

U.K. SOCIAL WORKERS' ATTITUDES TOWARD ASSISTED DEATH, POLICIES
GUIDING PRACTICE, AND TRANSFORMATIONAL COLLABORATION:
HOLDING FAST TO MEDICO-ETHICAL PRINCIPLES OF BENEFICENCE, NON-
MALFEASANCE AND SOCIAL JUSTICE

by

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Abstract

Social workers play a key, but unacknowledged role regarding end-of-life decisions. The dearth of research on social workers' attitudes toward assisted death is in stark contrast to the abundance of research on assisted death involving health care practitioners. Through analysis of data collected on members of the British Association of Social Workers (BASW) in 1998, this research examines attitudes of social workers toward assisted death (AD) including both voluntary euthanasia (VE) and assisted suicide (AS).

Several hypotheses are developed from the available literature on assisted death involving social work and medical practice. The quantitative data are supplemented with written responses by BASW members. There is variation between social workers' support of AD by country. English social workers are the most supportive, followed by Scottish, Welsh and Northern Ireland social workers. As a group, social workers support legalizing VE (72%) and AS (72.5%). A majority of social workers (69%) endorsed the Dutch model of legalized euthanasia. A minority of social workers (25%) indicated that they would report a colleague they suspected was involved in an assisted death. Catholics were less supportive of legalizing assisted death and the Dutch model of euthanasia but, regardless of religion, most social workers respect their clients' wishes regarding end-of-life choices. Although less than 50% of social workers want to be involved in the decision-making making process with clients, over 65% indicated a willingness to engage in policy development regarding assisted death.

Given their position, policy development is essential for social workers to be effective in end-of-life care. The theoretical perspective guiding the research shows that social workers support medico-ethical principles of autonomy, beneficence, non-maleficence and social justice in assisted death. This finding places social workers in an important position regarding care of the dying. Future research should include the development and test of a collaborative model of training for all practitioners working with those facing end-of-life decisions. As a profession, social work must prepare itself for the challenges posed by growing populations of persons facing end-of-life decisions.

Key words: Social work, attitudes, assisted death, euthanasia, assisted suicide, beneficence, non-maleficence, medico-ethical, transformational collaboration, social justice.

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Chapter 1

Introduction to Assisted Death

Death is not the worst evil, but rather when we wish to die and cannot. (Sophocles)

Death is not an enemy to be conquered or a prison to be escaped. It is an integral part of our life that gives meaning to human existence. It sets a limit on our time in this life; urging us on to do something productive with that same time as long as it is ours. (Kübler-Ross)

Advances in medical research and health care have significantly increased longevity and reduced morbidity and disability rates, particularly in Western nations. While it may be argued that not all segments of the population in all countries benefit equally from advances in biomedicine, people are living longer than at any other time in history. In the 20th century, life expectancy increased by over 25 years (Butler, 1997). It is estimated that by 2021, approximately 18% of Canadians (Statistics Canada, 1996) and 20% of Americans will be over the age of 65 (Marks & Lutgendorf, 1999). Estimates for Western Continental Europe and Great Britain suggest similar demographic trends (Butler, 1997).

Along with increased longevity rates, life-sustaining technologies have also significantly improved the quality of life for many people. Reductions in morbidity and disability rates allow many aging, chronically ill and disabled people to function at higher levels of independence (Rowe & Kahn, 1987). Joint replacements, organ transplants and improved treatments for cancer and cardio-pulmonary disease are examples of how medical research and practice have improved the quality, and often increased the length, of life for many people.

Unfortunately, there are negative aspects associated with increased longevity which undercut the many benefits of medical advances. Those over the age of 80,

representing the fastest-growing group of elderly persons, experience higher disability rates and dementias. Although the current trend toward unsustainable health care costs is related mostly to medical technology (Butler, 1997), caring for an aging population is becoming impractical in many countries. The relation between the percentage of gross domestic product devoted to health care and the percentage of elderly persons in the population is unbalanced. As the population in Western countries ages, the costs associated with caring for elderly persons will increase. With the exception of Great Britain, which has specialized geriatric services in place, healthcare policymakers have not developed long-term care plans for an aging population (Butler, 1997). The social safety nets designed earlier in the 20th century are not adequate to deal with the number of people living into old age. This situation is compounded by estimates suggesting that birth rates will likely continue to decline in the 21st century (Butler, 1997). Moreover, the primary caregivers of many elderly persons-women-have entered the workforce, often leaving the care of elderly family members in the hands of state-run or private care agencies. Assisted living arrangements (e.g. buildings that provide meal and cleaning services), community-based services, nursing homes and hospital services are quickly emerging as substitutes or ancillary methods of care for families unable to cope with the responsibility of caring for elderly family members (Mathiason, 2003).

More importantly, both providers and recipients of medical advances have called the perceived benefits of longevity into question because longevity is not necessarily related to quality of life. Whether they suffer from an incurable disability and/or disease or are otherwise at the end-of-life, regardless of age, some people may seek an assisted death to reduce the pain associated with prolonged dying. Indeed, results from

SUPPORT (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) in the U.S. indicate that while modern medicine is capable of managing virtually all pain experienced at end-of-life "...many people died with unrelieved pain and symptoms, that health care providers did not understand the patients' preferences at end of life..." (Bern-Klug, Gessert & Forbes, 2001 p.38). In addition, in most cases physicians were unable to predict which seriously ill people would die within a six-month time frame (Bern-Klug et al., 2001).

Although elderly people are more likely to fall into the category of wanting an assisted death, defined in the *definition of key concepts* on page 10, others have championed the right-to-die at a time of their own choosing through euthanasia or assisted suicide. In addition to the pain associated with illness, disease and injury, for many people the end-of-life is fraught with psychological or emotional distress. Many worry that they will be an economic, physical and/or emotional burden on their friends and family. The anticipation of a prolonged death aided by medical technologies is not a comforting thought to these people. Research shows that before swallowing a lethal dose of medication, an overwhelming majority of the 208 patients who died under the *Death With Dignity Act* in Oregon were concerned with issues related to personal control. While concerns about being a financial, physical or emotional burden were listed only by a minority, loss of autonomy (87%), less ability to engage in enjoyable activities (84%) and loss of dignity (80%) were identified as key concerns for these patients (Oregon Department of Human Services, 2005).

In addition to advances in medicine, the reemergence of the debate on euthanasia and assisted suicide parallels a growing social acceptance of the right for people to make

choices about their own health and body (Neron, 1996). From this perspective, the right to choose the time and manner of one's own death is grounded in the "...presumption that one of the essential attributes of the individual is precisely the liberty to govern oneself free from external constraints" (Salem, 1999 p.30). However, the prohibition against an assisted death has caused some people to take drastic measures to end their own lives, and in some cases, to assist in taking the lives of others. Those seeking and those providing an assisted death are met with both compassion and outrage. Examples of high-profile cases in the media illustrate the debate on assisted death. Some of these cases may not refer to acts falling explicitly under euthanasia and assisted suicide as defined later in this chapter, but they underscore the divisive controversy associated with the debate.

Many people already experience the dilemmas associated with withholding or withdrawing treatment from loved ones. In many cases, medical technology enables patients to be kept alive in a vegetative state almost indefinitely. Nancy Cruzan was kept alive for six years while her parents petitioned a Missouri court to have her feeding tube removed (*Cruzan v. Director, Mo. Department of Health, 1990*). Paralyzed from the neck down and afflicted with Guillian-Barre syndrome, Nancy B. endured a public debate about the right to have her respirator removed, which was eventually granted from a Quebec court (*Nancy B. v. Hotel Dieu de Quebec, 1992*). In New Jersey, Karen Ann Quinlan's parents fought and won a similar battle to have her respirator removed (*Matter of Quinlan, 1976*).

In some cases, the response of families is more drastic. In Chicago, a 15 month-old infant, Samuel Linares, went into a coma after he swallowed a balloon. After nine

months, his father entered the hospital where his son was being treated. He held hospital staff at gunpoint while he unhooked his son from a respirator (Mullens, 1994).

More recently, the death of Terri Schiavo in Florida caused an outpouring of ethical and legal debate on the right to die. Doctors predicted that Schiavo would remain in a permanent vegetative state following a heart attack that caused brain damage. Her husband claimed that Schiavo would not want to live in a vegetative state with no hope of recovery. As legal guardian, he requested that her feeding tube be removed in 2005. A previous decision to remove her feeding tube in 2001 was overturned after Schivo's parents petitioned the courts. This decision was overturned after Schivo's husband successfully argued that her parents did not have legal standing in the case (Bennett & Kennedy, 2005). The decision to remove Schaivo's feeding tube in 2003 was reversed after Governor Jeb Bush passed "Terri's Bill", legislation that allowed the State of Florida in intervene in the case and force its replacement. "Terri's Bill" was later ruled unconstitutional by The Supreme Court of Florida (Bennett & Kennedy, 2005). Despite attempts by Schaivo's parents and pro-life groups to have the act ruled illegal, Schiavo died on March 31, 2005, 13 days after her feeding tube was removed (Roh, 2005).

Others fighting for the individual choice to die have done so while paralyzed. *The Sea Inside* is the story of Ramon Sampedro, a quadriplegic, embroiled in years of court battles so that he could die by euthanasia. At the age of 26, Sampedro misjudged the depth of water and broke his neck in a diving accident. Unwilling to put other people at risk of prosecution by aiding his death, Sampedro spent the next 28 years battling some family members, pro-life advocate groups, religious leaders and the law for his right to die. In the end, his lawyer and focus of romantic attention, along with several friends,

volunteered to help Sampedro end what he believed had become a “life without dignity”. Sampedro died after swallowing a lethal dose of potassium cyanide (Amenábar & Bovaira, 2004).

Sometimes, the struggle with the decision to assist in the death of a loved one is more straightforward. People at end-of-life who are conscious can request the assistance of others for a hastened death. Pioneering work on the incidence of euthanasia in the HIV/AIDS community in Vancouver, B.C. reveals several botched cases likened to back alley abortions. Ogden (1994) paints a picture of HIV/AIDS infected men desperate to leave a life that has become focused on extensive pain management and invasive medical procedures. Attempts to hasten death are not always successful. The pain associated with the disease is exacerbated by illness caused by the ingestion of narcotics and other drugs. Participants worry that their acts will draw attention and result in criminal prosecution. Invariably, for those assisting in the death of a friend, the only regret was that the death had needlessly “...contributed to the horrific and miserable manner of their dying” (Ogden, 1994 p.84).

The Problem: The Unacknowledged Role of Social Workers

As professionals, social workers often work with needy and troubling people; they attempt to ensure that the same people are afforded basic human rights by offering financial and community-based resources. Social work is eclectic, but primarily deals with society’s problems related to distress and poverty. Addictions, child abuse, crime, discrimination, family breakdown, racism and unemployment are some of the main issues

dealt with by social workers (Hanvey & Philpot, 1994). In other words, social workers primarily deal with marginalized groups and their members in society (Carniol, 1990).

Social work organizations are mandated to promote the wellbeing and quality of life of individuals under care, their families and caregivers (e.g. friends who provide care). While social work in health care emerged in the early 20th century, geriatric social work is relatively new. It was not until the 1970s that the first training sessions for social workers dealing with elderly persons occurred in North America (Luptak, 2004). Even more recent is education and training focused on death and dying, which remains sporadic and uneven (Christ, 1999). That said, social workers in developed countries are becoming more represented in medical and palliative care settings and community-based facilities such as hospice care (Luptak, 2004).

The distress caused by death and dying has only recently emerged as a critical issue in social work. Social workers deal with a gamut of individuals, from dying persons to those touched by the experience of end-of-life issues. From newborn babies to the chronically ill and aged, social workers are involved in end-of-life care. The importance of end-of-life issues was highlighted at a summit on end-of-life care in 2002: "...participants designed an agenda for the profession to improve care and to elevate social work's role and contributions in the area." (NASW, 2005).

Social workers occupy multiple roles ranging from care provider to educator. Indeed, The National Association of Social Workers observes that, "...social workers have a multidimensional role as clinicians, educators, researchers, advocates, and community leaders" (NASW, 2005). The NASW further notes that social work is in a key position to deal with end-of-life issues because

[s]ocial workers have unique, in-depth knowledge of an expertise in working with ethnic, cultural, and economic diversity; family and support networks; multidimensional symptom management; bereavement; trauma and disaster relief; interdisciplinary practice; interventions across the life cycle; and systems interventions that address the fragmentation, gaps, and insufficiency in health care. These are critical areas for implementing change in palliative care and end-of-life care (NASW, 2005).

Despite the intense debate surrounding euthanasia and assisted suicide, there is a paucity of research on the topic as it applies to social workers. The values inherent in social work practice—self-determination, confidentiality, client wellbeing, not inflicting harm and social justice (BASW, 1996; Code of Ethics, 1984; NASW, 1994; Jansson & Dodd, 1998)—make assisted death an important issue for social work practice. Yet, available research is usually confined to the attitudes, experiences and opinions of physicians and other health care professionals. Moreover, research on the topic¹ often contextualizes euthanasia and assisted suicide within the physician-patient relationship, even though both issues affect other professionals involved with patients facing end-of-life decisions. In particular, social workers spend considerably more time with dying patients and/or families than do most physicians or other health care professionals. For example, persons living with HIV/AIDS disease (PLWHIV/AIDS) constitute a population that often consumes a considerable amount of social workers' practice time (Neron, 1996; 1998, Werth, 1999). As well, the potential for social worker involvement in cases where patients are afflicted with ALS is quite high as social workers deal with patients and their families over the progression of the disease. Thus it may be argued that social workers have an important role to play at end-of-life.

