EUTHANASIA AND ASSISTED SUICIDE IN PERSONS WITH ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) OR HUMAN IMMUNODEFICIENCY VIRUS (HIV)

by

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Euthanasia and Assisted Suicide in Persons who have Acquired

Immunodeficiancy Syndrome (AIDS) or Human Immunodeficiency Virus (HIV)

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ABSTRACT

The AIDS epidemic is confronting the euthanasia debate in an unprecedented fashion. That euthanasia is almost never prosecuted in Canada suggests that the practice is rare. Nevertheless, the lay press, medical, legal, and psychological literature indicate that euthanasia occurs among persons with AIDS, with and without the assistance of physicians.

This study investigated the views, attitudes, and experiences regarding euthanasia held by persons with HIV/AIDS and those who have been involved in assisting the deaths of persons with AIDS. A snowball sampling technique was used to gather data from two self-selected sample populations: i) persons with HIV/AIDS ($\underline{N}$ = 18); and ii) persons who have been involved in AIDS-related euthanasia ($\underline{N}$ = 17). Using an open-ended semi-structured interview, variables such as personal experiences with AIDS, terminal illness, moral and philosophical beliefs, legal and ethical issues, and practical considerations related to euthanasia were explored.

Fifteen (83.3%) of the persons in the HIV/AIDS sample said that euthanasia or assisted suicide was a choice for themselves, and eight (44.4%) had developed plans for their suicide or assisted death. Concerns regarding loss of control as their health deteriorates were expressed by 14 (78%) of the sample.

The euthanasia participant group identified 34 deaths by euthanasia or assisted suicide. Ten participants in the sample had been directly involved in performing at least one act of euthanasia or assisted suicide (n = 17 deaths). Six had either been present at, or involved in the planning of assisted deaths (n = 10 deaths), and six had reliable information regarding cases of euthanasia (n = 7 deaths).

Although the practice of euthanasia is illegal in Canada, the data show that it occurs with regularity in the AIDS population--at least 2.7% of all AIDS deaths in British Columbia involve euthanasia or assisted suicide. It is estimated that the real figure may be as high as 10 to 20 percent. Prescription medications and Hemlock-type techniques were the methods of choice. In this study, many of the acts of euthanasia occurred in such appalling circumstances that they may make the case for state regulation of voluntary euthanasia and assisted suicide.

"Imagine yourself in your own private holocaust, facing certain death. Your captor offers you a choice: a slow death by physical and psychological torture; or a quick death, medically supervised, via a painless overdose.

Which would you choose? Which would you choose for your mother? Which would your God choose for you/her?"

Dave Bosomsworth,
(*Vancouver Sun*, July 31, 1993, p. D13).

"Making someone die in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny."

Ronald Dworkin,
(*Life's Dominion*, 1993, p. 217).

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CHAPTER I

INTRODUCTION and BACKGROUND

The epidemic of acquired immune deficiency syndrome (AIDS) confronts society with a myriad of medical, legal, and ethical dilemmas. About 30,000 Canadians are infected with the human immunodeficiency virus (HIV)--the virus believed to cause AIDS ("Living with AIDS," 1992). To date, among the 9,083 cases of AIDS reported in Canada, there have been 6,187 deaths (Quarterly Surveillance Update, 1994). In British Columbia, since 1983, there have been 1,148 deaths amongst the 1,588 recorded cases of AIDS (Rekart & Roy, 1993).

AIDS is frequently accompanied by social stigmatization, poverty, inadequate medical services, loss of peer group, and a host of physiological pathologies. Opportunistic infections and cancers such as candidiasis, cytomegalovirus (CMV[1]), kaposi's sarcoma (KS[2]), chronic herpes, and recurrent pneumonia, contribute to profound physical debility.

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[1] CMV is a common virus that can be transmitted sexually, and may result in mononucleosis-like symptoms in young adults. In persons with depressed immune systems, the virus can reactivate and cause invasive disease of the eyes, lungs, bowels, and other vital organs (O'Malley, 1989).

[2] KS is a cancer that is characterized by cutaneous or subcutaneous lesions that may appear anywhere on the body (Nash & Said, 1992).

AIDS patients also face the threat of dementia. The neurological literature suggests that about 60% of AIDS patients are affected by mental deterioration, psychoses and dementia (Yarnell & Battin, 1988). Additionally, antiretroviral drugs and advances in the prophylaxis of opportunistic infections have contributed to an increasing proportion of AIDS patients with HIV encephalopathy. Cognitive impairment associated with HIV encephalopathy affects 65% of adults and 75% of children during the endstages of AIDS (Smith & Rekart, 1993).

Individuals living with AIDS face significant changes in lifestyle and habits. Amongst the top ten lifestyle and habit changes reported by members of the Vancouver Persons with AIDS Society is "thinking about death and dying" (Goldberg & Collins, 1991). Many people with AIDS die horrible deaths (Glaser, 1987; Quill, 1993).

Given the unpredictable characteristics of the disease, and the degree of associated suffering, it is understandable that some persons with AIDS prefer to avoid a miserable end to their lives. Paralleling the AIDS epidemic is an increased interest in euthanasia, the right to die, and assisted suicide. Yarnell and Battin (1988) argue that AIDS is *the* disease that makes the case for euthanasia. AIDS means a certain death, usually within a few years; an AIDS-related death is often gradual, prolonged, and complicated by infections that would normally be handled with ease. At the endstages of AIDS, patients may be unconscious for periods of a week or more (Sims & Moss, 1992).

The discourse on euthanasia and assisted suicide is focussed on theoretical issues in morality, ethics, and law. The euthanasia controversy embraces a variety of perspectives regarding cessation of medical treatment, refusal of medical treatment, and administration of treatment which hastens or directly causes death. Regular contributions to this topic appear in nearly all forms of print and broadcast media; yet, there is little indication of a resolution in terms of public acceptance or social policy. Nonetheless, the debate in Canada is intensifying as individuals, legislators, and lobby groups advocate increased individual autonomy regarding end-of-life decisions.

There is a paucity of scholarly literature documenting actual cases of euthanasia and assisted suicide. They are practices that exist to an unknown degree, and their documentation is largely anecdotal (See Anonymous, 1988; Charbonneau, 1992; Gomez, 1991; Humphry & Wickett, 1990; Kevorkian, 1991; Morganthau et al., 1993; Quill, 1991).

Research addressing euthanasia and assisted suicide is required because the current discussion on the right-to-die dilemma has centered around opposing ethical views, rather than verifiable data. Those involved in the right-to-die debate must move beyond speculative viewpoints and incorporate data gleaned from empirical research. Much of the right-to-die literature involves the views of those who are not having to deal with their own deaths, and who are not directly dealing with the deaths of others. Seminal research, incorporating the views and experiences of those with terminal illness, and individuals involved in euthanasia and assisted suicide, would be highly salient to the growing body of right-to-die literature, as well as to legal and policy analysts, legislators, ethicists, physicians, and the public.

This exploratory study is designed to identify views, attitudes, and experiences regarding euthanasia, held by persons with HIV/AIDS and those who have been involved in assisting the deaths of AIDS patients. Given the personal, legal, and political sensitivity of the information sought, data was gathered from a *self-selected* sample population of persons with HIV/AIDS, and persons who have been involved in AIDS-related euthanasia. The research explores variables such as personal experiences with AIDS, terminal illness, moral and philosophical beliefs, legal and ethical issues, and practical considerations related to euthanasia. In particular, this study was designed to gain familiarity with the euthanasia phenomenon in the context of AIDS. Since the study is exploratory, no specific hypotheses are identified.

Definitions

For the purposes of this thesis, the following definitions are employed:

The *Medical Dictionary for Lawyers* (1960) defines *euthanasia* as, an "act or practice ... of putting persons to death painlessly who are suffering from incurable or malignant diseases, as an act of mercy" (p. 287). Euthanasia has been categorized as active, passive, voluntary and involuntary.

Active euthanasia is distinguished from passive euthanasia in that it involves the administration of treatment or an act that induces death. *Passive euthanasia* is characterized by the withholding or withdrawal of life-sustaining treatment or nourishment. *Voluntary euthanasia* occurs when patients make the decision to terminate treatment or to end their lives. *Rational suicide* is included in this category. It refers to a decision to commit suicide where a mentally competent individual has realistically assessed his or her situation, and whose motives to commit suicide are understood by his or her peer group (Siegal, 1986). *Involuntary euthanasia* is the merciful killing of someone without their consent.

In this study, the term *assisted suicide* refers to active, voluntary euthanasia where one or more persons participate in rational suicide at the patient's request. Specifically, the patient has been knowingly provided with the means or assistance to carry out the suicide plan.

Theories of Suicide

No specific theory has been proposed to explain euthanasia and assisted suicide. However, scholars seeking an explanation for suicide have proposed a number of theories. Given the similarities between suicide and euthanasia, it will be useful to review suicide theory as a means to gaining insight into euthanasia. Some of these theories progress beyond explanation of the phenomenon and hold implications for prevention. In his book *Understanding and Preventing Suicide*, Lester (1990) argues that the psychological, psychiatric, and sociological theories fail to contribute to the prevention of suicide. Personality and Freudian theory, biochemical perspectives, and Durkheimian theories of social integration are not only inadequate in their explanations of suicide, but they do little to prevent suicide (Lester, 1990). Lester (1990) proposes that the interdisciplinary field of criminology, with its emphasis on early identification and intervention in deviant behaviour, could offer new insights and perspectives with respect to suicide. Therefore, Lester advances a series of criminology-based theories of suicide.

Criminological Theories

Classical Theory of Suicide

The characteristics of classical theory are: "an emphasis on free will choices and human rationality; a view of behaviour as hedonistic; a focus on morality and responsibility; a concern with political structure and the way in which government deals with its citizens; and a concern for the basic rights of all people" (Williams & McShane, 1988, p. 17).

Lester (1992) argues that a classical theorist would view suicide as a rational decision arrived at by an individual who has compared the costs and benefits of suicide to other alternatives. Such a viewpoint is rarely proposed for suicide in general (Lester, 1992), although it may be a useful concept for the interpretation of suicides in persons who suffer from terminal illness.

Yang (1990) proposes that an individual will commit suicide only if the benefits are greater than the costs;

"the higher the cost of committing suicide, the lower the probability that an individual will actually kill himself" [sic] (p. 19). In his demand-supply analysis of suicide, Yang (1990) converts the psychological variables of level of distress and future pleasure into separate units, thereby obtaining an equilibrium whereby one could equate the demand and supply for suicide. For example, in the context of terminal illness, an individual might find that treatment is either non-beneficial, or that the costs, monetary, physiological, or psychological, are too great. The level of distress and reduction of opportunities for future pleasure, combined with the costs of treatment, increase the probability of committing suicide.

Additionally, suicide may be interpreted as a rational choice where it meets the criteria for Cornish and Clarke's (1986) rational choice theory of criminal or deviant conduct. Their theory minimizes the significance of internal forces which influence deviance in favour of the perspective that criminals engage in deviant activity in order to satisfy their needs for material goods, excitement, and pleasure. Rational-choice theory assumes that criminals have selective responses to the characteristics of certain offenses, and to their opportunities. Costs and benefits are factored into the decision to choose alternative crimes if one becomes too difficult to commit. It is theorized that, if it is no longer possible to commit one crime, then the criminal, who selects a crime on the basis of costs and benefits, may actually seek non-criminal activities, rather than displace activity to other types of crime.

Clarke and Lester (1989) applied the rational-choice theory to the choice of method for suicide. They examined the use of guns, domestic gas, and car exhaust, for suicide in the United Kingdom, the Netherlands, Australia, and the U.S.A., and found "clear evidence that the availability of lethal agents is directly related to the extent of their use in suicide" (p. 110). They also found that people do not always switch to alternative suicide methods when one method becomes restricted. For example, when England and Wales detoxified domestic gas, the use of domestic gas as a suicide method dropped significantly, and the use of other methods did not rise at a corresponding rate.

In summary, a classical theory of suicide stresses the rationality of the act. It proposes that the decision to commit suicide is often premised upon an intelligent assessment of the costs and benefits of suicide, over other alternatives.

Positivist Individualistic Theory of Suicide

Whereas the classicists believe in choice or free will, positivists generally accept the idea that human behaviour is determined. "Most contemporary scientific criminology is positivist in method and in basic formulations" (Vold & Bernard, 1986, p. 45), and the majority of theories used to explain suicide are of positivist construction. In its search for the causes of suicide, positivist theory employs biology, psychiatry, and psychology. For example, a multitude of research findings on suicide have been attributed to the discipline of psychiatry (e.g. Barraclough, 1972; Hagnell & Rorsman, 1979; Modestin, 1989). According to Lester (1992), suicide has generally been found "to be more common in those with psychiatric disturbance, in those with psychosis, and in those with affective disorders and schizophrenia" (p. 311). Psychosis and substance abuse are also associated with suicide.

In addition to psychiatry, considerable inquiry has been conducted into the biochemical and physiological explanations for suicide (see Lester, 1992). Unfortunately, the majority of the research studies fail to control for the type and severity of psychiatric disturbance, and results have been influenced by confounding variables such as chemical changes prior to post-mortem examination, and medication taken by the patient (Lester, 1992).

The discipline of psychology has also contributed a moderate amount of theory regarding the causes of suicide (Lester, 1988). Freudian theory suggests that suicide is inwardly-directed aggression (McMahon & McMahon, 1983). Beck et al. (1975) demonstrated the association between depression and a sense of hopelessness, and suicide. Moreover, low self-esteem is consistently linked to suicidal behaviour (Lester, 1992).

Social Structure (Subculture) Theory of Suicide

Lester (1992) proposed that there are suicidal subcultures, particularly in small communities such as "schools, psychiatric hospitals and prisons, or native American reservations" (p. 80). Subcultural and strain theories tend to focus on the emotional experiences of individuals who have difficulty in achieving cultural goals through socially acceptable means (Williams & McShane, 1988). Individuals who are unsuccessful in achieving such tasks may experience frustration, abandon goals, and become "retreatists" (See Merton, 1957).

The notion that an individual has failed to achieve some goal is common in suicides. Livermore (Cited in Lester, 1990), found that 30% of suicide notes among completed suicides said, "You'll be better off without me" (p. 53). Furthermore, approximately half of the notes of those who killed themselves mentioned financial problems as a precipitating cause.

Learning Theory of Suicide

Whereas social structure theories emphasize that social structure is a primary cause of suicide, learning theory focuses on *social processes*; viz., those relationships between the individual and significant individuals in society. Learning theory suggests that behaviour "can be expected to be maintained if it is reinforced in the social environment" (Williams & McShane, 1988, p. 125). Lester (1992) suggests that "learning factors may play a strong role in the appearance of suicide in distressed individuals" (p. 81).

Durkheim's theories of egoistic and anomic suicide suggest that suicide would be common among those who are poorly socially integrated, and poorly socially regulated (Nisbet, 1965). Non-socialized individuals often associate with other non-socialized people, thus forming a small subculture. This subculture may share information about suicide, such as the methods to use, and the number of pills or pill combinations to take (Lester, 1990).

Additionally, it has been shown that the chronic suicide attempter is a social deviant who originates from locales where social deviance is common (Lester, 1992): for example, environments with a high incidence of drug abuse and delinquent behaviour. Children raised in such environments may fail to learn the values of the larger society, and may not be taught the interests and activities that could deter deviant activity. There is, however, very little research on the relationship between learning and suicide (Lester, 1992).

Social Control Theory of Suicide

The social control theory of suicide emphasizes the "social bonds and internal controls which prevent people from committing suicide" (Lester, 1992, p. 81). As mentioned previously, Emile Durkheim's sociological theory of suicide suggests that social integration and regulation reduce the likelihood of suicide (See Nisbet, 1965). Therefore, strong social bonds decrease suicide risk.

There is strong support for a social control theory of suicide. Much of the sociological theory about suicide is based on social controls, and considerable psychological research has demonstrated the relationship between poor parent-child relationships, social conflict, and isolation on the evolution of suicidal behaviour (Lester, 1990).

In some instances, however, social bonding may actually lead to suicide. For example, in 1978, there was the mass suicide of over 900 members of the People's Temple in Jonestown, Guyana (Cahill, 1979). In this social tragedy, the Reverend Jim Jones trained his followers in mass suicide "rehearsals," allegedly using physical coercion and misinformation. When Jones and his followers were threatened with intervention by outsiders, they destroyed themselves (Droge & Tabor, 1992).

Social Reaction (Labeling) Theory of Suicide

The social reaction theory of suicide examines how and why people might be labeled as suicidal, and how they respond to being labeled suicidal. According to Becker (1963), social groups may create deviance through the creation of rules, the infraction of which will be interpreted as deviance.

Lester (1990) proposes that there are both informal and formal opportunities to label a person as suicidal. Informally, survivors of a close relative who has committed suicide may be subjected to close supervision by family and peers for fear that they too may become suicidal. Formal labeling can occur among patients who are hospitalized for attempting suicide, and people who call suicide crisis centres. A potential effect of this labeling is the adoption of a "suicidal identity" or "career."

Social Conflict Theory of Suicide

The social conflict theory of suicide views suicide as the result of one group in a society dominating another group. For example, at Masada, in A.D. 73, rather than surrender to Roman invaders, 960 Jews killed themselves (Droge & Tabor, 1992). Thus, oppressed individuals may employ suicide as a political act as a means to manipulate power imbalances with their oppressors (Lester, 1992). Masada has become a national symbol of liberty for the Israeli people.

In recent centuries, society has proscribed suicide. In the Christian perspective, God gives life, therefore only God may take life (Coleman, 1987). Under canon law, a person who committed suicide was denied a Christian burial (Droge & Tabor, 1992). In totalitarian societies, one's life belonged to the King or leader, in communist countries, to the state (Lester, 1990).

The following account was written in England, in about 1860, by Russian exile Nicholas Ogarev. It illustrates the violent punishment of death, for a man who had attempted suicide:

> A man was hanged who had cut his throat, but who had been brought back to life. They hanged him for suicide. The doctor had warned them that it was impossible to hang him as the throat would burst open and he would breath through the aperture. They did not listen to his advice and hanged their man. The wound immediately opened and the man came back to life again although he was hanged. It took time to convoke the aldermen to decide the question of what was to be done. At length the aldermen assembled and bound up the neck below the wound until he died. Oh my Mary, what a crazy society, and what a stupid civilization (Cited in Droge & Tabor, 1992, p. 6).

Recently, consideration has been given to the notion that we own our bodies and that we may have the right to die in the manner and the time of our choosing (Humphry & Wickett, 1990). This concept is a considerable departure from the logic of secular law employed in 19th century England, and may be understood not only as the exercise of free-will, but as a protest against oppression.

Conclusion

Amongst Lester's (1990) criminology-based suicide theories, the classical theory of suicide is the most relevant to the AIDS context. It has been suggested that suicidal individuals make a rational choice of suicide method "based upon the effects of different methods for suicide on the body and on the mind" (Lester, 1992, p. 80). If euthanasia in the context of AIDS is seen as "not a choice between living and dying but between dying now or dying later in a more difficult way" (Yarnell & Battin, 1988, p. 602; See also Ogden, 1993), then suicide, euthanasia, and assisted suicide may all be seen as rational decisions.

The social conflict theory of suicide proposes some interesting questions regarding the political aspects of who owns one's life, and who may take one's life. In the AIDS context, persons with AIDS (PWA) are often subjected to numerous invasive treatments, as well as medical and scientific investigations. Such investigation and intervention may cease to benefit the patient long before the scientific fascination with HIV pathology is satiated. In these circumstances, the patient has a number of options which may include cooperation with benevolent medical paternalism, cessation of treatment, dedication of the body to scientific inquiry, or rejection of continued life. Suicide, or euthanasia, from a social conflict theory perspective, may be viewed as an effort where individuals who consider themselves to be oppressed, seek to manipulate their oppressors.

The Euthanasia Debate

Moral theorists, physicians, legal experts, academics and lay persons have contributed to an abundance of literature which both supports and opposes various aspects of euthanasia (Black, 1993; Brock, 1992; Fenigsen, 1989;

Fletcher, 1954; Gaylin, Kass, Pellegrino, & Siegler, 1988; Gay-Williams, 1979; Gomez, 1991; Kluge, 1981 & 1992; Quill, 1991; Rachels, 1975; Reichel & Dyck, 1989; Williams, 1958).

Supporters of Euthanasia

Supporters of active voluntary euthanasia argue that there is a moral duty to respect the wishes of a patient who desires death as a final treatment for uncontrollable pain, or incurable suffering. In their view, a death with dignity is a basic human right, and this should be legally sanctioned. "Heroic" or extraordinary medical treatments that prolong life and perpetuate suffering are considered dehumanizing and undignified--ignoring a patient's "quality of life." "Quality of life" is a legitimate factor in decision making, and should not yield to the quantitative preservation of life as an absolute value (Law Reform Commission, 1982).

Many proponents of euthanasia argue that the distinction between active and passive euthanasia is illusory since the passive form still requires an action of some sort. Specifically, an act of omission is equal to an act of commission since they have the same motive, and the same result (Browne, 1988; Fletcher, 1979; Rachels, 1975). Nevertheless, according to Rachels (1975), in medical ethics, the distinction is crucial. In some cases, it is considered permissible to withhold treatment and allow a patient to die, but it is never permissible to take direct action intended to kill a patient. The problem is that the process of being "allowed to die" can be relatively slow and painful. Rachels (1975) argues that the withdrawal of a breathing tube will cause death by suffocation--a most frightening experience--and less humane than a quick and painless lethal injection. According to Dutch physician Peter Admiraal, there is no ethical difference between not initiating life support and a lethal injection. In his words, "the only thing passive about passive euthanasia, is the physician" (Cited in Todd, 1990, p. C11).

Many euthanasia supporters base their arguments on the principles of liberty of choice, and the right to self determination. Thus, an incurable or terminally ill patient should have the right to choose the time, place, and manner of his or her death. Legalization of active voluntary euthanasia would provide an *option* for such patients, provided they have the cooperation of another party to assist them.

Opponents of Euthanasia

Many who oppose euthanasia argue that killing is wrong in any context. Central to this view is a Judaeo-Christian ethic; life is on loan to us from God, and "one's passage from this life is subject to the will and power of God" (Coleman, 1987). Specifically, it is God's right to determine both the beginning and end of life--euthanasia is, therefore, a violation of God's will. Nevertheless, under Roman Catholic doctrine, patients, as stewards of their bodies, are not required to use "extraordinary" treatments that might be considered therapeutically useless, even though the result may be to hasten death (Coleman, 1987). In addition, the Guild of Catholic Doctors state:

> "[We] do not object to the giving of appropriate pain-relieving treatment, even in the knowledge that this may shorten the sufferer's life, nor to turning off the respirator when the patient is already dead. We should not regard either of these as euthanasia, and consider that their introduction into the discussion will only serve to blur the real issues" (Cited in British Medical Association, 1988, p. 60).

In some situations, those who oppose euthanasia, support killing in other contexts. For example, the British Medical Association (1988), hereinafter BMA, identifies three situations where killing may be justifiable: capital punishment, self defence, and mercy killing. The BMA does not situate mercy killing in the context of terminal medical care. Rather, mercy killing is placed in a wartime context, such as that where a soldier might be killed as a means to prevent capture and torture by a cruel enemy (BMA, 1988).

Some opponents argue that physicians should adhere to the distinction between cessation of treatment and active euthanasia; to otherwise hasten the death of a patient is to violate a sacred canon of medical ethics: "doctors must not kill" (Gaylin et al., 1988, p. 2139). It is also suggested that in the doctor-patient relationship, which has an inherent power imbalance, patient trust of the physician would be seriously compromised if doctors were to be seen as both "healers" and "killers" (Reichel & Dyck, 1989).

Other arguments against voluntary euthanasia focus on the implications of decriminalization of the practice. The "slippery slope" argument (See Brock, 1993; Humphry & Wickett, 1990; van der Burg, 1991) suggests that legalization of voluntary euthanasia will lead to active involuntary euthanasia. The basic argument is as follows: if event A is allowed, then event B will likely follow. B is not morally acceptable, therefore A must not be allowed.

Those who employ the "slippery slope" argument often point to the alleged similarities between legalized euthanasia and the Nazi euthanasia program of the Hitler regime. Proponents of euthanasia argue that the suggestion that voluntary euthanasia is the "slippery slope" to involuntary euthanasia is flawed. Fletcher (1979) notes that the Nazi euthanasia program had nothing whatsoever to do with merciful or compassionate killing. Ethicist Daniel Callahan (1988) observes that the Nazis did not start with voluntary euthanasia and then shift to involuntary euthanasia. The Nazis began with involuntary euthanasia and their rationale was unrelated to the concepts of self determination or consent to treatment. The slippery slope argument is intuitively plausible, but "rests upon a calculus of probabilities that has little grounding in history or experience" (Callahan, 1988, p. 399).

Some opponents say the legalization of euthanasia would have a negative impact on the motivation to conduct research designed to develop new cures and treatment for the terminally ill (Browne, 1988; Drain, 1990). It is suggested that there is always a risk of diagnostic error, or the potential that a new cure or treatment will be discovered (Law Reform Commission of Canada, 1982). Proponents of euthanasia counter that the primary motivation behind medical research is the elimination or control of disease, not the avoidance of suffering, and therefore, euthanasia will never replace medical research (Browne, 1988; Fletcher, 1954).

The aged and the dying are frequently socially marginalized; hence approval of rational suicide or euthanasia for these groups risks becoming an obligation to commit suicide. Euthanasia opponents suggest that there exists the potential for a social climate where the aged, terminally ill, or otherwise dependent or infirm might experience subtle pressures to exercise the option of euthanasia (Law Reform Commission, 1982; Siegal & Tuckel, 1985; Tillock, 1991; Wanzer et al., 1984). Proponents of euthanasia argue that strict safeguards would prevent such abuse.

Palliative care is seen by some opponents as an alternative to euthanasia (British Medical Association, 1988; Law Reform Commission, 1982). Since the 1960's, palliative or hospice care has gained acceptance in the mainstream of medical care for people with advanced illness (Stoddard, 1992). Palliative care is defined as "active and compassionate care primarily directed toward improving the quality of life for people who are dying" (Latimer & Dawson, 1993, p. 933; See also Health and Welfare Canada, 1989). Palliative care involves a team approach that traditionally includes doctors, nurses, social workers, psychiatrists, counsellors, art and music therapists, clergy, dietitians, and volunteers. In addition to patients who are dying, palliation may apply to persons who suffer from incurable illness. Relief of suffering is at the root of palliative care, and its intent is to "neither hasten nor inappropriately prolong the dying process" (Latimer &

Dawson, 1993, p. 934). Despite this assertion, palliative care is sometimes referred to as "double effect euthanasia" because the "patient's death is a foreseeable potential effect of the treatment" (Council on Ethical and Judicial Affairs, 1992, p. 2229; See also Kluge, 1981). Certainly, the complex treatment conditions that prevail in the end stages of terminal care do not always allow a clear distinction between palliation and euthanasia (van der Sluis, 1989).

