature has the most significance for deliberations regarding euthanasia and
assisted suicide (i.e. issues about pace). For example:

I don't want to rely, or have someone bathe me, it would be different it if was a short term illness, like I've had, or I wouldn't want to see myself just slowly, slowly, slowly and have my friends and loved ones see me and see myself go slowly, I like fast decisions.

Broadly speaking, disintegration can be either physical, or mental, or both (functional effect). The extent of disintegration in each of these domains determines the loss of function experienced by the individual, and this loss of function, in turn, can lead to dependency, isolation and a perceived loss of personal dignity (extent). These changes are profoundly meaningful experiences—even hypothetically—for the individual and portend an existence limited to suffering, which in turn can influence the individual’s attitude toward death.

Disintegration was almost universally associated with suffering by the study participants. This is understandable for several reasons. First, 53% of study participants had cared for at least one friend or loved one while he/she was dying of AIDS. When compared to the general population, this willingness to care for the dying is likely quite remarkable. Yet it also seems likely, from the many accounts of the participants, that the technical quality of care that they were able to provide to people dying of AIDS was poor. The result appears to be that many of the study participants had powerful and terrible stories of the suffering of the friends and loved ones they had cared for. One of the participants was a health care worker. Even within the health care setting, where it would be reasonable to expect that the technical standards of care would be better than in the home, this participant’s experiences and perception of suffering were pronounced:

you turn them over they're in pain, they're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just...they're going to suffer the whole time, there's going to be no happiness, they're going to go down to 60-70 lbs, they're just going to....their whole last weeks of life is just going to be pain and agony
and people coming in, people being upset, them being upset.

Another participants said:

*AIDS, that's probably—seeing as I'm 41—that's probably what I'm going to die of, that is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded by all the loving people in your life, but you...., it's lonely, because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally...you don't know what's going on.*

It is important to qualify that this is an account of the “perception” of suffering, i.e. of the participant’s personal experience of the patient’s suffering. This is not to suggest that the patient referred to in the account is not suffering, nor that the participants are unable to identify suffering—many of the participants had also experienced personal suffering, in relation to their illness and in a wide variety of other ways. Rather, the qualification is an attempt to focus on the meaning of the patient’s suffering as interpreted by the study participant. In fact, these experiences of dying and death of others appear to play a powerful role in shaping, not only the participants’ views of what constitutes suffering, but also of what constitutes “unbearable”, “senseless”, or “pointless” suffering.

*I think once the person has reached the point of not having a quality of life, and their existence is more or less a day by day dregge, and they’re going in a scooter with a diaper on to go grocery shopping, and when you go grocery shopping they come home, and basically all they can stomach for the day is an apple and they’re vomiting and sick and...ginger ale and all you can do is smoke, then what kind of satisfaction or quality of life does that bring for that individual’s life; what kind of pleasure...basically you’re a vegetable, but you’re a walking vegetable.*

This subtle distinction between the participant’s suffering and his/her perception of the
suffering of others has important implications for the theory, since the expectations of how others will perceive their suffering appears to be have a strong motivating effect. These ideas are explored in more detail below.

Suffering ranges from purely "somatic" on the one hand, to purely "existential" on the other. Somatic suffering involves pain, discomfort and physical symptoms, whereas existential suffering involves deep rooted dissonance between the person's life circumstances and some internal referent for what circumstances are actually desirable or tolerable. Of course, individuals can and do experience both somatic and existential suffering simultaneously.

Some mental deterioration (i.e. one dimension of the functional effect of deterioration), for example AIDS-related dementia, may have more in common with "existential" suffering, though no participant had experienced this and hence there were no data to support this claim.

Somatic suffering can be powerful enough to lead individuals to suicide, but it was not the sole, or even major, preoccupation among participants who were deliberating about assisted suicide. For example, one participant reported that he attempted suicide to escape relentless night sweats. The participant did not seek assistance for these symptoms, which occurred early on in his infection, apparently because he was not yet familiar or comfortable enough with the process of seeking care for HIV-related issues, and/or as being identified as a person with HIV. This may have been especially difficult for this participant since he acquired HIV from his first experience with injecting drugs and he had a very difficult time telling his doctor about this, since he had known her for many years and was afraid that she would lose respect for him.

I Could we go back a bit? You mentioned your suicide attempt. Could you tell me a bit more about that?

P Well, I was going through probably about 5 nights of night sweats and day sweats....

I This was how soon after finding out you had HIV?
Within a few weeks or so...

Really soon afterwards.

It was about 5 nights of night sweats, it was horrible, I mean it was just terrible and uh I couldn't sleep, five nights in a row without sleep, I mean I had bags under my bags, under my bags, under my bags under my eyes, so that's when I thought, you know, I wish my heart would stop beating and stuff like that, so I did try to slash my wrists, a very futile, very, you know, not a serious attempt, but, at the point, I wish I had of died, I wish I was dead at that point. It was awful, awful..... I was hoping not to wake up, but I did, so, and I'm glad I did, so, but if I was, you know, like I said the point of, you know I was just 65 pounds, shrivelled up, drooling, you know, hooked up to breathing apparatus, unplug me, I'm all for it, doctor assisted suicide, I'd rally for it in a minute.

This passage begins also to illustrate the distinction between somatic suffering—which does not appear to be the focus of many participants’ concerns regarding death—and the deeper, more profound unease suggested in the final sentence of the participant’s quote above. Although the symptoms were eventually controlled and his somatic suffering alleviated, he had not lost the focus on the implications of his potential disintegration and existential suffering.

Concerns about adequate management of pain appear to be similar. People do not seem to desire euthanasia or assisted suicide simply because they are in pain, but pain is clearly associated in people's minds with the type of experience they hope to avoid by electing for euthanasia or assisted suicide. For example, in this discussion about pain, the participant identifies that the crux of the issue for him is not pain, per se, but rather his level of confidence that he will have some control of his pain at the time of his death, i.e. control of how the pain may threaten him at a deep personal level.

But is it...it's more about control.. This is...this is what I want. And I want...I just--I really don't think that, you know, palliative care situation, where the

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person is gonna die ultimately, that the pain... they're going to do much about the pain, really, from what I've experienced in my life with pain. But... if they could actually dull the pain, where you're out... you're not feeling any pain, then you're very.... you're not very kind-of-aware about what you're doing. Because the pain is so excessive, and you have to take excessive amounts of things to dull the pain, you know. And you become, then, dull as a person. You just can't... so... anyway. I'm not convinced about that palliative care thing. (laugh..)

Although participants expressed some hope and confidence that their somatic suffering could be alleviated, there was no parallel optimism regarding the alleviation of existential suffering. As the dissonance between the person's real circumstances and his/her concept of who she/he is (or would like to be) becomes more pronounced, the person approaches the point where living is no longer tolerable. At this point, euthanasia and assisted suicide become more immediate and viable options. This dissonance between the real and the image of self lies at the heart of existential suffering.

It's so degrading to the person that he's allowed to be kept alive and go through all the humiliation of that as well, because it must be humiliating to lie there and not be able to do a damn thing because you're incapable of doing it, doing anything.

At the point where living is no longer tolerable it is presumed that the circumstances are irretrievable, i.e. that no intervention could reverse the existential suffering, no matter how effectively the somatic suffering might be controlled.

If I was in a situation that I wasn't in any pain, if I was on some medication that was...that I knew I could go on for a period, and be coherent and still talk to people, still functioning, to a degree anyway, then I might not want to do it. I think it comes down to your life and what's left of it, and is there anything left of it, is there anything worth carrying on for. I think in some situations there isn't. And it's just better to say "that's it". I'm not going to get better, I'm just going to lie here, I'm going to suffer, I'm going to keep suffering and what is the point? Am I going to learn something from this, am
I going to become a better person? Is this going to help me in the future? Of course it's not. It's just a matter of....it might take a couple of weeks to die, but your just going to lie there and suffer, nothing's going to change for you, you'll benefit nothing from the process.

The loss of physical and/or mental function associated with disintegration can make it difficult or impossible for the individual to care for him or herself on a day-to-day basis. This often requires that others provide assistance in activities of daily living or other aspects of personal care. In other words, the person with HIV/AIDS experiences some form of dependency, a prospect that few study participants found appealing. Even in discussing their personal prospects hypothetically, participants' unwillingness to be cared for became almost absolute as the extent of the disintegration became more and more extreme. This is illustrated well in an exchange with one participant who was sure that his girlfriend would be willing to care for him under any circumstances. His response also provides an example of deliberation about the point beyond which existential suffering may be intolerable.

I Would it make any difference at all that she'd be willing to take care of you in that way?

P No, no.......would it make any difference? In the way I think? No, it wouldn't make any difference. That's my wishes, you know, you know, I'm saying worst case scenario, 65 lbs somebody else is wiping your bum for you, or you're wearing diapers. I want to go when I'm 85 lbs, which is two months away from 65 lbs and somebody else wiping my ass......I think doctor assisted suicide should be legal and I want to die, you know, just a couple of months before I get to the point where I'm not feeling much dignity, so I want to die at 85 lbs and not wait for the 65 lbs. ass-wiping part, I want to just, I want to go, I want to go...before I get that bad.

The unwillingness to be cared for appears to have two inextricably linked facets, the desire to maintain control and independence, and the desire not to be a burden on others. These concepts are explored in more detail in Chapter 9.
If someone feels "well, I'd like to go that way" [being cared for by others], due to their feelings and what they think, that is great. But I also think that other personalities like myself would not want to lay there have someone taking care of me and let me go slowly, I would not like that.... I like to be in control of my own life I don't like someone else to be in control of my life.

There's no way I would....I don't want to be spoon-fed, I don't want somebody else doing my diaper changing, I don't want that, I want to go just before that starts.

Dependency, or the prospect of being dependent on others had clear symbolic meaning for participants. Although many of them spoke in terms of "quality of life", it was clear from their stories that their aversion to dependency was also a reflection of a subscription to a broader concept of individualism and independence. The ideals of youth, beauty, vitality and productivity were readily apparent. For example:

So I figure, when the time comes, that I feel that I'm of no use anymore, to myself or to anybody, that I should have the right to be able to... do it myself...or have somebody assist me.

I'm unproductive, I'm unproductive, I'm not producing, I'm not making anybody else's life happier or anything, I'm inconveniencing—even though they chose to be in that field [i.e. palliative care]—I'm still inconveniencing other people who look after me and stuff like that, I don't want to be like that, I wouldn't enjoy it, I wouldn't, I wouldn't, no, I'd rather die.

If I was in a position where I could not function mentally at full capacity, and physically with any significant capacity, then I wouldn't want to exist, I wouldn't want to just be kept alive for the sake of keeping me alive. Life is all about living it, and you know, if I can't use my brain, or if I'm in such discomfort that I can't focus on the things I want to do—regardless of what those things are, then I don't see a point in continuing to exist.

The gay community is no different, I think, than the heterosexual community. That youth and beauty are the most prized features. That's where the meaning goes, whether it's gay meaning or straight meaning...And the
culture, for the most part, is geared for the young people. In fact, you don't typically see a lot of older people hanging around, whether it be in bars or clubs, or whatever. That's not where the market is, there. They're not, it's not marketed towards them. OK, they're kind of like marginalized off to like... go off to little suburbia; or go return to the country, or something. Because you don't see them as being an integral part of the community.

Disintegration is the progressive erosion of an individual's most fundamental human attributes. In other words, it is a disintegration of the self. This challenge to the individual's basic identity forces him/her to redefine the self—i.e. adopt a new, and perhaps completely unfamiliar, concept of their personal meaning and their place in the world. This challenge to personal meaning and identity is the very essence of what I have called existential suffering6. At this point, euthanasia or assisted suicide are options that many see to be compatible with (even protective of) their personal meaning and identity (self), and so provide a viable alternative to the daunting challenge of inventing themselves anew. (This idea is developed further in Chapter 9).

Many of the participants alluded to these deeper existential concerns using the concept of dignity.

I Just the last thing I'll ask you then, you've mentioned a number of times the term dignity. Could you give me a rough, kind of ball-park idea of what you mean by that. I mean you have already in context.

P A sense of worth, a sense of love, a sense of someone loving you, a sense of peace at what is going to happen with you, and the knowledge that you have done all that you could do to try to preserve your life and to try to set the lives of those around you at ease.