Given their role in the care of patients, and/or their families, social workers may find themselves having bioethical issues thrust upon them, even though they may feel

inadequately trained or otherwise prepared to deal with them (Holland & Kilpatrick, 1991). Many social work organizations have not articulated a policy statement on euthanasia or assisted suicide, leaving social workers in a quandary of interpreting the meaning of ethical standards for themselves. Practice standards for the Australian Association of Social Workers (2003) require that social workers involve clients as much as practicable in the decision-making process. Similarly, the British Association of Social Workers emphasizes the social worker's obligation "...to encourage and facilitate the self-realization of each individual person..." (1996 p.1). Implicit in this statement is respect for the value and dignity of every human being.

Some social work organizations have issued clear, if differing, statements regarding euthanasia and assisted suicide. In the U.S., the NASW supports the notion of self-determination for euthanasia and assisted suicide (NASW, 1994) while the Association of Oncology Social Workers does not (Association of Oncology Social Workers, n.d.). In response to the surge of attention to the issue in the mid 1990s, the British Columbia Association of Social Workers (BCASW) formed a Committee on the Right to Choose Life or Death. The Canadian Association of Social Workers (CASW) Committee on Euthanasia and Assisted Suicide identified euthanasia and assisted suicide as significant issues for social work (British Columbia Association of Social Workers, 1994; Canadian Association of Social Workers, 1994). Both committees submitted briefs to the Senate Committee on Euthanasia and Assisted Suicide but neither the BCASW nor the CASW took a definitive stand. Both associations called for further discussion and research on end-of-life decision-making, but neither association has followed up on these briefs.

The contradictory and somewhat inchoate positions regarding assisted death reflect differing agendas among social work organizations. Arguably, social work organizations are embedded in different national contexts, which influence their respective agendas. However, very little is known about how assisted death affects social workers or how social workers navigate the issues related to assisted death. Given the importance placed on the social worker's role in end-of-life decision-making, and the salience of assisted death generally, further research on the topic is necessary. Using both survey data and qualitative responses, this dissertation examines the attitudes and experiences of social workers in the United Kingdom. As outlined in Chapter 4, the rationale for this choice is based on my participation in the original research protocol and the fact that, to the best of my knowledge, the data set has remained dormant since it was collected. I was co-investigator in the BASW project with Russel Ogden. In this capacity I was involved in design of the research instrument and related research decisions (paraphrased from, Ogden, personal communication, April 2, 2006). Moreover, this research brings an international perspective to the small body of knowledge on social work and assisted death, which until now has been limited primarily to North America.

Definitions of Key Concepts

For the purposes of this dissertation, the major concepts are defined as follows:

- *Assisted death* – an umbrella term referring to assisted suicide and/or voluntary euthanasia.

- *Assisted suicide* – the act of killing oneself with the assistance of another person, i.e. the provision of the means (Asch, 1996).
- *Euthanasia* – an act by a third party that induces death, at a person’s request; e.g. a lethal injection (Letellier, 2003).
- *Informed consent* – a competent person’s legal right, or that of a person appointed by that person, to request or refuse treatment, including life-sustaining treatment. The decision is made after full disclosure regarding the nature and potential outcomes of the treatment (Saunders, 2001).
- *Living will* – a written statement specifying what treatment a person is to receive in the event that they are unable to specify their wishes (i.e. being terminally ill). The living will indicates a person’s wishes at end-of-life and becomes active when he/she can no longer communicate his/her wishes (Backer et al., 1994 in Leszczynska, 1997).
- *Medicalization* – a process whereby non-medical or social problems become defined and treated as bio-medical problems (Conrad, 1992).
- *Non-voluntary Euthanasia* – an act that induces death without the express consent of the person, regardless of whether or not that person is able to consent (Smokowski & Wodarski, 1996). Under criminal law, such acts are considered culpable homicide (Siegel & McCormick, 2003).
- *Palliative care* – involves advanced treatment of pain at end-of-life. It is intended to enhance the comfort and quality of the lives of patients and their families (O’Brien, 2003).

- *Physician-assisted suicide* – the act of killing oneself with the assistance of a physician, (e.g. overdose or lethal injection) (Searles, 1995).
- *Withholding Treatment* – a failure to initiate treatment knowing that such treatment may sustain a person’s life (Scanlon, 1996).
- *Withdrawal of Treatment* – ending treatment that is necessary to sustain a person’s life (Scanlon, 1996).

Organization of the dissertation

This chapter has shown that while medical advances have significantly reduced mortality and morbidity rates for people in Western countries, not all people benefit from life-extending practices. Caring for chronically ill and diseased persons and those who are otherwise at end-of-life, has become increasingly difficult as populations on the whole become older. It is anticipated that state-provided health care will be unable to keep pace with the demands placed on it. This will place additional financial burdens on the families and friends of dying persons, who also experience the emotional and physical burden associated with care of the dying. At the same time, proponents of assisted death argue that the loss of autonomy and dignity experienced by some people at end-of-life justifies an individual’s right to choose an assisted death. Several high-profile cases identify the loss of quality of life and the horrific existence faced by some people at end-of-life. The importance of social work in end-of-life decision-making and care is highlighted by reference to social work organizations in Australia and North America. The purpose of this dissertation—exploring the attitudes and experiences of social

workers toward assisted death United Kingdom—was articulated. This was followed by the identification and definition of key terms in the Definition of Key Concepts.

Chapter 2 discusses the theoretical orientation of this research. Teleological theories, which hold that death is immanent by nature, form the basis of medico-ethical principles. These include the principles of autonomy, beneficence, non-maleficence, and social justice as they apply to social work. Factors affecting the debate on assisted death are also examined. The concept of self-determination is discussed, as is the right to die. Major religious views (Catholicism, Protestant Christianity, Islam and Judaism) on assisted death are identified. As well, the argument that assisted death may become rampant if legalized, the philosophical slippery slope of assisted death, is discussed. Next, the effects of assisted death on the common good of society are outlined, as is the legal status of assisted death in Canada, the U.S., Australia, the Netherlands, Belgium and the U.K. The recent emergence of *suicide tourism* in Switzerland, where citizens from other nations travel to Zurich for an assisted death, is also discussed. The chapter concludes with a discussion of medical hegemony in assisted death and the challenges faced by the medical community as it attempts to control the dying process. As well, the unacknowledged role of social workers in death and dying is outlined and discussed.

In Chapter 3, the specific literature pertaining to social work and assisted death is reviewed. The body of research on this topic is sparse and primarily exploratory. Thus, this chapter includes a selective review of research on the attitudes and experiences of physicians and nurses toward assisted death. Together, these bodies of research suggest support for, and condemnation of, assisted death. A list of factors associated with legal attitudes toward assisted death, the focus of this research, are identified and used to

develop the hypotheses tested in the research. These factors include: (1) the social worker's practice setting; (2) the influence of the bio-medical model on the practice setting; (3) the social worker's relationship with other health care providers (e.g. physicians); (4) the social worker's belief in self-determination; (5) the social worker's relationship with his/her client and family; and (6) personal experiences with end-of-life decisions.

Following the literature review is the methodology section, set out in Chapter 4. Given that this research involves analysis of previously collected data, the strengths and weaknesses of secondary analysis are identified, together with updates on the best evidence since the original data were collected. The source and demographic characteristics of the sample are noted, as are the response rates and non-response rates of social workers selected for the study. Next, the measurement and coding of variables used in the statistical analysis carried out in the following chapter are identified. This involves an examination of the frequency distributions of social workers' responses to items on the questionnaire. Reference to the request made to social workers regarding written responses to an open-ended prompt appearing at the end of the survey concludes Chapter 4.

In Chapter 5, the hypotheses regarding the relationships between the factors identified in the broader literature, noted above, and support for assisted death are tested. As measured by social workers' attitudes, support refers to: (1) legalization of assisted death; (2) support for the Dutch model of euthanasia; and (3) the likelihood that a social worker would report a colleague whom they suspected had been involved in an assisted death. The hypotheses are primarily derived from the literature on euthanasia and

assisted suicide. In addition, the original BASW survey included items that were intended to determine social workers' attitudes toward assisted death based on certain characteristics such as religion. Together, these sources of information formed the theoretical background for the generation of the hypotheses. The stated hypotheses include:

- Social workers working in medical settings are more likely to experience the trauma associated with life-prolonging treatment and thus will be more supportive of assisted death.
- Social workers who play a major role in the lives of the terminally ill are less supportive of physician dominance at end-of-life and will be more supportive of assisted death.
- Social workers who advocate for client self-realization believe people should be able to choose whether to live or die and thus are more supportive of assisted death.
- Social workers holding religious beliefs will be less supportive of assisted death because they believe life belongs to God.
- Social workers who have had personal experiences with death and dying understand the anguish associated with dying and the problems associated with life-prolonging treatment and thus will be more supportive of assisted death.

Cross tabulation analyses of the variables are used to test the stated hypotheses.

In addition, the content of the qualitative responses appearing at the end of the survey are analyzed. The quantitative and qualitative responses are triangulated and the emerging themes identified.

A discussion of the themes and their implications emerging from the research is undertaken in Chapter 6. Limitations of the research and recommendations for future research involving social workers and assisted death are also highlighted in this final chapter.

Notes

1. For examples of physicians and health care workers' attitudes toward assisted death see, Back, Wallace, Starks, & Pearlman, 1996; Cohen, Fihn, Boyko, Johnson & Wood, 1994; Verhoef & Kinsella, 1993; Kuhse & Singer, 1988; Ogden & Young, 1998; Searles, 1995; van der Maas, van Delden, Pijnenborg, & Looman, 1992; Ward & Tate, 1994; Baume, O'Malley & Bauman, 1995; Young & Ogden, 1998.

Chapter 2

The End of Life is Immanent:

Teleological Theories and the Debate on Assisted Death

Theoretical orientation: medico-ethical principles

Social work remains at the periphery of the debate on assisted death. This rift remains despite the acknowledged role played by social workers in death and dying. Increasingly, social workers find themselves dealing with clients and/or their families suffering from incurable illnesses like HIV/AIDS (Neron, 1998). In impoverished areas, social workers often end up providing services traditionally carried out by nurses, and sometimes physicians. Psychological assessments and arranging aftercare are two such tasks carried out by social workers in health care settings (Egan & Kadushin, 1997).

Currently, the theoretical debate surrounding assisted death falls under the dominion of medicine and medical ethics. At the core of medical ethics are teleological theories that imply that death is immanent by nature. These theories hold that actions are either right or wrong depending on their end or intended purpose. Thus the core of medical ethics is thought to provide the medical profession with the basis for determining the best course of action at end-of-life. Logically, end-of-life situations, e.g. terminal illness, require solutions based on medical knowledge and best evidence. Accordingly, actions pertaining to end-of-life are judged right or wrong based on intentions and accepted clinical practices. It is argued in this dissertation that the scope of assisted death must be extended beyond the medico-ethical context to incorporate family members,

friends and other professionals. Given their relevance to social work, however, the extrapolation of medico-ethical theories to this dissertation is justified.

The emergent and dominant bio-ethical principles applicable to assisted death are a blend of several philosophical perspectives. An integral concept to the debate on assisted death is *autonomy*. Kant's notion of autonomy, the ability to choose and act for one's self, is a fundamental ethical principle for rational human beings (Gewirth, 1985). For Mill, happiness and wellbeing are best achieved through individual autonomy. When actions do not harm others, individuals should have absolute freedom to act. In Mill's words, "But neither one person, or any number of persons, is warranted in saying to another human creature of ripe years that he shall not do with his life for his own benefit what he chooses to do with it" (Mill, 1956 p. 93). Although popular today, this pragmatic approach is controversial because other people are affected by the choices of those around them. For example, a mother's children may be distressed and bereft by her choice to hasten death, even though she may be suffering from a terminal illness. At the same time, her death may bring relief to those around her, especially those responsible for her ongoing care.

Second, as noted in the *definition of key concepts*, Chapter 1, the concept of *beneficence* refers to the obligation to provide and balance benefits against costs of actions. Mill's theory of utility is significant here. The *Patient's Bill of Rights* in the U.S. clearly states that treatment of a patient with no prognosis of improvement cannot be justified, although cases where patients remain stable, but show no marked improvement or deterioration are less clear (Berubi, 1992 in Leszczynska, 1997). Even so, in managed care situations, care providers, including social workers, may find themselves in a

situation where institutional obligations outweigh the interests of patients. In other words, care may be provided in the face of minimal prospect of a patient's recovery. In these situations, social workers must balance bio-ethical principles with the interests of the patient and his/her family and other care providers (Csikai, 1999a).

Beneficence can also be traced to the theory of virtue and the ideas of Plato and Aristotle. With regard to assisted death, virtue assumes kindness and compassion for patients (Levine, 2004). For example, assisted death can be justified because it alleviates suffering; however, a premature assisted death so that body parts can be harvested for scientific purposes cannot.

The third concept, *non-maleficance*, is based on the responsibility to do no harm. Again, Mill's (1956) theory of utility is applicable. Prolonging life against a patient's wishes cannot be justified under a utilitarian ethic. In contrast, "...the sole end for which mankind are warranted, individually or collectively, in interfering with liberty of action of any of their number is self-protection" (Mill, 1956 p.13). Thus, withholding and removing treatment are common practices in medicine. Arguments for assisted death frequently turn on non-maleficance and the idea that prolonging life is tantamount to assault (Dworkin, 1998) or in extreme cases, torture. However, these arguments meet resistance, for some believe that assisted death threatens the common good of society by reducing the value and meaning of life (Callahan, 1994, 1997).

Finally, the concept of *justice* implies that there is fairness in the distribution of benefits and risk assessment. Related to autonomy, Kant's categorical imperative implies that we see others from the standpoint of their lived experience, not our own (Gewirth, 1985). A universal understanding of the benefits and risks associated with life-

prolonging treatment does not exist. Individuals' beliefs vary according to forces such as social and economic stratification. When we understand the influence of these forces on individuals, we are better able to understand the choices people make regarding assisted death.

In reality, there is no over-riding ethical principle or combination of principles applied to health care, particularly as it pertains to assisted death. Still, these principles provide a vital theoretical backdrop from which to proceed in this dissertation. As indicated in the following section, the four main principles identified here appear explicitly and implicitly in the debate on assisted death. As well, these principles figure prominently in research involving health care providers, although research involving social workers is limited.