The terminal stages of AIDS are frequently accompanied by numerous pathologies: kaposi's sarcoma, loss of vision due to cytomegalovirus (CMV), dementia, infections, lymphoma, and total body pain, to name a few. In the words of Irene Goldstone (1992), "AIDS palliative care pushes the boundaries of traditional care practices" (p. 27). Although palliative care has traditionally been reserved for cancer or AIDS patients, it has been argued that in Canada, even these groups are getting insufficient palliative care (van Bommel, 1992).

Nonetheless, palliative care remains an option for many who seek alleviation from physical suffering, and may help to reduce requests for euthanasia and assisted suicide. Indeed, it is often argued that palliative care is "the principal alternative to euthanasia" (Williams, 1991,

p. 47). Effective pain control, however, only deals with physical pain, and not mental pain. Although palliative care attempts, in theory, to address non-physical suffering, it is a form of treatment that the patient may not want. Palliative care is not always an option for persons such as *Nancy B.* (1992), or others who are totally dependent upon technology for survival. Such individuals may not experience physical suffering. Furthermore, palliation can not guarantee the relief of mental suffering, sense of physical loss, nor the reason for suffering. Medical ethicist Eike Kluge (1993) argues that in some cases palliation merely renders persons insensitive to their suffering, and "if that were ethically acceptable, we would never have to deal with the source of people's suffering. All we would have to do is drug them" (p. 1016).

Euthanasia Law, Policy, and Practice

Canada

In 1972, Canada abolished the offences of suicide and attempted suicide, but retained the offence of counselling or aiding suicide. Prior to 1972, there were "around 300 to 400 convictions" under the predecessor sections of the *Criminal Code* (See *Rodriguez v. Attorney General of B.C. and Attorney General of Canada*, 1993a, p. 151). Although counselling or aiding suicide is punishable with a maximum sentence of 14 years imprisonment, there are no reported examples of this provision ever having been invoked.

Although it is not an offence to commit suicide in Canada, it is unclear when society has the right to intervene in order to prevent a suicide. If it is accepted that there is the right to take one's own life, then what right do we have to prevent people from killing themselves?

A great deal of suicide prevention takes the passive and socially accepted forms of crisis and suicide-prevention centres. Other more active techniques include the installation of fences on bridges, and barred windows on tall buildings. Moreover, mental health legislation generally permits state intervention and temporary committal where, owing to mental disorder, an individual is considered to be a harm to himself or herself. These forms of suicide prevention appear to be socially acceptable, and to a certain degree, expected. What are, however, the social and legal limits with respect to the prevention of a suicide attempt by an individual who appears rational, and refuses intervention?

In the courts, suicide prevention has taken conflicting positions. In the matter of Mary Astaforoff, a hunger-striking member of the Sons of Freedom Doukhobors sect, the

British Columbia Court of Appeal ruled that "there was no statutory duty to force-feed a prisoner and it was not clear that such a duty existed at common law" (*Astaforoff*, 1983, p. 385; See also Picard, 1984). In the 1984 case of *Niemiec* (Sommerville, 1985), the Québec Supreme Court ruled that physicians could administer emergency medical treatment to a captive person, contrary to the competently expressed wishes of that person.

There is no official Canadian euthanasia policy. The *Criminal Code* prohibits the act of homicide, prohibits a person from consenting to having death inflicted on him/her (s. 14), places certain restrictions on the right to refuse treatment (s. 45), prohibits aiding or abetting a suicide (s. 241); and prohibits the acceleration of death, even if the victim is already dying (s. 226). (See Appendix A for relevant *Criminal Code* sections). It may be concluded from criminal law that the unwritten Canadian policy reflects life as having an absolute value, to be sustained at all costs. When the above-mentioned sections of the *Criminal Code* were drafted, the type of problem being discussed here had not yet attained the critical threshold required to generate a need for policy. Modern medical technology was not yet available and "sophisticated and scientific palliative care was either unknown or at best in its infancy" (Law Reform Commission, 1983, p. 9).

In 1984, a euthanasia-related protocol was developed by the Canadian Nurses Association--the *Joint Statement on Terminal Illness* (Canadian Medical Association, 1987). This protocol has been adopted by the Canadian Medical Association (CMA), the Canadian Hospital Association, the Canadian Health Association, and the Canadian Bar Association. The *Joint Statement on Terminal Illness* is intended as a "basic, national guideline for those involved in the care of the terminally ill" (p. 424A). The protocol recognizes that there are conditions of "ill health and inevitable death" where a physician may instruct that there should be no resuscitation of a patient (Canadian Medical Association, 1987, p. 424A). Such decisions involve seeking a second medical opinion and consultation with the patient. Where the patient is incompetent, family consultation is deemed appropriate and ethically acceptable. The protocol, which is under review, is widely used as a basis for hospital policy development (Canadian Medical Association, 1987).

The Canadian Medical Association also has a policy on informed decision making for consent to treatment. Informed consent is currently a requirement that has emerged from the courts' application of the tort of negligence (See *Hopp v. Lepp*, 1980, & *Reibl v. Hughes*, 1980; See also Picard, 1984). Thus, physicians are required to disclose relevant information to patients prior to obtaining consent for medical treatment (Canadian Medical Association, 1986). Implicit in the policy is the recognition that a patient may refuse to consent to treatment (Canadian Medical Association, 1986).

Canadian common law recognizes the right of competent adults to both consent to, and refuse, medical treatment (Rozovsky & Rozovsky, 1990). In 1990, the Ontario Court of Appeal upheld the right of a Jehovah's Witness to refuse a life-saving blood transfusion (*Malette v. Shulman*, 1990). It was recognized by the court that "the right of self determination which underlies the doctrine of informed consent also obviously encompasses the right to refuse medical treatment" (*Malette v. Shulman*, 1990, p. 328).

Recent developments in Ontario and British Columbia concerning substitute decision making appear to confirm the aforementioned trend toward patient autonomy and informed decision making for consent to treatment. Ontario's *Consent to Treatment Act* (1992), British Columbia's *Representation Agreement Act* (*Bill 48*, 1993) and *Health Care (Consent) and Care Facility (Admission) Act* (1993), and Nova Scotia's *Medical Consent Act* (1988) all provide for some form of substitute consent whereby adults may delegate the authority to make personal treatment decisions in the event that they become incapable of making such decisions.

A patient need not be incompetent in order to delegate treatment consent. Where a physician is prepared to accept responsibility for a treatment decision, a patient may waive the right to informed consent and informed decision making. In *Reibl v. Hughes* (1980), Chief Justice Bora Laskin stated:

> It is, of course, possible that a particular patient may waive aside any question of risks and be quite prepared to submit to surgery or treatment, whatever they be. Such a situation presents no difficulty (p. 895).

The Law Reform Commission of Canada (1982; 1983), hereinafter referred to as the LRCC, prepared both a working paper and a report titled *Euthanasia, Aiding Suicide and Cessation of Treatment*. The LRCC noted that the *Criminal Code* sections on homicide treat life in "an exclusively quantitative, rather than qualitative, sense" (LRCC, 1982, p. 3). The sanctity of life principle has given rise to "vitalism"--a doctrine whereby human life is of absolute value and must be preserved at all costs. The Commission felt that the evolution of medicine, science and technology, however, has called for reconsideration of the vitalist perspective. It contended that "quality of life" and "death with dignity" were increasingly becoming considerations for patients seeking greater participation in their health-care decisions (LRCC, 1982). The LRCC felt this concern for quality of life was being reflected in the use of palliative care as an option to continuation of useless treatment, or termination of all care.

Kuhse argues that quality of life judgments are fundamental to the sanctity of life view. "Not only is refraining from preventing death always an instance of the intentional termination of life, but the qualified Sanctity-of-Life Principle is also based on quality-of-life criteria whenever the withdrawal or non-employment of life-prolonging means is justified by the implicit or explicit claim that those means would not benefit the patient over and above prolonging her life" (Kuhse, 1987). That is, quality of life considerations are sometimes used to morally justify the intentional termination of life.

The LRCC observed that the Canadian criminal law on killing does not take *motive* into consideration; only *intent* to cause death is taken into account (LRCC, 1982). Criminal law merely makes a distinction between two types of behaviour; the action of killing and the inaction of allowing to die (LRCC, 1982). The LRCC (1983) concluded that euthanasia and assisted suicide should remain illegal. With respect to cessation and refusal of treatment, it recommended that physicians should not be held criminally liable for administering palliative care that may reduce life expectancy, nor for discontinuation, or non-initiation of therapeutically useless treatment.

The LRCC recommendations mirror the instructions given by Lord Devlin to the jury in the *Bodkin Adams* case in England in 1957. In that case, Dr. Adams had been charged with the murder of a patient to whom he had administered large doses of drugs. The defense successfully argued that treatment administered by Dr. Adams was designed to promote comfort. Even if the treatment shortened the life of the patient, if it was correct treatment, there could be no conviction of murder (Palmer, 1957).

In its Working Paper *Euthanasia, Aiding Suicide, and Cessation of Treatment* (1982), the LRCC noted that cessation of treatment may fall under a number of provisions of the *Criminal Code*, ranging from assault to homicide; failure to provide the necessaries of life; or failure to use reasonable knowledge, skill and care; or aiding suicide. The Commission found that the legal issues surrounding the cessation or withdrawal of treatment are complicated because of their association with euthanasia. The LRCC found no record of a physician being convicted for ending the life of a terminally ill patient through the administration of pain-killing drugs. Nor did it find any convictions for the termination of therapeutically useless treatment for a dying patient. The Commission also observed that Canadian courts have never directly blamed a doctor for refusing to prolong a patient's agony by not treating a secondary complication. The LRCC concluded that the medical profession probably has little to fear in terms of the criminal law. It warned, however, that complacency was not warranted:

> It must be borne in mind as well that the present policy of not laying charges could change under the pressure of events. Should this happen, a number of doctors might have to serve as test cases in order to determine just what the current state of the law is. The question is far too important and far too fundamental to be left in such a state of uncertainty (LRCC, 1982, p. 9).

Parliamentary Initiatives

Several Canadian Members of Parliament have recently introduced legislation addressing various aspects of the right to die. In 1991, MP Robert Wenman introduced Bill C-203, "an Act to amend the *Criminal Code* (terminally ill persons)." The legislation called for amendments to the *Criminal Code* which stated that physicians would not be under any legal obligation to administer treatment against the expressed wishes of a patient, or when treatment becomes therapeutically useless. The Bill "would also protect a physician who administers pain killing treatment to a patient even though the effect of that treatment will hasten death" (Bill C-203, p. 2).

Bill C-203 was intended to be a legislative solution to the potential criminal liability of physician's who respect patients' wishes to withhold or withdraw life-sustaining treatment or in providing palliative care. The Bill passed second reading in Parliament and was later defeated in a committee vote.

Bill C-261, proposed by MP Chris Axworthy, went considerably further than the mere cessation of treatment. Its purpose was to legalize euthanasia, and to protect physicians in euthanasia-like situations where pain-killing treatment hastens death. The Bill also intended to clarify some of the LRCC's concerns about criminal liability for not initiating or continuing treatment at the request of the patient. The Bill died on the order paper on October 24, 1991.

In 1992, MP Svend Robinson introduced Bill C-385, an Act to decriminalize physician-assisted suicide. This Bill was never debated in Parliament, and died on the order paper when an election was called.

B.C. Royal Commission Recommendations

The British Columbia Royal Commission on Health Care and Costs (1991) recently approved of what it felt was widespread support for the right to die with dignity. The Commission spoke in favour of euthanasia and assisted suicide, making four recommendations.

The first recommendation addressed the right to die with dignity. It suggested the provincial government lobby the federal government for *Criminal Code* amendments to "recognize the competent adult patient's absolute right to refuse medical treatment or demand its cessation, and that where the person is not competent, the right may be exercised by a duly appointed proxy" (B.C. Royal Commission, 1991, p. 181). The Commission did not clarify whether this would include statements made in living wills or advance directives.

The second recommendation pertained to requested mercy killing. The Commission suggested the provincial government lobby the federal government for *Criminal Code* amendments allowing terminally ill patients the right to request and receive fatal doses of pain medication (B.C. Royal Commission, 1991). It is puzzling that the Commission's recommendation only referred to the administration of pain medication for the purposes of mercy killing. After all, there are more efficient, non-analgesic medications which will hasten the death of a terminally ill patient.

The Commission's third recommendation was that the provincial government request the federal government to amend section 241(b) of the *Criminal Code* so that aiding the suicide of a terminally ill patient would not be a criminal offense (B.C. Royal Commission, 1991).

The final recommendation dealt with the withdrawal or withholding of therapeutically useless treatment when consent cannot be obtained. In cases where the consent of the patient or a proxy is not available, a physician would not be under legal obligation to provide such treatment nor criminally liable for the withdrawal of therapeutically useless treatment (B.C. Royal Commission, 1991).

The Sue Rodriguez Case

On September 30, 1993, the Supreme Court of Canada, in a 5-4 decision, turned down the petition of Sue Rodriguez for a physician-assisted suicide (*Rodriguez v. British Columbia*, 1993b). Rodriguez suffers from Amyotrophic

Lateral Sclerosis[3] and apparently has a physician who is willing to assist her death (Wilson, 1993).

Rodriguez had argued that s. 241(b) of the *Criminal Code*, which prohibits one from receiving assistance in committing suicide, was in violation of sections 7, 12 and 15(1) of the *Charter* (*Constitution Act*, 1982).

The Court stated that the prohibition on assisted suicide did not violate Rodriguez's *Charter* rights, and that the prohibition was grounded on a societal consensus against assisted suicide. In the majority decision, Justice Sopinka relied on the "sanctity of life" principle which he argued is embodied in s. 7 of the *Charter*: "Even when death appears imminent, seeking to control the manner and timing of ones death constitutes a conscious choice over life" (*Rodriguez v. British Columbia*, 1993b, p. 62).

Justice Sopinka's reliance on the sanctity of life principle will present a strong argument for pro-lifers in future right-to-life cases. Even in the landmark abortion decision of *Morgentaler* (1988), the sanctity of life principle received no mention from the Supreme Court.

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[3] Amyotrophic Lateral Sclerosis (ALS) is also known as Lou Gehrig's disease. It is an incurable condition which involves progressive degeneration of spinal, corticobulbar, and lower motor neurons, with subsequent spasticity and atrophy of cranial and spinal muscles (Miller, 1984).

In dissent, Justices L'Heureux-Dubé and McLachlin argued that s. 241(b) violates s.7 because it imposes an arbitrary limit on the right to deal with one's own body as one chooses. Section 7, "security of the person" was considered to encompass the notions of dignity and the right to privacy. For Justice Cory, "dying is an integral part of living and, as a part of life, is entitled to the protection of s. 7" (*Rodriguez v. British Columbia*, 1993b, p. 85). Justice Cory argued that a remedy to s. 7 was available through sections 1 and 15. Chief Justice Lamer determined that s. 241(b) "infringes the right to equality contained in s. 15(1) of the *Charter*" (p. 35). Lamer proposed a one year constitutional exemption to s. 241(b) whereby a superior court could grant the right to an assisted suicide to individuals unable to commit suicide without assistance. Justice Lamer suggested that Parliament should use this "time to decide what, if any, legislation should replace s. 241(b)" (p. 51) (See Addendum 1).

Addendum 1. Sue Rodriguez died on February 12, 1994. She apparently died with the assistance of an anonymous physician, and in the presence of her friend, Svend Robinson. The circumstances of her death are under investigation (Cernetig, 1994).

Rodriguez's death was followed by an announcement from the Federal Senate that it will study the legal, social, and ethical issues relating to euthanasia and assisted suicide. Prime Minister Jean Chrétien also announced that Parliament will hold a free vote on euthanasia (Bryden, 1994).

Earlier, in the B.C. Appeal Court, the three Justices of Appeal were unanimous in stating that the euthanasia issue belongs in Parliament, not the courts (*Rodriguez v. British Columbia*, 1993a). Only two weeks after that decision, Parliament defeated a motion to *consider* decriminalizing euthanasia by a vote of 140-25 (O'Neil, 1993).

Erwin Krickhahn

On October 30, 1993, Erwin Krickhahn, a Toronto man dying with ALS, invited the media and Toronto police to attend his suicide (Fine, 1993). Krickhahn had hoped that the Supreme Court of Canada would render a decision in favour of Sue Rodriguez, so that he could also obtain a physician-assisted suicide. Krickhahn called off his plan for a public suicide, but insisted that he would eventually take his life (Fine & Mitchell, 1993). He died of natural causes on February 8, 1994. In a written statement, Krickhahn said that he did not change his mind about committing suicide. Rather, a bleeding ulcer prevented him from being able to ingest an overdose of barbiturates that he had stockpiled for his suicide (Mitchell, 1994).

Euthanasia Cases in Canada

Dr. Natchum Gal

Very few cases of euthanasia in Canada ever come to the attention of the authorities. In 1983, the Canadian Government showed it was prepared to take action in the case of Candace Taschuk. On October 8, 1982, approximately 16 hours after her birth, Candace Taschuk, a severely brain-damaged infant, was removed from life-support systems. Under the authorization of Dr. Natchum Gal, she received a lethal 15 milligram dose of morphine from nurse Barbara Howell (Ferguson, 1988; McCarthy, 1983). The child died within 40 minutes (Sheppard, 1983). Dr. Gal, an Israeli, fled to his home country and was subsequently charged with murder by the Alberta Attorney General. An application for the extradition of Dr. Gal was unsuccessful (Ferguson, 1988; McCarthy, 1983). Dr. Gal denied any wrongdoing and declared "infant euthanasia is everywhere" ("Infant Euthanasia," 1983, p. 7). The Alberta Association of Registered Nurses issued suspensions of one year for Barbara Howell, and four months to Betty Schultz, her immediate supervisor ("Two nurses," 1983).

Dr. Peter Graff

In 1991, the British Columbia College of Physicians and Surgeons issued a statement against euthanasia after reviewing the deaths of two of Dr. Graff's patients (Wilson, 1991a). The two elderly male patients, one with ALS and the other with colon cancer, died of repeated doses of morphine and valium (Simpson, 1991). A provincial coroner's inquiry "urged a review by the College of Physicians and Surgeons as to whether Dr. Graff's actions were acceptable" (Wilson, 1991a, p. 8). Despite the professional association's ruling that Dr. Graff's method of treatment was unacceptable, and the coroner's conclusion that both patients died of morphine overdoses (Wilson, 1991a), no criminal charges were laid.

Dr. Tom Perry

During an interview in 1990, Dr. Perry, a British Columbia MLA, admitted to giving morphine injections to his father, who was dying with cancer: "If you asked me did it hasten the time of death, the answer is yes, it may have" ("B.C. Physicians Wary," 1993, p. 1366). A media, and political frenzy was quelled within days when the B.C. College of Physicians and Surgeons (BCCPS) stated that it believed Perry provided his father with quality palliative care--treatment that "may coincidentally hasten death but is neither illegal or unethical" (Hunter, 1991, p. B1).

The BCCPS claim that palliative, death-hastening treatment is not illegal is questionable. Dr. Perry's conduct may have been consistent with ethical medical practice and the common law. Nevertheless, in criminal law, palliative care, if it serves to hasten death, can theoretically be an act of murder. In 1987 the Law Reform Commission of Canada proposed that palliative treatment which shortens life be exempted from the *Criminal Code* provisions pertaining to murder, negligent homicide, manslaughter, and furthering suicide:

> Under present law, administration of palliative treatment likely to shorten life would in theory fall under subparagraph 212(a)(ii) [now 229(a)(ii)] and give rise to liability for murder. In practice, Canadian case-law has no record of conviction of a doctor for shortening a terminal patient's life by administering pain-relieving drugs. Moreover, most people, including religious leaders, see nothing wrong in giving treatment for the purpose of relieving pain in certain circumstances even though one result of such relief may be to shorten life. Clause 6(6) clarifies the law, reconciles it with present practice and brings the Code into line with current moral thinking (Law Reform Commission of Canada, 1987, p. 60-61).

Essentially, the LRCC recommendation affirmed the British decision of *Bodkin Adams*: it is acceptable to shorten the life of a patient with large doses of pain medication, provided that the primary intent is to alleviate suffering (See Palmer, 1957).

More recently, in the case of *Rodriguez* (1993b), Justice Sopinka expressed the view that distinctions based upon intent are important, forming the basis of criminal law:

> While factually the distinction may, at times, be difficult to draw, legally it is clear. The fact that in some cases, the third party will, under the guise of palliative care, commit euthanasia, or assist in suicide and go unsanctioned due to the difficulty of proof, cannot be said to render the existence of the prohibition fundamentally unjust (*Rodriguez v. British Columbia*, 1993b, p. 78).

Nancy B.

The case of "Nancy B." is another well-publicized example of euthanasia in Canada. "Nancy B." was a pseudonym to protect the woman's identity. Suffering from Guillain-Barré syndrome[4], 24 year-old Nancy B. had control of her mental faculties, but had full paralysis from the neck down, and was completely dependent upon a respirator (Deacon, 1991). Her request to have the respirator removed was granted by a Québec Superior Court on January 6, 1992 (*Nancy B. v. Hôtel-Dieu de Québec*, 1992). On February 13, 1992, Nancy's respirator was removed, and under heavy sedation, she died (Fennell, 1992; King, 1992). The likely purpose of the sedation was to induce a coma so that Nancy would not be conscious while she suffocated to death.

In his decision, Justice Dufour determined that under Québec civil law, Nancy B. had the right to require the

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[4] Guillain-Barré syndrome is a neurological disorder causing "acute febrile polyneuritis" (Dorland's Illustrated Medical Dictionary, 1981). Nancy's condition was diagnosed as incurable and irreversible, with a degeneration in the nerves that approached total denervation of the motor nerves.

cessation of the respiratory treatment she had received. Furthermore, he reasoned that the person who would perform the withdrawal of Nancy B.'s respirator would not "in any manner" (p. 460) commit the crimes of murder, manslaughter or the aiding of suicide. Mr. Justice Dufour concluded that there was no crime in removing Nancy B.'s respirator because it would not "cause" her death (*Nancy B. v. Hôtel-Dieu de Québec*, 1992). Fish and Singer (1992, p. 639) argue that Mr. Justice Dufour's reasoning on Nancy B.'s causation of death was "patently artificial." In order to avoid the *Criminal Code* provisions regarding manslaughter, murder, and aiding suicide, Dufour had "no alternative but to hold that the withdrawal of Nancy B.'s respirator would not cause her death" (Fish & Singer, 1992, p. 640). Nonetheless, it is clear that when Justice Dufour granted Nancy B.'s request for the withdrawal of her respirator, he, Nancy B., her physician, and all other involved parties were conscious that she would die without it (*Nancy B. v. Hôtel-Dieu de Québec*, 1992).

The critical issue in the Nancy B. case is that the patient had no power to turn off the respirator herself. One could argue that her physician was merely implementing the patient's competently expressed wishes, a position that is consistent with the common law; every competent adult has the right to be free from unwanted medical treatment and this right is not vitiated should such competently expressed decisions result in serious harm. Furthermore, a patient in anticipation of becoming unconscious or otherwise incompetent, may express his or her wishes with respect to medical procedures, and may issue advance notification of consent to, and refusal of treatment.

In the mental health sphere these common law principles have been extended to mentally competent patients in psychiatric and prison facilities. In *Fleming v. Reid* (1991) it was held that pursuant to the Ontario *Mental Health Act*, "prior competent wishes" are paramount over "the best interests" of a patient (p. 75), where the prior competent wishes of the patient are known. Additionally, section 7 of the *Charter* may also require that this principle be applied wherever substitute consent is given.

Carolyn Goguen

It is ironic that Nancy B. had to go to court to exercise her common law right to refuse treatment--a right that Canadians exercise daily. Less than a year prior to Nancy B.'s death, Carolyn Goguen died in an Edmonton hospital after the withdrawal of her respirator, at her request. Goguen was rendered quadriplegic after being shot by her estranged husband. Similar to Nancy B., Goguen's condition was irreversible, and not terminal. "The hospital consulted with the family, theologians, the in-hospital bioethics committee and the medical examiner before removing the woman from life-support equipment" (Sears Williams, 1993, p. 680). According to Edmonton physician Dr. Tom Noseworthy, "never once did we need legal input and never once did the hospital get concerned, back off and become [worried about the legal risks]" (Sears Williams, 1993, p. 680).

Although Mrs. Goguen had made the request that her respirator be discontinued, the underlying cause of death was determined to be the gunshot wound to her neck. Graeme Dowling, Alberta's Chief Medical Examiner, states:

> The concern about how her death would be certified was discussed between ourselves and her attending physicians. Both Dr. Denmark, the certifying Medical Examiner, and myself agreed that, given the underlying cause of death was a gunshot wound of the neck intentionally inflicted upon her by another individual, the manner of death would be homicide. Use of the term homicide in this case was not directed in any way, shape, or form to the fact that Mrs. Goguen had the ventilator turned off by her physicians at her request (Personal correspondence, Graeme P. Dowling, October 28, 1993).

Scott Mataya

In November 1991, Scott Mataya, a nurse at Toronto's Wellesley Hospital, administered a lethal dose of potassium chloride to 78 year-old Joseph Sauder. Evidence presented to the Court stated that Mr. Sauder had fallen into an irreversible coma and had been disconnected from a ventilator prior to Mataya's administration of the lethal injection (*R. v. Mataya*, 1992). Mataya panicked when Sauder began to convulse and vomit, and without doctor authorization he administered a six cubic centimetre dose of potassium chloride through an intravenous tube. Mr. Sauder died minutes later (*R. v. Mataya*, 1992). Mataya was charged with first degree murder and was later convicted on a lesser charge of administering a noxious substance. He received the maximum three year probation period, a suspended sentence, and was prohibited from ever practicing nursing again ("Nurse Spared," 1992; *R. v. Mataya*, 1992).

In *Mataya*, the Court avoided debate on euthanasia or mercy killing. It appears that since the exact cause of Mr. Sauder's death could not be determined, the Court was satisfied with addressing the issue in terms of the charge--administration of a noxious substance--although, in criminal law, there can be more than one cause of death.

Andrew Sikorski

The circumstances of the *Sikorski* (1992) case are as follows: On March 25, 1991, Andrew Sikorski's father was admitted to the Palliative Care Unit at Peel Memorial Hospital. He was dying with cancer and his physicians did not anticipate that he would live much longer. On March 28, 1991, Andrew Sikorski observed his father to be in "obvious and visible pain" and requested an increase in the morphine dose that his father was receiving. This request was not granted. Later, Mr. Sikorski tampered with the intravenous morphine pump so that the dose was increased to a flow of 100 cubic centimetres per hour. Mr. Sikorski's father died early the next morning.

Although Mr. Sikorski's act "had the potential to cause actual danger to the life of the deceased ... (it) did not ... cause any such harm since it was detected by the nursing staff well before any harm resulted" (*R. v. Sikorski*, 1992, p. 3). Nevertheless, counsel for the Crown and the accused agreed that the "increase in the morphine drip was caused ... to accelerate his father's death" (*R. v. Sikorski*, 1992, p. 3).

Andrew Sikorski was initially charged with attempted murder (Personal communication, Paul Taylor[5], November 22, 1993), and later convicted of "mischief causing actual danger to life" (s. 430(5.1); See Appendix A). He received a conditional discharge, and was sentenced to one year of probation and 150 community service hours (*R. v. Sikorski*, 1992).