Though “dignity” is notoriously vague and is understood in a variety of different ways(129,130) in common usage, in the following passage it clearly reflects the effects of existential suffering:

6The concept of existential suffering is not a new one. It has been used by many authors to describe similar circumstances, usually around dying and death (see for example Attig T. Beyond pain: the existential suffering of children. Journal of Palliative Care 1996; 12(3): 20-23 for a particularly salient account of existential suffering in children). However, the concept does reflect the essence of the data in this study.
disintegration on fundamental identity and personal meaning. For example:

You've become a bag of potatoes to be moved from spot to spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors appointments or wheeled in in a wheel-chair, and it really does take away any self-worth, any dignity, or any will to continue to live, and unfortunately in this point in our society, we don't have the ability to deal with that, and as we don't have the ability to deal with that, for God-sakes, the person who is being placed in that position should be given some alternative other than to lose complete and entire dignity and to be made feel that they're leaving their life behind and their loved ones behind with nothing more than a sack of bones.

This passage also alludes to another consequence of the loss of function. Depending on the extent of the loss and the specific functional effect, individuals may no longer be physically able to move and travel as freely, and this loss of mobility can result in isolation and loneliness, which, in turn, can exacerbate existential suffering. The concept of isolation will be discussed in more detail below, under “Community”.

Although the participants refer to a loss of dignity, some of their comments suggest that dignity is used to represent the very essence of the individual, i.e. the disintegration of the self. The quote above, for example, suggests that disintegration is a transforming process not only for the physical person, but also for the self. This idea is implicit in many of the other participants' responses as well. For example,

It's like people who are lying in hospital that are vegetables, and there's absolutely no chance of them ever returning to a normal life.

Although the preceding discussion about disintegration and willingness to be cared for by others reflects the experiences and perspective of the vast majority of the participants, there were some exceptions. Several participants saw little personal difficulty with accepting the care of others. One individual was a quiet and gentle man, less self assured (or apparently so) than many of the other study participants. He had struggled with substance abuse. His
willingness to be cared for did not surprise me.

I So do you have any thoughts about that how you would feel about that, about other people caring for you.

P Ah....it wouldn’t bother me. You know it would be good for people who want to help. You know the thing is you’re in a lot of...you’re yelling and screaming from the pain like sometimes I feel pain that just comes and goes, sharp pains once in a while, but I don’t...it’s like if they’re in pain from loss of weight or just from the disease getting worse, and they’re in a lot of pain crying or yelling or whatever frustrations they’re going through, I can understand them not wanting to be seen like their agony and they’re going to be dying, but if you’ve got no help, you can’t get better, so that wouldn’t bother me. It might bother me to an extent where they’re seeing me in pain, but I would like the help, you know, comfort, people there showing that they care and they hope you can get better or to help you live better.

This participant’s cautious willingness to be cared for reflects two key aspects of his life. First, he lives at home with his family and has a close relationship with his mother and siblings. Second, he is a very religious man and his views of his role in life are very clearly formulated around his understanding of God’s will.

All my life I’ve grown up knowing that like through God, through Jesus, if he’s part of your life and you pray, that God hears your prayers. And, you know, you live the way you should live, and God sees that, you know nothing’s impossible for God.

Rather than providing him with an exemption from existential suffering, the religious perspective provides this participant with a framework by which he can make sense of his suffering. In this participant’s case, this framework also provides an unambiguous role for his family members in providing care for him. The irony with respect to the majority of the other participants, is that they have cared for other people when they have died, often in very difficult and upsetting circumstances. This initially raised a paradox in my mind. Most participants were fully willing to provide care for others who were dying—and had done
so—yet they did not want others caring for them in similar circumstances. The paradox was explained to me by one participant:

I’ve heard an awful lot of people, so far, saying that they don’t want other people to have to do those things for them........ let’s say: clean them, clean their feces or, if they’re incontinent, or whatever. But...when I asked them whether they would be willing to do those things for someone else, that they cared about...... no problem.....

Oh yeah....unconditionally.... unconditional.....
And I’m wondering the...I mean there seems to be some kind of transferability, there...... Could you talk about that......
There’s, I-I don’t see that as a conflict. Because, again, it’s a matter of personal choice. And whatever the other person chooses, though I choose something different. I don’t see there’s any incompatibility, between the two willingness to-to carry out the wishes of someone, regardless of what they are, regardless of my own personal views.... But I-I don’t know why... that has not lead me.... the... It’s just the indignity. And, ah... I don’t want anyone else to have to go through that. Though I will do if for-for any and everyone, unconditionally.

It appears that the fact that participants were providing care for their dying friends and loved ones—perhaps doing something for someone else that they may view as unacceptable for themselves—is incidental to the fact that they are being respectful of that person’s wishes. This passage suggests that respect for the self-determination of others is among the highest of values for participants. This idea is developed more fully in the following section on “Community”.

Only one participant—the same religious participant described above—could not imagine a situation in which he agreed with, or would personally desire, euthanasia or assisted suicide:

I can understand that [the desire for euthanasia or assisted suicide] from the past, from their years of, you know, from before, how they lived, I could understand that they could be thinking there’s not going to be a cure and they’re fed up with life, I could take that into consideration and understand
it, but I still say it’s wrong, but I could understand that they’d want to do it, you know. If there was to be a law given to those people, you know grant them yes or no if they want to do that, I’d say not to give them a law. You know, if they get the permission from the doctor whatever, have to go to court you know, fight, fight, fight, and they’re really that persistent, if that’s what they want, but I find life too precious to give up.

Strong religious convictions appear to be the only a priori grounds for rejecting euthanasia and assisted suicide by participants, and most participants who reported being very or extremely religious admitted that they would entertain the option of having euthanasia or assisted suicide under certain circumstances. This raises some important questions about the nature and role of personal moral frameworks for participants, and how they view euthanasia and assisted suicide within these moral frameworks, though this lies beyond the scope of the current study.

In summary, disintegration gives rise to symptoms and loss of function. These in turn can result in dependency on others and/or isolation, both of which can result in a perceived loss of dignity (i.e. a loss of self) and can therefore give rise to existential suffering. Loss of function and symptoms can give rise to somatic suffering in the case of most physical symptoms (though depression may cross over both categories) and/or a perceived loss of dignity, which can give rise to existential suffering.

**Community**

Community is a difficult concept to pin down. But the accounts of the various interactions of participants with other people in their lives led me to adopt the term in a straightforward way to refer to the network of personal relationships within which the individual is situated. This framing accommodates the wide range, and quality, of relationships described by participants. I have also conceptualized community to include the resources that might be available to an individual as a result of his/her web of relationships.
At its core, community requires some level of basic acceptance by others and any of a number of types of interactions. These range from intimate relationships to casual acquaintances.

I  You mentioned the term ‘dignity’...there. Could you give me a sense about what that term means to you?

P  I think it’s very important for every single person to feel that they belong, and-and that they fit in a community, in a city, in a country, in a world.... Ah....in nature... The-the ah.... And I think when-when we no longer feel .... that you have these linkages, and that the linkages are valued for everything that you’re connected with...whether it, you know, family or friends or, you know associates, or whatever...... and your community, and city, and all the rest of....Once the-when you perceive that-that your relationships, all the links with-with other living things, have deteriorated, and then-and their not valued.... then you’ve lost face. Dignity, then, has for me..has an awful lot to do with face.

This passage also helps to illustrate the link between self and community. Several participants articulated (and many others alluded to) that fact that they understand community as an essential element of their identity, and that they do not exist as independent entities. In other words, someone’s perception of their value or self-worth, i.e. their dignity, appears to be at least partially determined by their acceptance by others. Therefore, erosion of community—as is suggested in the passage above—can lead to the perception of loss of dignity, and loss of self in the same way as disintegration. Another participant used a well known literary reference to make this point.

I  Now, let me tie that back to something that you brought up, with respect to relationships. I think you said: a sense of community. Could you elaborate on that, a little bit more, as well?

P  ...No... that’s John Donne’s poem “No Man Is An Island...” You know, I-I-I-I honestly.... ah.... believe we cannot survive without others. And-and ah..... if you’re going to ..... If you’re going to have any success and happiness in life, I mean, ....You work at your
relationships, in the community. Whether it be with friends, or people you work with, or ah... the institutions you come in contact with. Or whatever. And ah... you know, you're not isolated. You are linked.

The concept of acceptance has a strong individual and political meaning within the HIV/AIDS community, particularly within the gay community, where discrimination is so common. Some of the participants called themselves "lucky" and reported that they had never experienced discrimination. Ironically, these participants were either very attractive and/or less 'conspicuously' "gay". However, most of the participants reported personal experiences with discrimination as gay men and many of these had also reported additional traumatic experiences. These experiences, ranging from incest, rape, death of children, severe problems accepting being gay, drug overdoses, abandonment, molestation by a priest, and experience in a war, I have called "alienating" experiences, since they appear to have the effect of undermining or limiting community for the individual. Many of these experiences are also profoundly stigmatizing, even within the person's closest circles.

P I've experienced—in different sections of the population—stigma from having HIV and other sections at the same time are accepting of that fact and they don't feel threatened.

I Could you tell me a bit more about that before you go on, about the stigma?

P One section of the HIV community—"Oh, HIV, we don't want to have anything to do with you"

These alienating experiences are also often traumatic, i.e. they result in some injury to the person, most often of an emotional or psychological nature. These "injuries" appear to have two main consequences. First, they encourage feelings of "otherliness", i.e. of being different or "other" than the person responsible for the alienating behaviour. This is reflected in the following participant's experience while being treated in a hospital.

P I'm talking about dying at home, yeah. If I have my say, I'll never be hospitalized for anything. I mean I had a horrible experience when I
had esophageal thrush, it was horrible, I'll never go back to the hospital again. I told the doctor "the next time I'm dehydrated, you can give me my I.V. bottle and send me home on the TTC, I'll never go back into hospital again."

I Why was it a horrible experience?
P Oh God, it was terrible. The stigma, the AIDS-phobia in the hospital—this is just a few years ago—was horrible. I'd never do it again, I'd never go in the hospital again.

I Could you tell me more about that?
P well the nutritionist wouldn't even bring my food to me, she left it outside by the door, when I was finally able to eat. Uhm it was at [name of hospital] and there were [number] beds at the time, there was [number] beds for people with HIV/AIDS and outside of [number] doors was gloves and not outside any of the other doors, so everybody knew. I'm open, I'm really open about having AIDS, you know what I mean, but the person next door might not be, and I questioned "well why is it"—when I was able to get moving around—"why is it that you only have latex gloves outside these doors where people with HIV/AIDS are? Why don't you have latex gloves in every room?" You're labelled, I mean people walk down here, they know there are AIDS patients on this floor, they're going to look and see where the latex gloves are and so much for anonymity.

Second, experiences of alienation give rise to fears of rejection. These fears of rejection appear to also be encouraged by feelings of otherliness. Fear of rejection, particularly around communicating diagnosis with HIV, appears to present a barrier to establishing, maintaining and enhancing community. For example,

I Now in terms of other experiences, have you had any other experiences as a result of having HIV where you feel like you've been excluded, or not treated well or something like that?
P No....see those are the only people I've told, like my friends and that, and I really haven't told any. Except I'm going to tell a few other friends, but I haven't been excluded from anything. People who know me, that know I have it, they treat me the same. If I'm a bad or good
person they treat me the way they used to.

I And why then, could you tell me a bit about why you haven't told the other people, like your other friends?

P Oh, I don't know, maybe it's a fear...of support, rejection and in the area I live if I tell people they won't want me to hang around with them. But not all of them will be like that, but I just I haven't overcome that situation yet, just confronting the ones I want to or people in general, not that I'd tell everybody, but the people I hang around with and associate with..........It doesn't really matter, well it does matter if they know, but when they find out it's like it doesn't matter they reject me or don't I still have support from other people, it's just getting to that stage in telling the people, the ones I want to tell, having come around with it I'm just kind of like on the edge, just holding back and I'm not ready for that yet.

In some cases, the personal experiences of alienation involve remarkable layers of complication. The following lengthy account is included in its entirety to provide a more complete insight into the nature of the injury that results from experiences of alienation, how the injury gives rise to feelings of otherliness and to fear of rejection and how these in turn led to isolation and loss of community.

I You, you mentioned earlier on that you were on you own, ah, during the day. During that period. Could you tell me about that?

P Well, my partner just got... gotten a promotion at work. So he was putting in long hours to impress the, ah, ...his new bosses. And, ah, so he'd leave all the time before I was up in the morning. And he wouldn't get home till about 10 o'clock, 11 o'clock at night. So, there I am... See I've been used to being alone, most of my life.... being in my room, by myself....or.. When my parents found out I was gay they sent me away, and I was by myself, in their cottage, living. They'd come up there every other weekend, maybe...so.. And, I just.... I 'm really used to being alone. And when I was, like....really alone, when I was depressed, I didn't want to be.... I wanted him [partner] to be there all the time. But, it was like, on the weekends, when he was home, it was like I'd drive him crazy. Because I... I felt like I was
keeping him at home. So it got to the point where I...