The debate on assisted death

Whether it involves euthanasia or assisted suicide, assisted death is the subject of controversy in ethics, values, public policy, and religion. The concept of "euthanasia" can be traced to 5th century Greece and the poet, Kritanos who wrote of the good or gentle death. The humanistic connotation of euthanasia includes a gentle death, but the concept also includes deliberately-caused death (Lettelier, 2003). Of course, euthanasia differs from other forms of deliberate death (non-voluntary euthanasia) because it is requested; otherwise, the act could be considered culpable homicide (Cormack, 2006). For example, Tracy Latimer, severely handicapped from multiple sclerosis, died from carbon monoxide poisoning after her father placed her into the cab of his running pickup truck and vented a hose from the tailpipe into the cab of the truck. The court was

sympathetic to Robert Latimer's claimed merciful intentions. However, after two appeals, his actions resulted in a conviction of second-degree murder (*R. v. Latimer 1997*).

In present-day society, euthanasia is often perceived as a medicalized event: often it is the physician who brings about the death of a patient at his or her request (Downie, 2004; Manning, 1998). The rationale for requesting euthanasia is based on the notion of autonomy or patient self-determination (Dworkin, 1998). In general, patients want to minimize pain and suffering, to choose the time and place of their death, and to die in a dignified manner without being subject to heroic life-saving measures. In other words, they want control over their death and not to be the subject of medical hubris or God's will. This aspect of euthanasia is well illustrated in the events leading up to the euthanasia of Rémy in the movie, *The Barbarian Invasions*. Although not medicalized, the main character decides to die through lethal injection of heroin surrounded by his friends and family outside of a medical setting (Arcand, Louis, Robert & Vonier, 2003). In the 1981 feature film, *Whose Life is it Anyway?*, the character of sculptor and teacher Ken Harrison fights for the right to end his life after a car accident leaves him paralyzed from the neck down. After psychiatric evaluation, a judge rules that Harrison cannot be forced to stay in hospital for treatment, and he dies with the assistance of loved ones (Bradham & Schute, 1981).

Similarly, with regard to assisted suicide, the physician is usually the one (Downie, 2004; Manning, 1998) who facilitates the patient's death, but he/she does not perform the death-hastening act. Not surprisingly, physician-assisted suicide is also a medicalized event in present-day society. Indeed, as indicated in the following, the only

legally permissible form of assisted death in North America, physician-assisted suicide, is in the state of Oregon. As with euthanasia, the rationale for physician-assisted suicide is based on the notion of self-determination. On the one hand, physician-assisted suicide is viewed as necessary for the demedicalization of death. On the other hand, rather than promoting autonomy, it has been argued that physician-assisted suicide may actually medicalize suicide by making what has historically been considered a personal act a medical event, subject to public control (Salem, 1999).

The remainder of this chapter presents the controversy over assisted death starting with the debate on self-determination (the right to choose life or death) versus the sanctity of life. Because assisted death is a deeply personal and contextual issue, there are no clear winners in the debate; however, core arguments for and against assisted death are provided. This involves discussions of religious views, fear of the philosophical slippery slope that legalized euthanasia will result in non-voluntary euthanasia, and the effects of assisted death on the “common good” of society. As well, the legal status of assisted death in several countries is examined as it relates to challenges against legal prohibition and legalization. Many legal debates on assisted death include basic arguments raised in religious, philosophical and social contexts. Next, the wider literature on the attitudes of professionals working with people at end-of-life, and the contribution of this research to the debate on assisted death, is reviewed. Finally, the issue of medical hegemony over assisted death is examined as it relates to the question driving this research. This chapter concludes with the identification of the research question, which involves the attitudes and experiences of social workers in the United Kingdom toward assisted death. Non-medical professionals, like social workers, spend considerable time with dying patients

and their families, indeed, usually more time than physicians. The nature of their job mandates that social workers advocate for the interests of their clients, but little is known about if or how social workers do this on a regular basis.

The Emergence of Self-Determination

The option of patient self-determination in assisted death flows from several transformations in Western society. From the Enlightenment onward, the idea of individual autonomy has become a cornerstone in social consciousness. In the early 17th century, Sir Francis Bacon wrote of the physician's duty to help the dying pass in a comfortable manner (Letellier, 2004). As Western societies have become more secular and more impervious to religious doctrine, there is less faith in an omnipotent, omnipresent God who will care for people during their time of need or deliver them from suffering (Harpe, 2003). In the face of declining religious authority, many faith communities continue to voice opposition to assisted death. As illustrated later in this chapter, attitudes toward assisted death vary with religion. But generally, monotheistic faiths—Christianity, Catholicism, Judaism, Muslimism, Buddhism, and Hinduism—oppose assisted death. As “Agents of God”, followers are to be stewards, called to carry out God's divine will on earth.

As deference to religious authority has declined, bio-medical advances have created a dilemma: people are living longer, but increased longevity has lengthened the course of fatal illnesses and disease. In the 20th century, many causes of death were extinguished or controlled with the development of vaccines and the discovery of antibiotics (Star, 1982). As well, medical research and technological advances have

significantly improved the longevity of those suffering from the leading causes of death: heart disease and cancer. The same cannot be said about the quality of life for those people. Harpes (2003) confirms that over 55% of the population in North America and Western Europe reach 75 years of age, a stark contrast to the 8% who lived to at least this age 200 years ago. Today, many people die in nursing homes, hospitals or palliative care facilities away from their family, friends and familiar surroundings. The fear associated with not knowing when death will arrive and the pain associated with some incurable diseases generates a sense of futility and hopelessness. Likewise, for those in advanced stages of illness or disease, medicine and in particular palliative care, has decreased the suffering for many people at end-of-life, but a small percentage of the dying do not benefit from palliation and suffer until death (Downie, 2004; Magnusson, 2002). For some of these people, the right to choose the time of death has become the subject of debate between groups that advocate for or oppose patient self-determination.

The Right to Die

Public controversy surrounding assisted death gained momentum in the 1990s with several high-profile cases that challenged established legal prohibitions and much-debated changes in legislation that facilitated assisted death in several jurisdictions also fuelled the debate (Grubb, 2001; Magnusson, 2002; Mullens, 1994; Weir, 1997). Right to die movements have been advocating for the legalization of euthanasia and assisted suicide for several decades. In its current form, the pro-euthanasia movement can be traced to organizations such as the Voluntary Euthanasia Society in Great Britain, a society founded in the 1930s, as was the Euthanasia Society of America (Dowbiggin,

2001). Today, dozens of organizations advocate for legalizing assisted death. The World Federation of Right to Die Societies lists 33 organizations in 21 countries: Australia, Belgium, the United Kingdom, Canada, Columbia, Finland, France, Germany, India, Israel, Italy, Japan, the Netherlands, Luxembourg, New Zealand, Norway, Spain, Sweden, Switzerland, the United States and Zimbabwe (World Federation of Right to Die Societies, 2004, January 18).

At the opposite pole, several organizations are completely opposed to euthanasia and assisted suicide. As highlighted in the next section of this chapter, Catholic, Protestant, Jewish and Islamic religious groups, physicians, teachers, colleges, politicians, and groups representing the physically and mentally disabled have lobbied to keep assisted death illegal or to have its status reversed in places where euthanasia or assisted suicide was legal (Euthanasia.Com, n.d.). One of these organizations, the World Federation of Doctors Who Respect Human Life, has branches in over 70 countries with a membership of approximately 350,000 medical professionals (Euthanasia.Com, n.d.).

It is not my intention to debate the relative merits of either side of the assisted death debate in detail; rather, the salient aspects of the debate are highlighted as they provide background for the research that follows. At the core of the debate are issues of patient autonomy and/or self-determination, respect for human life, the slippery slope, and the common good.

Some modern philosophers argue that the right to choose one's own death is the ultimate expression of self-determination. The idea that one chooses death has ceased to be regarded automatically as sinful or morally wrong (Dworkin, 1998). *Sub rosa*, the tacit if not legal acceptance of assisted death in society is grounded in two principles:

non-maleficence or the obligation to do no harm, and beneficence, the requirement "...to do good by preventing or alleviating pain and suffering" (Hermerén, 2003 p.44). Self-determination, the right to choose one's own death, is considered essential for individuals seeking a dignified death that is as painless and empowering as possible.

Religious Views

A key aspect of the debate, respect for human life, is primarily based on religious doctrine which emphasizes the sanctity of life over self-determination. Christianity was founded on voluntary death/suicide. The death of Christ, or the ultimate sacrifice was also interpreted as suicide. St. Augustine changed that in the 5th century AD when he proclaimed that God divinely ordained life. Interfering with life was sinful, regardless of quality or level of suffering (Droge & Tabor, 1992). St. Thomas Aquinas reaffirmed the sanctity of life in the 13th century AD, arguing that mercy killings violated the sixth commandment "thou shall not kill".

The Catholic Church supports the notion of self-determination to a degree. The right to refuse treatment and the withdrawal of treatment are permissible but physician-assisted suicide and euthanasia are not condoned by the Church (Manning, 1998). In most cases, the same principle applies in Protestantism where the taking of life is considered murder, regardless of the circumstances. However, the Church of England has recently relaxed its condemnation of those who assist others to die. "Canon Professor Robin Gill, a chief adviser to Rowan Williams, the Archbishop of Canterbury, said people should not be prosecuted for helping dying relatives who are in pain end their lives." (Doward, 2005) Whether Gill's statement marks a fundamental change of

direction for all Christianity is unclear. Generally, however, assisted suicide and euthanasia are abhorrent to the fundamental theme of Christianity, which is to lead others to Christ through example. Death is to be encountered and endured, not induced. Support for withdrawal of treatment and for withholding treatment is justified because there is no effort to hasten death. Death and dying are considered an integral part of life and Christians are to support the dying process and thus improved palliative care is emphasized (Collange, 2003). In similar fashion, based on Christ's teachings, the Greek Orthodox Church believes that life is a gift from God and that assisted suicide and euthanasia are contemptuous of human beings and divine will. All things in life, including an individual's suffering, are to be treated as part of God's divine plan for that individual. Artificial life-prolonging technologies and treatments are not divine, but human, interventions. The withdrawal of treatment and withholding treatment are acceptable practices because, through dying, God's divine will for that individual is manifested (Stavropoulos, 2003).

In Judaism, the idea of terminating life is antithetical to the belief that a dying person is still a person in all respects and hastening death in any way is forbidden. Again, there is no obligation to prolong life by artificial measures. Though suffering may have an intrinsic value, relieving suffering and the right to die with dignity, are tenets of the religion. Accordingly, current practice emphasizes palliative care (Guigui, 2003).

In contrast to other religions, Islam considers passive euthanasia (withholding treatment and the withdrawal of treatment) as abusive (Ali, 2003). Active euthanasia is criminal under the Koran and Sharia (Islamic law). Even while a patient is dying, it is the physician's responsibility to ease suffering and not comply with suicide requests.

Moreover, the physician is obliged to identify the cause of illness, seek a remedy and provide care so that prolonging life is the rule, not the exception. Only the creator, Allah, has the power to give and take away life, which is considered sacred (Ali, 2003).

The Slippery Slope: From Individual Choice to an Epidemic of Hastened Deaths

Underpinning the issue of respect for human life versus the right to self-determination is the slippery slope argument. In fact, the year before the BASW study was undertaken, a monograph entitled *Forced Exit* was published. This book included references to policies that created “a caste of disposable people” and also the dichotomy between “hospice of hemlock”, i.e. palliative care versus poisoning at end-of-life (Smith, 1997). The slippery slope is a highly controversial topic that continues to attract research with no definitive resolution as to whether there is truly a slippery slope. Opponents of assisted death (i.e. the major religions) highlight the issue of misuse and abuse (Euthanasia.Com, n.d.). The slippery slope argument implies that if society accepts legalized assisted death (assisted suicide and voluntary euthanasia) the floodgates will be opened and involuntary euthanasia will become established as common practice. If society prohibits involuntary euthanasia, because it is tantamount to murder, how can it approve of legalized assisted death regardless of the benevolent intentions of those involved? Opponents of legalized assisted death frequently point to Nazi Germany and the Netherlands as evidence of the slippery slope. The sterilization and execution of people considered to be “lesser human beings” in Nazi Germany are well documented and will not be reiterated here (see, Manning, 1998). However, to argue that the Nazi program of genocide is analogous to voluntary assisted death is to ignore the motivations

of those involved, the physicians and patients. As Frey (1998) observes, the voluntary assisted death movement is based on an individual ethic and is not inflicted on people against their will. Manning (1998) cautions that one aspect of the slippery slope that is often not fully recognized is that of marketplace seduction; he argues that we should be wary of health rationing policies. In other words, Manning (1998) is concerned that the quality of one's life will be determined by the amount of money required to keep that person alive. If the cost is too high, and the political economy of health overpowers the principle of life as sacred, then society will attach a price tag to quality of life. Not surprisingly, the elderly, the seriously ill and infirm, and the disabled, especially those without means, have the most to fear from such an eventuality.

The Dutch have openly practiced euthanasia since 1973 (Magnuson, 2002). Illegal before 2002, euthanasia was tolerated, providing that the request was voluntary, the patient was experiencing unbearable suffering, and the attending physician had consulted with a colleague about the appropriateness of euthanasia (van Delden, 2004). The Dutch Government has commissioned three studies investigating end-of-life decisions, which include euthanasia and physician-assisted suicide in the Netherlands, in 1990, 1995 and 2001. Called the "Rommelink Report", these studies involve interviews with physicians and an examination of death-certificates that identify whether an assisted death was requested or not (Onwuteaka-Philipsen et al., 2003). Using death-certificate data, Table 2.1 shows that assisted deaths account for fewer than three percent of all deaths in the Netherlands. Euthanasia is more commonly requested than is assisted suicide.¹

Table 2.1

**Assisted Deaths as a Percentage of all Death in the Netherlands
According to Death-Certificate**

Year (Total Deaths)	1990 (128,824)	1995 (135,675)	2001 (140,377)
Assisted Suicide	0.2%	0.2%	0.2%
Euthanasia	1.7%	2.4%	2.6%

Source: Onwuteaka-Philipsen et al., 2003.