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[5] Paul Taylor is Crown Counsel, Peel, Ontario.

Dr. Alberto de la Rocha

On April 2, 1993, Dr. de la Rocha was convicted for the "administration of a noxious substance" to 70 year-old Mary Graham (*R. v. de la Rocha*, 1993). Mrs. Graham had been diagnosed with cancer in the summer of 1991. On October 14, 1991, during a biopsy on her neck, difficulties arose and she had to be placed on a mechanical ventilator. The next day Mrs. Graham indicated that she wanted the ventilator tube withdrawn from her throat, even though she was aware that this meant certain death.

In preparation for the extubation, Dr. de la Rocha gave Mrs. Graham two 10 milligram doses of morphine, and thereafter another 20 milligrams. With the assistance of an oxygen mask, Mrs. Graham appeared to be breathing slowly on her own. As the patient's heart rate slowed, Dr. de la Rocha asked a nurse about the availability of potassium chloride. The nurse confirmed that the drug was available, but refused to get it for the doctor. Dr. de la Rocha proceeded to get it, and administered it himself. "Once the potassium chloride was administered, death followed rapidly with an episode of ventricular fibrillation, and ... ventricular tachycardia" (*R. v. de la Rocha*, 1993, p. 7).

Dr. de la Rocha was given a suspended sentence with three years probation. Unlike Scott Mataya, the court did not make an order prohibiting Dr. de la Rocha from the practice of medicine.

AIDS-Related Euthanasia Cases

In recent years, there have been several well-publicized but non-adjudicated AIDS-related euthanasia cases in Canada. In June, 1992, the Corporation Professionelle des Médecins du Québec (CPMQ) admitted that it had reprimanded a doctor after he had given a 38-year-old AIDS patient a lethal injection of potassium phosphate. Apparently, the euthanasia was performed with the consent of the patient and his family, and in the presence of supportive friends (Charbonneau, 1992). The CPMQ disciplined the physician with three months probation; he was ordered to consult with another doctor within 72 hours of taking on a new patient, and to consult with a colleague before administering morphine injections greater than 600 mg. per day (Comité - Médecins - 1, 1992; King, 1992). No criminal charges were laid and the physician's name was not released by the CPMQ. Moreover, the death was not investigated by the Québec coroner (Personal correspondence, Louis Métivier, Québec Bureau du coroner, December 6, 1993).

In British Columbia, AIDS counsellor David Lewis attracted international attention when he reported that he had assisted eight AIDS-afflicted friends to die over a nine year period. Lewis said: "I am hardly alone. I know of dozens of people here who responded to similar wishes. The only difference is I'm talking about it." (Taylor, 1990, p. 14). Chapter 3 of this thesis presents a discussion of how Lewis, also an AIDS patient, had an assisted death through an overdose of prescription drugs.

In the October/November 1991 issue of the *Vancouver PWA Newsletter*, an anonymously authored letter was published (Almost Fearless, 1991). The letter was written by a woman who described her role in assisting the death of a heterosexual male friend who had been infected with HIV through intravenous drug use. The circumstances of this death are described in Chapter 3.

In 1991, Vancouver newspaper columnist Lyn Cockburn wrote an article describing the assisted suicide of a woman with AIDS. The death involved an overdose of seconal and asphyxiation with a plastic bag (Cockburn, 1991). The B.C. Coroner served Cockburn and her senior editors with subpoenas ordering their testimony about the death (Wilson, 1991b). In *Pacific Press Ltd v. Cain* (1993), the Court of Appeal for British Columbia ordered the plaintiffs to comply with the coroner's request. On December 10, 1993, at the coroner's inquest, Cockburn and two of her senior editors were found in contempt of court. They refused to identify their source--allegedly the man who asphyxiated the woman (Bellett, 1993). The coroner's decision has been referred to a judicial review by the B.C. Supreme Court.

Conclusions

There are a number of conclusions that may be drawn from Canadian legal experience with respect to euthanasia. Although the courts have had a limited involvement in the matter, they are apparently prepared to take a compassionate approach. In the cases of *Mataya*, *Nancy B.*, *Sikorski*, and *de la Rocha* the courts assumed compassionate and merciful positions. In the matter of Dr. Gal, the Attorney General's office was unsuccessful in its application for extradition of the accused. Nonetheless, it is notable that Dr. Gal was not tried *in absentia*, nor was the nurse who administered the lethal injection brought to trial. This sort of response suggests that prosecutors and the Canadian courts can be sympathetic in euthanasia-like cases, and in certain circumstances reflect a merciful attitude consistent with that of public opinion (See Bozinoff & MacIntosh, 1991; Bozinoff & Turcotte, 1992). Certainly, compassion and sympathy may in part explain why no legal action was taken in the cases of David Lewis, who assisted in several deaths (Taylor, 1990); Dr. Graff, who had two patients die by morphine overdose (Wilson, 1991a); and the anonymous Québec physician who administered a lethal injection to an AIDS patient (Charbonneau, 1992).

International Perspectives

Britain

In 1988, the British Medical Association (BMA) approved the *Euthanasia Report* (BMA, 1988). The BMA concluded that there is a distinction between an active intervention by a doctor to terminate life and the decision not to prolong life--to not treat a patient. The BMA opposed any movement toward liberalizing the active termination of life which would alter the "present ethos of medicine" (BMA, 1988, p. 68). Nonetheless, the Report found it acceptable that patients receive drug treatment that may involve risk to the life of the patient provided that the sole intention is the relief of pain, illness, or suffering (BMA, 1988). The BMA recommended no change in the law, and advised that the "deliberate taking of a human life should remain a crime" (BMA, 1988, p. 69). The BMA concluded that its rejection of a change in the law was "not just a subordination of individual well-being to social policy. It is, instead, an affirmation of the supreme value of the individual, no matter how worthless and hopeless that individual may feel" (BMA, 1988, p. 69).

Since the BMA report was published, there have been two significant euthanasia cases in Britain. The first case involved Dr. Nigel Cox, who administered a lethal dose of potassium chloride to 70-year-old Lillian Boyes, who was suffering from uncontrollable pain (Fleet, 1992a). The prosecution chose to charge Cox with attempted murder, rather than murder, apparently because it was unable to prove that the cause of death was the injection of potassium chloride. More probable grounds for the decision, however, were prosecutorial concerns for avoiding either a murder conviction that would require a mandatory life sentence, or a "perverse acquittal," which a jury might be tempted to award (Helme & Padfield, 1992, p. 1335).

Dr. Cox was convicted of attempted murder, and received a suspended 12-month prison sentence (Fleet, 1992b). The General Medical Council's Professional Conduct Committee allowed Dr. Cox to retain his medical licence and took no disciplinary action (Fletcher, 1992). The British Medical Association refused comment on the disciplinary ruling, but added "the deliberate taking of a human life is a crime and we do not believe that the law should change" (Fletcher, 1992, p. 1).

The second euthanasia case is that of *Airedale Trust v. Tony Bland* (1993). For three years, Bland had been in a persistent vegetative state, and had given no indication of consciousness or any other human response (Goodman, 1993). In Britain, the usual practice in such cases is to use minimum measures that will ensure the comfort of terminally ill patients; there is little concern if the dying process is hastened through the non-insertion of naso-gastric tubes (BMA, 1988). In Bland's case, however, feeding tubes had already been inserted, and he was able to breathe independently. Had Bland been "brain dead and able to breathe only with the help of a ventilator, doctors would have no problem with switching off his supply of air" (Doyle, 1992, p. 15). In this case, however, the failure to continue artificial feeding could be considered to be murder (Doyle, 1992). Bland's family and physician were granted House of Lords approval to have the feeding supply removed, and in March, 1993, after the withdrawal of the feeding equipment, Tony Bland died (Goodman, 1993).

There are serious implications flowing from the *Cox* and *Bland* cases. The consequence of the *Cox* verdict is two-fold. First, the finding of guilt avoided the possibility that euthanasia could become accepted in practice, if not in law, as is the case in the Netherlands. Second, the failure of the General Medical Council to discipline Dr. Cox indicates a tolerance for his behaviour. In *Bland*, a precedent amounting to non-voluntary euthanasia may have been set. John Keown (1993) sums up the *Bland* decision in the following manner: "A hard case which made bad law, largely by approving a consequentialist ethic radically inconsistent with the principle of the sanctity of human life. Apart from being sure to result in yet more hard cases, it may well serve to encourage the statutory legalisation of euthanasia" (p. 212).

U.S.A.

The euthanasia debate in the United States has recently been influenced by a number of events. *Final Exit*, written by the Hemlock Society's former leader, Derek Humphry (1991), was a how-to manual for suicide or "self deliverance," that sold over 500,000 copies within its first year of publication (Fennell, 1992). In 1991, Washington State held a referendum on the right to "Aid in Dying." The referendum, Initiative 119, failed by a vote of 54% opposed and 46% in favour (Carson, 1992). A similar proposal, California's Proposition 161, was also rejected by a 54-46 majority in 1992 (Capron, 1993). Had either Bill passed, it would have resulted in the world's first legalization of physician-assisted euthanasia.

Gallup Polls published prior to Initiative 119 indicated that 65% of Americans supported euthanasia (Gallup, 1991). The majority of the public approved of

Initiative 119 (Carson, 1992), yet it failed by a decisive margin. Carson (1992), suggests that the outcome of Initiative 119, rather than being based on the principles embodied in the proposed legislation, was based on external events. In the weeks prior to the vote, Derek Humphry, in marketing his book, *Final Exit*, was seen to be a "less than entirely prudent advocate" ("U.S. Hemlock Society," 1991, p. A12). Two months before the referendum, Humphry's ex-wife, Anne Wickett, killed herself with an overdose of drugs. In a lawsuit, she had accused Humphry of employing mental cruelty to push her to suicide ("U.S. Hemlock Society," 1991). Wickett also alleged that Humphry had also smothered his first wife Jean (Carson, 1992), rather than helping her take a lethal potion, as he had stated in his book, *Jean's Way* (Humphry, 1978). In addition to the Humphry controversies, just 11 days before the election, Dr. Jack Kevorkian assisted the suicides of two non-terminally ill women (Carson, 1992). This, coupled with a massive Vote "No!" campaign, supported by pro-life groups, and the Catholic Church, was sufficient to create voter doubt in relation to physician aid-in-dying.

Proposition 161 did not suffer from the external events of Initiative 119. Nevertheless, the Catholic Church organized a successful opposition to the vote. Whereas 75% of California voters had earlier been polled in favour of physician aid-in-dying, only 46% voted yes. Exit-pollsters were told that inadequate safeguards were the primary reason for the opposition (Capron, 1993).

A strong U.S. lobby for patient choice in treatment decision making is reflected by the 47 states which have passed "living will" or "natural death act" legislation (Downie, 1992). In 1990, Congress passed the *Patient Self Determination Act*, requiring Medicaid and Medicare health providers to advise patients about the right to refuse life-sustaining treatment and to complete living wills (Downie, 1992). American case law from *Quinlan* (1976) to *Cruzan* (1990) has also confirmed the right of mentally competent persons and substitute decision-makers to refuse life-sustaining treatment.

In Michigan, Dr. Jack Kevorkian has gained considerable notoriety for assisting the suicides of 20 people since 1990 ("Suicide Doctor," 1993). He has been the subject of several criminal investigations regarding the deaths (Katz, 1993), and the Michigan State legislature passed a bill prohibiting the act of assisting suicide, specifically to stop Dr. Kevorkian ("Doctor assists," 1993; Morganthau et al., 1993).

Michigan State's assisted suicide law was recently ruled unconstitutional by Wayne County Circuit Judge Richard Kaufman (Sanchez, 1993). Justice Kaufman argued that the ban was too broad and that terminally ill patients have the right to commit suicide. Dr. Kevorkian recently promised that he will not participate in any more suicides, and will instead lead a campaign to legalize assisted suicide (Lessenberry, 1993).

Switzerland

Contrary to the United States (Hirsch, 1990) and Canada (LRCC, 1982), where motive is immaterial in evaluating legal culpability, the Swiss *Penal Code* considers "the actor's motive as the essential factor in determining the actor's culpability" (Hirsch, 1990, p. 839). The likelihood that the offence will be repeated and the degree of criminal dangerousness is determined by motive (Hirsch, 1990; Silving, 1954). The philosophy of the Swiss law is that one who kills out of motivation to gain some sort of reward is at risk of repeating the act, whereas one who kills out of mercy is at much lesser risk of repeating the offence (Hirsch, 1990; Silving, 1954). If one is a physician or a nurse, however, there could be other motivations to repeat the offence.

In addition to the consideration of motive, article 114 of the Swiss *Penal Code* specifies "homicide upon request" as a separate crime with a lighter sentence than murder (Hirsch, 1990, p. 839).

The Netherlands

In the Netherlands, physicians practice active euthanasia on patients suffering from terminal illness or conditions that involve unbearable suffering (Admiraal, 1988). According to the Dutch *Penal Code*, euthanasia is illegal, but as a result of several court decisions dating from 1973, prosecution is not pursued provided that physicians follow certain prescribed guidelines (Gomez, 1991; Keown, 1992). According to van der Burg (1991), this tenuous legal relationship appears to be accepted by the majority of Dutch society and is more "justifiable than it would have been had somewhere in the process a political compromise resulted in legislation" (p. 54).

In February, 1993, the Dutch Parliament passed revisions to the guidelines that guarantee physicians immunity from prosecution. The regulations include: i) voluntary and persistent requests from the patient; ii) consideration of treatment alternatives; iii) "perpetual, unbearable and hopeless suffering" experienced by the patient; iv) consultation with relatives and at least one other physician, and; v) written documentation of patient history, and evidence of meeting the above criteria (Smit, 1993; "Dutch soften," 1993).

Despite the protective guidelines, there is considerable controversy regarding their application. The actual number of cases reported to the Attorney General is considerably fewer than the estimated cases. Opponents of euthanasia argue that many physicians do not observe the guidelines, and most falsify the cause of death on patient's death certificates for fear of being prosecuted (Bostrom, 1989; Fenigsen, 1990; Gomez, 1991; van der Sluis, 1989). In 1990, doctors reported 440 cases of voluntary euthanasia. In 1992, the number of reported cases rose to 1,318; an increase that experts attribute to a climate of more open discussion and greater consensus regarding the rules of conduct for euthanasia (Simons, 1993).

The journal, *Issues in Law and Medicine*, has published a number of Dutch pro-life authors who are highly critical of euthanasia. In a seminal article regarding Dutch physicians' attitudes toward euthanasia, van der Sluis (1989), alleges that doctors are developing the mentality that the killing of a sick person is the best service that could be offered. Van der Sluis (1989) cites several accounts, of which he claims direct knowledge, of gross abuses where doctors performed involuntary euthanasia on patients who had significant potential for continued life. Unfortunately, van der Sluis does not mention the ethical obligation he had in reporting his colleagues for their inappropriate actions. Nevertheless, his article does illustrate the magnitude of the emotional and philosophical conflict regarding the practice of euthanasia.

In the Netherlands, prior to 1991, there was considerable speculation regarding the number of acts of euthanasia being performed, with estimates ranging from 5000 to 20,000 cases per year (van der Maas et al., 1991). In 1991, the Dutch Attorney General, Professor J. Remmelink, released the comprehensive findings of the first nation-wide study on euthanasia and end-of-life medical decisions. The Remmelink Commission concluded that 1.8% (2,300) of all deaths are the result of voluntary euthanasia. Physician-assisted suicide accounted for 0.3% (386) of all deaths. A further 0.8% (1030) of all deaths were attributed to "life-terminating acts without explicit and persistent request"--for example, palliative-type measures that shorten life (van der Maas et al., 1991, p. 670).

Proponents of euthanasia applauded the Remmelink Report for what was interpreted as the first reliable evidence demonstrating that Dutch physicians are careful and responsible in carrying out euthanasia. Opponents, however, felt that the Report was far from reassuring. For example, Dutch cardiologist Richard Fenigsen (1991), argues that, included within the Report's data, there are an additional 23,006 euthanasia cases. To make his argument, Fenigsen employs a normative definition of euthanasia that includes passive euthanasia, palliative measures, and any other decision made by a physician that might hasten death (Fenigsen, 1991). It seems that Fenigsen's intent is not to demonstrate that there is little moral or ethical difference between active and passive euthanasia, assisted suicide, and treatment decisions that may shorten life; rather, Fenigsen wishes to create a sensationalistic statistic that suggests up to 56.5% of all non-sudden deaths may be the product of physician decision making (Fenigsen, 1991). Critics such as Dr. Fenigsen are in the minority; only 11% of Dutch physicians say they would refuse to practice euthanasia (Simons, 1993).

Summary

From these differing international perspectives, one may draw the conclusion that there is no consensus on the issue of euthanasia and the right to die. If developments in Canada, the U.S.A., and the Netherlands are any indication, it appears that euthanasia is increasingly becoming an option for some individuals. This interest is being manifested through organized lobby groups, individual legislators, and individuals who challenge legal prohibitions. The consequence is mounting pressure on the political system to initiate more progressive laws. The right to die may well become the moral issue of the 1990's.

Euthanasia and Public Opinion

Public attitudes concerning the issue of euthanasia have changed considerably in recent decades. In 1968, 45% of Canadians supported legalized mercy killing. In 1992, 77% of Canadians favoured physicians performing voluntary euthanasia on terminally ill patients (Bozinoff & Turcotte, 1992). In the United States, polls indicate that about 65% favour voluntary euthanasia for incurable patients (Gallup 1991). It is uncertain, however, if public opinion polls on euthanasia give an accurate measure of opinion on the issue, or if they actually reflect a fear of losing control of oneself and surrendering to excessive and invasive treatments when one becomes incompetent. Additionally, it is possible that public opinion may be tempered by concerns for increases in health care services that often prolong life, but do not necessarily contribute to a better quality of life.

Euthanasia and the Economy

As medical costs skyrocket and governments come under increasing pressure to control deficit spending, the implications for euthanasia on the economy become even more apparent. Socioeconomic factors play a critical role in health and death, and in some cases age alone is a criterion for determining who receives certain health care treatments (Tillock, 1991). In Britain, some surgeons refuse to operate on smokers if there is evidence that their habit would prevent a successful outcome (Looch, 1993). Many governments are experiencing pressure to consider health care rationing in an effort to control spending (British Columbia Royal Commission 1991; Callahan, 1987; Wigod, 1992).

In some traditional societies, the death-hastening behaviour of persons no longer able to contribute is considered normative (Freuchen, 1961; Glascock, 1990). Sociologist Harriet Tillock suggests that American society is moving in a similar direction: "Once an individual's life is no longer of economic value to the society and may become an economic liability, we may emulate primitive societies and establish our own death-hastening pattern by refusing economic and other support to dependent elders" (Tillock 1991, p. 10).

Tillock's suggestion that economics may become influential in decisions to support euthanasia can be generalized to the AIDS epidemic and the rapid escalation of health care costs. It is estimated that the first 10,000 AIDS cases in the U.S.A. resulted in over $1.4 billion in expenditures (Hardy et al., 1986). Such expense makes it easy to marry respect for euthanasia of the AIDS patient who requests it, with the need for greater cost containment. Former U.S. Surgeon General, C. Everett Koop, argues that in the absence of clear morals and ethics, euthanasia may be determined more by money than by ecological concerns (Koop, 1976).

AIDS and Suicide

The relationship between medical illness and suicide has generally been focussed on mental disorder or cancer (Lester, 1992), with little scholarly research about AIDS and suicide. In an attempt to identify risk factors for suicide in HIV screening, Rundell et al. (1992) compared 15 HIV positive suicide attempters with 15 HIV positive non-attempters of suicide. The risk factors for suicide attempts in the sample population were: "social isolation, perceived lack of social support, adjustment disorder, personality disorder, alcohol abuse, HIV-related interpersonal or occupational problems, and past history of depression" (p. 27). The authors urged caution in the interpretation of their findings because the study drew its sample from members of the U.S. Air Force, and therefore, may not be generalizable to the population as a whole.

Among persons with AIDS, accounts of suicide have mostly been anecdotal or clinical. In a study of factors that influence suicidal intent, Schneider et al. (1991) compared suicidal ideation in 778 bisexual and gay HIV negative men with 212 HIV positive men. They concluded that "among HIV-positive [suicide] ideators, AIDS-related death and illness events predicted suicidal intent, but not current distress symptoms. Some suicidal ideation in response to AIDS-related events may be an effort to cope rather than a manifestation of psychological distress" (Schneider et al., 1991, p. 776). That is, among the general population, suicidal ideation has mainly been associated with depression and hopelessness (See Schotte & Clum, 1982), whereas among HIV-positive men, "mood disturbance, loneliness, lack of perceived control over AIDS risk, and AIDS-related life events ... were associated with reporting suicidal ideation" (Schneider et al., 1991, p. 784).

Schneider et al. (1991, p. 785) theorized that, "in view of the severe, uncontrollable, future threat posed by AIDS, suicidal thoughts may serve the function of cognitive mastery (e.g., Taylor, 1983)." That is, for asymptomatic persons with HIV, consideration of suicide may be helpful for the individual to continue to manage with a "greater sense of control in the face of a severe future threat" (Schneider et al., 1991). The authors illustrate such coping with the following response of a suicide ideator:

> My suicidal thoughts were centered around what I would do if I developed AIDS. Suicide would be an option. A close friend of 32 years (he is now 35) is dying of KS [kaposi's sarcoma]. I try to imagine what I would do in his circumstances. This leads me to suicidal thoughts ... I guess I would do it if there was no other option and I was in a lot of pain.... I think that thinking about suicide alternatives is a way for me to cope, or deal with the what I would do question, if I were to develop AIDS (Schneider et al., 1991, p. 785).

The researchers reported that suicidal ideation as an adaptive or coping function has been "relatively unexplored in the research literature" and "demands further investigation" (Schneider et al., 1991, p. 785).

Copeland (1993) studied suicide in persons in Dade County, Florida, who were diagnosed with HIV/AIDS or who thought that they had the disorder. His study consisted of 25 case vignettes of completed suicides from 1985-1989. It appeared, in retrospect, that suicidal tendencies were observed in all of the cases. A range of methods were used, although it appeared that they used whatever was close at hand (see Table 1). Since the diagnosis of AIDS and the fear of an AIDS diagnosis were variables in the sample, the results are not generalizable to the AIDS population as a whole.

Table 1:

Suicide Methods Used Among PWA'S, or Persons Who Thought They had AIDS: Dade County 1985-1989 (Adapted from Copeland, 1993).

CO poisoning	2
Drowning	1
Drugs	5
Gun	8
Hanging	3
Jumping	3
Slashing	3
Total	25

Marzuk et al. (1988) conducted one of the few studies to attempt to measure suicide risk and AIDS. In New York City men, aged 20-59 years, they found the relative risk of suicide was 36 times higher for men with AIDS than for those without an AIDS diagnosis. Marzuk et al. (1988) estimated a 1985 suicide rate of 19 per 100,000 per year for men aged 20 to 59 without AIDS, and 681 per 100,000 for similarly aged men with AIDS.

Kizer et al. (1988) compared completed suicides in AIDS patients with the number of AIDS cases registered in

California, and estimated an annual suicide rate of 463 per 100,000. Thomason et al. (1988) conducted a study of 650 U.S. Air Force personnel who were HIV positive and estimated a shocking suicide attempt rate of 4,535 per 100,000.

Marzuk et al.'s (1988) study of 12 PWA suicides in New York City, and Kizer's study of 12 PWA suicides in California, drew from 1985 and 1986 data, respectively. Cote et al. (1992) noted that since these early reports, therapeutic advances that delay the progression of the disease, and possible reduction in social stigma against PWA's had occurred, potentially contributing to a reduced suicide rate among PWA's. Cote et al. (1992) used "multiple-cause death certificate data" from the U.S. National Center for Health to identify suicides among PWA's from 1987 though 1989. They concluded that male PWA's have a risk of suicide 7.4 times greater than demographically similar men in the general population.

Although Cote et al. (1992) were able to glean national data rather than regional data, they warned that "the use of multiple-cause death certificate data to determine the number of PWA's who commit suicide engenders biases that may have caused us to underestimate the association of these two causes of death" (p. 2068). The researchers note that it has been well documented that both AIDS and suicide are under-reported on death certificates. Another identified bias that may cause under-estimation of suicide risk among PWA's "is an acknowledged incompleteness of ascertainment of death in AIDS surveillance data" (Cote et al., 1992, p. 2068).

In British Columbia, there has been no formal study of the link between suicide and AIDS. The B.C. Centre for Excellence in HIV/AIDS has tracked the cause of death for all AIDS cases in that province since 1987. Table 2 describes males with HIV/AIDS in British Columbia who are recorded as having committed suicide for the years 1987 through 1992:

Table 2:

Males with HIV/AIDS in British Columbia who are recorded as having committed suicide, by year and age group.

Age-group	1987	1988	1989	1990	1991	1992	Total
30-34	0	0	0	0	1	0	1
35-39	0	0	1	0	0	1	2
40-44	0	0	0	0	1	1	2
45-49	0	0	0	0	1	1	2
Total	0	0	1	0	3	3	7

(Personal correspondence, Robert Hogg, Project Manager, B.C. Centre for Excellence in HIV/AIDS, November, 15, 1993).

Each of the above-mentioned studies suffers from methodological flaws, which in part stem from the difficulties in designing adequate research on suicide. It is a lesser challenge to criticize the research conducted by others, than it is to design and conduct superior studies. Nevertheless, although flawed in method, the accumulating results of several studies indicates a high suicide rate in patients with AIDS.

Establishing the extent of AIDS-related suicide behaviour is difficult. It is likely that the number of AIDS-related deaths due to suicide is under-reported (Marzuk et al., 1988; Cote et al., 1992). This may be attributed to medical examinations where the coroner is unaware of the suicide victim being diagnosed with AIDS. Some physicians may unwittingly register a suicide as an AIDS-related death simply because the suicide was unsuspected or carefully concealed. In other cases, suicides may not be documented at the request of family or friends, or to protect insurance benefits (Slome, 1990)

AIDS and Euthanasia

In an article on the ethics of euthanasia and AIDS, Yarnell and Battin (1988) argue that AIDS is *the* disease that makes the case for euthanasia, since for many AIDS patients it is not a matter of choosing between life or death, but between choosing to die now or to die later. They suggest that taboo ethics, based on rigid moral rules, govern current laws and regulations with respect to euthanasia.

The "taboo" view is an ethical system that asserts absolute moral rules that cannot be broken under any circumstances. Unlike "deontological" systems "that recognize moral rules for which rational argument can be offered, taboo systems typically promulgate absolute rules for which little rational basis is available" (Yarnell & Battin, 1988, p. 598).

The alternative, consequential or situational ethics[6] perspective (See Fletcher, 1979) proposed by Yarnell and Battin (1988), judges what is right or wrong from the consequences of a particular action. Within such a model is an acceptance for euthanasia where physicians can simultaneously be merciful and respect a patient's right to self determination.