I ...this is [partner's name]?

P ...yeah... when he was home, I'd tell him to go out with his friends. And I said: No, it doesn't bother me... it doesn't bother me. And like you know, of course, as soon as the door closes I'm crying. ....or he'd...

Stuf like that.

I And... what, why would you have him do that, then?

P Because I felt that I was uhm... like I liked it before: We'd go out together, go out separately, go out with friends. And then all of a sudden here I am stuck in bed; not wanting to get out. Uhm, not wanting to move... and, he's wanting to take care of me. So he'd have work, and then come home and take care of [partner's name].

And that's another life. So, I'd tell him to go... to go. And then he started getting used to going, and I didn't like that....either. But... now that I'm well, sometimes I wish he was out of the house more.

(snicker) Now that I feel better. But I didn't even.... when I was sick, and I had him at home, I didn't even care if he was with me. Like, as long as I knew he was in the house, it was fine. But, as soon as he left, then I'd go downstairs, and I'd crank up the stereo, and I sat and bawled... and so the neighbours couldn't hear it....or the tenant upstairs couldn't hear. But I liked being by myself, aaaaalll along... and then all of a sudden, when I got depressed I wanted him to be there. And when he was there I didn't want him to be there. ... right next to me. I didn't want that.

I Could you help me understand that a little bit?

P Uhm... cause he likes a lot of, uhm, contact. Like, you know, just arm around each other rest your head. And I had, uhm, a hard time... because we'd been together for so long, now, that it sort of not... it's not sex anymore. It's a relationship. So, in the beginning it was easy because it was...you know, he's even touched .. when touch, we were...it would end up in sex, or something like that. Uhm... and but I'm not used to, just like holding hands..... or being hugged, or resting my head on someone's lap, or having their arm around... It's just that, to me, it feels kind of creepy. Like even with strangers, I had
a hard time shaking their hand. Any kind of contact with a .... another person sort of, sort of bothers me. And I just think its because of, you know, from youth... from childhood up. That's the way I was brought up. And, you know, my .. my father was...is like [occupation]/ [motorcycle gang member].... so... what kind of love are you gonna get from that kind of man? And my mother, depressions all the time, so... And when she became angry, because of her depressions, you know, I was her punching bag. So, like you know, in our house their... their room was on the opposite, our ends were opposite. So, I felt safe in my room. And I could amuse myself, by myself. So that's what I learned to do since childhood. Like, a lot of the times I'd be in bed before the lights went out, or my friends had to go and leave. Uhm, I was beaten a lot by my father. Like I said, again, because he was a [motorcycle gang] member, WAS .... and he then went to [occupation], so my father neglected to take off his steel-toed work boots when, when he was hitting me or kicking me... or whatever. And I just got use to...I felt that if I stayed in my room, away from everybody, that was good. I just didn't have any fun, and not getting in trouble. And so I think it just grew on me, to be, you know, alone. As I got older and got my own TV, then the TV became my friend. So, I just got used to, you know, nobody touching me. I didn't want anybody touching me because I usually associated it... I associated it, when I got older, in my teenager years, with either sex and pleasure, or, uhm, pain and hurt. So, I didn't mind the sex and the pleasure; but I was reckless, obviously. And, there was like: I was reeling from the touch, but I wanted it so bad. And I ... when I did have sex, anonymous sex, I chose, a lot of the time, people who look like my father. And, uhm, I was just wild. When I... when I came back from my exile.... how do you say exile? When I was exiled, and I came back to the city, and I was more like an adult.... I feel if I wanted to I could be the host. So I just went crazy.... like, sexually. So... sex touch I can handle, intimate touch I couldn't. And that's how it was. That's how it is, still.

This participant's story reflects many of the concepts described in this section. The alienation is clear and powerful, it appears to have been profoundly traumatic and injurious, though the
precise nature of the injury is not clear. The participant’s parents’ behaviour clearly reinforced feelings of otherliness and in doing so created lasting barriers to community. It is important to note that many of the traumatic experiences occurred in the context of the family or close personal relationships. It is instructive also to compare this story—which, though extreme, is no more dramatic than many of the other experiences of alienation and trauma reported by other participants—with stories of participants who have not had these types of experience.

Participants who have not been subjected to the same types of traumatic experiences appear to have different concerns about the effect of their actions (i.e. euthanasia and assisted suicide) within their personal community. This results in a more restrained attitude toward euthanasia and assisted suicide in practice, even in those participants who expressed strong support for euthanasia and assisted suicide in principle.

I What was their [parents’] response? [to HIV diagnosis]
P Well, it was wonderful. I think it helped with the Minister coming over and he [father] could talk to the Minister about anything, problems he had and that too, and my brother was very supportive he said, you know, we’ve got to all stick together as a family, and then when I first started chemotherapy [for Kaposi Sarcoma] my mother came down and stayed with me for three weeks when I first...which was very helpful, you know it’s funny, you’re over forty years old and it was nice to have my mother around, she made sure I ate and everything.

This participant reported that he had had thoughts of suicide, but he knew he “couldn’t do that to someone else”. His father was a religious man who had never really come to terms with him being gay, but had nonetheless managed to provide him with a strong sense of belonging:

Even if he [father] didn’t like it, he’s never rejected me.

Aside from the trauma and stigmatization experienced within a community, people with
HIV/AIDS have also experienced the relentless attrition of their communities from death to AIDS. This loss has been substantial and has drastically altered the nature of day-to-day life for many participants.

I: could you tell me a bit more about losing friends and what kind of experience that's been and what kind of effect that's had on.....

P: Well it's kind of, let me draw a parallel. A friend of mine who is now in her late 70s was in England during World War II and was a teenager at the time of Dunkirk. And as she put it, you know, during the war you would hear first of all that Freddie got shot down over the channel, well then it was all boo-hoo-hoo for Freddie and you felt miserable about that for a few days, but then 5 days later, well George got shot in France last week, well then, and then, and then, and then. Well one becomes inured to it to a certain extent, .........but I wrote down that there are 8 friends who have died of AIDS, now those are friends, but when it comes to acquaintances, easily I've lost twenty. These are people I knew in the neighbourhood who aren't there anymore. Uhm...those are acquaintances. Friends are quite a different thing from acquaintances. And I have a wide field of acquaintances. And there's just in my age group there are other friends who have died, I have a friend who was a [occupation] at [organization] who got up from dinner one night and told his wife, gee I think I've got indigestion, she went away to get some Alka-Seltzer and by the time she was back he was lying on the floor, he had a heart-attack. He was 42 years old. Uhm...but uhm.......you see you can't replace these people.

In summary, the existence of community, or the web of personal relationships, requires acceptance by others. Many participants had experienced alienation, either through
discrimination or a wide range of other traumatic experiences. These experiences resulted in emotional or psychological injury, which in turn gives rise to feelings of otherliness and fear of rejection. The fear of rejection leads to various levels of isolation and thereby constitutes an important obstruction to community. It appears that these experiences may predispose individuals to be sensitive to the threat of existential suffering. This sensitivity may in turn function by exaggerating the threat of existential suffering in the individual's deliberations regarding euthanasia and assisted suicide. Feelings of isolation may also follow from the extensive attrition that has occurred in the HIV/AIDS community through death to AIDS.

Summary

In this chapter, I have described the two main categories of the theory, i.e. disintegration and community and how they can give rise to the perception of loss of self and existential suffering. These categories appear to be able to function cumulatively to give rise to the desire for euthanasia or assisted suicide through the process described in Chapter 7. Figure 1 (p. 130) illustrates the process of deliberation and the influence of disintegration and loss of community.
Figure 1: Process of Deliberation and Factors Affecting the Process
Chapter 9

Results: Limiting the Loss of Self, the Meaning of Euthanasia and Assisted Suicide

The previous two chapters present a theory of the process of deliberation about euthanasia and assisted suicide in people with HIV/AIDS and begin to articulate some of the factors and circumstances that may lead individuals to consider and decide upon these options. During the analytic process it became clear that the data could be understood at three distinct levels. The previous chapters represent increasing levels of depth of analysis, from a descriptive account of the process of deliberation in Chapter 7, to a deeper account of some of the factors affecting that process in Chapter 8. In this chapter, I continue to develop the theory by providing an account of the deepest level of the analysis, i.e. the meaning of euthanasia and assisted suicide to the study participants.

The Meaning of Euthanasia and Assisted Suicide

The central assertion of this chapter is that euthanasia and assisted suicide provide a means of limiting the loss of self that disintegration and/or loss of community can bring about. I will defend this interpretation by demonstrating its fit with the categories of disintegration and community, which are developed thoroughly in Chapter 8. Specifically, I will extend the argument—that I began very briefly in Chapter 8—that the self appears to be a product of the individual person and his or her perceived role or acceptance within a community. For participants in the study, this notion of self appears to be represented by the concept of dignity or self-worth. I will demonstrate that disintegration and loss of community give rise to the perception of loss of dignity, which in turn gives rise to existential suffering. Conceptually, existential suffering functions as a bridge between the factors described in Chapter 8 (i.e. disintegration and community) and the ultimate meaning of euthanasia and assisted suicide as means of limiting the loss of self.
Limiting Disintegration

The account of disintegration provided in Chapter 8 illustrates the gradual, progressive debilitation that can occur in AIDS and demonstrates its negative impact on the independence of the people affected. Furthermore, the gradual loss of independence and the cumulative effects of disintegration were shown to give rise to existential suffering.

These events currently occur within a context in which euthanasia and assisted suicide are illegal activities and not universally condoned ethically—even by people with HIV/AIDS, as the findings in Chapter 7 demonstrate. The result is a limited set of options available to people with HIV/AIDS who are experiencing existential suffering related to the loss of self. Most participants reported that these circumstances are more than they are (or are likely to be) willing and/or able to endure. The available options are further limited by the current infrastructure for the delivery of palliative care in Canada, and Ontario in particular, which has been widely criticized as being dramatically under-resourced. It is likely that many people with HIV/AIDS will not even have ready access to palliative care services.

Under these circumstances, euthanasia or assisted suicide provide possibly the only means to avoid existential suffering, by limiting the loss of self, i.e. by limiting the disintegration and/or loss of community that give rise to existential suffering. Furthermore, they do so in a way that is consistent with the fundamental values of control and independence (see discussion below), despite the possible conflict with other community or societal values.

My personal experiences in life ah have led me to be a supporter of the concept of euthanasia or assisted suicide. Again, just briefly. One thing I put in my Living Will was the fact that ah... when I was a young kid, my grandmother...who was one of these archetypal grandmothers. You know: the warm, loving big, cosy, you really felt comfortable with....fell over and died, qui...nobody was there. And the doctor said she was dead before she hit the floor. And ah... In contrast: my dad had congestive heart failure, and just kind of....withered away over about 6 or 8 months, in hospital. And three

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times we went home, because the doctors were sure it was the last trip...sort of thing. And so the one was almost my ideal. And the other is sort of the... the horror that I have in the middle of the night....Sometime..... So... As I, partly from practical experience, ah.... I was predisposed to- to feel: Boy if was ever in lingering situation, I would like there to be some mechanism that I could... have kick in on the spot. And that, hopefully I, to the degree there was any.....way of ah.... pre-arranging it...like friends, and families and doctor.....know that I was disposed in that direction.

The desire for control has murky origins. When asked directly where their desire for control comes from, most of the participants (for whom the question was relevant) said that it’s “just the way I am”, or “that’s just the way I was brought up”. This suggests that there are deep-rooted personality determinants involved, and that the value of independence has been inculcated upon the individual from an early age.

However, broader societal values also appear to shape the desire for control and independence. Although the nature of these social values and the mechanisms by which they are transmitted and propagated are complex and not easily understood, they leave a clear signature in the form of the concepts and ideas that participants use to express themselves. For example,

Dignity is that I have control over my body, when-when.... not-not a virus that is going to take my life. I’m the one who’s going to decide when my life will end. Not a virus, and not with great pain. Not...anything else other than in-in my control. It is my control. It is my choice to do.