According to Manning's (1998) interpretation of the 1995 Rummelink Report, up to 1,000 people in Holland annually receive hastened death without their request, a result of the slippery slope. However, more recent data published by the Dutch government place the number of involuntary cases at 22 (Onwuteaka-Philipsen et al., 2003), significantly below Manning's (1998) estimate. In most cases of involuntary euthanasia, the physician's motives are well intentioned and meant to ease the suffering of dying patients and may well have been the result of the "double effect". The double effect refers to the administration of larger and larger doses of pain medication (e.g. morphine) that eventually results in death (Downie, 2004; Magnusson, 2002). The primary intent is to manage pain, but the secondary effect is death. Onwuteaka-Philipsen et al. (2003) note that roughly 1,000 patients a year in Holland die from the double effect, but do not suggest that death is intentional. Manning (1998) implicitly interprets the double effect as an intention to kill. However, opponents claim that broad interpretation of the guidelines by some physicians leads to abuse. The elderly and mentally ill were more likely to receive a hastened death without their expressed consent (Manning, 1998; Davis, 2003). It may be argued that these people received a hastened death because they were unproductive or undesirable. Such action is tantamount to a kind of "soft eugenics" (McLaren, 1990 p.155). Prior to 2002, safeguards against involuntary euthanasia were minimal. Consensus between family members and the physician was often all that was required (Onwuteaka-Philipsen et al., 2003). As detailed below, new legislation in the Netherlands establishes clearer guidelines to control the practice of euthanasia. Notably, the definition of euthanasia refers to a requested death from a competent person. It is anticipated that the new law will reduce the number of cases involving involuntary

ethanasia and assist authorities in prosecuting physicians who operate outside the law. Even so, data from the latest replication of the original Rimmelin study in 2001 show no support for the slippery slope of assisted death practices in the Netherlands (Onwuteaka-Philipsen et al., 2003).

The “Common Good”

One aspect of the debate on self-determination and the right to die versus the inviolable right to life is the notion of the “common good”. This aspect is not well researched, probably because it is loaded with subjective interpretations such as the context that makes individualism excessive. Callahan argues that excessive individualism, of which the right to an assisted death is representative, ignores the fact that “...each person’s behavior is part of the whole and has an impact on the nature of the whole and on the common good (1997 p.244).” Related research identifies the “copycat” effect of suicide. Stake’s (2000) study on the impact of the media on suicide reveals that nightly publicized suicides of entertainment or political celebrities predicts increases in suicide rates. However, there is a paucity of research on the effect of assisted death on society and whether it affects the “common good” by increasing other suicides. Callahan (1997) warns that excessive individualism, most evident in the U.S. but growing in other parts of the western world, can damage the common good or the wellbeing of society. He argues that increasing rates of suicide are correlated with higher rates of depression, a loss of supportive community structures such as family and religious connections, and an over-reliance on one’s self. Yet, the data do not support his thesis. Time series analyses for all age groups in the U.S. show a slight increase in suicide rates from 1980 – 1986

(approximately 18 per 100,000 to 21 per 100,000). However, between 1987 and 1996 the rate actually drops back down to approximately 18.5 per 100,000 and has continued to decline to 17.9 per 100,000 in (National Institute of Mental Health, 2004). Whether this trend has continued into the 21st century has not been determined, but arguably, suicide rates vary depending on the availability of supportive structures, which may have declined since the late 1990s as a result of economic downturns.

Opponents of assisted death warn that the slippery slope to misuse and abuse may be the result of assisted death options. People who feel that they are not full contributing members of society or those who feel that they are a burden to their family, friends and society, may feel pressured to request an assisted death. Vulnerable populations (e.g. elderly, terminally ill, diseased, mentally and physically handicapped) would be at higher risk (Manning, 1998). To date, researchers neither confirm nor reject this claim, but proponents of assisted death argue that such concerns carry less weight when all citizens have access to quality health care, a situation that does not exist in the economically and racially stratified context of the U.S. (Snyder, 2004; Kirschner, Gill & Cassel, 1997). However, with regard to the potential for abuse in the U.S., the Supreme Court has concluded that legalizing assisted death options does not place vulnerable populations at risk. In *Washington v. Glucksberg* (1996) the court stated “[a]ll such persons are fully entitled to protection against coercion and other abuse, and all are, if competent, as entitled to a humane death as anyone else when they reach the final stages of dying.

The Legal Status of Assisted Death

Euthanasia and assisted suicide are conceptually distinct, but share two important commonalities. First, both definitions involve voluntary acts committed with the assistance of a physician(s) at a patient's request. Patients are considered to be rational at the time the request is made, meaning they are not suffering from a mental, physical or emotional condition that would affect their decision-making. *Euthanasia* refers to the administration of a treatment or an act that induces death, at the request of a patient, like Remy in the *Barbarian Invasions* (Arcand, Louis, Robert & Vonier, 2003). *Assisted suicide* refers to a situation where the patient has been provided with the means (e.g. drug overdose) specifically for the purpose of suicide. Usually, it is the patient who commits the final death-hastening acts (e.g. swallows a lethal prescription) like Sampedro in *The Sea Inside* (Amenábar & Bovaira, 2004). Researchers typically identify these cases as "physician-assisted suicide" (see Bachman, Alcser, Doukas, Lichtenstein, Corning, & Brody, 1996; Back et al., 1996; Hogg, Heath, Bally, Cornelisse, Yip, & O'Shaughnessy, 1996; Kluge, 2000; Smokowski & Wodarski, 1996). Accordingly, the definitions refer to active rather than passive euthanasia or assisted suicide. Passive acts include death that results from withholding or withdrawing medical treatment, which is accepted medical practice in Western nations. These acts are not classified as causing death because illness or disease are allowed to take their natural course (Cormack, 2006). Interestingly, the practice of withholding medical treatment is less controversial, but at least two parliamentary debates in the U.K. have focused on whether withholding hydration and nutrition amounts to a criminal offence (McLean, 2004).

A second theme emerging from the discourse is that euthanasia and assisted suicide are used interchangeably. At the international level, Article 1 of the Universal Declaration of Human Rights (UDHR) makes reference only to euthanasia, but the definition is broad enough to include assisted suicide. Under Article 1 euthanasia refers to "...death caused deliberately...is an action or omission with the primary intent of bringing about a patient's death in order to end his or her suffering" (Aumonier et al., in Letellier, 2003 p.21). Reference to euthanasia is also found at the national level. While legal provisions vary, legislation in the Netherlands and Belgium refers to physician-assisted suicide as euthanasia. Under Article 2 of the *Dutch Penal Code* doctors are not prosecuted for committing an act of euthanasia, providing they follow specific guidelines (van Delden, 2004). Similarly, Belgium's *Euthanasia Act 2002* outlines the conditions under which a physician may legally practice euthanasia (Englert, 2004). As indicated later in this chapter, legislation in both the Netherlands and Belgium stipulates, among other things, that only informed patients experiencing unbearable suffering can request an assisted death.

Alternatively, legislation in Canada and the U.K. speaks only to assisted suicide. In Canada, legislation prohibiting assisted suicide is found in s. 241 of the *Criminal Code*. Similarly, s.2 of the *Suicide Act* in England and Wales 1961 prohibits assisted suicide. Even though the conflation of the definitions may lead to conceptual muddiness, a review of the legal status of euthanasia and assisted suicide shows that the two concepts are often treated synonymously. The tendency to conflate euthanasia and assisted suicide appears to be related to their respective legality. For example, guidelines for physician-assisted suicide in Oregon clearly exclude euthanasia (Hedberg & Tolle, 2002 in, Snyder,

2004) while legislation in the Netherlands provides physicians with greater leeway (van Delden, 2004). In the U.K., Canada and the U.S. (except Oregon) any assistance with death is illegal so the terms appear to be used interchangeably.

The following section outlines the legal status of euthanasia and assisted suicide in nations where assisted death has been or is being debated. This includes a discussion of issues affecting the debate in Canada, the United States, Australia, Belgium, the Netherlands and the United Kingdom. Where applicable, the discussion includes the identification of salient cases that have emerged during the debate on assisted death. For example, while there is little research, Article 115 of the *Swiss Penal Code* stipulates that assisting another person to suicide (active, voluntary euthanasia) is not a crime in Switzerland if it is done for reasons of mercy, but not for profit (Bondolfi, 2004). Humphry (2001) observes that because most jurisdictions do not permit assisted suicide, desperate persons who believe in the freedom to die at a time of their choosing are looking to Switzerland. The Swiss treat the issue of assisted death differently from other nations. Indeed, the organization “Exit” has received permission from the municipality of Zurich to carry out assisted suicide wishes of elderly patients, but only under strict conditions (Bondolfi, 2004). Crude estimates place the number of assisted suicides for 2001 at 300. Of those, 55 were foreigners who traveled to Switzerland to die. Following an examination confirming terminal conditions, residents and visitors must obtain a prescription for pentobarbital, the death-inducing drug, from a licensed Swiss physician. To date, the Swiss government has not placed any limitations on what has come to be known as *suicide tourism* (Editor’s Choice, 2003). Given the focus of the present research, particular attention is paid to the legal status and debate in the U.K.

Cross-National Developments in Assisted death

Assisted Death in Canada: Constitutional and Legal Challenges

Criminal cases and non-criminal hearings involving assisted death are not new to Canada. Cormack (2006) documents several incidents where the courts and other regulatory bodies have dealt with euthanasia and assisted suicide. Over the years, the courts have been reluctant to pursue or convict in cases involving assisted death. In 1941, the parents of a two-year old boy afflicted with cancer were acquitted of charges that they asphyxiated their son with carbon monoxide. In 1991, a doctor was acquitted of homicide after administering a lethal dose of morphine to a patient. That same year, a nurse was convicted of administering a noxious substance after giving a lethal dose to an elderly patient. In 1992, a doctor suspected of administering a lethal injection to an AIDS patient was not charged on the advice of the Québec College of Physicians. And, in 1993, a physician convicted of administering a noxious substance received a suspended sentence and three years' probation for his part in the death of a patient removed from a ventilator (Cormack, 2006).

In Canada, the debate surrounding the topic reached a zenith in 1994 when Sue Rodriguez petitioned the Supreme Court of Canada for the right to an assisted suicide. Rodriguez suffered from Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease, an incurable and degenerative disease affecting the muscle and neurological systems. ALS is associated with progressive muscle weakness and atrophy accompanied by inordinately acute reflexes. Those afflicted with the disease usually die from respiratory failure due to weakened ventilatory muscles (Shaw, 1999). Ultimately, Rodriguez lost

her appeal in a narrow 5-4 ruling that favoured the sanctity of life over the right of the individual to an assisted death (*Rodriguez v. British Columbia*). Undeterred by the Supreme Court's ruling, Rodriguez maintained her position and took her own life by an overdose of barbiturates and morphine (Olsen, 1996). Rodriguez died in the company of a physician and also a friend, Svend Robinson, an outspoken advocate for assisted death a Member of Parliament at the time. No charges were laid in the case (Downie, 2004).

In addition to making a public statement about the right to die, the Rodriguez case is considered by some to be the catalyst for an outpouring of public debate on euthanasia and assisted suicide (Ogden & Young, 1998). Indeed a national survey of 1,410 adults conducted by Pollara in 1997 found that over 60% of Canadians supported legalized physician-assisted suicide (Culbert & Kennedy, 1997). Conjoined with the high profile of the Rodriguez case, the controversy surrounding the right to die in Canada was considered important enough for the Canadian government to warrant the formation of a Special Senate Committee on Euthanasia and Assisted Suicide (Senate of Canada, 1995). The committee heard submissions by groups for and against the right to die but recommended that euthanasia and assisted suicide remain criminal offences. Section 241 of the *Criminal Code* provides that:

Every one who
(a) counsels a person to commit suicide, or
(b) aids or abets a person to commit suicide,
whether the suicide ensues or not, is guilty if an indictable offence and liable to imprisonment for a term not exceeding fourteen years, those convicted of counseling, aiding or abetting suicide are still liable to a term of imprisonment for up to 14 years.

This prohibition remains even if the patient requests a hastened death. Under section 14 of the *Criminal Code*, “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.”

While there were diverse opinions, opposition to assisted suicide and euthanasia is grounded in a fear of abuse, or non-voluntary euthanasia (Senate of Canada, 1995). There were differing opinions within the opposition side. Some groups found assisted suicide acceptable, but acknowledged that legalization of assisted suicide would most likely lead to a challenge under section 15 of the Canadian Charter of Rights and Freedoms, “equality before and under law and equal protection and benefit of law”. For example, compared to a physically capable person, someone with ALS would not be able to choose the time of his/her death. Compared to other practices like withholding and withdrawing treatment, euthanasia requires an action to cause death. Thus, a clear distinction was drawn between actions to alleviate suffering and actions that directly bring about death (Senate of Canada, 1995).

Like their opponents, groups in favour of euthanasia noted that if assisted suicide were legalized then euthanasia should also be legal under section 15 of the Charter, equality under the provision. They argued that the distinction between hastened death (assisted suicide and euthanasia) and withholding and withdrawing treatment was minimal: suffering is alleviated and death ensues. In addition, these groups stated that the role of physicians to ease suffering supports a merciful death for competent individuals who choose assisted suicide or euthanasia (Senate of Canada, 1995).