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[6] Fletcher distinguishes between rule ethics and situational ethics. Rule ethics determines decision making from an *a priori* imperative, according to a predetermined precept or categorical imperative. The conscience is irrelevant as the rule dictates the response. For Fletcher, rule ethics is coercive, categorical, and not discriminating. It is a deductive, dogmatic, and ideological way of determining what is right. On the other hand, situation ethics assumes an *a posteriori* approach. It is an ethical strategy consistent with scientific method. It is open to judgment and seeks, for those involved in the situation, the greatest good for the greatest number. Depending on changes in situational variables, what is right in one situation, can be wrong in another (Fletcher, 1979).

Euthanasia and assisted suicide in patients with AIDS is occurring with an unknown frequency. AIDS patients often seek assistance from compassionate doctors who risk their careers and legal prosecution by facilitating their deaths (Slome, 1990). Persons with AIDS sometimes request medications from several physicians in an effort to accumulate enough pills to successfully commit suicide. To avoid legal liability, physicians who grant a patient's request for lethal medications may prescribe sedatives or narcotics with specific, carefully worded instructions about lethal dosage, and the dangers of combining the medication with alcohol (Slome, 1990).

Anecdotal evidence suggests that euthanasia and assisted suicide are practices that are increasingly being performed, in particular among AIDS patients (Almost Fearless, 1991; Aronson, 1987; Charbonneau, 1992; Freeman, 1992; Frierson & Lippmann, 1988; Gomez, 1991; Orentlicher, 1989; Reichel & Dyck, 1989; Slome, 1990; Taylor, 1990; de Wachter, 1991).

Research on Physicians and Nurses, and Euthanasia

Although there is a paucity of data regarding health care workers and euthanasia, several studies have explored physician and nurse involvement in euthanasia and assisted suicide.

The first study was conducted by Kuhse and Singer (1988). In 1987, among 2000 doctors from Victoria, Australia, 869 responded to a questionnaire. Of those respondents, 107 (12.3%) stated that they had "taken active steps to bring about the death of a patient" who had asked them to do so (p. 624). A proportion of 62% believed that "it is sometimes right for a doctor to take active steps to bring about the death of a patient who has requested the doctor to do this" (Kuhse & Singer, 1988, p. 624).

In 1991, Kuhse and Singer conducted a second study, this time with Victorian nurses (Kuhse & Singer, 1992). The researchers obtained a 49% response rate from 1,942 nurses. In the course of their work, 333 of the respondents had been asked by a patient to take active measures in hastening his or her death. Five percent said that they had complied with such wishes without consulting with a physician. Twenty-five percent of the respondents said that they had on at least one occasion been asked by a doctor to take measures that would "directly and actively" end the life of a patient who had requested it (p. 22). The exact figure is not given, but the researchers state "almost all of the 25% who had been asked by a doctor to engage in active steps to end a patient's life had done so" (p. 22). Interestingly, the studies showed that, overall, 68% of the Australian nurses indicated a willingness to be involved in voluntary euthanasia, whereas only 40% of physicians were willing. This may be attributable to nurses experiencing a greater degree of identification with their patients.

In a descriptive study of the attitudes and practices of California hospice nurses regarding euthanasia, Hammond (1991), surveyed 42 hospice nurses. The study found that the majority of nurses surveyed believed that doctors should be legally bound to respect the written wishes of patient's who wish to be allowed to die, and have no hope for recovery. Additionally, 81% of the sample was "extremely uncomfortable" with involuntary active euthanasia, 73% were "extremely comfortable" with voluntary passive euthanasia. The nurses were also asked if they had had to cope with the issue of euthanasia in their personal lives. "Twenty-two nurses or almost 54% stated that they had in fact coped with such issues" (Hammond, 1991, p. 56). The nurses were also "asked if they had ever actively assisted in voluntary euthanasia of another person (family of otherwise), [and] an impressive 25% (10 nurses) indicated that they had" (Hammond, 1991, p. 56).

A fourth study, *Euthanasia and Other Medical Decisions at the End of Life*, was conducted by the Remmelink Commission, appointed by the Dutch Ministers of Health and Justice. It was estimated that, in The Netherlands, between

10 and 20 percent of all deaths among terminal AIDS patients involve euthanasia or assisted suicide (de Wachter, 1991; van der Maas et al., 1992). The Commission also found "that 1.8% of deaths in the Netherlands are the result of euthanasia with some form of physician involvement" (van der Maas et al., 1991, p. 671). The study is a comprehensive report that involved three different studies: physician interviews, a death certificate study, and a prospective study. The favoured drugs used for euthanasia and assisted suicide are a combination of sedatives and curare-like agents (van der Maas et al., 1992).

A fifth study is Slome's (1990) investigation of the attitudes among San Francisco physicians toward physician-assisted suicide of AIDS patients. Of the total sample of 153 physician members of the San Francisco County Community Consortium ($\underline{n} = 68$), and the California Medical Association ($\underline{n} = 85$), 23 percent were "likely to grant the patient's initial request for a lethal dose of drugs to aid in a planned suicide" (Slome, 1990, p. 52). A belief in humane medical ethics was the strongest predictor of the physician's decision to assist a suicide (Slome, 1990). Identification with the patient also had significant predictive value ($\underline{r} = 0.358$, $\underline{p} < 0.001$).

The sixth study to be presented is the two-part *Alberta Euthanasia Survey*, which was conducted in 1991. Part one of the survey explored Alberta physicians' opinions "about the morality and legalization of active euthanasia" (Kinsella & Verhoef, 1993, p. 1921). Among the 2002 physicians surveyed, 1391 responded. Fourty-four per cent believed it is right to practice active euthanasia in some situations, and 28% stated that they would practice active euthanasia if it were legal. Over half (51%) believed that the law should be changed to permit patients to request active euthanasia. Nineteen percent of the physicians reported that they had received requests for euthanasia. The authors considered it "imprudent" to enquire into the physicians' actual behaviour and experience with respect to euthanasia, "because euthanasia is not legal in Canada" (Kinsella & Verhoef, 1993, p. 1923).

Part two of the *Alberta Euthanasia Survey* involved "physicians' opinions about the acceptance of active euthanasia as a medical act and the reporting of such practice" (Verhoef & Kinsella, 1993, p. 1929). The data, drawn from part one of the study, showed that 70% of the respondents felt that euthanasia should be "medicalized," and performed by physicians, should it become legal. Although active euthanasia is illegal, 33% of the physicians stated that they "would not report a colleague participating in the act to anyone, and 40% and 60% stated that they would not report a colleague to medical or legal authorities respectively" (Verhoef & Kinsella, 1993, p. 1929). The researchers stated that this finding highlighted a "serious problem in ethical judgment," demonstrating the need for revised health education policies that address the practice of ethical medicine (p. 1932).

In conclusion, the researchers considered the *Alberta Survey* data to reveal confusion and contradiction in the respondents' analyses of the moral, legal and medical issues pertaining to active euthanasia. They felt that this lack of consensus among the sample contrasts with other reports of massive public support for euthanasia (Bozinoff & MacIntosh, 1991), and suggested that lay press reports do not adequately cover the complexity of the involved issues.

A seventh study surveyed physicians in Rhode Island on their attitudes and practices regarding life sustaining treatment and euthanasia (Fried et al., 1993). Three hundred ninety-two physicians were asked: "1) whether or not they would comply with a specific patient request, 2) the justification they used in making their decision, and 3) whether they had been approached with such a request in their clinical practices" (Fried et al., 1993, p. 722).

The questionnaire asked the respondents if they would comply with any of five scenarios in relation to an aged patient who is competent, not depressed, well-known to the respondent, and with terminal metastic lung cancer. The questionnaire asked if the physician would comply with any of the following requests: 1) withholding ventilator support, 2) narcotic dosage to treat pain that may also compromise respiration, 3) cessation of ventilator support, 4) prescribing a lethal dose of sleeping pills, and 5) administering a lethal injection.

Of the 256 respondents, 97.7% agreed to withhold ventilator support, 86.3% would provide pain management despite the risks of respiratory compromise, 8.6% would issue a lethal prescription, and 1.2% agreed to give the lethal injection.

In all five case scenarios, the researchers reported that "the great majority of physicians who did as the patient requested chose the statement 'the patient's wishes about life-and-death issues should usually be complied with' as most important" (Fried et al., 1993, p. 724). Table 3 displays the primary justifications given by the physicians who chose not to comply with the request of the patient. Although many of the respondents who refused to comply with the patient's wishes, also listed "the patient's wishes about life-and-death issues should usually be complied with" as their main justification, other factors influenced their decisions. Many believed that the act would not be ethically acceptable, or identified conflicts with their moral beliefs. In scenario three--turning off the respirator--25.6% of the physicians were of the erroneous belief that such an act would not be supported by the courts.

Table 3:

Primary Justifications Chosen by Those Who Did Not Comply With Patients' Wishes [a]

Scenario [b]	Justification	% of Physicians
1 (n = 6)	Patients' wishes should usually be complied with	50.0
2 (n = 29)	Patients' wishes should usually be complied with	29.6
	Undermines my role as a physician	18.5
	Not ethically acceptable to give potentially lethal doses of medicine with intent to relieve pain	14.8
3 (n = 87)	Patients' wishes should usually be complied with	29.3
	Would not be supported by the courts	25.6
4 (n = 223)	Not ethically acceptable to give prescriptions with intent to help cause patients' death	29.3
	Patients' wishes should usually be complied with	16.3
	Would be assisting in suicide	15.3
5 (n = 244)	Not ethically acceptable to give lethal doses of medicine with intent to help cause patients' death	25.4
	Goes against my moral belief	13.8
	Patients' wishes should usually be complied with	12.9

[a] Justifications were listed in rank order from the most frequently cited until 50% accounting of the responses.

[b] 1) not withholding intubation; 2) not giving potentially lethal doses of pain medication; 3) not turning off respirator; 4) not giving lethal prescription of sleeping pills; 5) not giving lethal injection (Fried et al., 1993, p. 724).

Table 4 is a summary of the respondent's reporting of their clinical experiences. It is indicated that 1.1% of the respondents had "admittedly administered a lethal injection at a patient's request" (Fried et al., 1993, p. 726). Additionally, the authors note that 28% of the sample stated "they would comply with requests for lethal injections more frequently if such actions were legal, and 35% believed such actions should be made legal (Fried et al., 1993, p. 726).

Table 4:

Physician Reports of Clinical Practice [a]

Scenario	%	(No.)
Requested by a patient in respondent's practice		
1. Withhold intubation	91.8	(235/256)
2. Give potentially lethal doses of pain medication	49.2	(121/246)
3. Turn off respirator	65.1	(164/252)
4. Give prescription for lethal dose of sleeping pills	18.9	(47/249)
5. Administer lethal injection	13.2	(30/226)
Complied with request at least once		
1. Withhold intubation	98.3	(231/235)
2. Give potentially lethal doses of pain medication	95.5	(106/111)
3. Turn off respirator	93.6	(147/157)
4. Give prescription for lethal dose of sleeping pills	13.3	(6/45)
5. Administer lethal injection	10.3	(3/29)

[a] Percentage based on number of responses. (Fried et al., 1993, p. 726).

In 1993, the initial findings of an eighth study were presented at the annual meeting of the Canadian Medical Association (Sullivan, 1993a). The results are based on the initial data obtained from 30.8% of a sample of 2990 physicians. The preliminary findings show the following opinions:

> 35% favour *Criminal Code* modification to permit euthanasia in certain cases.
>
> 32% support decriminalization of euthanasia, provided there are legislated guidelines.
>
> 28% support decriminalization of physician-assisted suicide, provided there are legislated guidelines.
>
> 27.2% support *Criminal Code* amendment to permit physician assisted suicide in certain circumstances (Sullivan, 1993a).

Moreover, 60.5% of the survey respondents indicated support for one or more of the four proposed policy positions (Sullivan, 1993a). The CMA hopes to produce a policy on euthanasia and assisted suicide in time for its summer meeting in 1994.

Conclusion

The Canadian AIDS Society suggests that, with the compassionate help of a merciful physician, incurably ill AIDS patients should be permitted to "choose death as their next form of treatment" (Canadian AIDS Society, 1991, p. 2). The Society recognizes that in some cases death can be "the ultimate form of healing when those whose bodies are exhausted and racked with pain are able to achieve peace and closure in their lives" (Canadian AIDS Society, 1991, p. 2).

Given the significance of the euthanasia and assisted-suicide issue, the volume of discussion it receives in the media, and the number of physicians publishing opinions on these practices in their professional journals, it would appear to be a likely topic of inquiry for universities and other interest groups. Yet, the research has not been done. Certainly, this is not a topic that easily lends itself to empirical research, but the lack of knowledge is bewildering. In his book, *Regulating Death*, Gomez (1991) quotes Eugene Sutorius, a former Dutch prosecutor:

> Why has no one done this, I do not truly know. But maybe because it is an unhappy subject, or maybe we feel it is too private a problem. How many use euthanasia every year, no one can truly say. And if you ask if this does not make me, as a lawyer and once a prosecutor, uncomfortable, then of course it does, because we should know something more about what it is that people want, and how many times they want it (p. 51).

The AIDS epidemic is confronting the euthanasia debate in an unprecedented fashion. That euthanasia is almost never prosecuted in Canada suggests that the practice is rare. Nevertheless, the lay press, medical, legal, and psychological literature indicate that euthanasia occurs among persons with AIDS, with and without the assistance of physicians. Unknown, however, are the attitudes and perspectives of AIDS patients regarding euthanasia and assisted suicide, as well as the experiences of individuals who provide aid-in-dying to PWA's. With few exceptions (See Fried et al., 1993; Kuhse & Singer, 1988, and van der Maas et al., 1992), there appears to be a serious shortage of data regarding the perspectives of those who perform euthanasia or offer assistance in dying. In the *Alberta Euthanasia Survey*, by avoiding the question of physicians' behaviour and experience with respect to euthanasia, the researchers failed to gain insight into one of the most difficult aspects of the practice of medicine.

Additionally, there is a paucity of research regarding the perceptions of euthanasia by those suffering with a terminal illness. Although there are numerous accounts published by the lay press concerning the perspectives of individuals with various terminal or disabling illnesses (Gibbs, 1990; Kaye, 1993; Rodriguez, 1993; Van Biema, 1993; Wicker, 1989), and suicidologists have compiled statistics of suicides and illness (Lester, 1992; Bolund, 1985; Marzuk et al., 1988), there is a paucity of academic literature.

An investigation of the attitudes and perspectives of those with HIV/AIDS, and persons who have been involved in assisting the deaths of persons with AIDS, is necessary to identify variables in decision making and planning with respect to end-of-life decisions. Conclusions drawn from this investigation will have broad implications for the existing body of literature on euthanasia. By introducing a candid discussion of the actual practice of euthanasia in the context of AIDS, it will potentially contribute to the ongoing re-evaluation of law and health care policy.

CHAPTER II

METHOD

Participants and Procedures

Wright and Bennett (1992) suggest that "the offender's perspective is perhaps the most neglected area of criminological inquiry," yet it "is of crucial importance to the formulation of both theory and policy" (p. 138). Walker (Quoted in Kempf, 1992, p. 138) argues that theorists of criminology are "wasting their time" if they fail to consider the "states of mind" that influence criminal offences.

A considerable amount of criminal justice policy is derived from assumptions about the perceptions of criminals. An understanding of the offender's perspective, however, should also form the basis of criminal justice policy. Wright and Bennett (1992) state that "this perspective can be thought of as an important intervening variable that can determine, independently, the effectiveness of a crime prevention strategy" (p. 138). For example, the policy of deterrence assumes that offenders are rational, evaluating the costs and benefits of their deviant conduct. The primary objective of deterrence is to increase the perceived costs of crime, thereby influencing the offender towards non-offending behaviour. Little empirical attention has been devoted to the "way in which criminals perceive and make decisions in relation to the threat of apprehension and official penalties" (Wright & Bennett, 1992, p. 139). The following direct, field-based approach was designed to explore the perspectives of the offender, and potential offender, with respect to euthanasia and assisted suicide in the HIV/AIDS context.

Sampling from small populations involved in criminal or private behaviour is always a difficult task. For this reason, the snowball sample technique was employed. The "snowball" sampling strategy involves locating prospective participants who can potentially identify and refer additional participants (Babbie, 1986; Wright & Bennett, 1992). Although a snowball sample is nonprobabilistic, or not randomly selected, this does not mean that it is unrepresentative. The representativeness of a snowball sample population can be checked by assessing whether each relevant role is included, and by the level of knowledge held by participants within those roles (Wright & Bennett, 1992). Glassner and Carpenter (Cited in Kempf, 1992, p. 144) suggest that researchers may use informants to:

> ... reconstruct particular crime events. For example, one could take the end product of a burglary--an item that has been fenced--and use the pool of subjects to trace the item in other directions. In so doing, one is able to determine gaps in one's subject pool; for instance, if one is unable to ascertain through interviews or observations, who originally initiated the

> burglary, one can then conduct additional queries among informants to discover where the gap exists in the fieldworker's information chain, and which additional subjects need to be located.

For the purposes of this study, a self-selected sample of at least 30 participants was desired. Two participant groups were identified: individuals with HIV or AIDS, and individuals who had some involvement in the euthanasia or assisted suicide of persons with HIV or AIDS.

One of the most difficult challenges in using a snowball sample to recruit subjects is locating the initial contacts (Kempf, 1992). To ensure that there was awareness of the research project within the AIDS population, short articles were published in the *AIDS Vancouver Volunteer Voice*, and the *Vancouver PWA Newsletter* (See Appendix B). Additionally, there are a number of organizations dedicated to AIDS care and AIDS advocacy in Vancouver. A brief overview of the study and an information sheet (Appendix C) was presented to members in attendance at regular meetings of the following organizations:

--July 30, 1992, Adult Guardianship Forum for the HIV/AIDS Community.

--October 29, 1992, St. Paul's Hospital AIDS care team. St. Paul's Hospital provides primary and palliative care to the majority of AIDS patients in British Columbia.

--November 18, 1992, The AIDS Information Exchange. A monthly, multi-agency information meeting.

--November 26, 1992, Board of Directors of AIDS Vancouver.

To inform medical practitioners about the study, and to offer them an opportunity to participate, an information bulletin was published in the "Pulsimeter" section of the *BC Medical Journal* (Appendix D). The bulletin yielded no response.

Appendix B, an article published to solicit participants, states "the research is guided by the principles of respect for the individual, the right to privacy, and respect for the autonomy of individuals and their individual choices." Given the criminological nature of this study, the above value statement was designed to encourage the participation of pro-euthanasia respondents. It is acknowledged that the statement may have had the effect of discouraging the participation of anti-euthanasia respondents.

Due to the sensitive nature of the data sought, anonymity was guaranteed to all participants; there was no requirement for participants to give personal identifying information to the researcher. Participants were given an "informed consent form" (Appendix E) for their review. To further protect respondent confidentiality, participants were advised that verbal consent was sufficient; written consent would not be required. This option protects both the participants and the researcher by limiting identifying information. Each participant chose a pseudonym for the purposes of data coding. Because the respondents were asked to disclose their views, intentions, and experiences regarding highly controversial legal and ethical issues, the protection of the participants' identities was considered essential in order to encourage honest reporting as well as to safeguard respondents from criminal prosecution.

Respondents were asked to contact the researcher either by telephone or mail. Most PWA respondents were willing to participate without requiring much background information. On the other hand, those who had been involved in assisting the deaths of PWA's, were considerably more cautious. Many of the participants indicated they had discussed the study either with somebody who had already participated, or with an individual who had attended a meeting where an overview of the research had been presented.

Instrument

Two semi-structured questionnaires were developed for the two participant groups in this study (Appendix F). The questionnaire items were developed from the background provided by existing literature on related topics.

The questionnaires were administered in an open-ended semi-structured interview. This interview format is casual, and conversational; it has the potential to access the "broad underlying feelings or motivations" (Kidder & Judd, 1986, p. 276) of the respondents, allowing them to speak freely, without the imposition of artificial concepts and categories (Wright & Bennett, 1992).

Two categories of individuals were interviewed: persons with HIV or AIDS diagnoses, and individuals who had been involved with the euthanasia of PWA's. They were interviewed regarding their attitudes, perspectives, and experiences regarding euthanasia and assisted suicide. The respondents came from the Greater Vancouver Regional District, Fraser Valley, and Vancouver Island areas. The interviews took place between October, 1992, and November, 1993.

A) **PWA participant group**

The questionnaire for persons with HIV/AIDS included the following sections:

Demographics. This first section of the questionnaire collects demographic information. These demographic items were intended to assess characteristics which may be significant regarding participants' attitudes toward AIDS-related euthanasia. These include: age, sex, level of education, occupation, religious preference, length of time with HIV/AIDS diagnosis, and history of opportunistic infections.

Attitudes toward euthanasia and assisted suicide. Participants were asked an open-ended question regarding their attitudes toward euthanasia and assisted suicide. The open-ended nature of this question allowed for further probing and clarification of participant responses. For example, euthanasia has been said to be a response to a number of fears that are linked to a loss of control, pain, or dependency. Respondents were asked if these were fears that were applicable to their situations. A question regarding changes in views on euthanasia since being diagnosed with HIV/AIDS was asked. Participants were asked if they had any experiences that involved euthanasia or assisted suicide. They were also asked why they chose to participate in the study.

Social aspects/support and coping. The impact of AIDS on the participant's personal life was the focus of this section. PWA'S live in constant uncertainty as to how the virus will next affect them, and whether they will be able to cope. Because of this uncertainty, the respondents were asked about their perceived levels of support, both emotional and financial.

"Quality of life" is a frequently mentioned slogan in the euthanasia debate. Questions were asked about the PWA's perceptions of present and future quality of life, as well as perceived levels of mental distress.

There is an emerging discourse in the literature regarding inclusion and exclusion in the gay population, depending on one's diagnosis with HIV, and whether one is "out"[7] with HIV. Participants were asked if they had many friends whom they knew to have HIV, and if HIV was a significant factor in their social relationships and activities.

AIDS has taken the lives of many men between the ages of 25 and 40; it is common for gay men to report the loss of several friends to AIDS. In suicidology literature, a sense of loss for survivors is frequently cited. For this reason, participants were asked how many friends they had lost to AIDS, and whether this included any long-term partners. A final question addressed whether the knowledge that one can kill oneself facilitates coping.

Stigmatization. The focus of this section is on stigmatization related to AIDS and gay sexuality.

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[7] "Out" is a slang term derived from "coming out of the closet." To be "out" is to be public with one's gay sexuality. Hence, to be "out" with HIV, is to be public about having the virus.

Participants were asked about how they are treated in social situations as a result of their HIV diagnosis, and their sexuality. They were also asked if any stigmatization was experienced in their efforts to access medical treatment.

Legal/Ethical. In this section, there were three areas of focus. The first addressed the participant's views on the law as they pertain to euthanasia and assisted suicide. The second area related to preparations that participants might have made in anticipation of their deaths: wills, advance declarations, funeral arrangements, stockpiling of medications, etc. The third area dealt with ethical concerns. Where respondents had indicated that an assisted death was planned, they were asked about concerns they might have in carrying out the plan. They were also asked who might be involved in helping them to die, and what precautions, if any, were being considered in order to minimize legal risks to others who might be involved.

B) **Euthanasia participant group**

This category of participants included individuals who had assisted the death of a PWA, been present at an assisted death, or had reliable information regarding an assisted PWA death. The questionnaire for the euthanasia participant group includes the following sections:

Demographics. This section of the questionnaire collects the same demographic information as that for the PWA participant group. Participants were also asked to provide information regarding the age, sex, and year of death of the PWA.

Perspectives regarding euthanasia and assisted-suicide. This section addressed the same questions as those for the PWA participant group. Participants were encouraged to contextualize their responses to their specific euthanasia experience(s).

Relationship to the PWA. Identification with PWA's may be a significant factor in the decision to assist the death of a PWA (Slome et al., 1992). This section addressed the participant's relationship to the PWA and reasons for providing aid-in-dying.

Knowledge of euthanasia methods. Respondents were asked whether they have any medical training, and what knowledge they have about methods of facilitating death. Details regarding the euthanasia plan and method used were also requested.

The assisted death. This section focuses on the euthanasia or assisted death. Respondents were asked to provide as much detail as possible of the event. Questions were asked regarding the methods used and how the death occurred. Participants were asked to share information about events that took place after the death. They were asked what efforts were made to remove evidence that the death was assisted, as well as any concerns they had regarding autopsy results and the potential for an inquest or criminal charges. Participants were encouraged to give as candid an account as possible, within their personal comfort levels, and without disclosure of information that would reveal the identity of the deceased.

The final set of questions involved asking respondents if they had revealed their involvement to anybody else, and what kinds of concerns they had about this sort of disclosure. Participants were also asked why they chose to participate in this study.

Data collection

Each respondent was interviewed face-to-face. The location of the interview was selected by the participant, in order to ensure that it would take place in an environment where he or she would feel comfortable. Interviews took place in a variety of settings--private residences, cafes, restaurants, meeting rooms, public parks and offices. Respondents were asked for permission to record the interviews on audio-cassette--only two refused. The audio recordings were destroyed after being reviewed to verify notes taken during the interviews. All identifying information linked to the data collection was destroyed. The semi-structured interview format allowed for considerable probing and clarification of participant responses. As a result, there was considerable variance in the time it took to complete each interview, ranging from 45 minutes to five hours.

CHAPTER III

FINDINGS

Participant Honesty and Data Validity

The impression that the respondents answered the interview questions honestly is supported by the circumstances that the participants were anonymous, self-selected, and interviewed by a researcher with several years of investigative interviewing experience in social work. Moreover, the participants had little to gain in light of the potential risks. Given the voluntary nature of the study, it is pointless that participants would lie: they could decline to participate.

The approach of investigating the participant's perspective through interviewing allows for "first order data" collection (Frazier, cited in Kempf, 1992, p. 147), and can be expected to have high data validity, in that it reflects "what is going on in the offender's mind with considerable accuracy" (Wright & Bennett, 1992, p. 147). The veracity of participants' statements was checked through probing for further detail, and questioning any inconsistent responses. This did not present a problem with data collection.

In this study, there was consistency in the reactions of the individual participants when they indicated interest in the project. In general, the respondents expressed caution about participating in the study, and requested background information about the study and the researcher, before they agreed to participate.

Part I
PWA participant group

Response rate and demographics

The sample consisted of 16 male, and two female, participants (N = 18; mean age = 38.4 years old; SD = 4.8 years). According to the expanded surveillance case definition for AIDS (Centers for Disease Control, 1992), 72% of the participants had AIDS. The remaining 28% of the participants had been diagnosed with HIV. The date of diagnosis for HIV/AIDS ranged from 1983 to 1993. The average participant had been aware of his/her HIV/AIDS diagnosis for 4.5 years. Three of the respondents had received AIDS diagnoses within the previous eight months, and had formerly been unaware of having HIV. Whereas a healthy person has a CD4+ T-lymphocyte[8] count of about 1000 (Rabnett, 1992), the mean for the sample was 237. One

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[8] The CD4+ T-lymphocyte is significant in the categorization of HIV-related clinical conditions. The CD4+ T-lymphocyte is the primary target for the Human Immunodeficiency Virus.

participant had not received a CD4+ measure; another refused to disclose his CD4+ measure, claiming it reinforced "negativity."