As well, personal experiences with difficult dying and death of others appear to give rise to, or reinforce, fears that the disintegration and suffering they perceived in their friends and loved ones may also be visited upon them. These experiences have been extraordinarily common in the HIV/AIDS community and have likely given rise to a skewed perception of what the possibilities for end of life care may really be. These experiences have clearly shaped some participants’ consideration of euthanasia and assisted suicide as ways of taking control
and avoiding such a fate. The greater the overall impact of these experiences in people’s lives, the greater the desire for control appears to be.

**Limiting Loss of Community**

The process of disintegration gives rise to the perception of loss of dignity, i.e. feelings that the individual’s self has been altered or lost. From this perspective, it is easy to imagine participants concluding that their existence is of diminished value, or even a burden to others. These feelings are powerfully manifest in participants’ expressions of unwillingness to be cared for by others, usually in hypothetical conditions involving advanced disintegration and existential suffering.

Although these feelings (or fear of them developing) are common, the strength of the participants’ fears appear to be related to the extent of their emotional or psychological injury as a result of experiences of alienation and trauma. One indication that this may be true lies in the following account, by a participant who has not suffered alienation and trauma. This passage suggests that this participant does not adopt the stance of being a burden on others as readily as many other participants who had these experiences.

---

*I* Now you mentioned ...you were talking about dignity. How would you define ‘dignity’? What does ‘dignity’ mean to you?

*P* I think.... I can’t remember how I used it. But I-I-I- I think it came to a ...... a per- sort of a personal .....you know, be it like a personal line to cross. Ah..... I wrote a Living Will, quite a while ago

*I* You did, OK

*P* And I-I-I tried to explain that..... ‘dignity’ is for me to decide. I mean, today I might find --I might find it un-inconceivable to, you know, have to wear a diapers.... or something like that. And that would be.... a loss of dignity, in some people’s eyes. And yet, I’ve seen
people go through the, you know, the stages. And-and their definition changes, you know? And all of a sudden, it's not un-dignified to have to wear diapers, anymore. You know... So... it's-it's sort of a personal... definition. And, ultimately it comes t-to me---it-it's important to me to have this personal-personal decisions. Like I say,... definitions change.

1 OK. Let's take the diaper example. It's a fairly common one. I'm also interested, jumping back again..... Let's say that that's something you didn't want. I'm wondering, also from your perspective as a care giver, whether... I mean I guess to ask the directly, whether you thought someone was un-dignified if they had to wear diapers..... as a care giver..?

P No. In fact I ah..... the first time my friend (name) had an accident, he was extremely embarrassed. You know, apologizing up and down.... And.... As difficult for me as it was to actually do a changing, since I'd never even changed a baby...this diaper..... Ah..... I was sort of going the opposite way, saying: No, it's fine. Don't worry about it....I mean, I'm trying to comfort him.... trying to ease his mind.... He'd made such an idiot of himself....kind of thing..... I said: NO...... no, It's alright... it's alright... So.... I mean when I think about it, it-it's just a biological function.... that you lose control over. And... you know.... that...It's no big deal... Except in our--our pride, and our....

Although participants were not able to clearly identify or articulate the connection between these experiences of alienation and trauma and the emotional or psychological injury they caused, many had accepted that these experiences have contributed to their overall formation as people and, therefore have contributed to the way they approach any given problem. Presumably this would include the inclination to view oneself as a burden on others. The following passage is an example of an alienating experience that may have played a role in
predisposing the participant to see himself as a burden on others.

\[P\]  
Well, actually I’ve seen it in the hospital... when I was first diagnosed. Ah.... I....in those days, they used to put stickers across the forms....saying ah.... HIV and AIDS, and what have you....infectious... and what have you. Even over-over just a form..... Not even a blood product, and-and.....I was in a situation, in a-in a clinic... where a pregnant woman was standing beside me. And ah..... she looked down and saw the form.... and realised that she was 4 inches from my arm. And promptly started to scream and yell. And ah.... you know, and screamed at the nurse that, you know...... “I’ll come back when -when that thing is out of here....” And ah... stuff like that. Sh... the nurse was very good. And handled it. And ah.... But didn’t ask me how I felt.... and what this was doing to me.... And.... there are other people in the room. And they were like....with their faces hanging... and absolutely shocked. And-and I had a in..... And I felt extremely devalued. Because here is the pro....the professional. And, I mean, she’s being efficient; and handling things, and..... you know, my blood work ends up done. And this and that..... and all the other things that had to be done. But it’s ah.... but she never dealt with me as a.... as... other than just as --as a ....straight forward protocol person. She-she was not asking ah.... how I felt about that woman. And.... ...I felt extremely devalued... at that time.... And then I’ve--I’ve seen other situations with-with ah..... first hand, with friends. Where I, you know, ....I’m bringing them to their dentist. ..They’re obviously sick.... Ah, the dentist refuses to take care of them anymore. And what have you..... And ah.... “...No, I’m sorry. I didn’t know that you had AIDS. Ah... I think you should go somewhere else....” And if it had happened just once, I would have said it was rare. But I’ve seen it happen so many times. And as recently as only 5 months, ago.... with another dentist. It’s-it’s..... I...Yeah.... It’s extremely devaluing....

\[I\]  
Could you unpack that.... a little bit for me: the devaluing? I mean, I know what you mean. But I’d just to get out a little bit more.......

\[P\]  
Again... your own sense of-of where you fit in, on this planet. And your relationship with other people. And, you know, and-and..... your feelings of self esteem: that you are a moral person. You don’t harm
others. You do some things ah... for the betterment of the world, and
what have you. And then other people are just ah... Well they don’t
have to know your history. And it’s none of their business. But why
would they treat you with such disrespect? And-and-and just totally
devolve. Ah... And a strip your dignity. Cause there’s a---there’s
terrible lack of respect. And-and you’re-and you’re.... and, well wh-
what do you do about it, when it happens?...You know.... Ah...Make a
complaint to the College of....Physicians and Surgeons. And the other
one for dentist, or what have you.... and. You’d be dead before they
hear it--hear the case.

It is reasonable to suspect that the feelings engendered by alienation and trauma— that so many
participants have experienced—are similar in many relevant ways to feelings that arise through
the process of disintegration. The heightened sensitivity to these feelings acquired through
alienation may sensitize individuals and make them, not only more inclined to accept
themselves as a burden on others under conditions of disintegration, but also more actively
interested in avoiding similar experiences again in the future. It also is likely to shape
participants’ expectations of how others will perceive their suffering, and this too appears to
have a strong motivating effect.

The knowledge that others will suffer as a result of their own disintegration and death can
also be understood to compound the experience of existential suffering for the individual, i.e.
the sense of guilt or responsibility that she/he is inflicting pain and suffering on loved ones.
Thus, avoiding placing this burden on others by resorting to euthanasia or assisted suicide
appears to reflect a reasonable interest in limiting additional personal suffering. However,
imposing suffering on others can also be understood as a way in which community may be
stressed and/or eroded, and therefore, euthanasia and assisted suicide also represent ways in
which the loss of community may be limited. It is likely that a combination of both of these
rationales provides the strongest explanation for the phenomenon.

The data provide support for this combined interpretation.
... if I'm going to be rolling around in my old-own feces because I have no control, then forget it....

I

Ok. Why-why is that such an important thing?

P

Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is-it's cruel too-for others to have to do this, when there's no end in sight, other than death. To just-to clean me up. I just don't want that.

Another participants said:

I watched my mother care for my grandmother, with Alzheimers. And as a result of that I thought: if there was a similar situation... OK If I knew I was at that type of a state, that I couldn't function as I am now, I don't know if I'd want to continue living. ...And be the burden that it is on everybody else. Not just the physical burden, caring for the people. It would just... mentally and emotionally: how exhausting it is. And, in the sense of.....just... As it does with Alzheimers, you can live an incredibly long time with that.... And it just... It's a very slow, progressive thing, where you just get worse, and worse and worse. And it can go on for years and years and years. And I don't know if I'd want to do that to someone else..... Especially because there's no hope of correcting it.

The concern for causing suffering for others was not a distant one or some participants. In fact, the following accounts suggest that there is a spectrum of imposed suffering, from exhaustion, mental and physical torment that follows efforts to provide care and comfort, on the one hand, to “suffering” arising from the mere inconvenience of living with and/or caring for a sick and slowly disintegrating—but not gravely ill—person, on the other.

I

I'll just get you to tell me a little more about your decision, and how you arrived at that.

P

My decision was, is that: if I became at a place in my life, was unable to care for myself, and I was really a burden, to those who assist me, I would chose not to want to continue my life.

I

OK. Then can you tell me a bit more about what you mean by “being a burden on others...”?
P Being a burden, I mean obviously in the sense of being physically ill, and having to be assisted. Which is a lingering. A linger, that knows difficult of....of. There’s no possible medical way that they could revert me back to a status where I would have a quality of life, and the present to confirm it with.

I OK. And how is that a burden?...on other people?

P I’ve seen it in a lot of friends: who just get burnt out....waiting for the end to have to... I mean for their friend to depart. Whereas opposed to having that happen, and what it does to them. And it builds... I’ve seen how it builds a little bit of resentment against the person themselves. I don’t want to be in that position.

I Could you tell me about any more details about those cases that you’re aware of?

P I don’t know what....

I I’m sort of interested in the resentment part. Could you tell me a little bit about how that actually worked in your case?

P In one case, my friend’s partner was very, very ill. And it was more or less written off, he was going to die. And ironically that’s when a lot of new drugs became available. And he began to get well again. And so, the partner had already planned one of those... his funeral. And what he was going to do: get rid of the condo, and he was going to lead his own life. Now, that had been stunted. He thought he had a whole new life ahead of him, with someone new. And he had already set up everything for that. And this was fast... up and gone. It was just fine... having the guy die. And it wasn’t happening; and it wasn’t happening fast enough. But now, ...it was looking like it wasn’t going to happen. Now this is 3 years later, now. And so.... And you can see the difference..... the way they interact with each other.

One participant recalled a personal account of the same type of experience:

I had, in the past, a very long term relationship that, after my diagnosis, created a nightmare.... But I wasn’t aware of it. There was this whole other world going on, with my partner and, and as a result of what that did, as a result of what it did to me, I just thought..... here was another example of this partner had planned for a new life for us, and stuff. And he was kind of
influenced by that other friend that I had, who was... who was almost the same thing. And like I said, I was unaware of it at the time. It's only now, looking back, and having spoken to a lot more people, and with people being honest, you know... about what they knew, and when they knew it, that I've come to realize like... that "...you were, more or less, being written off..." It was just like marking the days down on the calendar. And when you weren't going fast enough, they were getting worried, and stuff. And at the time I thought, I wasn't about to roll over and die, just to accommodate somebody else's life.

These experiences clearly reinforce the notion that the dying person is somehow obstructing the pursuit of other life interests for survivors, i.e. posing an inconvenience for them, and thereby threatening the integrity of their community. It seems reasonable to conclude from these examples that this type of subtle pressure may be brought to bear by caregivers and that it might give rise to feelings of being a burden that might not otherwise have arisen in the individual who is sick and dying. In other words, the person's "community", has eroded in a specific way that results in harm or injury (i.e. feelings of being a nuisance or burden) to the person.

In terms of the process for deliberation outlined in Chapter 7, it seems likely that these feelings might prompt the individual to make subtle refinements in his/her goals with respect to death. For example, it is a subtle extension to move from a goal like "maintain control over the dying experience and minimize my own existential suffering" to "maintain control and minimize my own, and my loved ones' burden or suffering." In part, it is because this is a barely perceptible move that the experiences of participants described above are somewhat alarming. Again, euthanasia and assisted suicide provide a means to limit or manage even the potential exacerbation of existential suffering.

Summary

The findings in this study have allowed the proposal of an explanation of how and why
people with HIV/AIDS make decisions regarding euthanasia or assisted suicide. The explanation draws from the nature of the process of deliberation described in Chapter 7 and the main factors that appear to give rise to the desire to die by euthanasia or assisted suicide, described in Chapter 8, i.e. disintegration and community. In this chapter I have provided an account of the meaning of the process and factors. The core of the proposed explanation is that euthanasia and assisted suicide offer a means by which people with HIV/AIDS can limit existential suffering by limiting disintegration and/or loss of community that can give rise to the loss of self. In Chapter 10, I explore the implications of this account of euthanasia and assisted suicide for public policy and clinical practice.
Chapter 10

Responding to the Loss of Self: Implications for Public Policy

Overview

In the preceding chapters I have outlined the rationale for a grounded theory study of decision making regarding euthanasia and assisted suicide in HIV/AIDS and presented an account of the theory. In this chapter I will describe the contribution of the theory to the existing knowledge regarding euthanasia and assisted suicide and identify several ways in which it might be useful in framing and/or refining the response to euthanasia in public policy. I use the term “public policy” in a non-technical way to refer to the various instruments available within society that help organize and implement responses to foreseeable events or issues.