The impact of Rodriguez continued with the Special Senate Committee on Euthanasia and Assisted Suicide (Senate of Canada, 1995). In 1998, a Private Member’s Bill (M-123) tabled by Svend Robinson reintroduced the euthanasia debate to Parliament

(Hansard, 2005, 1730). The bill clearly defined assisted suicide and euthanasia as voluntary acts requested by competent adults wanting the right to die with dignity, but it did not include mercy killing (e.g. Robert Latimer who was convicted of killing his daughter who suffered from cerebral palsy) (Hansard, 2005, 1735). Despite attempts by proponents of the bill to highlight the issue of choice for patients at the end-of-life, debate on the bill focused on the potential for non-voluntary euthanasia for disabled and vulnerable populations like the mentally ill and elderly (Hansard, 2005, 1810).

Bill M-123 was defeated, but the debate surrounding assisted suicide and euthanasia has not abated. Indeed, the case of Evelyn Martens is one of several that underscore the need for Parliament to act on the issue. Martens, a euthanasia activist from B.C. was charged with aiding and abetting the suicide of two women. Martens was acquitted of the charges in November, 2004. Shortly after her acquittal, Justice Minister Irwin Cotler suggested that a review of the law regarding assisted suicide in Canada was in order (Interim, 2004). There has been no further serious discussion on assisted death in Parliament since then.

From Dr. Death to Dying with Dignity: Assisted Death in the United States

The legal status of assisted death in the U.S. varies by state. Euthanasia is illegal in all states, but assisted suicide is treated differently across the country. Assisted suicide is a common law offence in six states and the District of Columbia. In 41 states, assisted suicide is a codified criminal offence. Other states treat assisted suicide as homicide (Cormack, 2006).

Dr. Jack Kevorkian has highlighted legal and ethical concerns posed by assisted death. His notoriety surged after being charged in 1990 with first-degree murder for his role in assisting Janet Adkins to die. Adkins accompanied Kevorkian on a 2,000-mile journey to a campsite in Michigan where Adkins died of a lethal injection of potassium chloride in the back of Kevorkian's Volkswagen Van. The charge against Kevorkian was dismissed because Michigan did not have a law prohibiting assisted suicide (Magnusson, 2002).

Kevorkian continued to assist others to die. Under Michigan's new law prohibiting assisted suicide passed in 1993—he was charged and acquitted on three different occasions: 1993, 1994, and 1996. In another case, in early 1998, Kevorkian was discharged due to a hung jury. By late 1998, Dr. Kevorkian had assisted over 130 people to die (Magnuson, 2002). His personal crusade to challenge what he thought were barbaric laws against assisted suicide resulted in him performing an assisted suicide that was taped and later aired on national television in November, 1998. He was subsequently charged with the death of Thomas Youk, who was afflicted with Lou Gehrig's disease, and convicted of second-degree murder. He is eligible for parole in May 2007 (New York Times, 1999).

While the Kevorkian case adds a sensational element to the issue, the debate surrounding assisted death in the U.S. has been the subject of two major constitutional challenges. After deliberation on two separate petitions, one from the state of New York (*Vacco v. Quill*) and the other from Washington (*Washington v. Glucksberg*), in 1997 the U.S. Supreme Court upheld the argument that assisted suicide could be constitutionally prohibited by individual states. The debate turns on the tension between individual self-

determination and the potential for abuse. On the one hand is the view that patients should have the choice as to how and when they die. On the other hand is the concern that vulnerable populations (e.g. elderly and disabled persons) may be abused if assisted death was legalized. The Supreme Court did not rule out the constitutional validity of assisted death. Speaking to the decision in *Washington v. Glucksberg*, Supreme Court Justice Stevens stated that:

I agree that the state has a compelling interest in preventing persons from committing suicide because of depression, or coercion from third parties. But the State's legitimate interest in preventing abuse does not apply to an individual who is not victimized by abuse, who is not suffering from depression, and who makes a rational and voluntary decision to seek assistance in dying (1997 p. 2308).

In 1994 Oregon passed the *Oregon Death With Dignity Act*. After three years of delay, injunctions and a U.S. Supreme Court ruling, the Act came into effect in November 1997, making Oregon the first North American jurisdiction to legalize assisted death by physician-assisted suicide (Oregon Department of Human Services, 2004). The Act allows medical doctors to prescribe a specified lethal dose of a drug or drugs to a terminally ill patient, with the specific provision that patients self-administer the lethal drugs. A key problem with this guideline is that it places full responsibility on the patient and prohibits the direct assistance of other people, including the doctor. Thus, someone with a disability like ALS in advanced stages would be ineligible. In addition, if something goes wrong with the self-administered death process, doctors and family members are legally at risk of prosecution if they provide assistance to hasten death (*Oregon Death With Dignity Act, 1995*). In essence, the Act is an incremental policy that supports patient self-determination on the one hand, but discriminates against those who have the most to gain from an assisted death, the seriously and terminally ill, on the other

(Ogden, 1997). The 6th Annual Report of the *Oregon Death with Dignity Act* (2004) outlines one complication in implementing the Act after Attorney General Ashcroft issued a new guideline for the *Controlled Substances Act* in 2001. In effect, this guideline, which was appealed (MedicineNet.com, 2004), would have prohibited Oregon doctors from prescribing the drugs required for assisted suicide. On April 17, 2002, a U.S. District Court upheld the *Death with Dignity Act* and, on January 17th 2006 the U.S. Supreme Court voted to support the Oregon legislation allowing physician-assisted suicide. “The court ruled that the federal Controlled Substances Act does not allow the U.S. Attorney General to prohibit doctors from prescribing regulated drugs for use in physician-assisted suicide” (LifeSite, 2006). To date, Oregon remains the only state that permits physician-assisted suicide (Oregon Department of Human Services, 2004).

The Role of Parliamentary Supremacy: Assisted Death in Australia

In practice, Australia was the first country to legalize voluntary euthanasia when the *Northern Territory Rights of the Terminally Ill Act* (RTI) was enacted on July 1, 1996. Initially, the private member’s bill presented by former Chief Minister Marshall Perron, enjoyed considerable support. Adult patients, 18 and over, could request that a health care practitioner assist them dying. The practitioner did not have to be a physician and the patient had to be afflicted with an illness that caused pain and suffering. The practitioner had to be satisfied that there was little prospect for the patient’s cure and that the patient was not suffering from treatable depression (Cormack, 2006).

The first case of euthanasia occurred shortly after the passage of the RTI on September 22, 1996 with the death of Robert Dent. Dent died following a lethal infusion

of morphine and a sedative (midazolam) under the supervision of Dr. Phillip Nitschke and his “death machine”. The machine brought about death by a lethal injection of morphine and midazolam. The patient was kept unconscious and death was painless (Magnusson, 2002). In 1997, using its power to make laws for the territories, the Australian Parliament overturned the Act and replaced it with the *Euthanasia Bills Act* (EBA).

Opposition to euthanasia came from religious groups like ‘Euthanasia No’, a Catholic-supported activist organization. Along with other anti-euthanasia church groups and right-to-life organizations, the “no” side of the euthanasia debate exerted considerable influence on the Senate Committee, which conducted hearings into the Andrews Bill, later the EBA. Introduced by a Catholic federal Parliamentarian, Kevin Andrews, the Bill passed by a majority of five votes. In effect, the new Act made it impossible for Australia’s three territories to pass any laws to allow euthanasia. As outlined by the Parliament of Australia Library (2001), the three salient arguments used to overturn the RTI include:

- To protect Australia from international disrepute: They would be the first country in the world to legally allow a doctor to end the life of a patient.
- To protect Australian Aboriginal peoples: the existence of a law legalizing the ending of a person’s life was offensive to their customs and beliefs about death.
- To protect basic human rights principles: i.e. ensuring that no territory of Australia could legislate euthanasia at any time in the future.

Despite the change in legislation, right-to-die activists remain committed to their cause. For over 20 years, high-profile physicians like the Melbourne 7 of which Nitschke

is a member, have practiced euthanasia behind closed doors. The group's actions have made them targets of numerous police investigations by the Victoria State police and the Medical Practitioners Board of Victoria. None of these investigations resulted in a criminal conviction or board censure affecting group members' medical practices. Instead, the group received a community service award from the Victoria Volunteer Euthanasia Society in 1995 (Magnusson, 2002). The death of Nancy Crick in 2002, however, has opponents concluding that euthanasia is too dangerous for Australian society. Crick sought an assisted death because she suffered from painful cancer, but an autopsy revealed that she did not have the cancer she claimed (Goodenough, 2002). In the face of ongoing investigations by the Australian Medical Association, Dr. Nitschke continues to operate advice clinics for those seeking technical knowledge on ending their own lives (Goodenough, 2002). Not surprisingly, discussion of legislative options for euthanasia in 2003 indicates that the debate on assisted death in Australia was contentious and unresolved (Goodenough, 2001; Magnuson, 2002; World Federation of Right to Die Societies, n.d.). One troubling aspect of the debate for the right-to-die side is the documentation of cases involving LAWER, which refers to life-terminating acts that occur without the patient's explicit request. A replication of the Rummelink study (discussed below) involving interviews with 800 physicians showed that 3.5% of deaths in 1995 were the result of LAWER. This finding is significantly higher than the 0.7% of LAWER in the Netherlands (Cormack, 2006). However, proponents of the right-to-die argue that the higher percentage of cases involving LAWER in Australia is evidence of the need for regulation.

From Acceptance to Legalization: Assisted Death in the Netherlands

Prior to legalization in 2002, assisted death occurred *sub rosa*; euthanasia was an illegal, but accepted practice in the Netherlands². Dutch courts began to recognize the defence of necessity in 1973 which, in effect, allowed physicians to practice euthanasia out of the obligation to reduce suffering and a “respect for personality” or patient autonomy (Griffiths, Bood & Weyers, 1998; Magnusson, 2002). Dutch policy on assisted death requires that physicians report death-hastening acts on patients’ death certificates (see Cormack, 2006). However, the number of cases involving euthanasia has been hotly debated due to accusations of poor reporting policies and concern about abuse, i.e. non-voluntary euthanasia. The implementation of new reporting procedures in 1990 led to an increase of 13% in the notification rate by 1995 (41% to 54%) (van Delden, 2004). In 1998, an additional reporting procedure was developed and five regional assessment committees were established to investigate all cases of reported euthanasia. It was hoped that the new procedure and investigatory team model would increase physicians’ participation in reporting cases of euthanasia because the Dutch changed the definition of euthanasia to only include cases involving a specific request. The narrowed definition and related changes to reporting criteria did not result in an increased number of reported cases. As Table 2.2 illustrates, there has been little change in reported cases of euthanasia since 1998. This statistic may be misleading because the true number of cases involving euthanasia is unknown (van Delden 2004). While the consistency in reported figures suggests *prima facie* accuracy, Table 2.2 shows that less than one half of suspected cases of assisted death were officially reported.

Research conducted by the Rummelink Committee in 1990 examined the claim that assisted death was occurring non-voluntarily (Van der Maas et al., 1992). The data collected involved interviews with 405 physicians (PI) and an analysis of 7,000 death certificates (DC). The study was replicated in 1995 and again in 2001 (Onwuteaka-Phillipsen et al., 2003).

The Rummelink data show that death by euthanasia was more frequent than assisted suicide. As illustrated in Table 2.3, the number of deaths by euthanasia reported by physicians increased between 1990 and 1995 and declined slightly in 2001; death by assisted suicide varied. The DC data show an increase in euthanasia from 1990-2001 while death by assisted suicide remained constant (Onwuteaka-Phillipsen et al., 2003). Analyses of the Rummelink data show that LAWER cases accounted for 0.6% and 0.7% of deaths in the Netherlands (Onwuteaka-Phillipsen et al., 2003). These include acts like the administration of drugs and non-explicit or vague requests (Cormack, 2006). It may be argued that LAWER data underestimate non-voluntary deaths because the data do not capture the double effect of pain management (Cormack, 2006). Thus, it can be tentatively concluded that involuntary euthanasia comprises at least a portion of the dark figure of unreported cases of assisted death in the Netherlands. However, the majority of unreported cases involved patients near death or those experiencing unbearable suffering. Data from the first Rummelink report indicated that in more than 59% of LAWER cases patients had previously indicated their wish for assisted death (van der Maas et al., 1992).

Table 2.2

Number of Reported Cases of Euthanasia and Assisted Suicide in the Netherlands*

Years	Absolute Numbers	% of VE/AS Cases Reported**
1995	1,466	41
1996	1,700	***
1997	1,900	***
1998	2,590	54
1999	2,216	***
2000	2,123	***
2001	2,064	***
2002	1,882	54

*Adapted from van Delden (2004 p.71).

**Represent estimates of suspected cases only.

***Cannot be estimated reliably.

Table 2.3

**Cause of Death According to Physician Interview (PI) and
Death Certificate (DC) Data in the Netherlands**

Year/Number of DCs	1990 n=5197	1995 n=5146	2001 n= 5617
Physician Interview			
Euthanasia	1.9%	2.3%	2.2%
Assisted Suicide	0.3%	0.4%	0.1%
Involuntary Assisted Death	NA	0.7%	0.6%
Death Certificate			
Euthanasia	1.7%	2.4%	2.6%
Assisted suicide	0.2%	0.2%	0.2%
Involuntary Assisted Death	0.8%	0.7%	0.7%

Source: Onwuteaka-Philipsen et al., 2003.

In response to the large number of unreported euthanasia cases and the hypocrisy of tolerating what is technically illegal behaviour by physicians, the Netherlands legalized assisted suicide and euthanasia in 2002. As van Delden (2004) observes, acts of euthanasia or assisted suicide performed by a physician will not be punished, provided that the physician reports the case and has acted in accordance with the rules of due care.

Article 2 of the *Dutch Penal Code* requires that the physician:

- a) should be convinced that the request of the patient was voluntary and well considered;
- b) should be convinced that the suffering of the patient was unbearable and without prospect of relief;
- c) should inform the patient about his or her situation and prospects;
- d) should come to the conclusion, together with the patient, that there is no reasonable alternative solution to the situation the patient;
- e) has consulted another independent physician who has seen the patient and agrees with the evaluation of the physician on points *a to d*;
- f) performed euthanasia in a careful way (van Delden, 2004).