At the time of their participation in the study, only three (16.7%) of the participants were employed, of whom two were asymptomatic. The remainder of the participants (83.3%) were unemployed, although many were providing volunteer services--usually to AIDS organizations. Many of the participants had previously been employed in the social service or health-care fields.

The respondents were generally well-educated (See Table 6). Four had completed grade 12; seven had some university training, or held diplomas; three had completed undergraduate degrees; two possessed graduate degrees, and two had achieved partial completion of graduate studies.

Among the respondents, 44% held agnostic or atheist views. The remainder held some religious beliefs. Only one participant identified religious belief as an influence on his views regarding euthanasia.

Table 5:

Demographic Characteristics of PWA and Euthanasia Participant Samples

	Total (N = 31)[a]		PWA (n = 18)		Euthanasia (n = 17)	
Variable	n	(%)	n	(%)	n	(%)
Sex						
Male	27	(87)	16	(89)	15	(88)
Female	4	(13)	2	(11)	2	(12)
Religion						
Atheist/ Agnostic	10	(32.2)	8	(44.4)	6	(35.3)
Catholic	5	(16.1)	3	(16.6)	2	(11.8)
Protestant	5	(16.1)	4	(22.2)	1	(5.9)
Other	11	(35.5)	3	(16.6)	8	(47.0)
Employment background						
Health care	6	(19.4)	3	(16.6)	3[b]	(17.6)
Social servs.	9	(29)	4	(22.2)	6	(35.3)
Other	16	(51.6)	11	(61.1)	8[c]	(47.1)

[a] four respondents are represented in both the PWA and euthanasia sample groups.

[b] includes two physicians and one nurse.

[c] includes two members of the clergy, four service industry workers, one teacher, and one writer.

Table 6:

Level of Education of PWA and Euthanasia Sample

	G.V.R.D.[a] pop. 15+ years (n = 1,023,415)		PWA (n = 18)		Euthanasia (n = 17)	
	n	(%)	n	(%)	n	(%)
less than gr. 9	103,425	(10)	0	(0)	0	(0)
gr. 9-13, no cert.	267,055	(26)	0	(0)	0	(0)
gr. 9-13, cert.	121,515	(12)	4	(22.2)	1	(5.9)
trade cert/ diploma	271,490	(27)	4	(22.2)	2	(11.8)
univ, no degree	131,895	(13)	3	(16.6)	2	(11.8)
univ, with degree	128,320	(13)	7[b]	(38.9)	12[c]	(70.6)

[a] Greater Vancouver Regional District, 1986 Canada Census Data (PCensus: Tetrad Computer Applications Ltd.).

[b] Two participants had graduate degrees, two had partial completion of graduate studies.

[c] Four participants had graduate degrees, two had partial completion of graduate studies.

The respondents offered a variety of reasons for their decision to participate in the study:

> To make a contribution to research regarding AIDS.
>
> To contribute to research that might be of value to others who are considering euthanasia.
>
> To clarify one's views and ideas on the subject of euthanasia.
>
> To discover potential information sources that might be useful to themselves.
>
> To openly discuss a taboo issue in a non-threatening environment.
>
> To contribute to research that would "go somewhere."

Attitudes toward euthanasia and assisted suicide

Table 7 shows that 83.3% of the PWA sample said that euthanasia or assisted suicide was a choice that they were considering. Of the sample, 16.7% said an assisted death was not a choice that they would consider for themselves. In general, the participants were of the opinion that end-of-life decisions should be supported, especially where AIDS has reached its final stages:

> Euthanasia has to always be there as a choice ... whether one is going to act on it or not ... it is a dignified option, a very valid one.
>
> At one point in the disease cycle, euthanasia provides, when few other treatment options are available, a very comfortable transition from life.

> Just as we assist people with birth, we should assist them with death.
>
> I have good reasons for assisted suicide. Suicide is no less a valid way to go than by this horrible, disfiguring disease.

Thirty-nine per cent of the respondents reported that euthanasia parallels the abortion issue; what they choose to do with their bodies is a personal choice. Some were of the opinion that euthanasia is not necessarily a medical procedure that requires a doctor's involvement. They felt that they should be able to access a suitable euthanasic, and the decision to use it should be a personal choice that should be respected. Respondents felt that the euthanasia should be performed in a manner that allowed a safe, non-violent, non-disfiguring, quick and painless death.

Table 7:

PWA perception of euthanasia or assisted suicide being a choice for oneself

Euthanasia as an option for self	Total (N = 18)	(%)
Yes	15	(83.3)
No	3	(16.7)

Seventy-eight per cent of the PWA sample expressed concerns about loss of control as their health deteriorates. For them, the decision to plan an assisted death was based on a desire to maintain control of what happens to their bodies. Almost all of the PWA's (83%) had seen or known of other AIDS-related deaths that they described as "horrific," "undignified," "violent," "excruciating," or "unjustified":

> In my experience, many who die of HIV die very violent, brutal, and painful deaths, because that is the nature of HIV.
>
> I just don't think it is right that someone should have to go through the pain and the suffering, day after day, after day, when you know damn well there is no hope they are ever going to recover from it.
>
> Euthanasia is not a way of giving up, it is a way of stating one's final decision. For me, it is an issue of not wanting to lose control of how I relate to the world. It is a response to a desperate situation.

One participant, who had been diagnosed with HIV in 1985, described his search for a friend with whom he had lost contact. In 1988, he learned that his friend had AIDS and had been hospitalized. When the respondent visited, he found his friend in restraints, and dementia had set in. "My God," the respondent stated, "I knew I had to get busy--I didn't want to go through that."

It appears that for many of the PWA sample, euthanasia is a potential solution that allows them to set the terms and conditions on how they would complete their lives. Also, there were perceived advantages for their survivors. For example, some reported that planning an assisted death was a thoughtful process that enabled them to complete old business, clarify issues and relationships, and bring closure to their lives in a way that was comforting. Some PWA's said that they had experienced anger and frustration at the prolonged, lingering deaths of friends with AIDS. They felt that their grieving processes, and the manner of dying for the patient, would have been improved if uncertainty around the moment of death could have been controlled by a form of euthanasia:

> One of the dangers is that one risks becoming very cold emotionally to having to endure the martyrdom that wears people out. Like the encore after the last act--and they become more obnoxious every time they come back. With euthanasia, having it planned and carefully discussed makes it easier. This argument is one of the reasons why I would do what I will do.

The pro-euthanasia PWA's specified a variety of conditions that they felt should be met prior to an assisted death. All reported that depression was an inappropriate reason for euthanasia. It was noted that PWA's experience considerable anxiety and distress after learning of their HIV/AIDS diagnosis, and may express suicidal thoughts. It was felt that such circumstances were transitory, and would likely improve. Many noted that being diagnosed with AIDS had forced serious reflection on living, and in most cases, resulted in a greater appreciation for life. At the same time, however, life was seen as having clear limits.

PWA's have concerns for becoming dependent on others or technology. The participants in the sample placed much value on their independence; their ability to do things for themselves; their ability to make decisions. There were fears about having to rely on the assistance of others for routine daily tasks such as feeding and bathing. Fears related to uncontrolled pain and AIDS-dementia were also expressed:

> For me, the loss of mental faculties is the main criterion.
>
> I don't think there is a lot to be learned by suffering. All those accounts of how people battle death ... so what? They mean something to the non-dying, not to me.
>
> It [euthanasia] is definitely a response to pain and suffering.
>
> Dependency really scares me. I don't find anything attractive about being dependent on someone.
>
> My biggest fear is total disability. I don't want to be dependent on machines.

Four of the respondents in the sample stated that hospitalization was a criterion that would determine their decision as to when they would want an assisted death. They had known friends to enter hospital, and not come out. For these respondents, hospitalization symbolized the end of quality of life.

Three of the participants did not see euthanasia as a choice for themselves. The first based his position on religious grounds that oppose an actively facilitated death. He had, however, prepared a living will and health care directive specifying that no heroic measures should be taken, and no artificial life-supports should be employed. This participant also argued that euthanasia should be available, in certain cases, for those who want it.

The second was reconsidering his formerly pro-choice values with respect to euthanasia. He had recently witnessed some unexplained recoveries of friends with AIDS who were on their death-beds. He interpreted this as evidence that life at all stages has hope and potential. Nevertheless, this participant did state he could see himself facilitating the "self-deliverance" of another person, provided that "there was unbearable pain," and the request was "adamant."

The third anti-euthanasia participant felt strongly that there is always value in living, no matter what the degree of suffering: "... if people euthanize, then they have lost something in life, lost something natural. Even if it was a painful time they missed out on, it was there for a reason." This participant, like the previous two who shared her position, still respected the choices of others: "I can only speak for myself. I can't legislate society. People have to do what is right for themselves."

Table 8:

PWA attitudes toward euthanasia/assisted suicide before and after diagnosis of HIV/AIDS

Variable	Total (N = 18)	(%)
Before diagnosis		
Pro choice	17	(94.4)
Pro life	0	(0)
Undecided	1	(5.5)
After diagnosis		
Pro choice	16	(88.9)
Pro life	1	(5.5)
Undecided	1	(5.5)

Table 8 shows that 94% of the sample reported that they had been pro-choice on the issue of euthanasia prior to their illness. All but one from this group stated that there was no change in opinion. Although the respondents were not specifically asked if their pro-choice views had been reinforced as a result of their HIV/AIDS diagnosis, 50% stated that this had occurred:

> Living as a person with HIV influences a new identity. People take on a new identity and are expected to take on new behaviours and expectations. With HIV there is an acceptance of euthanasia as an option. HIV influences the acceptance of euthanasia.

Only two participants reported that they had changed their opinion on euthanasia since diagnosis of HIV/AIDS. One participant had previously been pro-choice, and was now undecided. The other was previously undecided, and had become pro-life. Both individuals denied religious influence on these changes in perspective. Rather, the shift was attributed to personal reflection and clarification of values.

Social aspects/support and coping

None of the respondents presented themselves as being unduly distressed or unsettled during the interviews. All appeared to have given abundant consideration to their circumstances and had made significant lifestyle adjustments in order to preserve their health. Most of the respondents were "out" regarding their HIV/AIDS status. This appearance of being socially and emotionally well-adjusted may be indicative that members of a particular cohort within the AIDS population chose to participate in this study.

The impact of AIDS on the lives of PWA'S has been devastating. The uncertainty regarding health, reduced ability to work, and the corresponding decline in quality of life compounds the debilitation of an already incapacitating disease. Additionally, many PWA's suffer loss as AIDS claims the lives of loved ones and friends. One third of the sample reported the loss of a partner to an AIDS-related death. Participants reported considerable numbers of AIDS deaths within their peer group. The numbers of AIDS-related deaths known to each participant ranged from zero to 180 (mean = 29).

To put such loss into perspective, many of the respondents indicated fatigue with attending funerals. Some commented that they had seen more death within their peer group, to one disease, than had their parents in a lifetime. Living with AIDS brings with it a heightened sense of mortality, and watching AIDS kill one's peer group is a constant reminder of the inevitability of death from AIDS. Many of the respondents seemed to have a familiarity and comfort with death. Death was not something that they feared; rather, a distinction about death and dying was frequently made. A fear of dying without control, without dignity, and of dying alone was expressed by several of the sample: "Death for me is easy, it's getting there [with this illness], that is horrifying."

Despite feelings of isolation due to the loss of friends, and fears of dying alone, 78% of the participants indicated satisfaction with their support system. Many were in relationships with an understanding partner; others drew most of their support from friends and family. All of the participants received some form of services from AIDS support agencies, and generally identified these as being helpful. Several respondents participated in counselling, or therapy. Some indicated that their social relationships had improved significantly as a direct result of their AIDS diagnosis: they have an enhanced regard for life, and a better appreciation for social relationships.

Fourty-four per cent of the participants identified financial stresses. Most were unemployed, drawing social assistance[9]. Social assistance was perceived as helpful in off-setting high costs of medication, but inadequate in meeting the needs of PWA'S who wish to follow a healthy diet or take vitamin and homeopathic remedies. Many respondents indicated an awareness of a correlation between income and health, and expressed concern that with reduced income, their health would suffer.

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[9] In British Columbia, the social assistance rate for an unemployable adult is $585.00 per month (Programs for Independence, M.S.S. 3.32.2, February, 1993). At a time when PWA'S are challenged to take optimal care of themselves, welfare rates present obstacles in securing suitable shelter and maintaining a proper diet. Welfare does cover most medical expenses.

Three of the respondents were drawing disability benefits from their employers, four others had income from family. These individuals appeared significantly more optimistic about coping with the progression of AIDS than did their poorer colleagues.

Among the sample, 55% perceived moderate to high levels of psychological distress. Three participants within this group had been advised of their AIDS diagnoses within the past eight months, and previously were unaware of having contracted HIV. They perceived high levels of distress. Participants with poor short-term prognoses also perceived high levels of distress. Fourty-five per cent of the sample perceived low levels of psychological distress. Respondents within this group had been aware of their HIV/AIDS diagnoses for three to nine years (mean = 5.5 yrs.). Thus, perceived levels of psychological distress may diminish with time, but increase again as health deteriorates.

Present quality of life was assessed by 78% of the participants as "good." Only 11% rated their quality of life as moderate, and 11% rated it as poor. A majority, 78%, expressed concern that their quality of life would deteriorate significantly in the future, leading to hospitalization. Three participants refused to discuss future quality of life, believing that this was negative, and therefore not conducive to a healthy state of mind. One participant expected no change in quality of life. He considered AIDS to be a chronic condition that could, with proper care, be maintained throughout a normal life span.

A majority of the PWA sample (67%) reported that the knowledge that they could take their own lives helped them to cope. Many stated that they liked to be in control of all aspects in their lives, so it made sense that they be in control of their deaths:

> Yes, that would help [to cope], because I wouldn't feel like I was destined to a horrible, long, slow death. It helps to relax me--knowing there is a way to avoid a long slow death. It gives me a feeling of being cared for. If my doctors could help me to end my life, then that would extend to my care.
>
> It brings back feelings of my independence, and my control of my life. It helps to alleviate fears of ending up comatose, or on machines.
>
> It gives me a sense of control over my suffering, and for the suffering of my friends.
>
> My family and friends plead for me to hang on for a few more years. I like to know that when I can't cope anymore, that I don't have to ... that I have a choice not to suffer ... it feels safer, and more secure.

Stigmatization

All of the participants in the sample had disclosed their HIV/AIDS status to either family or close friends. As a consequence of having HIV/AIDS, 27.7% of the respondents identified experiences that they perceived as discriminatory. On the whole, however, respondents felt that they had been treated appropriately in public, and did not perceive any serious victimization as a direct result of their illness. This finding may be attributable to the particular participant cohort, and is not generalizable to the whole AIDS population.

A majority of the respondents (61%) gave accounts of subtle discrimination experienced in social settings by other gay members. A tension within the gay population was identified; some without HIV/AIDS may not associate with men who have HIV/AIDS. Respondents said this makes them feel like they are not part of society, and do not even belong amongst their own peer group:

> The greatest stigma comes from the gay community. This is where I have felt the greatest rejection and disappointment. Former friends see us as already dead and buried. This [discrimination] comes from the HIV negative population ... there is almost a moral mentality that we deserved to get AIDS due to our sleeping around. I hate the stigma attributed to innocent victims [hemophiliacs], versus deserving victims [gays] [sic].

In addition to perceived discrimination within their peer group, three of the gay participants perceived stigmatization as a consequence of their homosexuality. They reported that in environments where their sexual orientation is known, there is a subtle assumption made that they also have AIDS.

Because participants were not specifically asked about their sexual orientation, it is unknown what the overall composition of the sample was with regard to this variable. Therefore, the findings regarding gay sexuality and discrimination are not even generalizable across the participant sample. Nevertheless, a majority of the participants identified some form of discrimination.

Thirteen of the respondents felt that, although such stigmatization exists, it was either not of concern to them, or not a part of their experience. They attributed their positive experiences to good interpersonal skills, and open attitudes. It would appear, from the following comments, that the perception of being discriminated against has much to do with how one frames the experience:

> I have some friends who I know are afraid to touch me, but I understand that this is due to their lack of knowledge about AIDS.
>
> I have experienced ignorance, but not discrimination. I think this is attributable to my open behaviour. Until people get out of the AIDS closet, things won't change much.
>
> It is steeped in the old Judaeo-Christian ethic. Society will open up eventually because in having to deal with AIDS, it will also have to deal with sex, sexuality, and the taboos of death.

Medical care

Perceptions regarding medical care were generally good. Eighty-three per cent of the participants expressed satisfaction with the availability of medical care pertinent to their illness, particularly with respect to specialists. There were only three accounts where respondents had experienced discrimination or been refused service from ill-informed general practitioners and dentists. A majority (72%) of the respondents expressed a lack of confidence in general practitioners who, although well-intentioned, are in their view poorly educated with respect to AIDS. Respondents frequently said that they take responsibility for researching new treatments, and then educate their general practitioners. Some respondents indicated a lack of faith in traditional medicine. They had seen so many of their friends die that they found little reason to believe in doctors:

> I'm very suspicious of the 'mind set' of being a patient all the time. One doctor had this guy coming in for B12 shots weekly. I just don't want to do it. If I can't do it at home, I don't want it done.
>
> My doctor means well, he's very nice, but not informed.
>
> I try not to put too much emphasis on doctors ... they're just guessing.
>
> I get tired of being in doctors' offices. I'm becoming a professional patient.

Legal/Ethical

All of the participants felt that there should be some change to the laws with respect to euthanasia and assisted suicide, ranging from legalization to reduction in the severity of penalties. They described the present law as "antiquated," "dated," and "archaic." Nevertheless, the respondents generally indicated a lack of concern for legal issues that they believed would remain unresolved in their lifetimes. Many believed that there is a need for law to protect vulnerable individuals, but did not consider themselves as falling into that category. All of the pro-choice participants felt there should be a right to an assisted death in certain circumstances, whereas the pro-life participants were of the moderate opinion that the law was either too strict or too punitive. Five of the respondents wrongly assumed that attempting suicide is a crime in Canada.

A living will, or health care directive, had been prepared by 55% of the respondents. Those who had not prepared such documents indicated plans to do so. All of the participants had discussed treatment issues related to their health care with their physicians, friends, or family, and believed that their wishes would be respected, in the event they become incompetent.

Two participants had been particularly attentive in making preparations for their deaths. Each had prepared wills, living wills, health care proxies, funeral arrangements, and one had written his obituary. Both respondents noted that they maintain a lot of control in their lives, and that control extends to the manner of their deaths.

Nearly half (44.4%) of the participants indicated that they had stockpiled medications in preparation for an assisted death. Difficulties in obtaining lethal doses of the preferred drugs were frequently identified. Concerns were expressed that physicians are reluctant to prescribe reliable euthanasics, and averse to becoming directly involved:

> I think I will go the seconal[10] route. I don't have a doctor that will prescribe that for me. I've just changed doctors, and ... I have to have this conversation with my doctor--about prescribing me barbiturates. Once I know that, I'll feel much more comfortable. I don't want to get myself into the situation that _____ did, where he didn't have a clear understanding with his doctor, of what his last days were going to be like .... I think the doctor baffled him on purpose. He said, "Oh, I'll help you, I'll help you," and when it came right down to it, he backed out. He said _____ was not sick enough to be assisted .... What's sick enough? Three more weeks of stomach cancer, in agony? Enough!

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[10] Seconal or secobarbitol, is sleep medication containing barbiturate. In large doses it can arrest the heart, causing near-immediate death.

Amongst the 15 respondents who stated euthanasia was an option for themselves, 53% had developed plans for their suicide or assisted death. A serious concern was that their attempt to die might fail, resulting in vomiting or convulsions, coma, and potentially, hospitalization.

The respondents expressed some disturbing anxieties: What would happen if they fell into a coma? What suspicions might arise if they were hospitalized after a failed euthanasia attempt? How could those involved in the attempt explain themselves? What might the impact be upon others involved, if, rather than alleviating suffering, they were to cause more?

The respondents' euthanasia plans varied in method and sophistication. All involved the use of prescription drugs, usually to be taken orally in a fashion consistent with the methods outlined by right-to-die societies. Three involved ingestion of a combination of alcohol and sleeping pills to induce a deep sleep, followed with death by asphyxiation.

The following are summaries of typical plans for an assisted death:

> Case 1:
>
> John has had AIDS for two years. He has uncontrolled wasting, mycobacterium avium

complex[11], and has survived one bout of PCP[12]. His physician has prescribed a lethal dose of seconal. John has a friend who will help him take the medication and wait until he is dead, at which point the physician is to be called. John states that his doctor has agreed to declare the death as being AIDS-related, rather than suicide.

Case 2:

Mark has HIV and considers his present quality of life to be good. He rejects hospitalization, follows a naturopathic regimen, and refuses to become a "professional patient." Mark actively assisted the death of a friend who had AIDS, but believes mistakes were made, and that there was unnecessary suffering. As a result, he greatly fears "botching" his own assisted suicide. Mark has formed a pact with a friend for help, and intends to overdose on prescription drugs--seconal if he can obtain it. To protect others involved in his death, Mark wants his death to be recorded as a suicide. He plans to leave a suicide note, and a copy of *Final Exit* near his bed.

Case 3:

Paul has lost more than 30 friends to AIDS, including a partner. He recently recovered from lengthy illness, and says this reminded him of the potential that he could lose control of his ability to make treatment decisions, and his choice to avoid extended suffering. Paul's CD4+ T-cell count is insignificant. He suffers from a variety of AIDS-related infections, such as recurring herpes. He also has kaposi's sarcoma. Since his long term prognosis is poor, Paul wants to prepare a fail-safe plan soon. He has discussed the issue with his family and doctor, and believes they know he will commit suicide. He has a pact with a friend who has agreed to help

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[11] Mycobacterium avium complex is more common in AIDS patients, than other patients. It can cause pulmonary disease and disseminated disease affecting the intestines, bone marrow, liver, lung, spleen, adrenal glands, brain, lymph nodes and kidney.

[12] PCP, pneumocystis carinii pneumonia, is an AIDS-related pneumonia, related to diminished immune response.

him. The method has not yet been determined but he believes they will rely on an overdose of street drugs.

Case 4:

James was diagnosed with HIV in 1985, and recently his health has begun to deteriorate. He dislikes the idea of dying alone, but given the legal climate feels it would be unethical to involve others directly in his death. James plans to take a heavy dose of sleeping pills with his favorite liqueur, and then secure a large plastic bag over his head. "It's a shocking image, isn't it?," he says, referring to the plastic bag, "I just couldn't bring myself to ask someone else to be there for that." Nevertheless, James does not know how he can avoid the inevitably grisly discovery of his body.

Part II

Euthanasia participant group

Response rate and demographics

The sample consisted of 15 male, and two female, participants (N = 17; mean age = 41.5 years old; SD = 4.8 years; See Table 5). Nearly a quarter (23.5%) of the sample had HIV/AIDS, and had also participated in part one of the study. The euthanasia group was very well-educated (See Table 6). One participant had completed grade 12; four had completed some post-secondary education; six had bachelor's degrees; and six had graduate level education. The respondents came from a variety of professional backgrounds, including physicians, health care workers, social workers, counsellors, the clergy, sales, and labourer positions.

A total of 35 deaths were identified. Thirty-four involved persons with AIDS, and one involved a cancer patient. The latter death is excluded from the data. The respondents offered accounts of several other assisted deaths, but these were excluded from the data for reasons of lack of detail, or the inability to rule out the possibility that the death had already been described by another participant. The less-structured interview format permitted considerable probing of detail regarding cases of euthanasia. In some instances, respondents offered information about deaths that they had not played a role in planning or assisting, but nevertheless believed that their information was reliable. As a result, details such as location of death, year of death, method used, and other characteristics of the deceased, proved useful in evaluating whether the same death was discussed by different subjects. Table 9 shows some characteristics of the deceased and the methods used in the assisted deaths. Overdose of prescription medications was the favoured method for euthanasia.

As shown in Table 10, ten participants in the sample had been directly involved in performing at least one act of euthanasia or assisted suicide ($\underline{n}$ = 17 deaths). Six respondents had either been present, or involved in the planning of at least one euthanasia or assisted suicide ($\underline{n}$ = 10 deaths). Six respondents had reliable information regarding cases of euthanasia ($\underline{n}$ = 7 deaths).

In one case, a participant discussed his plans to assist the death of his partner; however, the partner died an unassisted death only a few days after the interview.

Table 9: Characteristics of the euthanasia/assisted suicide

Variable	Total (N = 34) n	(%)
Sex of deceased		
Male	33	(97)
Female	1	(2.9)
Location of death [a]		
Home	21	(61.8)
Hospital	11	(32.4)
Other	2	(5.9)
Year of death		
1980	1	(2.9)
1981	2	(5.9)
1982	1	(2.9)
1983	0	(0)
1984	1	(2.9)
1985	1	(2.9)
1986	2	(5.9)
1987	2	(5.9)
1988	4	(11.7)
1989	5	(14.7)
1990	5	(14.7)
1991	4	(11.7)
1992	5	(14.7)
1993	1	(2.9)
Method		
Barbiturates	7	(20.6)
Carbon monoxide	1	(2.9)
Cessation of treatment (non-voluntary [b])	1	(2.9)
Cessation of treatment (voluntary [c])	1	(2.9)
Gun	1	(2.9)
Heroin	2	(5.9)
Injection of unknown substance	2	(5.9)
Insulin	1	(2.9)
Morphine	6	(17.6)
Morphine & pills	3	(8.8)
Pill combination	3	(8.8)
Pills & asphyxiation or suffocation	5	(14.7)
Razor blade	1	(2.9)

[a] includes 5 deaths outside of British Columbia.
[b] patient was comatose, had not earlier expressed his wishes.
[c] patient gave consent for cessation of treatment.