In particular, I will focus on the relevance of the theory for any potential legislative response to euthanasia and assisted suicide that might be forthcoming in Canada by briefly reviewing the requirements of legislation and guidelines in three jurisdictions in which euthanasia and/or assisted suicide are (or recently have been) legally permissible—the Netherlands, the State of Oregon, and Australia’s Northern Territory. I will suggest that the laws in these diverse jurisdictions are constructed on a framework of shared clinical assumptions and will consider the strength of these assumptions as a framework for these legislative policies in light of the findings in Chapters 7, 8 and 9. I will then revisit the review of the ethics and policy in Chapter 4 and identify several specific ways in which the study findings may contribute to each area.

Although the study focussed specifically on people with HIV/AIDS, the review of the literature in Chapter 2 demonstrates that the incidence of euthanasia and assisted suicide is extremely high in this patient population, making findings relevant even to a general
evaluation of the respective policies.

Before outlining some of the implications of the study findings, I will first describe some of the study's limitations in an effort to provide a realistic account of the scope, generalizability, and relevance of the findings.

Study Limitations

In qualitative research, methodological limitations are often reported in terms of their effect on the trustworthiness of the study findings. In this chapter, I will briefly outline the concept of trustworthiness as it relates to qualitative research and identify some of the specific impediments to trustworthiness that resulted from the methods used in this study.

Trustworthiness

Trustworthiness is a multi-faceted measure of the credibility or validity of the findings or interpretations of a given research project. Trustworthy findings should satisfy four broad criteria: truth value, applicability, consistency, and neutrality(240). Although these concepts are presented in different ways by different authors, these general requirements are common to most accounts of trustworthiness. There are several ways of demonstrating that the requirements of trustworthiness have been satisfied. These are outlined in detail under each of the four broad requirements of trustworthiness outlined above.

Truth Value

‘Truth value’, or the apparent likelihood that the findings faithfully reflect the experiences of participants, may be demonstrated by prolonged engagement in the field, persistent observation, (multiple opportunities for observation or interviewing), triangulation in data collection (the use of more than one source of data), referential adequacy (the extent to
which the raw data were referred to in the interpretive process), peer debriefing (activities that introduce external scrutiny on the research process), member checks ('testing' findings back with the study participants), and keeping of a reflexive journal. Truth value is similar to the concept of internal validity in quantitative research and is often referred to as credibility in naturalistic inquiry.

**Prolonged Engagement in the Field**

During the process of research ethics review it was determined that the risk to me as an investigator who may acquire special knowledge of criminal activities would increase with the level of contact I had with my individual participants. This, in turn, would make it more difficult to demonstrate to the participants that I had done everything in my power to minimize the risk that identifying information about them would be disclosed if I were to be subpoenaed to testify in a criminal or coroner’s investigation. Therefore, the findings do not reflect prolonged engagement in the field.

Although I was able to talk to people for whom euthanasia and assisted suicide had real significance and meaning, very few of the participants appeared to be thinking about these options as imminent for them. There are two main implications of the hypothetical nature of their accounts. First, participants may have over-estimated the strength of their conviction to have euthanasia or assisted suicide under the conditions they described. Their perception of other people’s suffering, or the image of future disintegration that appears so incompatible with their current wishes, may not be so incompatible at a time when it really does matter. Therefore, the theory presented in Chapters 7 and 8 may present the process and the utility of euthanasia and assisted suicide too linearly and simplistically.

**Persistent Observation**

For the reasons cited above, it was not possible to conduct follow up interviews with
participants.

Triangulation

Because the participants provided accounts of their own personal experiences, there were no alternative or complementary sources of data for this study.

Referential Adequacy

One of the noted advantages of qualitative research software is the ability to instantly reference the raw data, and/or to quickly examine and/or compare large numbers of quotes in context. The software chosen for this study, ATLAS/ti has the added advantage of allowing graphical depictions of objects such as memos, codes, categories and the relationships between and among them, which allow the raw data to be “attached” to these objects and viewed from within the graphical interface. This allows for a streamlined process of comparative analysis. Therefore, the analytic methods clearly facilitated adequate reference to the raw data.

Peer Debriefing

Because of the legal implications of the study, I sought peer input sparingly. However, there were three main stages at which this input was elicited. First, after the initial three interviews were transcribed, I provided two experienced qualitative interviewers with copies of the interviews and sought their comments and criticisms of the interviews and their assessment of their general productivity. Later, after approximately 10 interviews were completed, I presented an interim analysis to a group of researchers and some people with HIV/AIDS and sought their feedback with respect to the plausibility of the findings. Finally, the first draft was used as a vehicle for my thesis committee to provide substantive input into the interpretations and conceptualizations as presented in the findings. These discussions resulted
in some refinements to the interpretations and some re-evaluation and subsequent amendment to other findings and interpretations. Throughout the entire process, I had extensive informal (and some formal) discussions with my supervisor, Dr. Peter Singer, regarding the evolving findings and theory.

**Member Checks**

For the reasons outlined above under "Prolonged Engagement in the Field" and "Persistent Observation" the option of performing follow-up interviews with participants was not available to me. As well, given the length of time it took to recruit the 32 participants, even the feasibility of follow-up interviews is questionable. However, informally through the course of the interviews—where appropriate—and in a more structured way in the later interviews, I presented the main elements of the emerging theory to participants and sought their reflections on how well these findings seemed to resonate with their own experience. Their feedback resulted in several refinements of the theory.

**Reflexive Journal**

Although I did not keep a journal *per se*, I made extensive use of the software's ability to "attach" notes and memos to objects in the analysis. I made memos on the selected names of codes, particular decisions about coding and interpretation, to document where theoretical questions had arisen in the analysis and at numerous other points in the study.

**Applicability**

The concept of ‘applicability’ or generalizability of the study findings is a troublesome one for qualitative research in general, since the aims of qualitative research have more to do with discovering patterns of process and meaning and constructing explanations *within* a sample, than in drawing conclusions about the population supposedly represented by the sample. The
process of judging the applicability of qualitative research findings, in my view, is a subtle extension of ‘truth value’, i.e. it is primarily about forming an impression of the credibility of the work and that impression is based, in large part, on the persuasiveness of the account and the familiarity and plausibility of the theory’s concepts and general structure. Though the resulting judgements may ultimately prove to be correct, neither of these criteria logically implies that the findings will be generalizable to a broader population.

In this study the applicability is reinforced by some of the similarities between the concepts reported in the literature and the concepts discovered in the process of analysis. However, there are two main problems associated with the applicability of the findings. First, because of the introduction of potent new combination anti-HIV therapies during the early phases of this study, the assumption that many people would still be “terminally ill” appears to have been undermined. This therapeutic advance may have also undermined the trustworthiness of the data to some extent by making the focus of the study, i.e. decision making regarding euthanasia and assisted suicide, more remote and hypothetical in the minds of participants.

Second, because all the participants were seeking care at HIV specialty care clinics in Toronto, the findings may reflect more of the culture of the city—particularly the gay community—than might be expected in other geographic areas. This may have specific importance given the relevance of prevailing societal and community values in the proposed theory.

Thick Description

The accounts in the study, though not the product of prolonged engagement or persistent observation, offer a rich, detailed account of the phenomena. Many participants informed me that they had not had a similar opportunity to discuss euthanasia and assisted suicide and appeared not to be inhibited about providing me with deeply personal details about their lives, as many of the quotes, above, illustrate. I have also tried to include some longer
quotes—where appropriate—to provide a better account of the phenomena, or specific aspects of the phenomena, for the participants.

*Purposive Sampling*

Once again, for the reasons outlined above, the option of identifying particular informants through purposive sampling methods was not available to me. However, there is one sense in which the sampling strategy does approximate a purposive sample. It seems reasonable to expect that the stronger an individual’s support of euthanasia and assisted suicide in principle in advance of disintegration, the more likely she/he will be to at least consider these options seriously should they find themselves in an unacceptable condition in the future. It is likely that the corollary is true, i.e. that those more strongly opposed to euthanasia and assisted suicide will be less likely to consider these options for themselves. If these propositions are true, then the fact that most of the participants were either strong supporters of euthanasia and assisted suicide or fairly strong opponents (though many could not rule out euthanasia and assisted suicide as options for themselves) might indicate a trend of self-selection for those for whom euthanasia and assisted suicide have the most meaning, i.e. the very people who may be most likely to seek and carry out these acts.

*Consistency*

The concept of consistency is related to the concept of reliability in quantitative research. In quantitative studies, reliability is about the stability of a particular measure across different instances of a phenomenon, at different points in time, or across different individuals who may perform the measurement. In qualitative inquiry, consistency refers to the likelihood that another interpreter would have reached the same conclusions from interviews with the same participants. In this context consistency is sometimes referred to as dependability. Most of the suggested solutions require that another analyst or analysts be involved in substantial portions of the work, or that they be introduced to perform an audit of the interpretation.
There were two main obstacles to the use of co-analysts in this study. First, for the reasons described above related to the potential legal issues associated with the study. And second, because the study was conducted in partial fulfilment of degree requirements, which may not be shared to the extent required by a full co-analyst. However, as described above under “Peer Debriefing”, I did make several efforts to elicit input regarding the interim analysis. As well, at the time of writing of the final draft of the thesis planning is underway for an independent audit to ensure the authenticity of the interview transcripts as a measure to protect against claims of academic dishonesty since the protocol requires the destruction of the interview tapes (this issue is discussed in more detail in Chapter 6).

Neutrality

Like consistency, above, the most effective means of ensuring that something resembling neutrality or objectivity is a confirming audit. However, it is important to note that the presumption underlying most qualitative research is that the investigator is not entirely neutral, but is engaged in the study for a number of reasons, some of which may pose direct challenges to objectivity. For the purposes of demonstrating how I have approached my personal biases and preconceptions with respect to euthanasia and assisted suicide in people with HIV/AIDS I have included a section entitled “Role of the Investigator” above. This section outlines my important personal convictions and indicates the steps I took to ensure that they did not interfere with my objectivity or ability to hear and represent participants stories fairly.

The Uniqueness of the Study

The study has some important limitations. These are presented in detail above in an attempt to provide a clear sense of the process and to allow readers to make informed assessments about methodological rigour. The account of the limitations is not an attempt to undermine the quality or the importance of the study. It is important to take a step back and view the
study within a broader context. The study is unique and innovative in several important ways. First, the study provides an empirically derived theory of how and why people with HIV/AIDS make decisions regarding euthanasia and assisted suicide that is grounded in the experiences and meaning of people with HIV/AIDS. Despite some of the specific limitations described above regarding the characterization of decision making regarding euthanasia and assisted suicide in light of improved prospects for survival for people with HIV/AIDS, to my knowledge, no such account has previously been published. In itself, this contribution promises to provide a useful tool for guiding further research in the field, as well as a point of departure for further investigations of the generalizability of the theory and of possible differences and/or variations that may arise in different contexts and different patient populations, e.g. cancer.

Second, the study describes a feasible—if limited—method for filling an important gap in knowledge regarding euthanasia and assisted suicide, while at the same time successfully addressing some of the difficult ethical and legal problems that have confronted investigators working in this field. Therefore, despite its limitations, the uniqueness of the study and its findings warrant some modest conclusions regarding the contribution of the grounded theory to the debate about the ethics, law and policy regarding euthanasia and assisted suicide. These conclusions are presented below.

**Implications**

The question of liberalizing access to euthanasia and/or assisted suicide has been dealt with conclusively in a variety of settings in Canada—the Supreme Court, the Law Reform Commission, the Special Senate Committee—and in each one the answer was essentially the same: the *Criminal Code* prohibitions against euthanasia and assisted suicide should stand, though some recommendations for increased prosecutorial discretion and a new charge of compassionate homicide have been well received in principle, though not adopted into law. However, despite these efforts, and given the extent of the recent activity described in
Chapter 4, it seems likely that Canadian policy makers will—sooner or later—amend the existing policies concerning euthanasia and/or assisted suicide. At the federal government level, these amendments would likely come in the form of changes to the Criminal Code, such as those recommended in the Special Senate Committee Report (see Chapter 4). In order to “sell” these changes to the Canadian people, the government will have to provide a compelling account of why these policies, or the specific ones proposed, represent an improvement over the current policy.