The new legislation clarifies roles and responsibilities of physicians. It clearly delineates criteria to be used in cases of assisted death. Nevertheless, it is doubtful that the trend of under-reporting cases of assisted death by physicians will change in the near future. The new legislation provides safeguards implemented to protect vulnerable persons, but similar safeguards have not worked well in the past (Davis, 2003). In addition to poor reporting practices, there has been a tendency to overlook important criteria once a decision has been made that a person's life is no longer worth living. Of 4,500 cases reported in 1995, one in five (900) people had their lives ended without an explicit request (Jochemsen & Keown, 1999). As indicated in Table 2.1 and the above discussion, the number of cases recorded by the researchers in the Rummelink study is considerably lower than Jochemsen & Keown's (1999) account. Moreover, data from the

latest Rimmelink study indicate that very few cases of reported euthanasia were carried out without patients' expressed consent (Onwuteaka-Philipsen et al., 2003). Arguably, comparisons of this type are erroneous as researchers may be using different definitions of the terms in research on assisted death (e.g. euthanasia, consent, request, and the like). Indeed, social science methodologists observe that researchers frequently operationalize their definitions to suit their own research and/or ideological perspectives (Denzin & Lincoln, 2000). This problem of obtaining the best possible information is exacerbated with behavior such as assisted suicide, which is practiced illegally, behind closed doors.

Clearly, the debate about assisted death in the Netherlands is far from over. Concerns about reporting practices and consent are complicated by the fact that the new legislation does not endorse the right to die; rather, it treats assisted death as an act of last resort. As van Delden (2004) argues, future debate in the Netherlands will need to extend the argument beyond the medical domain. According to the Royal Dutch Medical Association, 1995 (van Delden, 2004) discussion will need to expand beyond patient self-determination and compassion to include autonomy. This issue will invariably lead the debate into the realm of a patient's right to request an assisted death and the obligation of physicians to comply. The new legislation does not provide for such eventualities and the debate continues.

Following the Dutch: Assisted Death in Belgium

After more than a decade of public and political debate, Belgium's *Euthanasia Act* was passed in May, 2002. The medical community is credited with providing the impetus to reform anti-euthanasia legislation by officially recognizing assisted death as a social reality in Belgium. Researchers studying assisted death conducted by the Belgium

Medical Association found that both physicians and nurses overwhelmingly supported euthanasia³. A statement by the National Council of the Order of Doctors (Englert, 2004) tacitly approved euthanasia for patients. More concrete support for euthanasia came in a joint statement of the University of Louvain, a Catholic University, and the heads of two university hospitals, St. Luc and UCL Mon-Godinne.

The culture of continuing care provides an immediate solution to the problem of prolonging life by artificial means. It implies that suffering from which there is no escape, and which defies all forms of treatment, must be identified and addressed. In this the care teams must be trusted and allowed, should their efforts fail, to assist the end of life by medical means if such remains the wish of the patient (Englert, 2004 p. 17).

While debate on euthanasia in the medical community moved toward consensus, both Belgian Catholic parties announced that, while they did not support legalization, they no longer condemned the act of euthanasia. The official position of the Social Christian Party (PSC) states that:

Although we reject any change in the Criminal Code provision that prohibits killing, we can none the less (sic) envisage the possibility of doctors finding themselves in, legally, a situation of necessity in which they may respond to a request of euthanasia (Englert, 2004 pp.17-18).

The televised assisted death of a Belgian man seeking reform of law on euthanasia on French-speaking television in Antwerp served as the final event to heighten the need for reform of legislation involving euthanasia. The Belgian *Euthanasia Act* is similar to Dutch legislation in that it sets out the criteria to be followed by physicians in order for the death to be legal. It requires:

- that the patient must be adult and conscious;
- that the request be made of the patient's own volition, after reflection, and be repeated

- that there be no medical solution to the situation;
- that the patient be experiencing constant, unbearable physical or mental suffering that cannot be relieved;
- that the patient's condition as a result of accident or illness be serious and incurable (Engelert, 2004 p 22).

Similar to the Dutch experience, the debate on euthanasia in Belgium has focused on compassion and self-determination. The debate is quickly shifting to the issue of patient autonomy, much like it has in the Netherlands. Senator Philippe Mahoux, who helped to draft the Act, stated that the legalization of euthanasia is “recognition that a dying patient in constant and unbearable...pain should be the only judge of their quality of life and the dignity of their last moments” (Euthanasia.com, 2002).

Assisted Death in the United Kingdom: Hypocrisy in Law?

As indicated above, assisting another to end his/her life is illegal under section 2 of the *Suicide Act* 1961. This section states:

- 1) A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years...
- 2) If on the trial of indictment for murder or manslaughter it is proven that the accused aided, abetted, counselled or procured the suicide of the person the jury may find him guilty of that offence.

As with Canadian legislation, the law does not distinguish between compassionate killing (euthanasia or assisted suicide) and other forms of homicide. But, a person accused of killing a relative can have their charge lowered to manslaughter if the defence can show an “abnormality of the mind” leading to the conclusion of “diminished responsibility” of the accused (Grubb, 2001). This defence is not available to physicians. British courts

have recognized that while physicians bear the professional responsibility of maintaining life, they also have the duty to prevent pain and suffering. Thus, the use of drugs, primarily opiates, in pain management that inadvertently results in premature death is considered legal under the doctrine of “double effect” established in *R v. Bodkin Adams* (Griffiths, 1999). Interestingly, the death of King-Emperor George V was hastened by an injection of morphine and cocaine, a concoction now known as a “whizzball” (King-Emperor George V, nd <http://cocaine.org/misc/george-v.html>).

The doctrine of double effect does not support deliberate physician-assisted death in the U.K. Nevertheless, the courts have been reluctant to pursue the maximum penalty for physicians accused of assisting in the death of their patients. Dr. Nigel Cox was convicted and given a one-year suspended sentence for administering a lethal dose of potassium chloride to a terminally ill, elderly woman who begged him to help end her life. Interestingly, the GMC (General Medical Council) did not remove or suspend Dr. Cox from the medical register (Griffiths, 1999; Grubb, 2001; McLean, 2004).

Over the past decade, the debate on euthanasia has reaffirmed its illegality in many jurisdictions. Given advances in life sustaining-technologies and related medical advances, the courts have recognized the right to refuse treatment for persons not wishing to prolong the suffering associated with terminal illness. In England, this right was upheld in a case involving a 59-year-old woman who was totally paralyzed following several strokes. Unable to take her own life or to receive an assisted death, Ms. Stroher decided to end her life by refusing to eat or drink. Using the provisions in the *Mental Health Act* 1983, her care team detained her for treatment of “depression”, which involved electroconvulsive therapy. Ms. Stroher’s lawyer and daughter appealed the

treatment decision to a mental health tribunal, which resulted in acceptance of her decision to die of starvation (Griffiths, 1999).

Another case concerning refusal of treatment involves a patient's request not to be kept alive by artificial means. In 1999, Ms. B was paralyzed by a hemorrhage in her spinal column. Two years later she was admitted to hospital in serious condition requiring artificial life support. Despite her having written an advance directive, doctors refused to remove the breathing ventilator necessary to maintain Ms. B's life. At issue was the claim that Ms. B was not mentally competent to make such a request (McLean, 2004). In many cases, the hospital authorities and/or physicians are reluctant to grant such requests because they fear lawsuits. Legislation and insurance concerns take precedent over patients' wishes. As in many like cases, requests for a hastened death are treated as indicators of mental illness. Indeed, the tautology of psychiatric diagnoses involving suicide proceeds from the assumption that a request to die is a sign of mental illness because the latter renders people irrational and only an irrational person would consider suicide (McLean, 2004). Thus, the notion of a "rational suicide" for persons suffering from terminal illness put forth by Werth and Holdwick (2000) is anathema to those providing treatment.⁴

After an independent psychiatric assessment, Ms. B was found to have the capacity to make an informed decision. Clinicians caring for Ms. B claimed that removing life support would be the same as killing her. Ms. B's decision to refuse treatment went to the High Court in England, which upheld her decision to have the ventilator removed. She died on April 12, 2002 (Slowther, 2002).

Perhaps the most important case involving the right to withdraw treatment in the U.K. is *Airedale NHS Trust v. Bland*. Bland suffered extreme oxygen deprivation after his lungs were crushed in a football stadium accident. His father appealed to the House of Lords to have life support removed from his son. Bland remained in hospital in a persistent vegetative state (PVS) suffering from higher-brain death, the loss of feeling, memory, thought and consciousness (Magnusson, 2002). Bland's condition gave rise to a discussion on what it means to be dead rather than whether or not he was alive. Catholic bioethicists argue that patients in PVS are "...human subjects with dignity whose lives are morally inviolable..." (Ford, 1994 p.14 in Magnusson, 2002 p.56). In practice, higher brain death is considered sufficient cause to remove life-sustaining treatment. While reemphasizing that euthanasia was illegal, in *Bland* their Lordships drew the distinction between an act and an omission. Bland would die of underlying reasons and not through the actions of another (e.g. a lethal injection administered by a physician). The apparent hypocrisy of this decision and the acts/omissions distinction is not without criticism, but the court held that to maintain Bland's life was futile and his life support was removed.

On the one hand, the right to refuse treatment and the practice of passive euthanasia (withdrawal of treatment) have been accepted with *Stroher* and *Bland*. On the other hand, with the Cox decision the courts in the U.K. have confirmed their stance against physician-assisted suicide (e.g. active euthanasia), but are reluctant to impose the full weight of the law. The Dutch experience, with accepted and now legalized euthanasia in 2002, has prompted much debate in the U.K. The medical community, politicians and judges are concerned that legalizing assisted death will result in a slippery

slope and the elimination of undesirable human beings. In the 20th century, eugenicists argued that inferior humans could be eliminated through selective breeding (positive eugenics) and sterilization (negative eugenics). Physical and mental competencies were identified as key criteria to determine human worthiness. The reproduction of children from poor, criminal and otherwise immoral individuals was considered harmful to society in economic and social terms. Although the threshold of perfection was arbitrary, that inferior human beings could be identified scientifically was championed by some medical practitioners. Selective elimination of individual humans was not the goal of eugenics in the U.K. or North America (McLaren, 1990). Both positive and negative eugenics lost influence with the end of World War II and the revelation of the Nazi genocide program.

Nevertheless, in the Netherlands, it is estimated that 300 newborn babies with birth defects are left to die through starvation and dehydration each year. In addition, approximately 10 babies a year receive a lethal injection and many older disabled children go without required surgeries because physicians refuse to operate on them (Griffiths, 1999). In 1994, the House of Lords Select Committee conducted a comprehensive review of issues surrounding euthanasia. The committee concluded that, "...the deliberate taking of life should remain illegal" (Government Response to House of Lords Select Committee on Medical Ethics, 1994 in, Grubbs, 2001 p. 90). Their Lordships went on to add that relaxing the laws would give rise to the many dangers associated with euthanasia, including elimination of less than perfect human beings.

In addition to the House of Lords' decision, the political will to change the law regarding euthanasia has been weak. In a White Paper regarding mental health patients and decision-making, the government denounced euthanasia. Even though Parliament

has not had the opportunity to debate the issue fully, both sides of the debate are concerned about the implications. Proponents of assisted death point out that the majority of British citizens endorse euthanasia and assisted suicide, and despite it not being the policy of the British Medical Association, many physicians support assisted death options for the terminally ill (McLean, 2004). Detractors argue that decisions in cases like Bland place far too much power in the courts (Hansard, May 22, 2002 in, McLean, 2004).

The most recent challenge to the prohibition against euthanasia in the U.K. came in the form of an appeal by Diane Pretty to the House of Lords in 2001. Pretty, suffering from an incurable motor neuron disease (MND) that paralyzed her from the neck down, sought the right to have her husband assist her to commit suicide (Dimond, 2004). She based her appeal on the provisions in the *Human Rights Act, 1998* which, in essence, follows the *European Convention of Human Rights*. As Grubb (2001) notes, this Act "...allows challenges to Government action and legislation that infringe an individual's convention rights (2001 p.91)." The House of Lords rejected the appeal. Referring to the *Suicide Act, 1961*, their Lordships noted that any change to the law on euthanasia would have to be made by Parliament.

Pretty appealed the House of Lords' decision not to be allowed an assisted death to the European Court of Human Rights on several grounds. She claimed that the *Suicide Act, 1961* violated: her right to life (Article 2); the prohibition of humane or degrading treatment or punishment (Article 3); the right to respect for private life (Article 8); freedom of conscience (Article 9); and prohibition of discrimination (Article 14). The court rejected Pretty's appeal on all grounds and held that the *Suicide Act, 1961* did not

contravene her rights under the European Convention (Dimond, 2004). Pretty died a natural death in May 11, 2002, shortly after entering hospice care for complications associated with MND (BBC, 2002).

Two years after Pretty's death a bill enabling terminally ill persons the right to die with medical assistance was introduced in 2004 by The Lord Joffe. HL Bill 17, *Assisted Dying for the Terminally Ill*, provided that physicians could prescribe medication intended to bring about the death of a patient. The bill was subsequently replaced in 2005 by a new version of the Act, which is to be tabled in 2006. Under this bill, a mentally competent and informed patient has the right to forego treatment, for example to reject palliative care, and the choice of an assisted death. In the event the patient is unable to self-administer the medication, the physician can, with the assistance of a designated member of the patient's health team, provide the means for the patient to ingest the medication (Assisted dying for the Terminally Ill, HL 36).

Medical Hegemony and Assisted Death

Assisted death is confined to terminally ill persons or others at the end of life. Voluntary euthanasia and assisted suicide are end-of-life issues framed primarily in the physician-patient relationship. The legal, moral and ethical issues surrounding assisted death are complex and involve members of patients' families and other health care providers. Thus, the choice to hasten death moves beyond the simple physician-patient relationship, but physicians are the only professionals considered appropriate to hasten

death in places where voluntary euthanasia and assisted suicide have been legalized (i.e. the Netherlands, Belgium, Oregon and Australia).