Chart 1

Euthanasia Method: Total 34 deaths

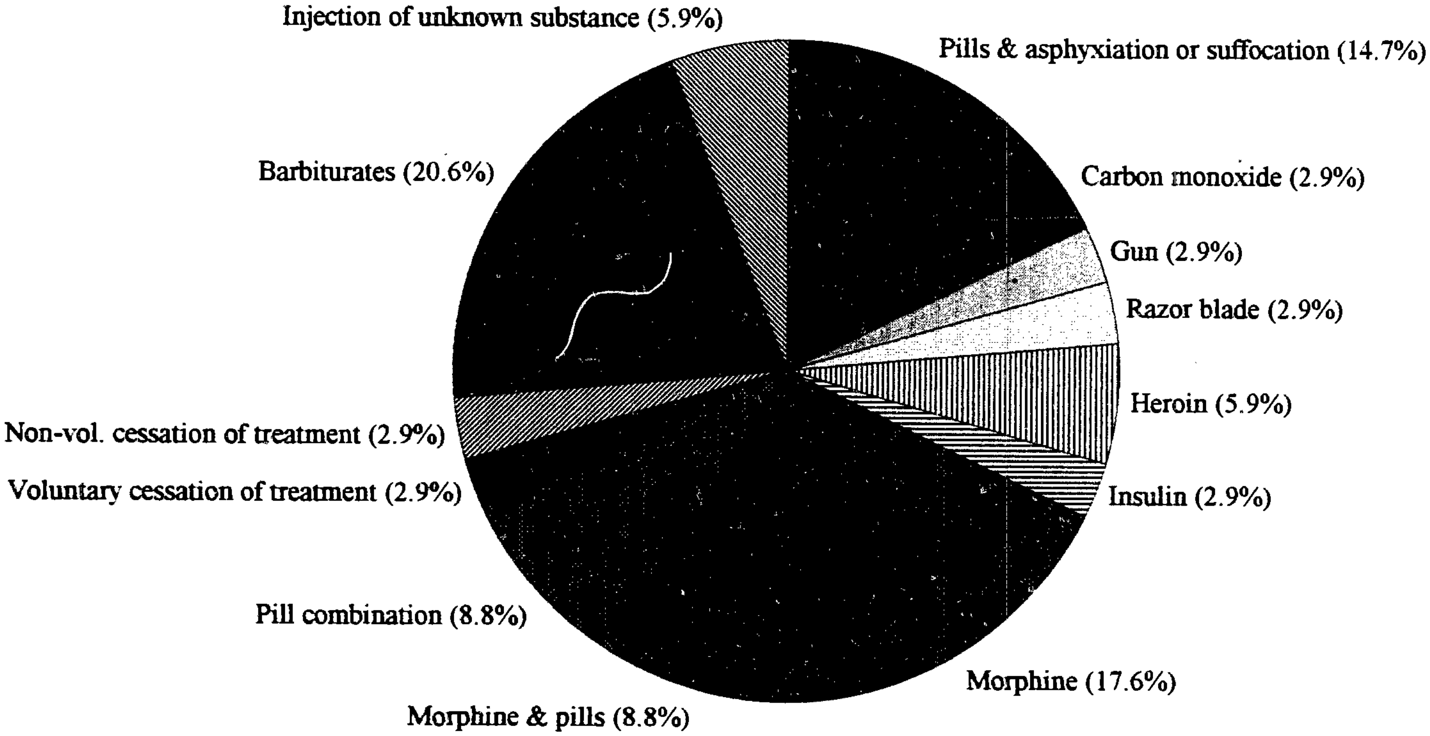

Table 10:

Type of involvement in the assisted death

Type of involvement	# of Respondents (N = 17)*	# of Deaths (N = 34)	(%)
Actively participated	10	17	(50)
Reliable knowledge	6	7	(20.6)
Either present at, or involved in planning the death	6	10	(29.4)

* Some respondents were involved in more than one death.

Respondents in the euthanasia sample, like those in the PWA sample, offered a number of reasons for participating in the study. For many, it appeared that they hoped to contribute their personal experiences to a body of knowledge that might help to legitimate their behaviour. For some, participation in the study offered a catharsis--the chance to disclose their activities in a confidential, safe, non-judgmental environment. Assisting the death of another is arguably the most significant event of the respondents' lives; yet there are serious constraints on the liberty to discuss it, even with close friends.

Perspectives regarding euthanasia and assisted suicide

All the participants within this sample supported the choice of euthanasia. They accepted the idea that individuals should be allowed to plan an assisted death, and had agreed to support that plan on at least one occasion. A number of conditions were identified, which according to the respondents, were crucial to their decision to assist in the death of another. Twelve stated that the euthanasia recipient should not be suffering from depression. Nine felt that there must be no hope for recovery, and four believed that they should know the patient well. Additionally, the respondents identified a variety of other factors that they believed were pertinent to their involvement:

Dying should not occur alone. Nor should the decision to die be made alone.

People should be able to make informed choices. It's similar to abortion that way. The choice rests with the individual, but should also be in consultation with family and the doctor.

I have no problem with that [performing euthanasia] at all. I have more difficulty with the fact that I'm healthy, HIV-negative, and I have all these friends who are sick. I have more problem with losing a peer group.

The individual must be ready to die, and they must request it.

... euthanasia timing should be very specific and not out of a sense of depression .... [It] should be done when one has relatively little time left--for example one to two days, where if one does not do it, one causes extreme distress ... the best reason would be in cases of pulmonary edema with kaposi's sarcoma--they drown in their own pulmonary secretions and it is a horror show ... when it [pulmonary edema] can't be controlled, it's time. That's really the only group that I have been aware of and approved of what's going on.

When a person has reached a point of misery, then the individual should have the right to choose.

Before all this [AIDS], I felt that it was the right thing to do. Since I've been involved and actually done it, I believe even more so it's the right thing to do. I think there should be strict controls ....

The desire of the patient is the overriding concern .... In the case of terminal illness, where the quality of life is very low, and under appropriate controls, then it [euthanasia] is an appropriate procedure, providing of course that depression has been ruled out, because depression is treatable.

It is not my decision when life loses its meaning for someone else. I've learned to let go of my wants and desires for other people.

Relationship to the Person with AIDS

All of the respondents identified strongly with the suffering of the PWA'S whom they had helped to die. Similar to the respondents in the PWA sample, the members in the euthanasia sample had known many PWA'S who had already died. The majority of the respondents had known the PWA whose death they assisted for a considerable amount of time. Some were living in relationships with the patient, or had been long-term friends, and others involved professional relationships. In most cases, discussion regarding the euthanasia had been ongoing for months, and in some cases years.

Knowledge of euthanasia methods and concerns about the law

The respondents varied in expertise regarding euthanasia techniques; only three had medical training. Ten had read materials published by the Hemlock Society, which describe methods of euthanasia and "self deliverance." Three volunteered that they were aware that gravol is a useful medication to reduce the risk of vomiting pills, and that valium acts as an anti-spasmodic.

Three of the respondents, in particular those who had been involved in more than one assisted death, indicated they had access to drugs through an underground network. It was mentioned by several that connections were important.

Patients who are not well-connected risk having second-rate deaths through the use of second-rate drugs.

Eight respondents described difficulties in accessing the appropriate medications for a quick, safe, painless, and assured death. A major consideration for those planning an assisted death is that the death not attract unnecessary attention. Therefore, the ideal euthanasic should not be disfiguring, nor should the attending physician, when pronouncing the cause of death, suspect anything but a natural death. Four participants expressed that their greatest fear had been that they would "botch" the assisted death. In some cases, difficulties were encountered when a PWA suddenly experienced a rapid decline in health. The appropriate drugs could not be obtained quickly enough to avoid admission to hospital. For this reason, violent methods were used. For example, in one case a gun was used. In another, a razor. Nevertheless, the most frequently employed methods were non-violent.

In other examples, unreliable methods were used simply because the involved parties did not know any better. The consequence, was that some deaths did not come about easily, and were fraught with additional agony.

The threat of legal sanction yielded an unusual response. Although the respondents were universally critical of the legal penalties for euthanasia and assisted suicide, many seemed relatively unconcerned that they could have been discovered, and believed that if they were, the courts would be lenient. In some instances, the euthanasist never anticipated the possibility of an autopsy, either through naivety, or because, as an attending physician, they could simply note a natural death, or because a physician had already agreed to pronounce an AIDS-related cause of death. Interestingly, getting caught was not the primary concern expressed by the respondents. Rather, they gave considerably greater consideration to comfort maintenance, and alleviation of the suffering of the PWA.

The respondents described some of the precautions that are taken to protect themselves from unnecessary interruption, and detection, of the act. If the death is to occur at home, appointments with visiting home care are cancelled. Word is put out that the patient has taken a turn for the worse and will soon die. Unannounced visitors are politely turned away. If it is understood that the patient is to die soon, then the risk of arousing suspicions is reduced. Every effort is made to make it appear that the death occurred naturally. "This makes it much easier for the attending physician and those involved ... then the body is sent for cremation as quickly as possible." Finally, a suicide note is written, to be produced later if suspicions are raised. In one instance, a participant recalled having to alter the date on a suicide note to make it correspond with the date of the death.

The Assisted Deaths

Descriptions of the assisted deaths were generally quite detailed. This section describes the circumstances of 17 deaths, three of which were previously made public. The remaining 17 of the total 34 deaths are detailed in Table 9:

The Public Cases:

Case 1
David Lewis

The death of David Lewis in 1990 was documented by the B.C. Coroner as a suicide by an overdose of seconal (Robinson, 1991). Three of the participants in this study claimed to have been at Lewis's home when he died, and disclosed information that confirms that his death was actually an *assisted* suicide.

One of the respondents said that he had known David Lewis for two decades. This respondent said he had obtained a prescription of seconal, which to the best of his knowledge Lewis used. Another participant described discussions with David Lewis over the course of the year prior to his death. The discussions centred around how Lewis would eventually take himself out. This respondent said he was at Lewis's home on the day of his death, but did not witness the death. The third respondent claimed to have been in the room, providing support to Lewis and others who were present when he died.

David Lewis had been the focus of considerable media attention as a result of his disclosure that he had aided the deaths of eight friends who had AIDS. A consequence of the publicity was that he had great difficulty in obtaining lethal drugs for himself. Another unforeseen obstacle was that Lewis had anticipated living for several months longer than he did, but a stroke, and the sudden decline of his mental faculties--attributable to AIDS-dementia--forced him to move up his deadline. David Lewis was adamant that he not be hospitalized. Apparently, he was prepared to asphyxiate himself with a plastic bag if necessary, but his friends dissuaded him from pursuing the idea.

In obtaining the lethal dose of seconal under his own name, the first respondent declared that the prescribing physician knew the purpose of the prescription, but not for whom it was intended. The respondent also sought legal advice regarding his involvement in assisting with Lewis's death. The advice was that the respondent not do anything that would confirm that the seconal was used in Lewis's death; that the respondent not be in the room with David Lewis at the time of his death, and; that the respondent not be in the position of knowing who else was in the room:

> I went downstairs to his bedroom, and said goodbye .... [I] sat in a chair in the (notes location) of the living room, so that I could not see who was in the kitchen, or who was going downstairs. I made every effort not to remember anything. I wanted to be able, if there was an inquest ... to go before a judge and honestly say, "I did not remember," without having to perjure myself. I did not want to have to testify against my friends. I sat and waited one and a half hours. I later went downstairs to see David after being told he was dead. I paid my respects and left.

A nurse provided an intravenous drip apparatus for David Lewis to administer the lethal medication. To reduce the risk of criminal liability for those involved, Lewis made it clear to all who were present that he had placed the intravenous drip into his own paralyzed hand, and indicated he would be responsible for turning the spigot that would begin the drip.

The intravenous drip was left in place for the coroner to view; it was David Lewis's wish that the public know how he died.

Case 2
An Act of Courage

In 1991, *Vancouver Province* columnist Lyn Cockburn wrote *An Act of Courage*. The article described the assisted suicide of an anonymous woman suffering from AIDS. Two of the participants in this study offered information regarding the death described in Cockburn's article. One claimed to have been present at the woman's death, but denied any active involvement with assisting her death. The other was a physician who had refused to issue a lethal prescription to her, claiming "she had a lot of time left and it was totally inappropriate."

The assisted suicide of the woman involved ingestion of a lethal dose of seconal. Her death did not come easily; she vomited the medication, and was asphyxiated by her assistant with a plastic bag.

An Act of Courage caused considerable controversy regarding the ethics of journalism and confidentiality. Subpoenas were issued to Lyn Cockburn and the senior editors of the *Vancouver Province* newspaper in an effort to force compliance with the B.C. Coroner's inquest. As already mentioned in Chapter 1, Cockburn and her senior editors were found in contempt of court for refusing to disclose the name of the man who asphyxiated the woman. The matter has been referred to the B.C. Supreme Court for review of the decision.

Case 3
Choosing to go and saying good-bye

Choosing to go and saying good-bye was a letter published in the *Vancouver PWA Newsletter*. It described the assisted death of a Vancouver man with AIDS (Almost Fearless, 1991). The author, a female friend of the deceased, participated in the study.

The participant, "Mary," had known "Daniel" for a number of years. Daniel had been diagnosed with AIDS two years earlier--probably the result of intravenous drug use in his youth. Soon after his diagnosis, Daniel began discussing the issue of euthanasia with some of his friends. About seven months prior to his death, Daniel and Mary made a pact that she would be with him when he decided to die.

A recovered drug addict, Daniel had no desire to return to a life of suffering and drugs, even if it was within the legitimated environment of a hospital. Daniel equated hospitalization with loss of control, and loss of independence. With the support of his friends he lived at home until he died.

Daniel followed the traditional AIDS remedies--AZT and DDI. But his condition deteriorated, his nervous system began to fail, and he showed signs of dementia. His nights became filled with sweats; near the end he had great difficulty walking, and relied on large doses of morphine for his pain.

Mary contacted the Hemlock Society for help in planning Daniel's death, but found them to be of little help. She sought advice through AIDS Vancouver and the PWA Society and was told that they did not provide counselling with respect to euthanasia or assisted suicide. Finally, Mary read some "how to" British publications that she found were oriented toward the dying person, with little emphasis on those who might assist.

Daniel had done his own research, and decided that he would rely on morphine and large quantities of prescription drugs to assist his death. One day he announced to Mary that "tomorrow is the day." Apparently, "everybody, including his doctor was aware" what Daniel intended to do.

Mary, however, was unprepared for Daniel's announcement that he would die the next day, so they agreed to wait two more weeks. Although Daniel appeared ready to die, Mary said she was not yet ready to help him, and spent the next two weeks getting prepared.

During the two weeks, Daniel's condition rapidly deteriorated. The thrush in his esophagus was so bad that Mary worried he would be unable to swallow all his pills. On the eve of the agreed day, he was slipping in and out of a coma. Mary anticipated that Daniel would soon require hospitalization:

> I suggested he could not wait until tomorrow. I said, "The decision is going to be taken away from you." Then I went out to run an errand, and when I returned, he was in the living room with his bottles (of pills) all lined up. Somehow, I don't know how, he had managed to take a shower.

Mary called a friend to bring over a blender to mulch some food so that Daniel would not have an empty stomach. Another friend brought some flowers and said goodbye. When the others had gone, Daniel took most of the pills himself, and at one point vomited a small amount. Mary then helped him to his bed and fed him the last of the pills, "because at that point we had to make sure it was going to work."

To Mary's surprise Daniel died quickly, while she was still with him. She had planned to leave for a few hours, return to discover his body, and then notify the authorities, but "he died so fast." Mary left the building to collect her thoughts, and returned later to call 911. This resulted in the attendance of the police, fire department, and ambulance officials. She has since learned that had she called Daniel's physician, he would have probably pronounced the cause of death as AIDS-related, and an autopsy would not have been performed.

Daniel had left a note stating his intent to suicide, and his death was attributed to an "overdose":

> That pissed me off. It was a choice. "Overdose" implies an accident or a mistake. This was planned, and the note stated that.

Mary's regret is that in trying to talk about the event with others at a PWA support group, she encountered admiration for her openness; yet others who shared similar experiences, said that they could only speak in private:

> I'm really glad that I had the courage to do that. I would want someone to do that for me. I would want someone to do that for my child .... I feel very privileged to be the one who got to do it. I think it is a high honour that someone feels comfortable enough with you, and wants you to be the last face they see.

The Unpublicized Cases

Cases 4-8
The Physician accounts

Two physicians participated in the project. One had prescribed seconal to two patients who were at the endstages of AIDS, suffering from pulmonary edema with kaposi's sarcoma. He estimated that both patients would have likely died within 24 hours, by drowning on their lung secretions. The physician was not present at either death, which were aided by other individuals. In both instances, he attended later to pronounce a natural death:

> If I'd had my druthers, I would have liked to be there at the time .... An autopsy does not happen. I know what the cause of death is. It's pulmonary edema caused by K.S. (kaposi's sarcoma). The mere fact that they chose to get something which would give symptomatic peace from the cause of death is immaterial .... The fact that it hastens death by a few hours is totally irrelevant. The choice of watching them suffer, or helping out, is not a choice. It's back to the wall, with no recourse. Slow drowning offers no recourse. If one needs to use a barbiturate to get over the distress, then so be it.

The two respondents disclosed several other euthanasia-deaths, which for reasons of confidentiality are not described. Several of the deaths are, however, documented within Table 9. Two additional scenarios involved morphine overdoses in hospital settings:

> ... the patient was requesting euthanasia. He was in considerable pain, very poor quality of life,

> at the endstages of the illness. He was never going to recover and get out of hospital. He was not depressed or demented, quite lucid. We told the patient that we could not provide euthanasia, but could put up a morphine drip which would depress the respiratory system. So, *it is like doing it, but saying you are not doing it. That was a semi-active way of hastening death* (emphasis added) .... He died within ... hours.
>
> ... one other with kaposi's sarcoma and pulmonary edema in hospital. He got horrendous doses of morphine for three or four days to accomplish the same thing that 30 seconal would do in 20 minutes. It just doesn't make sense to me; a $3000.00 death versus one that takes 20 minutes, is quiet, easy, and under the patient's control, as opposed to somebody else doping them up.

Cases 9-11
Theologians

Two theologians participated in the study, giving three accounts of assisted deaths. To protect their identities, their denominations and religious titles are not disclosed. The first respondent said that he had performed one act of euthanasia, and been present at another. The second theologian said that he had provided a spiritual presence to support a patient and his partner at an assisted suicide.

The first respondent stated that the decision to have an assisted death should not be spontaneously made: the patient must be well-informed and aware at the time of planning, and if possible, should discuss the matter with friends and family.

The first respondent described a situation where he had been working as a chaplain in an American hospital. Over a period of several months he got to know an AIDS patient who had repeatedly asked for euthanasia. The patient had kaposi's sarcoma throughout the intestinal tract, and would sometimes pass out from uncontrolled pain. He had also suffered bouts of PCP and was not expected to live much longer. The physician and the chaplain had several discussions with the patient regarding his request for euthanasia, and they eventually agreed to respect his wishes. For legal reasons the physician did not want to administer the injection, so he drew a lethal substance into a syringe, and the chaplain then injected it directly into the patient's intravenous tube. The patient died quickly and painlessly.

In a second situation, several years later, the respondent recalls the assisted death of a friend in a Canadian AIDS hospice. In this case, the patient had survived several attacks of PCP. He was also suffering from dementia caused by toxoplasmosis. The issue of euthanasia had been discussed between the patient, his partner, and the respondent long before the onset of dementia--at least a year earlier. Here, a nurse injected a substance into the patient, and 16-17 hours later he died. Apparently the death was deliberately drawn out over a lengthy period so that the patient could be seen to take a turn for the worse, and foul play would not be suspected.

The second theologian said he had been called to a hospital to consult with an AIDS patient for religious advice regarding euthanasia. The patient was going blind as a result of cytomegalovirus retinitis and had suffered a couple of traumatic bouts of PCP. Kaposi's sarcoma was evident, and the patient's body was wasting away as a result of cryptosporidiosis, a chronic intestinal disorder:

> Our ability to prolong (life) and to terminate life has changed very quickly, more quickly than our ability to think ethically and morally .... I would not say that euthanasia would always be right where an individual wants to do it, but I do question whether it always has to be wrong. That idea is born out of experience and theological reflection.
>
> In Genesis, where God says 'life is good', I think there is a kind of separation between physical existence and a kind of metaphor for fullness. If life was so restricted, decayed, and full of agony that it was no longer capable of the fullness that God looked down on and was pleased with, then, it may be possible to end that.

The patient is described as "a thoughtful and practical individual." He was terrified of incontinence and dementia, and was not managing his pain very well. He had talked to his partner, his parents, and his partner's parents about euthanasia. It appeared to the respondent that the patient was not carrying an agenda to seek more love or attention.

About two months later, the patient chose to die. It was of great comfort to him that he had a spiritual presence, as well as the presence of his partner and another friend at his death. The patient took some relaxants first, followed by an oral potion. The respondent said that, although it took several hours for the patient to die, he did not appear uncomfortable.

The respondent notes that the patient's partner appeared to cope very well with his loss; better than many other survivors of PWA's with whom the respondent had worked.

> There was no guilt for the partner. He appeared to deal very well with the grief. The euthanasia did not seem to make grieving more difficult.

Case 12
Lucas

"Lucas" and some others were caring for a friend, "Peter," who had decided to leave hospital so that he could die at home. Peter disliked being in hospital; he disliked waiting for visiting hours, and he hated feeling hurried and crowded when all his visitors arrived at once. At home, Peter was not expected to live more than another week, but with the full attention of friends and family, he lived several weeks longer.

Lucas described Peter as intelligent and articulate. Peter had witnessed other friends' experience the slow progression of AIDS to the point of dementia. It was fear of dementia, and his fatigue with fighting HIV infection for years, that contributed to Peter's decision to attempt suicide with morphine tablets.

The suicide attempt failed, and Peter fell into a coma. His physician advised Peter's caregivers to await the eventual shutdown of Peter's body, and to keep him comfortable by administering morphine injections:

> I felt sadness that he had tried to kill himself and failed. The first couple of days we had to sort out our own feelings and decide what to do. We injected him with massive amounts of morphine and he didn't die. We used a month's supply of morphine in three days. We were triple dosing him every hour, because the information we had was that eventually the morphine would arrest his respiratory system ... I think in some ways his doctor knew too, because he was prescribing the medication .... We kept injecting him until we ran out of morphine .... [and] he died ... [notes the time of death].

Lucas says he is aware of four other euthanasia cases, and suspects more (these cases are not included in the data). Since his participation in Peter's death, Lucas has been in the company of others who have disclosed similar situations where they have helped a PWA to die. Despite strong identification with the experiences of these individuals, Lucas says he has never been able to disclose his ordeal to them.

Lucas admits to having felt guilt: "the bottom line is that we killed him." Nonetheless, he believes that what he and his friends did was justifiable, and consistent with Peter's wishes. He does not rule out the possibility that he could be in the same position again one day.

Cases 13-14
Jonathan

"Jonathan" participated in the study twice. In the first interview he discussed his role in aiding the death of "Mark," two years earlier. During the interview he disclosed that he was in the midst of planning the death of another friend, and agreed to participate in the study again, once he had assisted the second death.

In the first interview, Jonathan said Mark had been raising the issue of euthanasia for two and one-half years prior to his death. When he decided to die, Mark had lost mobility, was in constant pain, and his health was declining rapidly.

To facilitate Mark's death, Jonathan had done some careful research. Nevertheless, Jonathan says he was terrified that he could "botch" it, and cause Mark additional suffering. He was also concerned about the risk of criminal charges. When the time came, Mark was given a double dose of gravol, for nausea. This was followed by some chicken broth so that his stomach would not be empty. Ten to fifteen minutes later, he was given a cocktail which contained barbiturates and alcohol. Mark took the cup and drank it. He fell into a coma, and everyone except for Jonathan left the room. Jonathan then took out a plastic bag that he had placed under the mattress, and tied it over Mark's head with a ribbon. Apparently Mark's breathing ended quickly, and he died without any of the complications that Jonathan had feared. Mark's doctor was called, and suspecting nothing unusual, he pronounced a natural death.

Jonathan says that he went through considerable distress in the weeks that followed:

> I called myself a liberator and a murderer .... I am in the eyes of the law, a murderer. I know this, but it can't be proven any more. He (Mark) told me I was giving the greatest gift of all time .... I kept this to myself, and then somehow, came across a subculture who have done the same--that helps.

Jonathan contributed to the study a second time. Approximately a month after the first interview, shortly after midnight, he telephoned, to disclose that only a few hours earlier he had helped end the life of his friend Josh.

He and Josh had been discussing the assisted suicide since 1989. Josh had apparently been reduced to a "skeleton" of his former self. Amongst a variety of infections, mycobacterial avium complex had caused his body to waste; neuropathy was affecting his nervous system.

Josh had been in hospital palliative care a few days earlier. He had come home for a short break, and then asked to die. Jonathan employed a similar procedure to that which he had used with Mark two years earlier: gravol to settle the stomach, soup, followed by four Serax, 14 Halcion tablets, and a small amount of liqueur. When Josh fell into a coma, Jonathan and another friend secured a plastic bag over Josh's head and sealed it with a red ribbon. A few minutes later, Josh stopped breathing.

Josh was then bathed and given a change of clothes. Josh's physician was called to the house; he suspected nothing unusual and pronounced a natural death. Later, after Josh's body had been removed, Jonathan gathered up the remaining medications so that they could be donated to PWA's who were unable to afford them, or ineligible for medical coverage in Canada.

Cases 15-16
Paul

"Paul" has been present at seven deaths, four of them were assisted, and in two he played an active role. Paul says he has discussed limited details with some close friends, including his mother. He says it is ridiculous to "bottle it all up," and that it is healthy to talk about it. He says talking about it has helped his own mental health, and denies ever feeling guilt or having a bad dream about his experiences in helping others to die.

Paul described two deaths that had disturbing complications. In the first, his friend "James" had decided that he had enough of living after being hospitalized five times. James had suffered a bout of PCP, kaposi's sarcoma lesions were evident, and he had lost control of his bowel. He decided to die at home, and threw his own goodbye party, which was attended by a number of friends. After taking a large oral dose of morphine, James said goodbye and went to sleep. A few hours later Paul was awakened by a horrible "keening," and he discovered James huddled in the corner of the room. James was still alive, and apparently thought he had died and gone to hell. After a few hours James recovered and eventually calmed. Paul rubbed his feet, somebody read a prayer, and another held James's hand:

> We chatted a while and then he said he was ready. He took the medication (morphine and seconal), and

> said, 'This is it', and within 20 minutes he was dead .... And then the nightmare began. We couldn't reach his doctor. Finally we reached a doctor who knew the score--there was an unspoken understanding.

In the second death that Paul assisted, his friend "Clement," took seconal, and died eight hours later:

> It was not a pleasant death. His breathing would stop, and then start. I called the doctor on call, and was lucky to get a sympathetic one. I told him that I had discovered [Clement] this way. He asked me what really happened, so I told him. He said 'okay', and took a lot of the pills away. Fortunately, [Clement] had left a suicide note.
>
> People don't realize that when you do this, it is not cold-blooded. You are attached to these people. When they actually die, it leaves you with an empty, sad, lost feeling. It's a bizarre initial experience I guess. It's a terrible feeling, and then all of a sudden there is a body there, and you panic, not for what you've done, but for what has to be done. And then you shake for three days until they are cremated.

Case 17
William

"William" has HIV and plans to have an assisted suicide when he becomes unable to do the things that give him enjoyment. His story involves the assisted suicide of his roommate.

William had a pact to assist his roommate to die, but because his roommate appeared relatively healthy, and a physician had indicated willingness to assist, the plan was never seriously organized. When his roommate's condition deteriorated quite suddenly, he was hospitalized. The medical team scheduled a series of tests--chemotherapy and invasive procedures--something that the roommate had always rejected. After two days in hospital, the roommate discharged himself and returned home. He announced to William that he had come home to die. He was in considerable pain, and was taking liquid morphine.

Two days later, the roommate abruptly announced that he was going to die that afternoon. He had spoken with his physician and was convinced that the doctor was going to administer a lethal dose later that afternoon. Elated and relieved, the roommate began calling all his friends to say goodbye. To clarify the euthanasia plan, William telephoned the doctor:

> The doctor told me that it would be illegal for him to give a lethal injection, but said "I will give him something that will make him really comfortable." The way he said it, I thought he was going to prescribe a combination of drugs that I could give, and inform us that if we mixed A, B, and C, it could be lethal.