Any attempt at changing public policy regarding euthanasia and/or assisted suicide beyond the existing prohibitions will require balancing powerful competing principles and interests. Policies must balance concern for alleviating suffering with the protection of the vulnerable, the right to self-determination with the importance of symbolic prohibitions against killing in society, and the actions of physicians and others who end their patients’ lives out of compassion and an authentic desire to alleviate suffering with other instances of culpable homicide. As well, in Canada, any legislative policies must be formulated and implemented within the constraints of the Charter of Rights and Freedoms, and must attempt to achieve some balance in terms of reflecting the prevailing public attitudes and values.

Before outlining the contribution of the findings reported in Chapters 7, 8 and 9, drawing from material in Chapters 4 and 9, I will first summarize the current state of policy in the Netherlands, Oregon and Australia’s Northern Territory. Then, I will briefly describe the shared conceptual framework that appears to underlie the three approaches, and finally, I will compare this framework to the findings of my study.

It is important at this point to emphasize that the theory developed through the study described in Chapters 5-9 is based on the personal experiences of a small number of individuals living with HIV. The theory is an account of the meaning of these experiences to the participants and the main ideas discovered through the analysis of their interviews. The theory is meant to provide a plausible explanation of why people desire and make decisions.
for euthanasia and assisted suicide and thereby a framework for considering the broader implications of these findings. In my following comments about the implications of the findings for ethics and policy, I am assuming simply that the theory provides a plausible account of why people desire and make decisions for euthanasia and assisted suicide, not a definitive one. As with any theory, this one will require verification and will no doubt undergo many subsequent elaborations and revisions.

**Practice in the Netherlands**

While technically illegal, the practice of euthanasia is officially recognized and regulated in the Netherlands. The Royal Dutch Medical Association's 1984 guidelines, endorsed by a government commission the following year, stipulate: the patient must be a mentally competent adult; the request for euthanasia must be voluntary, repeated over time, and documented; the patient must be suffering, with no prospect of relief, though the disease need not be terminal; and the attending physician must consult with another physician(29). It is believed that between 2.5 and 3 per cent of deaths in the Netherlands are due to euthanasia and assisted suicide, with 0.7 of the total done without the explicit, concurrent request of the patient(27). Patients with non-terminal psychiatric illness have had their lives ended, with 6 per cent of surveyed Dutch psychiatrists indicating that they had complied with a patient’s request to end life(32). Only forty per cent of all assisted deaths are actually reported as such(28).

**The Oregon Death With Dignity Act**

American physicians are ambivalent about assisted death (see Chapter 2). The Oregon Death with Dignity Act intruded onto this medical landscape of moral ambivalence in 1994 and, not surprisingly, met a divided reception. Passed by a referendum, it was blocked by an injunction pending the outcome of a court challenge. When the legal challenge was dismissed by the United States Supreme Court, 60 per cent of Oregon voters defeated a referendum to repeal
the legislation and its provisions finally became law in 1997(241). The law requires that two verbal requests, separated by 15 days, be made by a competent adult deemed by two physicians to have a life expectancy of less than 6 months. The request, confirmed as voluntary, must be given in written form and witnessed by 2 individuals. In the event that any psychological disorder is suspected, a consultation with a psychiatrist is required. Forty-eight hours following the appropriate written request a physician can prescribe a potentially lethal dose of medications(242).

**Legislation in the Northern Territory, Australia**

Surveys confirm that 30 per cent of Australian physicians have participated in life-ending interventions, and twice that proportion believe the law should be changed to permit such activity. In May of 1995, the Northern Territory passed legislation permitting physician-assisted death under the following terms: mentally competent patients over the age of 18, suffering unacceptably from an illness known to be terminal and for which no treatment is available, could make verbal request for termination of life; the request must be voluntary and the patient must be made aware of the prognosis of their disease and all treatment options; the attending physician must have a minimum of five years experience; a specialist in the type of disease experienced by the patient must confirm the details of the case and a psychiatrist must be consulted to exclude a diagnosis of depression; one week after the verbal request, a written request must be made and the lethal treatment can not be given for another 48 hours(163). In the first 7 months under this legislation, 3 patients were known to have died(243), and an additional patient died before the legislation was overturned by the Australian House of Representatives and Senate in March, 1998.

**A Shared Conceptual Framework**

Despite obvious differences, the laws from the three jurisdictions discussed above share a number of similar features that flow from shared clinical assumptions. These appear to be: (i)
the need for objective verification, often by more than one physician, of the authenticity and durability of the individual’s desire for death; (ii) a requirement to document the presence of irremediable suffering, usually in a terminally ill patient; (iii) the importance of ensuring that depression and other psychiatric conditions do not influence the decision process. How robust is this framework for supporting decisions regarding euthanasia and assisted suicide?

The majority of writings and studies on assisted death, like the legislation in the field, focus on physical or medical aspects of patients’ experiences. But increasingly, evidence is emerging that suggests that the non-physical dimensions of terminal illness and their challenges to personal integrity and identity play at least as important a role as the physical determinants of the desire to die. Existential factors are those that have direct relevance to the individual’s personal system of meaning and identity such as religious beliefs or close personal relationships. Until now, the precise role of these existential factors in bringing about decisions for euthanasia or assisted suicide were not known.

Assessing the Desire to Die

Based on the findings in Chapters 7, 8 and 9 the desire to die by euthanasia or assisted suicide appears to be the product of a complex set of interactions among the individual’s disintegration and the loss of his/her community, and the way that these interact to shape the individual’s overall deliberations about euthanasia or assisted suicide.

Physicians have two distinct tasks in assessing the desire to die: (i) to assess the durability of the stated desire; and (ii) to assess the authenticity of this desire, i.e. that it is not the product of an untreated or undiagnosed psycho-pathology and that it appears to be reasonably consistent with the values of the individual. Yet it is likely that physicians conflate the two tasks and, in so doing, often accept that the durability of the individual’s request is an indication of its ‘authenticity’, all things being equal.
The findings in Chapters 7, 8 and 9 suggest two things: first, that conflating the two tasks may result in an under-appreciation of the root causes of the desire to die; and that even if the question of authenticity is tackled head-on (i.e. not conflated with the question of durability), these determinations may prove to be beyond the scope of physicians. If, as the findings suggest, the desire to die originates from a fundamentally existential concern, i.e. the loss of self, then the physician’s ability to make these determinations will only be as good as his/her knowledge of the patient’s deepest beliefs and values and the many life events, such as experiences of alienation and traumatic experiences, that have influenced his/her position.

As well, even if the physician has success in determining—i.e. understanding—the factors that have given rise to the individual’s desire to die, he/she still must determine whether or not the desire to die is “acceptable” (i.e. is the desire to die more or less ‘authentic’ if it stems from a long history of alienation and traumatic life experiences? And how do these factors bear on whether or not the physician should approve the request?). Therefore, the findings in Chapters 7, 8 and 9 have helped to show that the assessment of the authenticity of the individual’s desire to die is fundamentally an ethical judgement, as opposed to a clinical one, and that physicians are likely to be no more capable of making these judgements than anyone else, and perhaps worse than anyone who knows the patient more intimately.

Furthermore, preliminary evidence has begun to suggest that the values and attitudes of care providers may have an important influence on their ability to make objective assessments of end-of-life requests. While in legislation they are portrayed as external reviewers of a decision process occurring entirely within a patient, physicians actually participate in the decision in their role as the assessors required by law and often as the individuals charged with initiating a course of action likely to result in death. Both in their initial willingness to act as an assessor and in the manner in which they communicate with the patient, physicians may, albeit unwittingly, allow their own legitimately held perspectives to influence the decision-making process.
The literature reviewed in Chapters 2 and 3, at the very least, casts doubt on the assumption that physicians are able to make accurate prognoses, that they are skilled and sensitive communicators, and that they are able to interact with patients impartially and without imposing their own values. The findings reinforce the emotional and psychological complexity of physicians’ role in the withdrawal of life-sustaining treatment—as a related example—and may begin to provide clues as to specific targets for physician training and professional support. If the data are at all accurate, then the enterprise undertaken by physicians in assessing requests for euthanasia and/or assisted suicide may hold untold opportunities for inadvertently framing momentous life decisions inappropriately for terminally ill patients. The findings suggest that the physician may not always be able to act as an objective assessor of a patient’s end-of-life decision process and raise important questions as to whether they should be so portrayed in law.

**The Requirement to Document Irremediable Suffering**

Another requirement of physicians in these policies is to document, and thereby attest to, the presence of irremediable suffering—often, though not always, associated with terminal illness. The policies either explicitly require, or imply, that all reasonable efforts to alleviate the suffering by the available means have been tried.

But how should physicians approach this task if, as the findings in Chapters 7, 8 and 9 suggest, the suffering that gives rise to requests for euthanasia and assisted suicide is existential in nature, i.e. relates directly to the individual’s personal system of meaning and identity, and not primarily physical, or possibly even mental (here the lines may blur)? There are several possible scenarios. First, the physician may simply accept the patient’s presumably durable request for euthanasia or assisted suicide (presumably also in the absence of depression) and accept the patient’s report of relentless suffering as the grounds for acceding to the request. This approach gives rise to all the normative questions outlined above. It also gives rise to another question, namely how does the physician know if she/he has exhausted
all the treatment options for existential suffering before granting the patient's request?

Assuming that there are no medical treatments for existential suffering, there are two possible answers. Either all patients with existential suffering are refused on the grounds that no treatment is available for their 'condition', or all patients with existential suffering qualify by default for euthanasia or assisted suicide, since there is no treatment available for their 'condition' (this appears to have been the rationale of the Dutch Supreme Court in its ruling that expanded the eligibility criteria to include unbearable suffering as a result of depression—see below)(32).

Either way, the physician faces a conundrum, either refuse all requests, or potentially open the flood-gates to an entirely new dimension of suffering that has not explicitly been included until now. All of this discussion, of course, presumes that physicians can reliably identify existential suffering and reliably differentiate it from different kinds of suffering.

A central assumption in the long-standing debate about euthanasia and assisted suicide has been that euthanasia is usually requested in order to alleviate pain and that, if pain were to be well controlled, requests for euthanasia and assisted suicide would be significantly reduced. Certainly, pain has been shown to be an important determinant of an individual's desire for death(40,108), though more recent findings have begun to challenge the strength of this assumption(17,22,41,66,106). It seems reasonable to conclude, on the basis of these studies, that pain contributes to the desire to hasten death in terminal illness for many patients, but it should not be considered the sole determinant of requests for euthanasia or assisted suicide. Yet these studies do not provide a compelling reason for why this should be so.

The findings of this study may begin to provide an explanation for why pain and physical symptoms appear to be insufficient, in themselves, to bring about requests for euthanasia or assisted suicide. Somatic suffering (pain and physical symptoms) does not appear to threaten individuals' fundamental identity or meaning (i.e. the self) and therefore does not give rise to existential suffering, unless it is sufficiently extreme, of sufficient duration and refractory to
treatment. It is likely that these conditions are most often met in terminal illnesses in which disintegration may also be involved, which again can give rise to existential suffering. In other words, pain and physical symptoms rarely constitute a profound challenge to an individual’s identity and meaning as long as there is some reasonable expectation that relief is available. When this expectation fails and when disintegration proceeds, existential suffering occurs and with it the strong desire to be free of it.

The Exclusion of Depression

The evidence of an association between depression and the desire to die is now compelling(88). The association has been demonstrated in cancer patients(19) and depressed mood is known to affect care preferences in patients with HIV/AIDS(115,114) and give rise to requests for euthanasia and assisted suicide in terminal illness(116,117). A legitimate concern is the stability of the desire for death in the face of regressing depressive symptoms, treated and otherwise. A recent study reviewed 6 patients two weeks after documenting a pervasive desire for death, and found both depressive scores and the desire for death had decreased in 4 individuals(44). This phenomenon may be of particular importance in the elderly. During the terminal phase of illness, many geriatric patients develop psychiatric complications that subsequently have profound effects on their quality of life(124). However, it is also known that treating depression can change elderly patients’ preferences for(125), and attitudes toward(126), life-sustaining treatments.

Recently in the Netherlands the definition of “unbearable suffering”, a criterion of the Dutch policy, was expanded by a Supreme Court ruling to include intractable depression and—presumably—other similar refractory manifestations of psycho-pathology (see Chapter 4) as legitimate grounds for euthanasia(32). Depression remains a valid reason for refusal of requests in Oregon and in the suspended Northern Territory legislation. Not surprisingly, this expansion of the acceptable ‘pool’ of eligible patients has been controversial. At issue is whether or not patients can be depressed and still form a competent desire to die.
The study findings may complicate matters further. First the findings may challenge the scope of the Dutch Supreme Court ruling, by begging the question of why intractable depression should be considered a legitimate basis for euthanasia (even when no treatment has been able to resolve the depression, i.e. with the persistent concern that the patient’s desire to die is being unduly influenced by the depression) while the existential suffering associated with disintegration and loss of the self is not. Or the findings may suggest that existential suffering warrants consideration as an independent qualification for euthanasia and assisted suicide.