Death, and particularly suicide, has not always resided so squarely in the realm of medicine. Growing dissatisfaction in late 18th century England with religious explanations of “self-destruction” (suicide) as the work of Satan on Earth led to the development and adoption of secular explanations of self-harm. While still considered immoral and potentially harmful to the fabric of society, the explanation for suicide shifted from demonic possession to lunacy (McDonald, 1989). Lunatics were considered innocent victims, not representations of Satan in need of demonic purging through physical torture of the body. Consequently, attitudes and responses to suicide were medicalized by default; physicians have maintained this authority ever since (McDonald, 1989).

Medical control over life and death has become so pervasive that only physicians can register a new life when it enters the world and confirm its demise when it leaves. Accordingly, in the 20th century, research and understanding on death has been primarily visible through objective scientific language, which locates death within disease, mortality, and etiology. References to social attitudes and sentiments are not to be found in the discourse (Clark, 1993; Prior, 1984). The advent of the hospital in the 19th century resulted in the transfer of death and dying from communities to medical settings. From that point, the discourse reveals that the medicalization of death was bureaucratized and conjoined with other methods of social surveillance, which focused on registration, calculation, examination and physical control over bodies (Turner, 1987; Prior, 1984). Interestingly, the study of suicide as a social phenomenon appeared in the late 19th

century with Durkheim's 1897 pioneering research on suicide in France (in Durkheim, 1951).

The social reclamation of death occurred in the twilight of positivism in the 1950s, with the recognition that the promise of medicine to control death, and the pain and suffering associated with dying, was not a *fait accompli*. Clark (1993) argues that the establishment of hospices in the 1960s suggests that death and dying are no longer taboo subjects, but are social phenomena whose expanding social recognition and relevance make it possible to discuss physician-assisted death as a medicalized process. Studies show that death takes on different meanings depending on a variety of factors.

Durkheim's original study paved the way for "suicidology" and the identification of social facts associated with suicide. For example, Durkheim's analysis of the relationship between religious affiliation and suicide shows that, compared to Catholics, Protestants were more likely to attempt and successfully complete suicide (Durkheim, 1951). The concept of anomie suggests that people who are poorly integrated in society are more likely to commit suicide (Durkheim, 1951). Likewise, groups that are excluded will have higher rates of suicide than groups that are more integrated (Douglas, 1967). Today, a growing body of research shows that many people seek an assisted death for reasons unrelated to religious affiliation, anomie and a host of other physical and mental reasons that can be ameliorated. Euthanasia and assisted suicide cast new meaning on medicalization, and there are implications for the medical community.

Importantly, the medicalization of death has been affected by the transformation of near-absolute medical dominance to relative dominance. Like other professions, medicine has come under the influence of the *corporate imperative*. Corporatism

recognizes the increased dependence of physicians on complex bureaucratic organizations and the potential for these organizations to appropriate physician autonomy (Light & Levine, 1988; Wolinsky, 1993). Medical dominance is thus challenged by the need for bureaucratic expediency, which influences the type, quality and quantity of the services physicians deliver to their patients. The interdependence of physicians with other professional groups (i.e. nurses and social workers) that has increased the latter's influence in the medical setting further challenges autonomous medical dominance in decision-making. That said, the discretion of individual rank-and-file physicians may have decreased, but the ability of the medical profession and the influence of professional medical associations to control the type of work done by physicians has not (Wolinsky, 1993). Thus, the relative dominance of medicine to control the medical agenda remains intact, albeit less absolute. Right-to-die organizations are involved in promoting assisted death options, but medical decision-making and physician hegemony still dominate discussions on the legal and ethical dimensions of assisted death (Magnusson, 2002; Weir, 1997).

Given the curative ideal inherent in medicine, assisted death is still considered antithetical to medical practice. Indeed, the Hippocratic Oath sworn by physicians prohibits the practice: "I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect." The oath is obviously subject to interpretation and contains other sections that may support assisted death practices. Legalized euthanasia and assisted suicide in Europe and the state of Oregon indicates some medical, public and governmental support for assisted death, which contradicts the Hippocratic Oath and the codes of ethical conduct of several medical associations. The Canadian

Medical Association (Senate of Canada, 1994) and the Australian Medical Association (World Medical Association, n.d.) have rejected euthanasia and assisted suicide. With the exception of assisted suicide in Oregon, the same is true in the U.S. (Phillips, 1997; Wenger & Carmel, 2004). Although originally opposed to euthanasia and assisted suicide (Beecham, 1997), The British Medical Association changed its position, stating that it is willing to discuss the BMA's position if assisted suicide were legalized (LifeSite, 2005). Given the current contradictions in law, the role of physicians remains convoluted. As suggested in the following chapter, this is especially true in Australia, Canada, Great Britain and the U.S. where individual physicians both support and oppose euthanasia and assisted suicide. Similarly, support for euthanasia and assisted suicide among other professionals involved in end-of-life care and decision-making also varies, but research on these professions is meagre.

Notes

1. Not all requests for an assisted death are granted in the Netherlands. For example, for 2001, it is estimated that physicians received 44,500 requests for euthanasia or assisted suicide. This is considerably higher than the actual number of assisted deaths reported in the Rummelink Report, n=3,930. Similar patterns emerge for the other years that data were collected for the Rummelink Report (Onwuteaka-Philipsen et al., 2003).
2. Although they are recorded separately, some researchers of the Dutch experience treat assisted suicide as a variant of euthanasia (see: van Delden, 2004; van der Maas et al., 1992).
3. The National Council of Doctors (2000) in Belgium does not provide exact data on physician and nurse support of assisted death. Of approximately 4,000 registered physicians in Flanders, 2,400 expressed support for a clearly worded bill decriminalizing euthanasia and assisted suicide. Other than the author's estimate regarding the nursing profession, no empirical data on nurse support were provided.

4. Werth defines a rational suicide as "...that following a sound decision-making process, a person has decided, without being coerced by others, to end his or her life because of unbearable suffering associated with terminal illness."
(2000, p. 513)

Chapter 3

Professional and Public Attitudes Toward Assisted Death

Social workers' attitudes

Generally, research on social workers and euthanasia/assisted suicide has been confined to briefs and reports without any empirical reference to social work practice. The majority of surveys on euthanasia/assisted suicide are confined to the attitudes of physicians and, more recently, the nursing profession (see Anderson & Caddell, 1993; Bachman et al., 1996; Hogg et al., 1996; Lee, Nelson, Tilden, Ganzini, Schmidt & Tolle, 1996; Leiser, Mitchell, Hahn, Slome, & Abrams, 1998; Young & Ogden, 1998; 2000). A review of Social Work Abstracts PLUS from 1977 to 2005 yielded only 10 articles pertaining to social work practice and euthanasia/assisted suicide. With the exception of three articles, these too are devoid of original research. Even so, the issues identified in the available literature bear directly on the present exploratory research, which advances the body of knowledge on the role of social workers regarding assisted death. The following discussion includes the research on the attitudes and experiences of social workers toward assisted death (i.e. euthanasia and assisted suicide). Given the paucity of research from the social work perspective, the literature on health care practitioners provides a point of reference for the present research, especially where it involves end-of-life decision-making and the role (or potential role) of social workers.

Over 20 years ago, Holmes (1980) identified the emergence of bioethical issues in social work resulting from the effect of scientific and technological control over life processes. She observed that changing public values and morality required the

development of public policy aimed at the legal, ethical and moral dilemmas posed by euthanasia. For social workers to play a meaningful role, the profession needed to be involved in the formulation of public policy on euthanasia (Holmes, 1980; Neron, 1996; 1998). Werner and Carmel point out that end-of-life decision making frequently involves social workers "...as facilitators in the communication between the family unit and health care providers and as advocates for the family's interest" (2001 p.395). With regard to assisted death, Neron (1996) adds that social workers are increasingly involved in end-of-life decision making with populations seeking euthanasia or assisted suicide. In particular, those afflicted with HIV/AIDS have been quite vocal about the right to an assisted death (Canadian AIDS Society, 1991; British Columbia Persons With AIDS Society, 1994; van Reyk, 1994; Werth, 1995). Estimates place assisted deaths among persons with AIDS (PWAs) in the Netherlands between 10 and 20 percent (de Wachter, 1991) and possibly over 25% in Amsterdam (Laane, 1995).

To date, the involvement of the social work profession in the formulation of public policy regarding euthanasia/assisted suicide has been sparse. Indeed, Holland & Kilpatrick (1991) argue that social work, as a profession, has neglected to conduct systematic research about ethics in social work practice. Current discourse focuses on the problems encountered by social workers regarding the ethics associated with euthanasia/assisted suicide. In reference to a dignified death, Moody (1998) argues that "dignity" is probably most important in old age but he takes issue with the term "dignity" as it applies to death and the elderly. As a concept, "dignity" is complex, ambiguous and multivalent. The implication for social work practice lies in the observation that, without conceptual clarity, a "dignified death" can take on many meanings, which must be

negotiated on a case-by-case basis. A dignified death for a non-religious person may include euthanasia whereas a dignified death for person of faith may include dignity in suffering. This lack of conceptual clarity is inherent in the general hallmarks of social work practice (e.g. self-determination and self-realization) making policy formulation almost unreachable for social work.

Other issues emerging in the literature on social work and euthanasia/assisted suicide highlight dilemmas faced by social workers regarding the right to self-determination or self-realization and the constraints the sanctity of life principle imposes on this right. This is exacerbated by recent advances in medical technology, which have the ability to prolong life considerably for many geriatric and terminally ill patients (Mitchell, 1996; Werner & Carmel, 2001). In 1993, the National Association of Social Workers (NASW) in the U.S. passed a policy statement that recognized client self-determination trumps other considerations, including the sanctity of life (NASW, 1994). The policy states, "When confronting ethical dilemmas in palliative and end of life care, social workers can draw on the principle of client self-determination in matters where clients or their proxies are faced with such issues." (NASW, 2003 in Baily, 2005) Nonetheless, opponents of the policy contend that assisted death in any form is unethical. Analogous to the arguments put forward by pro-life advocates (Euthanasia.com, n.d.), Callahan (1994) argues that most suicides are committed by people with impaired judgment resulting from depression or other mental illness. Others may be coerced into requesting an assisted death by family members or care providers. The notion of "rational suicide" is rejected because it most likely occurs in a small minority of cases (Callahan, 1994; Pritchard, 1995).

Clearly, the available literature touches on important issues facing social workers involved in end-of-life decision-making. The moral and ethical issues surrounding euthanasia and assisted suicide, and the fact that most social work organizations² have not taken a firm position on either practice, underscore the need for research on the topic (Canadian AIDS Society, 1991; British Columbia Persons with AIDS Society, 1994). Both the NASW and the CASW acknowledge that social work practice in North America is grounded in the ethical principles of self-determination and individual autonomy. In the U.K., the BASW recognizes the salience of self-realization of persons and the responsibility of social workers to encourage people to achieve it. To avoid ambiguity, the BASW avoids the term self-determination and instead holds that basic ethical principles of social work require that the individual's self-realization be achieved by considering the interests of other persons (BASW, 1996). Nevertheless, self-determination and self-realization present unique problems when applied to seriously ill persons seeking a hastened death because there is a need to balance these considerations with the ethical obligation to protect vulnerable persons (i.e. the elderly and the disabled). However, little is known about the way social workers translate self-realization or self-determination into practice when applied to euthanasia and assisted suicide.

Few studies have explored the moral, ethical and practice-related concerns of assisted death as it relates to social work (see Smokowski & Wodarski, 1996) and even fewer studies have examined the specific attitudes and experiences of social workers regarding euthanasia and assisted suicide. The following review includes research from the U.S., Israel and Canada. As will be shown, the emerging picture from these studies is a need for greater involvement of social workers in the debate so that their role in

situations regarding death and dying is less ambiguous and more effective. How social workers arrive at this position is not well researched, but the few studies reviewed here provide some insight into how this gap in knowledge can be narrowed.

The first piece of research involves a case study of a social worker counselling a family regarding the decision to remove life support from a terminally-ill family member (Neuman, 1998). Although Neuman's (1998) research is not directly related to euthanasia or assisted suicide, his experience leads him to reject assisted death as defined in this study. Without any cogent argument, he concludes that American culture has not come to terms with its own mortality and, therefore, is not in a position to explore euthanasia or assisted suicide. Presumably, this implies that a greater understanding of human nature and suffering is required before assisted death can be contemplated in the U.S., but no direction for pursuing this line of inquiry is offered. Unfortunately, Neuman (1998) disregards the fact that social workers frequently find themselves having to deal with bioethical issues like assisted death. The call for research on the topic has resulted in only a smattering of research in Israel and North America.

Although not related to assisted death, per se, empirical research has examined social workers' beliefs about end-of-life decision-making in Israel. In a sample of 68 health care social workers, respondents were less inclined (46%) to become involved in decisions regarding life-sustaining treatments (e.g. withdrawal of treatment) or to be consulted by physicians regarding such decisions (42%). However, the same research showed more support for the assertion that social workers had the responsibility to involve patients and/or their family members in decisions regarding life-sustaining treatment (Werner & Carmel, 2001).

Other research based in Israel determined that social workers' attitudes toward end-of-life decisions are shaped by the organizational and cultural context of their profession. Leichtentritt (2002) used a phenomenological method to capture the voices of social workers regarding moral concerns, meanings and explanations of their attitudes toward assisted death. Case studies were used to distinguish between the various forms of what the author defined as "euthanasia", which depicted withholding treatment, the withdrawal of treatment, assisted suicide and active euthanasia (Leichtentritt, 2002).