When the doctor did arrive, he left only liquid morphine; no euthanasic. Later that evening the roommate announced that he was ready to die. William was prepared to help, but lacked confidence. He had consulted on the telephone with a member of the Goodbye Society[13] earlier that day, and had received instructions regarding the use of plastic bags:

> Even after reading *Final Exit*, I was not very conversant. The roommate did not have any barbiturates ... he had maybe two seconals. But he had so many pain killers, tranquilizers, sleeping pills, [and] one-half litre of morphine .... I fed him about 30 pills with some vodka, and he threw it up. He said, "Go away, leave me alone for a few minutes." In the meantime these two guys phone--they are in the neighbourhood, and want to stop by. One had been around earlier. I explained what was going on, and they agreed to come over.

A short while later the roommate announced that he was ready to try again. This time he refused alcohol, blaming it for causing the earlier vomiting. Instead, the pills were mixed with yoghurt and morphine. As he began to lose consciousness, he asked, "have you got the plastic bag ready?"

> We thought we would basically poison him. We thought the morphine would be enough to stop his heart. After 20 minutes, he lost consciousness, and we monitored his breathing. For a while, the other two didn't want to touch [him], [or] touch the bag, [or] help prop his head .... They did not want to be directly involved .... So we got the bag on, and thought this was all going perfect. The guy at the Goodbye Society had said it would all be over in one-half to an hour .... An hour later he's not dead.

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[13] Goodbye, is a right-to-die society in Vancouver, B.C.

> So we thought about it, and another half-hour later he is still breathing. I thought, "maybe there's a hole in the bag" ... so we double-bagged him. I had set an egg timer, just to keep in touch with reality, and the timer went 'ding,' underneath my pillow, and oh God, like here's [the roommate] laying in bed, right--he sat up! He had heard the bell, and then he quickly plopped himself down! It was just some sort of automatic reflex.
>
> One of the others became concerned about the length of time it was taking, and that it was not fair to [roommate], and he suggested the cushions. So basically what we did was smother him, and that took about 10 minutes, to smother him .... I'm really glad we took a proactive stance. It would have been very sad to have revived him.

This death is one of four that were achieved with methods that involved prescription medications, and asphyxiation or suffocation. In two of the cases, when asphyxiation by plastic bag failed, pillows were used to achieve suffocation. Where external asphyxia occurs, and in suffocation such as that with a pillow, petechial[14] haemorrhages may occur. If a plastic bag is employed, petechia may be evident internally and externally.

For forensic experts, plastic bag asphyxiation presents difficulties in the investigation of unnatural death. Where a toxicology report also shows the presence of sedative drugs, "one should always be careful because the deceased may have been too incapacitated to respond to a homicidal

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[14] Petechia is defined in Dorland's Illustrated Medical Dictionary (1981), as "a pinpoint, non-raised perfectly round, purplish red spot caused by intradermal or submucous hemorrhage."

attack" (Martinez et al., 1993, p. 75). In other words, in the case of assisted suicide, a coroner who encounters a body with a plastic bag over the head, and presence of sedative drugs, may be prudent to question how the deceased managed to secure the bag over the head in a sedated state. Petechial haemorrhages, which are useful in determining cause of death, may or may not appear. For example, Martinez et al. (1993) examined 18 cases of plastic bag asphyxia, and only six were found to have evidence of petechial haemorrhage, four of which were internal haemorrhage.

CHAPTER IV

DISCUSSION and POLICY IMPLICATIONS

In this chapter, the salient findings of the study are reviewed and their implications for law and policy reform are addressed. First, a discussion of the research methodology and its strengths and weaknesses is presented. Second, the characteristics of PWA's who plan an assisted death, and persons who have given aid in dying are specified. The generalizability of the findings is presented in the context of the representativeness of the sample and the sample size. Third, the difficulties of performing euthanasia are enumerated, with reference to the challenges in securing a safe, reliable method of achieving death. Fourth, the rational choice perspective is proposed as a theoretical framework for understanding the perspectives grounded in the views and experiences of the participants in the study. Fifth, legal and philosophical distinctions are drawn, highlighting some of the perplexities and confusions regarding moral, ethical, and legal thinking about euthanasia. Sixth, suggestions for public policy development are presented. Finally, conclusions are drawn from the results of the research, and recommendations for future research are proposed.

Strengths and weaknesses of the methodology

In this study, the snowball sampling and semi-structured interview technique offered an effective means to obtain large amounts of data from a difficult-to-access population; the quality and nature of the data obtained is a testament to the sampling method.

Given the risks involved for participants, it was anticipated that members from the HIV/AIDS participant group would be a more responsive target group than the euthanasia participant group. There were, however, a similar number of respondents from each subject category--and fewer responses from PWA's than anticipated. Explanations for this result are: First, persons with HIV/AIDS, as a consequence of their illness, are a target for many competing clinical and social science studies. Second, many AIDS patients are fatigued, and prefer to volunteer in studies that offer insight or benefit to their health. Third, although death and dying is on the minds of PWA's, the subjects of euthanasia and assisted suicide are still social taboos. These factors undoubtedly influenced the decisions of PWA's to not participate.

On the other hand, there was a remarkable and unexpected response from the euthanasia participant sample. It appears that the methodology was an effective recruitment technique, although physicians are under-represented. It is suspected that physicians believed that their participation would carry too great a professional and personal risk. Although the non-physician participants were cognizant of the risks, their participation suggests that the act of contributing their experiences overrides any perceived risks of participation. Additionally, some of these participants were encouraged to volunteer by other participants, thus, having greater confidence in the assurance of anonymity. Moreover, the study took place at a time when the high profile *Sue Rodriguez* case was before the courts, which may have contributed to a climate more receptive to open discussion.

A weakness of the snowball sampling method is its inefficiency in recruiting large participant samples. In this case--for an exploratory study in a previously unresearched field--the sampling technique proved effective. For larger studies, however, a randomized sampling method may prove more useful, provided there is a suitable population from which to draw participants.

There were striking similarities amongst the participant cohort. In general, respondents in both the HIV/AIDS and euthanasia categories were above average in education. They also appeared to be confident individuals--

sufficiently self-assured that they were willing to participate in the study. This may be attributed to the nature of the study, and the use of advertisements to recruit respondents; under-confident individuals would simply not respond, and lesser-educated respondents would not be targeted by the publications in newsletters and presentations at meetings. Therefore, the cohort reflected in the data is not necessarily representative of the AIDS population in general, nor persons who are involved in acts of euthanasia.

The semi-structured interview technique provided a potent interview instrument. Two participants specified that they would not have volunteered if the research involved a response-limiting, structured questionnaire. The casual, conversational style of the interviews fostered a non-threatening environment for the participants. Most of the participants commented that they enjoyed the interviews and appreciated the casual format. Some found the process therapeutic.

In addition to the participants' perspectives on the advantages of the interview method, the casual semi-structured questionnaire format afforded considerable probing and teasing out of additional data. Also, the presence of the researcher promoted rapport building, which was important in the establishment of participant trust.

The time required to complete an interview varied considerably. Interviews varied between 45 minutes and five hours to complete. Although such lengthy interviews may be considered an inefficient use of time, they yielded profitable data.

The interviews with the respondents were frequently intense and emotional, the content disturbing. Due to the sensitivity of the data, and the necessity to respect participant anonymity and the confidentiality of certain information, the researcher was severely constrained in his ability to debrief after each interview. As a consequence, the researcher inherited a weighty emotional burden. In hindsight, this issue should have been addressed at the outset of the study.

In summary, the methodology employed in this study was effective. The desired number of participants was obtained, procuring a significant quantity of remarkably pertinent data. Most participants were cautious during the interviews, providing key details only when rapport had been established with the researcher. The veracity of the data is estimated to be highly truthful. As discussed in

Chapter 3, the participants were anonymous, self-selected, and interviewed by a researcher with investigative interviewing experience. The impression is that the participants were honest, their data, accurate.

Characteristics of a potential euthanasia recipient

The findings in part one of Chapter 3 reveal that a significant percentage of the PWA sample consider euthanasia to be an option for themselves. Since the study did not conduct a longitudinal analysis of the respondents, it can not demonstrate whether any of the participants went on to die an assisted death. That is to say, the data reflect the present opinion of the future behaviour of the PWA sample, but can not predict the actual future behaviour of the sample. The following are general characteristics of those who had developed a clear euthanasia plan:

1. Diagnosis of HIV/AIDS.
2. A strong desire to live well with AIDS, characterized by careful monitoring and treatment of opportunistic infections.
3. A clear understanding of HIV disease progression, and the limits of therapy.
4. Had witnessed the loss of several friends to AIDS.
5. Had the support of a partner, friend, physician, or family member to provide assistance with their death.
6. A basic knowledge of lethal drug combinations.
7. Access to lethal doses of prescription medications--usually sedative and hypnotic drugs.

Characteristics of persons who assist PWA's with dying

Although many of the euthanasia respondents mentioned indirect physician cooperation with aid-in-dying, only two physicians volunteered for the study. It is altogether probable that there are other local physicians who have experiences regarding euthanasia, but were either unwilling to participate, or unaware of the study. The following are characteristics of persons who had been involved in aiding the deaths of PWA's. In general, the respondents were in a position where they could identify strongly with the euthanasia recipient:

1. A close relationship to the involved PWA.
2. A high degree of empathy for the suffering of the PWA.
3. Well-educated; employed in the social service or medical professions.
4. Strong identification with PWA's, either through work, social relationships, or by having HIV diagnosis.
5. A philosophical outlook that included a high degree of respect for the choices and values of others.

Estimated proportion of euthanasia in the AIDS population

Among the PWA participant sample, 13 had AIDS, thus, at the time of the study, they represented only 3.5% of British Columbia's AIDS population of 424 persons (Rekart & Chan, 1992). Caution is urged in generalizations of this sample to the total AIDS population given the size of the sample, and the self-selected, non-randomized method used to recruit the sample. Nevertheless, it is pertinent that 83% of the PWA sample supported euthanasia, a figure that closely resembles that of Gallup Poll results (77%) published at the same time that this study was in progress.

In the Netherlands it has been estimated that between 10 and 20 percent of AIDS patients die by euthanasia (van der Maas et al., 1992). No similar estimates have been proposed elsewhere. The data herein account for 34 assisted deaths between 1980 and 1993, of which 29 occurred in British Columbia. To June 30, 1993, there were 1,060 documented AIDS deaths in B.C. (Rekart & Roy, 1993), yielding a proportion of at least 2.7% being the result of euthanasia. Given the small sample of this study, and that several of the participants reported additional incidents of euthanasia, but with insufficient detail to be included in the data, it is estimated that the actual rate is considerably greater--perhaps, as in the Netherlands, between 10 and 20 percent.

The difficulties of euthanasia

It is not easy to kill a person quickly, painlessly, without violence, and still minimize the risk of detection by the coroner's office. PWA's at the end stages of HIV disease face staggering obstacles in hastening their deaths. Candida of the throat, and cancers of the stomach make swallowing and digesting large quantities of pills extremely difficult. Many PWA's, because of their illness and multiple disorders, acquire a refined understanding of pharmacology and have the potential to access a variety of sleeping pills, analgesics, and anti-emetic drugs. Nevertheless, many physicians are sensitive to the risk of suicide in PWA's and are prudent in their prescribing of potentially lethal drugs. It is rumoured that one of the consequences of *Final Exit* was that it effectively restricted the kinds of drugs that some physicians were previously willing to prescribe.

An anxiety commonly expressed by both participant groups was the fear that an assisted death would be "botched." A consistent theme related by the PWA sample was that they did not fear death, but that they feared the process of dying. Even more, they feared being brought back to life after a euthanasia attempt, in considerably worse shape than they would have begun.

This trepidation was not without foundation. As illustrated by the case scenarios, many of the assisted deaths involved substantial additional suffering. One respondent stated: "There is nothing worse than in the process of trying to alleviate suffering, to see that you are causing more." Many of the acts of euthanasia took several hours, or longer, to be completed. For example, in case scenario 12, it took several days for the patient to die. Acts of euthanasia that had the benefit of an experienced euthanasist, or solid medical advice, were generally completed more quickly, and with fewer complications than those which lacked expertise.

In the Netherlands, the Remmelink Commission found that in two thirds of euthanasia acts, the elapsed time between the start of the procedure and death was no more than one hour. In 28% of the cases, death was achieved within 10 minutes (Van der Maas et al., 1992).

Distressing images equal to those of deplorable back-alley abortions are conjured up by the appalling and torturous conditions amongst which some of the assisted deaths in this study took place. This may make a case for state regulation of euthanasia. The data indicate that individuals are involved in euthanasia and assisted suicide in a completely unregulated, underground environment. Ted Boadway of the Ontario Medical Association echoed this finding at the August, 1993 Canadian Medical Association conference:

> ... and at the present time, it (euthanasia) is happening with no record, no discussion, no consultation, no consistency, no direction, no guidance, and no comfort to the public that it

> is being done well or correctly (Tibble & Boadway, 1993).

Through the provision of regulatory euthanasia services, the state need not approve of the actual behaviour, but could exercise the societal interest that acts of euthanasia occur safely for those who want it. Those who oppose euthanasia, however, will counter that state regulation will weaken the moral argument against euthanasia.

Further Thoughts on Euthanasia

The rational-choice perspective

In Chapter 1, seven criminological theories for suicide were presented. It would appear that a rational-choice theory, where one weighs the costs and benefits of living with AIDS, versus hastening one's death, is the perspective that is grounded in the perceptions of the majority of the PWA sample.

Taylor's (1983) theory of cognitive adaptation to threatening events proposes that a sense of cognitive mastery over a threatening event such as cancer, may enable a person to "return to or exceed their previous level of psychological functioning" (p. 1170). Schneider et al. (1991) propose that for asymptomatic persons with HIV, suicidal consideration might be helpful in gaining a greater sense of control.

In this study, two thirds of the PWA sample report that the knowledge that they can take their own lives helps them to cope. Overwhelmingly, the participants in both samples of this study advance the perception that euthanasia is a calculated act of *taking* control, *and* alleviating suffering. The formulation of a euthanasia plan, discussions with persons who might assist, and the stockpiling of medications are all part of the arrangements a PWA might rationally make in preparation for an assisted death.

The limits of care

Euthanasia, for the respondents in this study, is not a fleeting spontaneous decision made in a transitory moment of distress. It is an act that involves careful planning and discussion. Many of those who had performed euthanasia had been engaged in lengthy discussions that took place months and even years before implementation of the plan. The PWA respondents who had made preparations for an assisted death were all well-aware of the consequences of their strategy, but from their perspectives, the disease offered no better solutions. Goldstone (1992) notes that at St. Paul's Hospital, where the majority of B.C. AIDS patients receive care, a trend of "more deaths occurring in the category 'aggressive therapy, no code' " (p. 24), has been observed. This is attributed to "patients' tenacious desire to live, and the promise of advances in therapy, but with the full realization that there are limits to the benefits of aggressive therapy" (Goldstone, 1992, p. 24).

Persons with AIDS are keenly aware of what to expect at the end-stages of the illness. They know that a great deal of their suffering can be alleviated by aggressive pain-management therapy. Nevertheless, being heavily drugged and unaware of one's environment, unable to communicate and interact for prolonged periods, is an unappealing existence for many PWA's.

Similarly, outside the hospital environment, the poor prognosis of HIV disease may engender euthanasia attempts, yet the hope of new treatments may explain why euthanasia is often delayed until the end-stages of the disease:

> All these choices are being increasingly taken away from us, by the disease. At least if we could choose Thursday, and not Saturday, we could go out feeling strength, courage, independence, and not a victim.

Euthanasia as a political act

Euthanasia can also be seen as a political act. One's social actions are governed by policy and law, and to be effective they require societal support. In ethics, however, "individual conscience is the key, and consensus is no guarantee of legitimacy" (Sawyer et al., 1993, p. 2130). Therefore, those who assist with euthanasia act in their conscience, outside the realm of social policy.

Additionally, euthanasia may be understood as an unlegitimated form of health care. Four of the PWA sample expressed the opinion that entry into hospital signaled the end of their quality of life. For them, although they were following traditional medical therapies, they expected only finite benefits from medical science. That is, euthanasia would determine the end-point of their lives--an act deemed preferable to the possibility that the end-point of life would be blurred in a medical environment. As an alternative to having physicians or others determine when their lives would end, many of the PWA's would prefer to make the decision for themselves. This perspective is articulated in the words of the following participants:

> [For me] it [euthanasia] is a political response. Many gays are social outcasts, and make decisions that are contradictory to what society may support. At present, society's view sees euthanasia as the promotion of death .... To a certain degree, many gay men are decision makers of their own destinies. There are no societal institutions that have encouraged gay men to make decisions. Therefore, they are often the sole deciders of their own destinies.

> [Euthanasia is a response to] loss of control. It has an enabling function. It's therapy, an intervention by choice to maintain control. It allows one to set the terms and conditions as to how one wishes to complete life .... It is healthy for those around you, and for yourself. It's a form of health promotion.

In Clarke and Lester's (1989) application of rational-choice theory to the choice of method for suicide, it was theorized that the availability of lethal agents was "directly related to the extent of their use in suicide" (p. 110). In this study, 80% of the euthanasia acts involved the use of prescription medications, to which persons with AIDS have access. Among the PWA sample who said they would choose euthanasia, all wished for a safe, reliable medication that would bring about a quick death. Such medication, however, is not readily available; hence, the reliance on various combinations of prescription medications.

There are a number of costs associated with euthanasia. The most obvious cost is the shortened life of the recipient. Additionally, there are the significant emotional and potential legal risks to those who offer assistance in dying. Ultimately, one who aids the death of another could be convicted of murder, and lose one's liberty, career, and reputation. Yet, despite these enormous potential costs, the practice of euthanasia continues, and it would appear that there is no shortage of individuals who are willing to do it--repeatedly in some cases--as demonstrated by the respondents in this study.

Why would someone voluntarily take the life of another who has requested it? Rational-choice theory would suggest that there must be a benefit that exceeds the costs. Certainly, in this study, it appears that there was no financial or material advantage gained by the respondents in the euthanasia sample.

It is the less quantifiable things--one's moral and ethical outlook, compassion, trust, honour, and respect for the choices of others--that seem to be the primary motivating factors behind the question of why someone would deliberately break the law, and assist the death of another person. The experience of euthanasia has been called a loving act: "People have told me it was the most wonderful thing they have done for their lover or the most wonderful thing that they have ever done in their life" (Aronson, 1987, p. 5). Two of the respondents in this study confirmed similar attitudes:

> Euthanasia is a courageous act, very intimate for the participants. In my situation we all jumped into bed with him. It was very tactile.
>
> I feel very privileged that I was the one who got to do it .... I think it is a high honour, that somebody feels comfortable enough with you, and wants you to be the last face that they see.

In the majority of the cases, there was a lengthy relationship between the assistant and the euthanasia recipient. Therefore, identification with the deceased appears to be a significant variable in the decision to commit the act of euthanasia.

Implicit support for euthanasia by other groups

That euthanasia can be both rational and supported by other uninvolved parties is evidenced by the responses of several physicians in the scenarios presented in Chapter 3. According to the B.C. *Coroner's Act* (1979), physicians are required to report to the coroner any death that occurs "as a result of violence, misadventure, negligence, misconduct, malpractice or by suicide" (p. 3). The physicians who attended the deaths described in cases 15 and 16, allegedly reported that suicides had occurred, but they deliberately omitted pertinent information out of empathy for the respondent. The conduct of the physicians in the above cases, and that of the physicians in cases four to eight, as well as the apparent willingness of some physicians to prescribe lethal medications with agreement to pronounce a "natural" AIDS-related death, would indicate a degree of professional empathy for euthanasia. In the United States, it has been reported that "the coroner's office generally accepts the word of the doctor that the person died of

AIDS--and performs no investigation" (Aronson, 1987, p. 5). It would appear, from the comments of one of the physicians in this study, that a similar practice exists in British Columbia: "An autopsy does not happen. I know what the cause of death is. It's pulmonary edema caused by K.S."

Another example of professional empathy for euthanasia may be found in the manner that the death of David Lewis was investigated. The B.C. Coroner determined that suicide was the cause of his death (Robinson, 1991), although there was plenty of evidence to suggest that Lewis's death could have been assisted; the intravenous drip apparatus that he used was still in place, and several people were present when the coroner was called to view his body. Perhaps out of compassion and sensitivity to the issues, the possibility that Lewis's death had been assisted was overlooked by the coroner's office.

Although there appears to be a general consensus among the AIDS population regarding decisions at the end of life (Canadian AIDS Society, 1991), and a certain degree of complicity in this view by the medical profession (Charbonneau, 1992), there is considerable legal confusion regarding the issues of killing, letting die, and suicide. The following section delineates the perplexity of the problem with a discussion of the recent Nancy B. case.

Legal and Philosophical Distinctions

Killing versus allowing to die

In the case of *Nancy B.*, the act of stopping life-sustaining treatment was interpreted by the court as an act that would allow death to occur, through the natural progression of the disease. If there is no moral significance whether the life-sustaining treatment was stopped, then it would seem that it is also morally insignificant whether it was the act of the physician that led to Nancy's death. Because Nancy had requested cessation of the treatment, and because her family, physician, and the court respected her civil rights and her desire to be self-determinate, her death was seen to be morally justified: it was not seen to be killing.

Perhaps Nancy's death was morally justified, but was she allowed to die, or was she killed, or both? Suppose she was prepared to remain on the respirator indefinitely, but her doctor turned it off and she died. Suppose her doctor's actions are discovered and she claims, "I did not kill her, Guillain-Barré syndrome was the cause of her death. My action only allowed her to die." Certainly, in this context, the argument that Nancy was "allowed to die" would be dismissed; the physician would be seen to have killed the patient. Although the actions and the motive in both examples are the same, there is no consent in the latter case. Instead of making the moral distinction between killing and letting die, it would be more helpful to understand the cessation of life-sustaining treatment as killing, and in some cases where consent exists, as morally permissible. According to this line of argument, which has been advanced by several influential bioethicists (Rachels, 1975; Brock, 1993), Nancy B. was killed. The following section presents the argument that, not only was Nancy B. killed, but she also committed suicide.

Is voluntary cessation of life-support suicide?

Even if one resists the notion that Nancy B. was killed, the question still arises as to whether or not she committed suicide. Justice Dufour, in his judgment for Nancy, agreed with the American decision of *Conroy* (1985) that interpreted the cessation of life-sustaining treatment as not constituting suicide (*Nancy B. v. Hôtel Dieu du Québec, 1992*):

> In any event, declining life-sustaining medical treatment may not properly be viewed as an attempt to commit suicide. Refusing medical intervention merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease, and not the result of a self-inflicted injury. In addition, people who refuse life-sustaining treatment may not harbor a specific intent to die, rather, they may fervently wish to live, but to do so free of unwanted medical technology, surgery, or drugs, and without protracted suffering.... Recognizing the right of a terminally ill person to reject medical

> treatment respects that person's intent, not to die, but to suspend medical intervention at a point consonant with the "individual's view respecting a personally preferred manner of concluding life." The difference is between self-infliction or self-destruction and self-determination (*Re Conroy*, 1985, p. 1224).

The claim that a patient is not committing suicide because a natural death is desired, and not self-destruction, "assume(s) that the discontinuation of life-sustaining treatment does not 'cause' a patient's death" (Harvard Law Review, 1992, p. 2030).

It is possible that such a distinction is in part formulated to protect physicians, families, and other individuals from potential criminal liability under laws that prohibit assisting in a suicide (Brock, 1993). Also, it is a distinction that the Catholic Church, for example, has promoted for reasons of justification. Although this sort of distinction between cessation of life-support and suicide may appear plausible, it is also problematic: What is the difference between a terminally ill individual who chooses to cease life-sustaining treatment because expected future life is judged to be worse than no life at all, and a healthy person who ingests a lethal poison for the same reason? Both deaths are self-inflicted. The decisions and the end results are the same; just because a person is terminally ill, or dependent upon technology for survival, is no reason to suggest that she or he could not commit suicide.

The preceding sections have shown how the courts have crafted a certain moral, ethical, and legal solution that allowed for Nancy B.'s death. Nevertheless, despite the legal denial, Nancy B. was killed *and* she committed suicide, *and* her death was morally justifiable.

Active voluntary euthanasia

If a competent person is legally entitled to refuse life-sustaining treatment, knowing that death will result, and if a competent person is legally entitled to commit suicide, are they also entitled to have the assistance of others to end their lives through a lethal injection or some other euthanasic? Certainly, the vast majority of the participants in this study support the notion of legalized euthanasia and, although it is illegal, they are prepared to defy the law.

The central ethical argument for euthanasia is based on the values of individual self-determination and well-being (Brock, 1993). Self-determination, for the participants in this study, may be interpreted as making the most important decisions of their lives, in accordance with their own values and perceptions of what constitutes a good life.

Self-determination allows individuals to exercise control over their physical and mental state, as well as when and where they die. "The principle of self-determination demands that the state respect the individual's judgment about how much pain he wishes to tolerate before death, unless there are overriding public policy interests" (Harvard Law Review, 1992, p. 2026).

The second value, well-being, is based on the notion that there are circumstances where "life is no longer considered a benefit to the patient, but ... [is] a burden" (Brock, 1993, p. 207). Well-being defies quantification. It is based solely on the judgment of a competent patient as to whether the benefit of a continued life overrides the benefit of death.

As mentioned earlier, there is considerable public support for euthanasia, as well as evidence that the medical community sees euthanasia as falling within the domain of practitioners (Verhoef & Kinsella, 1993). If it can be agreed that there are circumstances where the values of self-determination and well-being support euthanasia, then the issue of public policy should be addressed. The next section considers some public policy concerns, and advances the potential benefits of a policy that permits euthanasia and aid-in-dying.

Public Policy

A public policy on euthanasia should bring the *Criminal Code* into balance with the common law and current euthanasia behaviour, as well as recognize the principles of individual autonomy, equality and justice, and self-determination. The aforementioned principles are consistent with the values articulated in the *Charter of Rights and Freedoms*. Section seven of the *Charter* provides:

> 7. Everyone has the right to life, liberty and the security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice (*Constitution Act*, 1982).

The right to life, liberty and the security of the person involves distinct, independent interests which have been affirmed by the court (*Reference re. s. 94(2) of Motor Vehicle Act*, 1985). Included within s. 7 is the respect for human dignity. In *Morgantaler* (1988), Justice Wilson stated that "an aspect of the respect for human dignity on which the *Charter* is founded is the right to make fundamental personal decisions without interference from the state" (p. 42).

In *Rodriguez* (1993a), Chief Justice McEachern noted that the rights guaranteed by s. 7 should be considered in the context of the values and principles that underly the *Charter* as a whole. Chief Justice McEachern referred to

Oakes (1986), where it was concluded that that the essential values and principles for a free and democratic society include:

> ... respect for the inherent dignity of the human person, commitment to social justice and equality, accommodation of a wide variety of beliefs, respect for cultural and group identity, and faith in social and political institutions which enhance the participation of individuals and groups in society (p. 136).