It is not my intention to propose new justifications for euthanasia and assisted suicide, though limiting the loss of self may serve as a justification. Rather it is my intention to demonstrate that the current criteria are not well equipped to deal with the type of circumstances that the study findings suggest give rise to requests for euthanasia and assisted suicide.

In light of the concerns raised above, it would appear that the absence of a framework by which to make sense of, and be responsive to existential factors such as those outlined above is a serious gap in the clinical management of patients for whom euthanasia and assisted suicide may hold an interest. Although the existence of a history of traumatic experiences and progressive disintegration will not always be predictive of an interest in euthanasia or assisted suicide, it may be reasonable when faced with a patient with this type of history for physicians to be aware that this patient’s life circumstances may predispose the person to view euthanasia and assisted suicide favourably.

At the very least, the findings suggest that a thorough family history and perhaps also a brief discussion of the person’s available community might be helpful for physicians to help them gauge the kinds of issues that may be important for the specific patient. As well, the extremely poor familiarity with palliative care and other legal approaches to end of life care in this patient sample suggests that physicians would do well to assist their patients in becoming more familiar with these services.
Contribution to Ethics

In Chapter 4 I referred to Hoffmaster’s challenge to those practising applied ethics that they seek out rich qualitative studies on the phenomena that applied ethicists concern themselves with. By doing so, Hoffmaster suggested that we could enhance our understanding of moral decision making as it occurs in real life, as opposed to the elegant philosophic depictions of how moral decision making ought to occur in real life. This study makes just such a contribution.

In Chapter 8, I begin to demonstrate the interrelationship between the self and community, a relationship that has been explored in great detail by many philosophers (244, 245). For the study participants, it appears to be only when disintegration and the erosion of their personal communities begin to alter their fundamental meaning and identity as persons, i.e. when the self is threatened and ultimately lost, that the decision to have euthanasia or assisted suicide is crystallized. This is important because it suggests that, although the ethical dimensions of euthanasia and assisted suicide are clearly important, for individuals engaged in deliberations and decisions about euthanasia and assisted suicide, the issues are primarily metaphysical. As Hoffmaster has suggested, the broad philosophic debate about the ethics of euthanasia and assisted suicide may bear little resemblance to the complex struggle about limiting, or coping with, the loss of self that appears to give rise to decisions about euthanasia and assisted suicide.

Despite often vociferous shows of support for euthanasia and assisted suicide by study participants, it appears that even the most adamant supporters do not seek euthanasia and assisted suicide as ends in themselves, i.e. as outcomes that they simply desire or feel entitled to. Rather, their process of deliberation about these options follows the trajectory of their own disintegration and/or loss of community and gradually takes on a more concrete form as these progress.
One interesting—if potentially controversial—implication of this finding is that it may be seen to narrow the gulf between combatants in the polarized debate about the ethical acceptability of euthanasia and assisted suicide, ironically, by posing difficult challenges to both sides in the debate. On the one hand, though the experiences of participants are powerful and inspire a great deal of sympathy, liberalizing access to euthanasia and assisted suicide promises little in the way of alleviating the social, as well as clinical, determinants that appear to give rise to the desire for these options. Rather, liberalizing access may actually shift the focus away from the social determinants and inadvertently perpetuate the notion that euthanasia and assisted suicide are primarily clinical phenomena.

On the other hand, the profound experiences described by participants provide a cogent reminder that the desire for euthanasia or assisted suicide is—at least in part—socially mediated and that we have not yet exhausted the legal means at our disposal to recognize and respond constructively and compassionately to the plight of people seeking these means. Denying people with HIV/AIDS more liberal access by appealing to moral frameworks that may have little meaning to them, without real efforts to alleviate their social and clinical circumstances, may be simply one further way of demonstrating that they are not valued as full members of society. The findings of this study should make it difficult to reject this assertion too readily.

**Contribution to Policy**

The first contribution of the study findings to policy involves the extent to which they call into question the ability of doctors to make determinations about the appropriateness of requests for euthanasia and assisted suicide (see the discussion under Assessing the Desire to Die, above). The findings in Chapters 7, 8 and 9 suggest that the real basis for decisions regarding euthanasia and assisted suicide may lie in the desire to eliminate the existential suffering that follows from the deterioration of self and that physicians have no special expertise in evaluating the authenticity of these motives and may in fact be worse than other more intimate relations in making these determinations. More importantly, these findings may
offer practical support for the claim that euthanasia and assisted suicide are fundamentally social (as opposed to medical) responses to progressive illness and various manifestations of suffering.

The second issue relevant to policy, and related to the issue of doctors' place in the practice of euthanasia and assisted suicide, is the assessment of the acceptability of palliative care to study participants as an alternative to euthanasia and assisted suicide. This question was asked specifically in the recommendations of the Senate Committee Report and the study offered some useful preliminary observations. Many of the participants had mentioned that they thought palliative care was an important component of end of life care, but they didn't see it as an option for them personally. It is important to note here that many of the study participants were unfamiliar with even the basic nature and goals of palliative care, so their assessments of their acceptability are somewhat suspect. The significance of their statements did not strike me until the process of selective coding was complete. If, as the theory suggests, people decide upon euthanasia and assisted suicide as means of ending existential suffering that results from the progressive disintegration of self, then it could be argued that palliative care might be unable to achieve this objective, even with sophisticated programs of spiritual care.

A third important policy issue involves the effective prohibition of discussions about euthanasia and assisted suicide between doctors and patients. The unwillingness of many doctors to discuss these issues with patients is understandable, given the Criminal Code prohibition against counselling someone to commit suicide, but there appear to be no "safe" venues where patients can discuss euthanasia and assisted suicide without having to fear criminal liability or without having to feel that euthanasia is the only legitimate option. Unlike depression, which can compromise an individual's ability to evaluate options soberly and with due hopefulness, injury caused by factors such as alienation may simply predispose people with HIV/AIDS to actively avoid existential suffering without necessarily compromising their judgement. This knowledge may demand an entirely different conceptualization of
“counselling” patients who express a desire for assisted death, or who may simply desire an honest discussion about these and related end of life issues(79).

I was struck by the way the participants’ stories appeared to focus their thinking about end of life care and about the goals of care, i.e. what they wanted to achieve by their end of life care and the situations they wanted to avoid in addition to euthanasia and assisted suicide. This struck me as effective advance care planning. I remain concerned about the lack of opportunities for patients to express their fears in a supportive environment. Many participants told me that their interview was the first opportunity they had ever had to speak truthfully about their feelings about euthanasia and assisted suicide.

Conclusion

The theory proposed in this thesis may be unsatisfying to both sides of the euthanasia and assisted suicide debate. On the one hand, perhaps requests for euthanasia are the ultimate reminders that we have failed, not only to provide sufficient technical care for patients suffering from terminal illness, but that we have also failed to construct a sufficiently decent society, where the types of alienation and traumatic experiences recounted by the study participants do not initiate a relentless process of disintegration, often long before even the earliest experience of disease. Seen from this perspective, the study findings lend credence to calls for increased emphasis on improving every aspect of care—both medical and social—for people with HIV/AIDS (and others with terminal illnesses) rather than liberalizing access to euthanasia and assisted suicide.

But on the other hand, the study findings also suggest quite powerfully that the feeble array of last-ditch efforts that make up the current “system” of end-of-life care for people with HIV/AIDS (and most people who require end-of-life care) are insufficient, both in quality and in availability. In fact, the question remains whether any health services will be able to approximate the effects of euthanasia and assisted suicide in terms of limiting disintegration
and loss of community for some people. If these truly are deep metaphysical issues for people with HIV/AIDS (and perhaps others with terminal illnesses) and reflect the loss of self, then there may be little that medicine can offer as alternatives. Though the prospect of liberalized access to euthanasia and assisted suicide is seen by many as a mark of failure as a caring society, there is much work to be done before these protests will be accepted respectfully by many individuals with HIV/AIDS.
References


10. Wysong P. Doctors divided on euthanasia acceptance: preference is to refer to another doctor. Medical Post 1996; 32(34): 1, 90.


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64. Brown GR, Rundell JR. Prospective study of psychiatric morbidity in HIV-seropositive women without AIDS. General Hospital Psychiatry 1990; 12: 30-35.


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92. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals. Ethical and practice implications. Archives of Internal Medicine 1996; 156:
2130-2136.


133. Compassion in Dying v. Washington, 79 F.3rd 790 (9th Cir. 1996).

134. Quill v. Vacco, 80 F.3rd 716 (2nd Cir. 1996).


172. H.R. 4006, the "Lethal Drug Abuse Prevention Act of 1998".


179. Novak D. Suicide is not a private choice. First Things 1997; Aug/Sept: 31-34.


197. Miller JA. Hospice care or assisted suicide: a false dichotomy. The American Journal of Hospice and Palliative Care 1997; May/June: 132-134.


203. Caralis PV, Davis B, Wright K, Marcial E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments and euthanasia. The


213. Martin DK, Thiel EC, Singer PA. A theory of advance care planning: Observations from people with HIV. Archives of Internal Medicine, In Press.

214. For example, Dying With Dignity: A Canadian Society Concerned with the Quality of Dying, Toronto.


228. Novick A. Some needed research in the HIV realm. AIDS and Public Policy Journal 1994; Fall.


231. Public Health Service Act § 301(d), 42 U.S.C § 241(d).


APPENDIX "A"

Participant Information Sheet
Euthanasia and Assisted Suicide in HIV/AIDS

Information Sheet for Prospective Participants

You have been given this information sheet because you indicated an interest in being contacted about further research when you enrolled in the HIV Ontario Observational Database (HOOD). Information sheets will be distributed to all HOOD enrollees who have indicated an interest in further studies, regardless of their views or health status. This information sheet is for a study of the experiences and decision making of persons with HIV/AIDS (PHA) concerning euthanasia and assisted suicide. Euthanasia and assisted suicide are controversial issues. This study is being undertaken to further understanding of these phenomena from the perspective of persons with HIV/AIDS.

The study aims to explore these issues by talking to persons with HIV/AIDS about their views and experiences. Specifically, the views and experiences of the following PHA are required: (a) those people who have participated in planning and/or carrying out acts of euthanasia and/or assisted suicide of others; (b) people who have made a personal decision in favour of E or AS for themselves; (c) people who have made a personal decision against E or AS for themselves; and (d) people who are undecided about E and AS for themselves. Each of these perspectives is important in developing an adequate theory of decision making regarding euthanasia and assisted suicide.

Study Purpose

The purpose of this study is to develop a theory of decision-making by persons with HIV/AIDS (PHA) regarding personal decisions for or against euthanasia (E) or assisted suicide (AS).

Study Procedures

If you decide to participate in this study, you can expect the following procedures to take place:

- at this regularly scheduled appointment, your physician has informed you of the study, and provided you with this information sheet. Your physician will have no further involvement in the study and you will not be asked whether or not you have contacted the investigators to participate in the study. In this way, neither your doctor, nor any other clinic staff, will know whether or not you have decided to participate in the study;

- if you are interested in participating in the study, you can contact the investigators directly at the number provided below. If you decide to call the investigator, YOU MUST NOT IDENTIFY YOURSELF. You must either decide on a false name (pseudonym) to use at
all times throughout the study, or simply do not use any name in your discussions with the investigator. This is for your own protection, so that the investigator will not know who you are;

- if you call, a brief statement will be read to you outlining the risks of the study and detailing your potential involvement;

- if you are still interested in participating, you will select a time and place that is convenient and comfortable for your interview;

- before starting the interview, you will be reminded of the risks of participating and asked whether you will consent to be interviewed. You will then be told that you are free to withdraw from the study at any time;

- if you consent, you will be interviewed. All interviews will be tape-recorded. The interview should take between 30-60 minutes;

- after the interview, you will be given an opportunity to ask any further questions you may have about the interview;

- the audiotape of your interview will be transcribed (i.e. typed word-for-word) within two weeks of your interview;

- immediately after transcription, the audiotape will be destroyed;

- any identifying remarks that you might have made during the interview either about you personally or any other identifiable person or place (i.e. all proper names) will be removed from the transcripts;

- the transcript of your interview will be analysed.