The right to die has been afforded limited recognition in the form of advance directives, and some case law. Since it has been established that the right to die exists, it follows that individuals who seek to exercise this right, and suffer from terminal illness or unbearable suffering, should have a remedy available to them.

In addition to its recognition of fundamental principles of justice, euthanasia policy has significant social benefits. First, it allows individuals to take control of their lives. How one dies is part of life itself, and one should be able to exercise choice on this aspect of life. Often just knowing one has control of one's death leads to a greater feeling of control of one's life. A sense of control is essential to quality of life, especially when one is confronting death while living with

AIDS (Personal communication, Dr. Peter Jepson-Young, January 31, 1992 [15]).

A second benefit of a euthanasia policy is the ability for an individual to choose a less violent and therefore less tragic means of death. In this study, a significant number of the assisted deaths did not proceed well: patients vomited, medications proved unsatisfactory and slow-acting, violence was employed, and in some cases, the involved parties witnessed enhanced suffering, rather than the desired alleviation of suffering.

Additionally, there are numerous examples of AIDS-related suicides that leave behind tremendous pain and guilt. Amongst these suicides, many are violent (Marzuk et al., 1988; Kizer et al., 1988), others involve the grisly discovery of a decomposing body (Profili, 1992). Given that suicide is not a criminal offense in Canada, it seems rational that in certain circumstances, individuals should have the choice of a controlled, non-violent, assisted death.

As already discussed in this thesis, voluntary euthanasia has significant economic benefits. Resources

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[15] Dr. Peter Jepson-Young, a physician with AIDS, was noted for the award-winning weekly CBC television news segment, "AIDS Diary."

that are saved by euthanasia could be redirected to other areas of health care.

A fourth benefit is the savings in legal and court costs. Individuals should not have to go to court to obtain permission to die an assisted death. The expenses incurred in cases such as those of Nancy B. and Sue Rodriguez are prohibitive; the emotional cost and invasion of privacy immeasurable. A quasi-judicial board would be more cost-effective, and offer greater privacy in decision making.

Brock (1993) identifies another good consequence of legalizing euthanasia. Where death is expected and has been accepted, it is more humane that death occur "quickly and peacefully, when that is what the patient wants" (p. 217). We have concerns about the manner of our deaths, in part due to our desire that we will be remembered by others in times that we were happy, functioning, and contributing. Those who die suddenly, whether in their sleep or by accident, are often considered to have been fortunate to have died swiftly. For some people, euthanasia will be a more humane death than protracted dying in a suffering, drugged, or comatose state.

A final benefit is that the policy will allow individuals to make critical decisions regarding organ donation. Although persons with AIDS may not be able to donate their organs, the lives of up to five people can be saved with the harvested organs of euthanasia recipients (Kevorkian, 1991), and up to 13 lives may be significantly improved (B.C. Registry for Organ Donors, 1993).

Who should perform euthanasia?

If a policy legalizing euthanasia is ever approved, who should be responsible for performing it? In the Netherlands, it is the exclusive domain of physicians. As we have seen in this investigation, there are good reasons for the involvement of the medical profession, the main one being to ensure that a safe and effective method is employed. Nevertheless, this investigation has also shown that individuals other than physicians are prepared to perform euthanasia. Just as midwives argue that birthing is not a medical procedure, neither is aiding death. Helping a person out of this world need be no more a medical procedure than is assisting an infant into this world.

The act of voluntary euthanasia is a relatively simple one, provided that one has the methods available. In many instances, the recipient could even activate the final treatment, although this should not be viewed as morally or ethically different than if another person was to voluntarily perform the task.

Brock (1993) has suggested that there are at least two reasons for limiting the practice of euthanasia to physicians. First, he suggests that physicians have a legitimate role in assessing informed consent, treatment alternatives, prognosis, and patient quality of life. Second, one way to limit the potential for abuse is to restrict the number of persons authorized to perform it. Physicians, "whose training and professional norms give some assurance that they would perform euthanasia responsibly, are an appropriate group of persons to whom practice may be restricted" (Brock, 1993, p. 230).

Brock's perspective may appear sensible, but it is subject to the same criticisms that have been leveled at Dutch physicians. In the Netherlands, physicians have been accused of failing to obtain a clear request from the patient, failing to consult with colleagues, and falsification of death certificates. A more suitable alternative is to refer all such cases to a quasi-judicial tribunal that reviews applications for aid-in-dying. The onus would be on the patient to give evidence regarding his or her clinical condition, and consideration must be given to alternative treatments. The application would be completed with the assistance of a professionally trained aid-in-dying counsellor who would evaluate the applicant's ability to give informed consent and ensure that all relevant social, medical and psychiatric information was included. Approved applicants would be issued an aid-in-dying licence, which would allow for voluntary euthanasia to be administered under medical supervision, but not necessarily by a physician (See Ogden, 1994).

Within such a policy, one must recognize that although a number of the variables concerning euthanasia decisions can be clearly and validly delineated, each decision must be focussed on the completion of life for one specific individual. That is, a policy on euthanasia must not lose sight of respect for the values and the uniqueness of each individual that it considers.

Suggestions for further research

This study has explored euthanasia and assisted suicide in the context of only one terminal disease--AIDS. "In Canada, the issue of euthanasia has reached the 'emerging policy' stage of development" (Ogden, 1993, p. 9). Good policy, however, must be based on solid research.

There is an increasing interest in researching euthanasia and assisted suicide from the perspectives of those who are involved in the acts. For example, Dr. Roy, of the *Center for Bioethics Clinical Research Institute of Montreal* is preparing a proposal for a province-wide study similar to this one (Personal communication, Dr. Roy, September 16, 1993).

Nevertheless, a national euthanasia study is the best way to generally address the issue of euthanasia and assisted suicide. Such a study would best proceed in four parts: First, a retrospective study of acts of euthanasia and assisted suicide should be performed. The retrospective study would require Attorney General exemption from prosecution for all participants. A comprehensive questionnaire could be administered to doctors, nurses, and health care workers, regarding their attitudes and experiences with euthanasia and assisted suicide.

Second, interviews could be conducted with a sample of the respondents who have had experiences with euthanasia and assisted suicide. From these interviews, case studies could be accumulated, and additional interviews could be conducted with other individuals identified by the participants.

Third, interviews with a sample of Coroners and Medical Examiners from each province would address cases of suspected euthanasia or assisted suicide. The following statement from a B.C. Coroner suggests that some coroners are aware that euthanasia occurs:

> I don't doubt that euthanasia goes on in the AIDS population, and I do believe that some doctors note an AIDS death instead of suicide .... It is often difficult to tell if a suicide was assisted. Where I have suspected it, it appears to have been voluntary, at the end stages, and where there was no hope for recovery (Personal communication, anonymous B.C. Coroner, July 26, 1993).

If the above statement is a reflection of coroners' attitudes, this group is in a position to contribute some interesting insights.

Fourth, a death certificate study could be completed. A sample of all death certificates would be drawn and the attending physicians would be asked to provide specific information regarding each case. In essence, information regarding the actions and intentions of the physician, and the patients' role in decision making would be requested. For example, this would include information regarding use of pain-relieving drugs that may coincidentally hasten death, the physician's intent in the administration of the drugs, and the expressed wishes of the patient.

Conclusions

The results of this investigation indicate that the development of opinion within the AIDS population and among their caregivers can make a significant contribution to the quality of decisions made regarding euthanasia, assisted-suicide, and other decisions regarding terminal care. For example, in this study several of the respondents from the PWA sample indicated that the interview itself had made an important contribution to their thinking regarding euthanasia and assisted suicide. In particular, several of the respondents expressed the view that more thoughtful discussion and planning needed to occur regarding their end-of-life decisions. This included enhanced consultation with their physicians and family regarding future treatment decisions; legal housekeeping in the areas of wills and advance directives; and careful research into euthanasia techniques. In general, the participants were appreciative of the opportunity to discuss the most important decisions of the their lives in an open, non-threatening and non-judgmental environment.

Similar opinions and feelings were expressed by the participants from the euthanasia sample. Some said that they had been looking forward to the interview because they had either never before discussed their euthanasia behaviour, or had a very limited peer group with whom they could share their experience. One participant noted that being involved in the act of euthanasia was the most significant and memorable event of her life, yet she felt very much restricted as to whom she could disclose. Moreover, several of the euthanasia respondents indicated that their decision-making would be more thorough in future cases, and that they hoped to provide a better and more humane death if they were to be involved in another act of euthanasia.

The main purpose of this investigation was to unveil, as well as possible, the phenomenon of euthanasia in the context of HIV/AIDS. The intensive interviews with 18 PWA's regarding their views on euthanasia, and 17 individuals who have been involved in euthanasia, should make a significant contribution to the growing body of literature on euthanasia and assisted suicide. The research demonstrates that not only is euthanasia a consideration for some PWA's, but also suggests that it is a vital choice that is exercised by many. The decision to accept an assisted death is not one that any of the involved parties takes casually. Rather, the decision is the product of considerable discussion and planning; action on the decision is initiated out of love, respect, compassion, and the understanding that there is no hope for recovery.

An important question is whether the participants from the euthanasia sample may have described their roles in the euthanasia decisions too favourably. Given the frank discussion, and frequently unsettling descriptions of the horrendous difficulties in completing a act of euthanasia, it appears unlikely that the respondents were dishonest. As mentioned earlier, a high degree of participant openness was demonstrated, and participants had little to gain by volunteering for the research.

Euthanasia and assisted suicide are issues that will increasingly present themselves in the future, and not just in the context of AIDS. First, as a consequence of the aging North American population, there will be increased mortality rates amongst the aged. Additionally, the average age at death will increase; therefore, the number of persons who are unable to express their own wishes with respect to treatment decisions will increase. Second, the continued advances of medical technology will increase the possibilities that life may be prolonged, and in doing so, we will encounter more situations where decisions about the initiation, cessation, and withholding of treatment will have to be made. Third, there is an increasingly aggressive lobby for active voluntary euthanasia. As discussed earlier, this lobby has surfaced in the form of *Charter of Rights* challenges and parliamentary initiatives such as the Ontario *Consent to Treatment Act*, and B.C. *Representation Agreement Act*. Even the Canadian Medical Association recognizes that it can no longer avoid the issue, and as a result, recently prepared a series of discussion papers for its membership in preparation for a policy to be developed by 1994 (Sullivan, 1993b).

Individuals who choose to involve themselves in euthanasia and assisted suicide should be accountable for their decisions. The present legal climate, with its inconsistencies and confusion about killing versus allowing to die, imposes a barrier that precludes any accountability for justified killing. There is a prevailing taboo surrounding the topic of euthanasia. Even those who are comfortable enough to perform the act are extremely cautious about disclosing their behaviour to others. Acts of euthanasia and assisted suicide are occurring in the Greater Vancouver AIDS population. The opportunity for more open discussion has been cleared by the contributions of those who have volunteered for this study. The practice of justifiable euthanasia should not continue to be a closeted behaviour. AIDS has succeeded in uncloseting much about sexual behaviour and sexuality, perhaps it will also succeed in being the disease to uncloset euthanasia.

APPENDIX A

RELATED CRIMINAL CODE SECTIONS

APPENDIX A: RELATED CRIMINAL CODE SECTIONS[16]

Consent to death.
14. No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given. R.S., c. C-34, s.14.

Surgical operations.
45. Every one is protected from criminal responsibility for performing a surgical operation on any person for the benefit of that person if

(a) the operation is performed with reasonable care and skill; and
(b) it is reasonable to perform the operation, having regard to the state of health of the person at the time the operation is performed and to all the circumstances of the case. R.S., c. C-34, s.45.

Duty of persons to provide necessaries - Offence - Punishment - Presumptions.
215. (1) Every one is under a legal duty

(a) as a parent, foster parent, guardian or head of a family, to provide necessaries of life for a child under the age of sixteen years;
(b) as a married person, to provide necessaries of life to his spouse; and
(c) to provide necessaries of life to a person under his charge if that person
  (i) is unable, by reason of detention, age, illness, insanity or other cause, to withdraw himself from that charge, and
  (ii) is unable to provide himself with necessaries of life.

(2) Every one commits an offence who, being under a legal duty within the meaning of subsection (1), fails without lawful excuse, the proof of which lies on him, to perform that duty, if

(a) with respect to a duty imposed by paragraph (1)(a) or (b),
  (i) the person to whom the duty is owed is in destitute or necessitous circumstances, or
  (ii) the failure to perform the duty endangers the life of the person to whom the duty is owed, or causes or is likely to cause the health of that person to be endangered permanently; or
  (b) with respect to a duty imposed by paragraph (1)(c), the failure to perform the duty endangers the life of the person to whom the duty is owed or causes or is

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[16] *Criminal Code*, R.S.C. 1985, c. C-34.

likely to cause the health of that person to be injured permanently.

(3) Every one who commits an offence under subsection (2) is guilty of

(a) an indictable offence and is liable to imprisonment for a term not exceeding two years; or

(b) an offence punishable on summary conviction ....

R.S., c. C-34, s.197; 1974-75-76, c.66, s.8; 1991, c.43, s.9.

Duty of persons undertaking act dangerous to life.
216. Every one who undertakes to administer surgical or medical treatment to another person or to do any other lawful act that may endanger the life of another person is, except in cases of necessity, under a legal duty to have and to use reasonable knowledge, skill and care in so doing. R.S., c. C-34, s.198.

Duty of persons undertaking acts.
217. Every one who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life. R.S., c. C-34, s.199.

Abandoning child.
218. Every one who unlawfully abandons or exposes a child who is under the age of ten years, so that its life is likely to be endangered or its health is or is likely to be permanently injured, is guilty of an indictable offence and liable to imprisonment for a term not exceeding two years. R.S., c. C-34, s.200.

Acceleration of death
226. Where a person causes to a human being a bodily injury that results in death, he causes the death of that human being notwithstanding that the effect of the bodily injury is only to accelerate his death from a disease or disorder arising from some other cause. R.S., c. C-34, s.209.

Counselling or aiding suicide.
241. Every one who

(a) counsels a person to commit suicide, or

(b) aids or abets a person to commit suicide,

whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years. R.S., c. C-34, s.224; R.S. 1985, c. 27 (1st Supp.), s.7(3).

Administering noxious thing
245. Every one who administers or causes to be administered to any person to take poison or any other destructive or noxious thing is guilty of an indictable offence and liable

(a) to imprisonment for a term not exceeding fourteen years, if he intends thereby to endanger the life of or to cause bodily harm to that person; or
(b) to imprisonment for a term not exceeding two years, if he intends thereby to aggrieve or annoy that person.
R.S., c. C-34, s.229.

Overcoming resistance to commission of offence.

246. Every one who, with intent to enable or assist himself or another person to commit an indictable offence,
(a) attempts, by any other means, to choke, suffocate or strangle another person, or by any other means calculated to choke, suffocate or strangle, attempts to render another person insensible, unconscious or incapable of resistance, or
(b) administers, or causes to be administered to any person, or attempts to administer to any person, or causes or attempts to cause any person to take a stupefying or overpowering drug, matter or thing, is guilty of an indictable offence and liable to imprisonment for life. R.S., c. C-34, s.230; 1972, c.13, s.70.

Mischief

430....
(5.1) Every one who wilfully does an act or wilfully omits to do an act that it is his duty to do, if that act or omission is likely to constitute mischief causing actual danger to life, or to constitute mischief in relation to property or data,
(a) is guilty of an indictable offence and liable to imprisonment for a term not exceeding five years; or
(b) is guilty of an offence punishable on summary conviction. R.S., c. C-34, s.387: 1972, c.13, s.30; R.S. 1985, c.22 (1st Supp.), s.57.

APPENDIX B

ARTICLE PUBLISHED IN AIDS VANCOUVER AND PERSONS WITH AIDS NEWSLETTERS

APPENDIX B: ARTICLE PUBLISHED IN AIDS VANCOUVER AND PERSONS WITH AIDS NEWSLETTERS (October, 1992)

SIMON FRASER UNIVERSITY RESEARCH on HIV/AIDS and END-of-LIFE DECISIONS

There is a wide consensus within the AIDS movement that end-of-life decisions are personal decisions that should be supported. If you have HIV or AIDS, or have provided care to somebody with AIDS, your views, perspectives, and experiences regarding end-of-life decisions are needed.

You are invited to participate in a confidential, unstructured interview to share your opinions and experiences on this topic.

Individuals affected by HIV and AIDS courageously confront issues regarding the quality of their lives with an urgency that most people never experience. Persons living with AIDS reflect deeply upon their lives and develop tremendous insight into their concepts of personhood.

This research involves the subject of euthanasia and assisted suicide in persons with HIV or AIDS. The research is guided by the principles of respect for the individual, the right to privacy, and respect for the autonomy of individuals and their individual choices.

It has been estimated that persons with HIV and AIDS are at much greater risk of suicide than the general population. Many people with HIV infection or AIDS stockpile medications in preparation for their death. Often they fear an uncomfortable death and question whether their physician will be able to offer adequate pain relief. There are also concerns about becoming permanently dependent on other people, pain medication or machinery, with no hope for any improvement in health. Some AIDS patients find that living with AIDS is seriously compromised by the disablement that sometimes accompanies the illness.

For many PWA's, death is not the worst alternative available to them. Some may choose death as their next form of treatment.

The act of suicide is not illegal in Canada. However, counselling or assisting somebody to commit suicide is a crime punishable by up to 14 years in prison. The *Criminal Code* treats euthanasia (merciful or compassionate killing) as murder. Arguably, such laws are outdated and require extensive reform.

In the Netherlands, physicians regularly perform euthanasia. In 1991, the Dutch Remmelink Commission estimated that between 10 and 20 percent of all deaths among terminal AIDS patients in the Netherlands involved physicians performing euthanasia or assisting suicide.

Persons with AIDS are rational adults who are facing a loss of autonomy, and a loss of the freedom to make the most important decisions and choices of their lives. For many persons with AIDS, self-determination is central to their very being, and they wish to remove barriers to their self determination.

Your participation in an interview will help to challenge those involved in the right-to-die debate to move beyond speculative viewpoints and incorporate your perspectives and experiences.

The results of the research will be of significance to those with AIDS as well as others who are facing end-of-life decisions. It is expected that the research will make a significant contribution to the morals and ethics of law and medicine, as well as provide important data for public policy development and law reform.

Confidentiality and anonymity of all research participants is protected. Personal identifying information will not be required. You may offer a pseudonym if you choose.

For more information please contact in confidence:

Russ Ogden, BGS, BSW
331 Strand Avenue
New Westminster, B.C.
V3L 3J1

Phone: 525-9152

APPENDIX C

PARTICIPANT INFORMATION SHEET

APPENDIX C: PARTICIPANT INFORMATION SHEET

EUTHANASIA AND ASSISTED SUICIDE IN PERSONS WHO HAVE ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) OR HUMAN IMMUNODEFICIENCY VIRUS (HIV)

This exploratory study is in partial fulfillment of an M.A. degree in criminology. It has received approval from the SFU Ethics Review Committee. The research addresses individual attitudes, perspectives, and experiences with respect to euthanasia, assisted suicide and other end-of-life decisions. The study will also attempt to discover the extent to which euthanasia and assisted suicide are practiced in the HIV/AIDS population.

If you have HIV or AIDS, or have provided care to somebody with AIDS, your views, perspectives and experiences are needed.

You are invited to participate in a confidential unstructured interview to share your opinions and experiences on this important topic.

Your anonymity and confidentiality is assured. There is no requirement for any identifying information to be released to the researcher.

This is a vital and sensitive subject that has not been researched to any great extent. The information that is sought is directly applicable to the AIDS population, legal reformists, physicians and the general population. The proposed research will create an opportunity to marry theory and opinion with current behaviour and perspectives. It will challenge those involved in the right to die debate to move beyond speculative viewpoints and incorporate the experiences of the principles.

For more information, please contact in confidence:

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APPENDIX D

ARTICLE PUBLISHED IN B.C. MEDICAL JOURNAL

APPENDIX D: EUTHANASIA/AIDS RESEARCH

BC Medical Journal - Volume 35, Number 5, May 1993, p. 317.

Although anecdotal evidence suggests that physician-assisted suicide is increasingly being performed, particularly among AIDS patients, there is a paucity of scholarly literature documenting actual cases of euthanasia and assisted suicide. The nationwide attention to the case of Sue Rodriguez of Victoria, B.C., demonstrates the growing public interest in the euthanasia issue. Rodriguez, who suffers from amyotrophic lateral sclerosis, is now appealing to the Supreme Court of Canada for the right to a physician-assisted suicide.

Given the importance of the issue, media attention, and the number of physicians publishing opinions, euthanasia would seem a likely subject of inquiry for researchers. Given the large HIV-positive population of the Lower Mainland, it is highly probable that B.C. physicians who treat AIDS patients possess information crucial to the right-to-die issue.

Current discussion of the right-to-die dilemma has centred around opposing ethical views, rather than facts. Research is needed to move the right-to-die debate beyond speculative viewpoints. Such research would make a significant contribution to the morals and ethics of law and medicine, as well as provide important background data for those considering policy development and law reform.

Russel Ogden is a graduate student of criminology at Simon Fraser University. He is conducting research on euthanasia and assisted suicide in the context of HIV/AIDS. The research project has been approved by the SFU Ethics Review Committee. Physicians who have treated AIDS patients who have died an assisted death are invited to participate in a confidential interview to share their experiences on this topic. Confidentiality and anonymity of all research participants is assured. Personal identifying information is not required. Participants will be offered a copy of the completed study.

For more information, please contact in confidence:

Russel Ogden,
331 Strand Avenue
New Westminster, B.C.
V3L 3J1

Phone: 525-9152

APPENDIX E

INFORMED CONSENT FORM

APPENDIX E: INFORMED CONSENT FORM

SIMON FRASER UNIVERSITY
INFORMED CONSENT BY SUBJECTS TO PARTICIPATE IN THE RESEARCH PROJECT:

EUTHANASIA AND ASSISTED SUICIDE IN PERSONS
WHO HAVE ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)
OR HUMAN IMMUNODEFICIENCY VIRUS (HIV).

Note:

The University and those conducting this project subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of subjects. This form and the information it contains are given to you for your own protection and full understanding of the procedures, risks and benefits involved. Your signature on this form will signify that you have received a copy of this document which describes the research project, that you have received an adequate opportunity to consider the information in the document, and that you voluntarily agree to participate in the project.

This research study involves euthanasia, assisted suicide, and other end-of-life decisions in persons with HIV and AIDS. Your cooperation with this project will make a significant contribution to the morals and ethics of law and medicine, as well as provide important data for public policy development.

In an interview you will be asked to share your perspectives and experiences with respect to end-of-life decisions. It is recognized that you may reveal information that could be regarded as illegal behaviour. For the protection of all participants, no identifying information is required.

In the event that the identity of participants becomes known to the researcher, such information shall be secured in locked storage, the location of which will be known solely to the researcher. Only the researcher will have knowledge of the identity of participants--anonymity and confidentiality will be respected.

Upon completion of the study, all participant-identifying details, including this consent form will be destroyed.

Having been asked by Russel Ogden of the School of Criminology of Simon Fraser University to participate in a research project, I have read the procedures specified in this document.

I understand the procedures to be used in this research and the personal risks to me in taking part.

I understand that I may withdraw my participation in this project at any time.

I also understand that I may register any complaint I might have regarding the research with the researcher named above or with Dr. Margaret Jackson, Director of the School of Criminology, Simon Fraser University.

Copies of this study, upon its completion, may be obtained by contacting:

Russel Ogden
School of Criminology
Simon Fraser University
Burnaby, B.C. V5A 1S6

I Agree to participate in an interview where I will discuss my views, perspectives and experiences about HIV, AIDS, and end-of-life decisions.

NAME (please print):______________________________

ADDRESS:______________________________

SIGNATURE:____________________ WITNESS:______________

DATE:______________________________

APPENDIX F

PARTICIPANT QUESTIONNAIRE

APPENDIX F: PARTICIPANT QUESTIONNAIRE

Part A: Schedule of Questions--HIV/AIDS Participants

Demographics

1. Age, sex, level of education, occupation.

2. What is your religious preference?

3. When were you diagnosed with HIV/AIDS? Do you know what your t-cell count was at that time? What is your most recent t-cell count?

4. What course has the illness taken to date? List AIDS related illnesses/opportunistic infections to date.

5. What are your views and perspectives regarding euthanasia and assisted suicide?

6. Do you have any experiences with euthanasia or assisted suicide?

7. Euthanasia has been said to be a response to a number of fears--fear of machines, fear of uncontrollable pain, and fear of losing control of oneself. Are these or any other fears applicable to you?

8. Is assisted suicide or euthanasia an option you are considering?

9. Have your views regarding euthanasia and assisted suicide changed since diagnosis with HIV?

10. Under what conditions would you consider aid-in-dying? Who might be involved in helping you (without naming persons)?

11. Why did you choose to participate in this study?

Social aspects/support & coping

13. How do you perceive levels of support (emotional and financial) while living with AIDS?

14. Do you have many friends with HIV? Do these relationships make up a significant part of your social life?

15. How many friends have you lost to AIDS? Does this include any long term partners?

16. How do you perceive your present quality of life? Future quality of life?

17. How do you perceive levels of support for euthanasia/assisted suicide? Where does this come from?

18. Does the knowledge that you can kill yourself help you to cope?

19. How do you perceive your present level of mental distress?

Stigmatization

20. Do you have any concerns regarding the social stigmatization of AIDS and gay sexuality?

21. Do you have concerns regarding doctors not making themselves available for AIDS patient care?

Legal issues

22. What kinds of preparations have you made for your death? eg. living will/advance directive, will, health care proxy, discussed with doctor, stockpiling medications etc.

23. What knowledge do you have about accessing aid-in-dying?

24. What are your views regarding the law and euthanasia and assisted suicide?

25. In the case of an assisted death, do you have concerns for others who may be at risk for prosecution? How will you minimize the risks?

Part B: Schedule of Questions--Euthanasia Participants

Demographics

1. Age, sex, level of education, occupation.

2. What is your religious preference?

3. Description of the patient: age, sex, year of death.

4. How ill was the patient at the time of the assisted death? Include clinical and subjective details if possible.

Attitudes toward euthanasia and assisted suicide

5. What are your views and perspectives regarding euthanasia and assisted suicide?

6. Euthanasia has been said to be a response to a number of fears--fear of machines, fear of uncontrollable pain, and fear of losing control of oneself. Are these or any other fears applicable to your circumstances?

Relationship to the PWA

7. What was your relationship to the PWA? Why did you decide to help?

8. Under what conditions would you/did you give aid-in-dying?

Knowledge of euthanasia methods

9. What knowledge do you have about accessing aid-in-dying information?

10. How did you plan the assisted death?

The assisted death

11. What details of the euthanasia(s)/assisted suicide(s) can you share? What method was employed, effectiveness, complications, etc?. Do you accept the decision that was made?

12. Were there any efforts to conceal the euthanasia/assisted suicide? Concerns regarding autopsy or criminal charges.

13. Have you been able to discuss your involvement with anybody else? Do you have concerns about sharing such information with others?

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