**Risks and Benefits**

You will not benefit personally from participating in this study.

Because of the nature of the proposed study, some of the participants may have had previous involvement in acts of assisted suicide or euthanasia. These are currently criminal acts under Canadian law. Although the audio tapes of interviews will be destroyed, and no names will appear anywhere on the transcripts, it may still be possible to recognize the participant, or someone else involved in the criminal activity, from information in the transcript. The transcripts would be turned over to authorities only under a formal court order, e.g. as part of a coroner’s or
Lavery, JV and Singer, PA. Euthanasia and Assisted Suicide in HIV/AIDS

criminal investigation. Under those circumstances, the study investigators have no legal privilege that allows them to withhold transcripts from the authorities. This is the main risk of participating in the proposed study. There is no way of determining how likely it is that this would occur. If you have not been involved in any of these activities, this risk does not apply to you.

This risk will be explained to you on three separate occasions before you consent to be interviewed: once in this information sheet, once in the initial phone conversation, and once immediately prior to beginning your interview.

The other main risk involved in this study is that the discussion of euthanasia and assisted suicide may be emotionally upsetting for you. If this is the case, you will be reminded that you are free to stop the interview at any time. If you become upset, but would like to continue the interview, you will be given as much time as you need to continue the interview. You will also be given the names and phone numbers of clinic staff at the clinic you attend (i.e. at all four participating clinics) who are best trained to help you in the event that you are upset by your participation. Other numbers for contacting emergency services at your clinic/hospital will also be provided.

Use of Existing Records

Even though health-related information about study participants exists in the HOOD database, none of this information will be used for the purposes of this study. Only information that is freely given during the interviews will be used in this study.

Informed Consent

In order that your name does not appear anywhere in the study records, you will be asked on three separate occasions to give your verbal consent to participate in the study. In addition, you will be reminded several times before your interview that you are free to stop the interview and/or withdraw from the study at any time.

Compensation

All participants will be given $20 to cover any expenses that may have been incurred by agreeing to participate in the proposed study. You will be given $20 even if the interview is not completed.

Dissemination of Results

The study results will be distributed to AIDS Service Organizations in Ontario and published in the peer review literature.
If you have read the previous pages of this information sheet and wish to participate in the study, or find out more about the study, please call

JIM LAVERY

at

(416) 576-3182

**Between 9:00 a.m. and 5:00 p.m. Monday-Friday**

**PLEASE REMEMBER NOT TO IDENTIFY YOURSELF WHEN YOU CALL**

Calling DOES NOT mean that you have consented to participate in the study. You will be asked on 2 more occasions if you consent to participate. You are free to withdraw from the study at any time.
Script for Initial Phone Contact for Study of Euthanasia and Assisted Suicide in HIV/AIDS

The following script will be read to each person who calls expressing an interest in the proposed study.

Investigator: Thank you for calling. Before we begin, I would like to read you a brief statement to remind you of the risks of participating in this study.

There are two main risks of participating in this study: one, that information you may give me could be used against you in criminal proceedings if the study data are seized by legal authorities; and two, that you may become upset by talking with me about euthanasia and assisted suicide.

We have taken steps to minimize these risks and these are outlined in the information sheet that you were given. You will not be identifiable through your participation in the study.

If you agree to participate, I will ask you several questions about your personal views and experiences with euthanasia and assisted suicide. The interview should take between 30 minutes and one hour. You may stop the interview at any time and withdraw from the study at any time.

Do you understand these risks and procedures?

Do you consent to participate in this study?
APPENDIX "B"

Letter to HIV Outpatient Doctors
Letter to Clinic Physicians Regarding Distribution of Information Sheets for the Study Euthanasia and Assisted Suicide in HIV/AIDS

Dear Physician:

Enclosed, please find patient information sheets for the study *Euthanasia and Assisted Suicide in HIV/AIDS*. This study has been approved by your hospital's Research Ethics Board, the University of Toronto Human Subjects Research Review Panel, and the HOOD Research Review Committee.

The study utilizes the HIV Ontario Observational Database (HOOD) research registry, i.e. those HOOD enrollees who indicated that they wish to be informed, by their physician, about other studies. Please have the HOOD data collector in your clinic match the HOOD unique identifiers provided with the appropriate patient's chart. As we have discussed, the information sheets should then be placed in the patient's chart and passed to the patient at his/her next visit.

Please **DO NOT** **DISTRIBUTE** **INFORMATION SHEETS** **TO** **PATIENTS** **WHO ARE SUICIDAL, OR WHO MAY BE IMMINENTLY SUICIDAL**. The subject matter of the study interviews may be upsetting and we would like to minimize the risk of harm to those patients who might be most vulnerable to this type of response. It is important, however, not to impose other selection criteria arbitrarily.

All patients will be provided with a list of personnel and services available at your clinic/hospital, should the need arise to seek assistance on an urgent basis.

Thank you for your continued assistance with this project.

Sincerely,

Jim Lavery, M.Sc.
Coordinator
HIV Ontario Observational Database

Peter A. Singer, MD, MPH, FRCPC, FACP
Director
U of T Joint Centre for Bioethics
APPENDIX “C”

Demographic Questionnaire
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Comments</th>
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<td>Age?</td>
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<td>Gender?</td>
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<td>Date of Dx of HIV?</td>
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<td>Likely mode of infection?</td>
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<td>Lowest CD4 + date?</td>
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<td>Most recent CD4 + date?</td>
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<td>Combination Tx (i.e anti-retroviral(s) + protease inhibitor)?</td>
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<td>Asymptomatic?</td>
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<td>Non-AIDS defining?</td>
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<td>AIDS defining?</td>
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<td>CDC Classification?</td>
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<td>Hospitalized for HIV/AIDS related illness?</td>
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<td>Dx of Depression</td>
<td>(If yes, before or after HIV+)?</td>
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<td>POMS Score</td>
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<td>Highest level of education attained?</td>
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<td>Currently working?</td>
<td>(If no, are you looking for work?)</td>
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<td>Financially secure?</td>
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<td>Life insurance?</td>
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<td>Religious affiliation?</td>
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<td>Religiosity (1-5)?</td>
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<td>Active in an ASO?</td>
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<tr>
<td>Question</td>
<td>Answer</td>
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<td>Level of activism (1-5)?</td>
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<td>Spouse or partner?</td>
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<td>(If yes, HIV+?)</td>
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<td>(If yes, same attitude to E/AS?)</td>
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<td>Have you lost friends/loved ones to AIDS?</td>
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<td>(If yes, how many?)</td>
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<tr>
<td>(If yes, did you ever participate in their care?)</td>
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<tr>
<td>Personal Decision (Y, N, Undecided)?</td>
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<tr>
<td>Have you ever discussed E/AS with a doctor?</td>
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<td>Have you ever asked a doctor to assist you in ending your life, or discussed the feasibility of him/her assisting</td>
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<td>(If yes, was he/she willing to assist?)</td>
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<tr>
<td>Have you ever participated in E/AS?</td>
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<td>(If yes, how many E?)</td>
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<tr>
<td>(If yes, how many AS?)</td>
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APPENDIX “D”

Notification of Approval/Refusal from Research Ethics Boards
PROTOCOL REFERENCE # 147/96

April 16, 1996

Dr. P. Singer
Centre for Bioethics
88 College Street
University of Toronto

Mr. J. Lavery
HIV Ontario Observational Database
Sunnybrook Medical Science Centre
2075 Bayview Avenue
North York, Ontario

Dear Dr. Singer and Mr. Lavery:

We are writing to advise you that a Review Committee composed of Dr. A.N. Doob, Professor K. Roach and Mr. W. Rush has extended approval to the research study entitled, "Euthanasia and Assisted Suicide in HIV/AIDS (The Hood Project)". The approved patient information sheet is attached.

During the course of the research, any significant deviations from the approved protocol and/or any unanticipated developments within the research should be brought to the attention of the Office of Research Services.

Best wishes for the successful completion of your project.

Yours sincerely,

Susan Pilon
Executive Officer
Human Subjects Review Committee

SP/hg

cc: Sunnybrook Medical Science Centre
MEMORANDUM

TO: Mr. J. Lavery/Dr. P. Sincer
    HIV Data Centre
    G-326 Wing

FROM: Philip Hébert MD.

DATE: April 29, 1996

SUBJECT: Euthanasia and Assisted Suicide in HIV/AIDS

Project Identification No: 090-1996
Approval Date: April 29, 1996

The Research Ethics Board of Sunnybrook Health Science Centre has reviewed the research protocol referenced above on the above captioned date and approved the involvement of human subjects as specified in the protocol. A copy of the approved Information Sheet is attached.

The quorum for approval did not include any member associated with this project.

Should your study continue for more than one year, you must request a renewal on or before one year from the date of this letter. Please advise the Board of the progress of your research annually and/or any adverse reactions or deviations which may occur in the future. The above Project Identification Number has been assigned to your project. Please use this number in any future correspondence.

Yours sincerely,

Philip Hébert MD., Ph.D., CCFP(C).
Chair, Research Ethics Board

2075 Bayview Avenue
North York, Ontario
Canada M4N 3M5
University of Toronto
June 25, 1996

Dr. Peter A. Singer
Centre for Bioethics
88 College Street
University of Toronto
M5G 1L4

Dear Dr. Singer:

I am pleased to inform you that as of 17/06/96, The Toronto Hospital Committee for Research on Human Subjects has tabled and approved the following research project which received approval from The University of Toronto Human Subjects Review Committee on 16/04/96:

96-U098  #147/96 Euthanasia and Assisted Suicide in HIV/AIDS (The Hood Project)

The consent form is approved as well.

Best wishes for the successful completion of your project.

Yours sincerely,

(Mrs.) M. Evis
Administrative Assistant
Research Directorate

cc: Dr. M. Baker
    Dr. A. Detsky
    Medical Records
    Nursing
October 10, 1996.

Mr. Jim Lavery,
Coordinator,
HIV Ontario Observational Database,
Sunnybrook Medical Science Centre,
2075 Bayview Avenue,
North York, Ontario.
M4N 3M5

FAX #: (416) 480-6060

Dear Jim:

Re: REB 96-082: Euthanasia and Assisted Suicide in HIV/AIDS.

Enclosed is a copy of Dr. Baker's letter from our IRB on the above noted study.

If you would like to approach this differently, maybe we could meet to discuss this further.

I am sorry that the IRB decision is not more favourable.

Many thanks for your assistance.

Sincerely,

Dawn Bajhan,
Administrative/Research Assistant,
Division of Infectious Diseases and HIV Clinic.

DB
Encls.
October 7, 1996

Dr. I. W. Fong
Director,
Division of Infectious Diseases and HIV Clinic

Dear Dr. Fong:

Re: REB 96-082 Euthanasia and assisted suicide in HIV/AIDS

The Research Ethics Board of St. Michael’s Hospital has met and discussed the above protocol. The Board did not approve the protocol for the following reasons:

In this protocol, St. Michael’s patients are identified as being eligible by being registered with HOOD and also having volunteered to participate in epidemiologic studies. If the staff physician in the clinic does not feel that the patient is suicidal or imminently suicidal, the patient will be given an information sheet entitled “Euthanasia and Assisted Suicide in HIV/AIDS”. If the patient calls the study telephone number they will be warned that one of the two risks is they “may become upset by talking with me about euthanasia and assisted suicide”.

Those who live with a terminal disease are a particularly vulnerable group. This is echoed in the protocol background material. For example, I refer to the quote of Dr. David Roy’s Special Senate Committee testimony: “I have seen that, particularly with respect to AIDS patients who have been totally abandoned by their parents, brothers and sisters and by their lovers. In a state of total isolation, cut off from every source of life and affection, they would see death as the only liberation open to them. In these circumstances, subtle pressure could bring people to request immediate, rapid, painless death, when what they want is close and powerful support and love.” Furthermore the background material would suggest that, for many people with HIV/AIDS, suicide does not often represent the effects of a major affective disorder nor a impulsive event - this makes an assessment of a person being “suicidal or imminently suicidal” a task unlikely to be very accurate.

Thus it struck the committee that the title and thrust of the study and the two limits to participation (suicide risk and “becoming upset”) were at direct odds with the background material presented. The committee was struck by the lack of perspective in the study of alternate
end-of-life-care presented to PHA. While the committee was particularly impressed with the value of exploring end-of-life decision making, it felt strongly that this study did not represent an ethical method of achieving that end and other methods should be sought.

Sincerely,

Andrew J. Baker, MD
Chair,
Research Ethics Board
St. Michael’s Hospital