The data were compiled and arranged into thematic narratives of social workers' views and experiences, an approach used in ethnographic research. Analysis showed two themes joining all forms of euthanasia for all respondents. First, related to moral-ethical perspectives, euthanasia indicated a diminishing value for human life. Withdrawing treatment and active euthanasia were considered less morally acceptable than withholding treatment or assisted suicide. The former suggests lack of patient control while the latter suggests patient autonomy. Second, euthanasia was considered a call for help regarding patients' wishes, which raised therapeutic considerations for social workers because it requires others, including social workers, to act as providers of death (Leichtentritt, 2002). Moreover, the role of social worker, which is marked by the contradiction between patients' wishes at end-of-life (autonomy) and protection of life (social paternalism), is further complicated by the Orthodox Jewish perspective, which promotes the sacredness of life principle. Social workers are forced to navigate end-of-life issues within a "...communitarian-paternalistic version of autonomy" (Gross, 1999 in Leichtentritt, 2002 p.411). Not surprisingly, Israeli social workers felt the need for clear guidelines for dealing with end-of-life issues.

In North America, there is a small body of empirical research on attitudes and experiences of social workers toward assisted death. Csikai's (1999b) study of 122 hospital social workers in an unspecified southern American state found that 55% of the respondents disagreed with the statement that euthanasia is unethical. As well, 57% of the respondents agreed that euthanasia should be legal in some situations, but only 47% agreed that assisted suicide should be legal in some situations. A minority of social workers indicated a willingness to participate in euthanasia (23.7%) and assisted suicide (19.7%). For those willing to participate, the main justifications for euthanasia and assisted suicide included "A patient's pain is beyond control...There is a poor quality of life, despite adequate pain control...An ill patient has a poor quality of life with a life expectancy that may extend for several years...A patient's life expectancy is less than six months" (Csikai, 1999b p.63). However, 45.1% of social workers were opposed to participating in euthanasia and 50% were opposed to participating in assisted suicide.

American research has also followed the implementation of the *Oregon Death With Dignity Act, 1995* (ODDA). A survey of 306 hospice nurses and 85 social workers in Oregon found that social workers were more supportive of the ODDA and more supportive of a patient's request for a lethal injection. The great majority of the sample (95%) felt that their organization should support or be neutral regarding a patient's request for an assisted suicide. Roughly 60% of all nurses and social workers had discussed assisted suicide with their patients. While the difference between professions was not noted, a small number (15%) had initiated discussion. Social workers were more comfortable with discussing assisted suicide than were nurses (Miller et al., 2004).

Two other American studies have examined the attitudes and experiences of social workers toward assisted death. Leszczynska's (1997) MSW thesis involving 47 social workers in several California counties found minimal support for assisted suicide (34%). Although she did not include any questions directly related to self-determination, slightly more social workers (42.6%) indicated support for assisted suicide as an option for terminally ill patients. In contrast, an MSW thesis examining the attitudes of 38 social workers in Orange County CA showed strong support for euthanasia. Using Hallway's (1994) Euthanasia Attitude Scale, Van De Kreeke (1998) found that 84.4% of the respondents had positive or very positive attitudes toward euthanasia. In addition, 81.5% of the respondents agreed or strongly agreed that terminally ill patients should have the right to choose death. The majority of respondents also indicated that it was unethical for physicians to prolong life needlessly. However, social workers were more mixed in their views on the termination of life out of mercy. Over 50% disagreed and 37% agreed with the statement that the termination of someone's life for reasons of mercy was unacceptable.

Finally, research on the attitudes of registered social workers toward euthanasia and assisted suicide has been conducted in British Columbia and Washington State. In a sample of 527 social workers in British Columbia, Ogden and Young (1998) found considerable support (upwards of 75%) for the legalization of euthanasia and assisted suicide in certain circumstances. Similarly, over 75% of this sample of social workers believed that the law should be changed to allow physician involvement in death-hastening acts. Almost two thirds (65.5%) supported adopting the Dutch model of euthanasia, as it existed prior to the new legislation in 2002. Over 80% of social workers

wanted to be involved in the formulation of policy on euthanasia and assisted suicide and 70% stated that social workers should be involved in end-of-life decision-making with clients. Finally, over 21% of all respondents, and almost 40% of social workers in medical settings, had been consulted about euthanasia or assisted suicide.

In Washington State, well over 70% of 862 social workers supported the legalization of assisted suicide, but support for euthanasia is slightly lower than in B.C., 72.4% compared to 75.9% (Ogden & Young, 2003). As in B.C., approximately 75% of Washington State social workers indicated support for physician-assisted death and 65% supported adoption of the Dutch model (pre-2002 legislation) in the U.S. Similarly, over 80% of social workers in Washington State wanted to be involved in the formulation of policy on euthanasia and assisted suicide and 75% indicated that they wanted to be involved in the decision-making process with clients. Approximately 21% of social workers had been consulted about euthanasia or assisted suicide, and like their B.C. counterparts, social workers in medical settings were two times more likely to have been consulted.

Both the B.C. and Washington State surveys contained a question on self-determination. As expected, the majority of social workers in both studies supported the notion of self-determination, but not all social workers extended this right to assisted suicide or euthanasia. Social workers in B.C. were slightly more supportive of self-determination for assisted suicide and euthanasia than Washington State social workers, but both groups were less supportive of assisted suicide. In B.C., 70.2% of social workers supported self-determination for assisted suicide and 73.1% supported self-determination for euthanasia (Ogden & Young, 1998). The comparable data for

Washington State social workers were 65.2% and 70.8%, respectively (Ogden & Young, 2003).

Although Ogden and Young's (1998) article on social workers in B.C. does not include qualitative data collected at that time, their (2003) study on social workers in Washington state provides responses to an open-ended prompt appearing at the end of the survey, encouraging social workers to document any concerns they may have had about euthanasia and assisted suicide, issues related to the topic, or the survey instrument itself (Ogden & Young, 2003). Given the broad support for assisted suicide and euthanasia, most of the comments emphasized the need to reduce suffering and the right of individuals to choose the place and time of their own death. These social workers caution that checks and balances need to be in place so that mistakes and abuse do not occur. Interestingly, both proponents and opponents expressed concern about the decision-making capacity of patients experiencing depression. Additionally, while some highlighted the fact that religious beliefs prohibited assisted death, social workers opposed to assisted death pointed out that the dying process was beneficial for family members, loved ones and the patient him/herself. It allowed for healing of family ties and a chance to further explore spirituality and what it meant to be human (Ogden & Young, 2003).

Medical practitioners and support for assisted death

Since the late 1980s, a considerable amount of survey research has examined the attitudes of medical practitioners toward assisted death. The majority of this research has concentrated on physicians, but a small body of research on nurses also exists. For both

professions, the research examines several aspects of assisted death, including moral and ethical concerns, frequency of requests for assisted death, compliance with requests, and law reform. The stated purpose of this dissertation is to examine social workers' support for law reform. Nevertheless, the attitudes of medical professionals toward law reform are important considerations because of their relationships with patients at end-of-life. While research on law reform is more prevalent in the literature, the attitudes of medical professionals toward support in principle of assisted death are also considered here because approval in principle may influence endorsement of law reform. Although there is little uniformity in the instruments used to determine physician and nurse attitudes toward assisted death, the research does provide some insight into support in principle for assisted death and the factors that may affect this support.

Medical practitioners' support in principle of assisted death

Assisted death has been practiced in the Netherlands since the early 1970s, but there is a paucity of research on medical practitioners' support in principle. Research documenting physician practice and/or approval indicates that approximately 88% of physicians support assisted death (Cormack, 2006). This leaves a small, but significant minority of physicians opposed to VE/AS. The majority of medical practitioners in the Netherlands view patient autonomy in dying as paramount, but requests for an assisted death are not granted in all cases (Cormack, 2006). Indeed the guidelines established by the Dutch government and the Royal Dutch Medical Society constrain assisted death practices. In addition, physician attitudes are also shaped by personal values and ethical principles, which limit the practice of death-hastening acts (van Delden, 2004).

Regarding nurses' attitudes, the available translated literature is confined to one anthropological study of nurses working in respiratory care. Support in principle for assisted death was assumed in the study; however, the fact that assistance in dying had become a "business transaction" was cause for concern (Verpoort, Gastmans, De Bal & Casterlé, 2004).

Research on the attitudes of medical practitioners in the U.K. regarding support in principle is lacking. A comparative study found that geriatric medicine physicians were less likely to consider assisted death as justified ethically than were intensive care specialists (Dickinson, Lancaster, Clark, Ahmedzai & Noble, 2002). In other research, a survey of psychiatrists in the U.K. revealed that support for assisted death in principle was not high (13% AS and 9% VE). However, the findings also indicated broad support for the notion that suicide may be a rational act (Shah, Warner, Blizard & King, 1998).

Using a national survey, other research in the U.K. has explored the attitudes of hospice workers toward assisted death. Compared to nurses and volunteers, physicians were least supportive of euthanasia, but all groups indicated opposition toward helping patients die. These views were influenced by the practice context, which emphasized pain management as an element of care for the "whole person", not just his/her physical needs (Addington-Hall & Karlsen, 2005).

Research in Manitoba, Canada, shows that, 60% of physicians support assisted death in principle; however, fewer (52%) would participate in a death-hastening act. Most physicians believed that the pain associated with dying can be managed with medication. Interestingly, 95% of physicians agreed with the notion that medicating patients to the point of death, the double effect, is justifiable (Searles, 1995). Similarly,

data from a national sample of nurses working in AIDS care indicated support for assisted death in principle. However, several nurses cautioned that checks and balances had to be in place so that patients' rights were not abused. In particular, nurses were concerned that health care rationing may result in the abuse of assisted death practices. The notion of decision-making teams was proposed by some nurses as a way to ensure that patients' needs at end-of-life were met (Young & Ogden, 2000).

A comprehensive review of American research by Dickinson et al. (2005) reveals that physicians in the US are more supportive of AS than VE. With one exception, oncologists are generally less approving of assisted death, compared to physicians of mixed or various backgrounds and/or specialties. In one study, 46% of oncologists indicated support for AS and 23% for VE (Wolfe et al., 1999). In another study of oncologists, 53% approved of AS and 24% supported VE. With the exception of one study that found equal support for VE and AS (63%), research involving physicians from various backgrounds show more support for AS than VE. In one case the difference is almost negligible (60% AS and 59% VE). In the other study, 50% of practitioners approved AS and 42% supported VE (Dickinson et al., 2005).

Although dated, American research provides some insight into the factors that may influence medical practitioner's attitudes toward assisted death. A study of oncology professionals shows that the majority of practitioners (60%) agreed with death-hastening acts for patients near end-of-life. Agreement with assisted death was associated with religion and professional norms. Protestants were more likely than Catholics to agree with assisted death, but practitioners with higher levels of self-reported religiosity were less likely to support death-hastening acts. As well, those practitioners

least in favour of assisted death noted fear of legal reprisals and adherence to the medical ethos of preserving life (Anderson & Caddell, 1993).

More recent research from Australia indicates that religion, age and practice experience affect attitudes toward assisted death (Kitchener, 1998). Anglican nurses and nurses not identifying a religion were most supportive of assisted death whereas Catholics were least supportive. Increasing age was associated with negative attitudes toward assisted death, as was experience working with the terminally ill. As with research involving Australian oncology nurses (Aranda & O'Conner, 1995), those with more exposure to dying were less likely to endorse assisted death (Kitchener, 1998).

Medical practitioners' support for legalized assisted death

Medical practitioners are more likely to be involved in the decision to hasten death and/or carry it out. Therefore, it may be argued that the moral and ethical concerns of this group may not correspond with those of social workers. However, the views of medical practitioners with regard to law reform may be of significance given that social workers' responsibilities frequently overlap with those of medical practitioners. Moreover, social workers and medical practitioners have input into social policies regarding caring for patients. Table 3.1 shows that support for law reform is higher amongst nurses than physicians, but varies slightly according to country and/or region.

Table 3.1

Medical Practitioner Support for Law Reform Regarding Voluntary Euthanasia (VE) and Assisted Suicide (AS)

<u>Country (region)</u>	<u>Source</u>	<u>Profession</u>	<u>Sample Size</u>	<u>Percentage</u>
Australia Kuhse & Singer (1988) (Victoria)		Physician	869	59 VE
Australia Kuhse & Singer (1992) (Victoria)		Physician	1942	78 VE
U.S.A. Anderson & Caddel (1993) (Midwest)		Physician	63	60 VE
Australia Baume & O'Malley (1994) (NSW)		Physician	68	59 VE
England Ward & Tate (1994) (N/A)		Physician	309	47 VE
Canada Searles (1995) (Manitoba)		Physician	110	60 AS/VE
U.S.A. Bachman et al. (1996) (Michigan)		Physician	998	56 VE/AS
Canada Hogg et al. (1996) (National)		Physician	788	60 AS
U.S.A. Lee et al. (1996) (Oregon)		Physician	2761	60 VE
U.S.A. Beder (1998) (New York)		Nurse	100	46 VE/AS

Table 3.1 Continued

U.S. Meirer et al. (1998) (N/A)	Physician	1902	36 AS, 24 VE
U.K. Shah et al. (1998) (National)	Physician	100	60 VE
Canada Young & Ogden (1998) (National)	Nurse	45	64 AS, 62 VE
U.K. Dickenson et al. (2002) (National)	Physician	742	52-80 VE*
Belgium Mortier et al. (2003) (Flanders)	Physician	92	46 VE

*Fewer intensive care physicians (52%) supported VE than physicians working in gerontology (80%).

While not pertaining to legal attitudes per se researchers have explored factors affecting attitudes toward assisted death among medical practitioners. Table 3.2 provides a tentative list of these factors as identified through an analysis of the medical and nursing literature on death and dying.

The most salient factor related to medical professionals' attitudes toward euthanasia and assisted suicide is the influence of the organizational environment on beliefs and behaviour. Generally, the dominant bio-medical model in health care delivery places other health care providers in a subservient position to physicians (Friedson, 1986). However, medical dominance often decreases in situations where physicians do not or cannot maintain authority. Seale and Addington-Hall (1995) conducted research on the attitudes of family members of patients who died between 1987 and 1990 in London, England. They hypothesized that patients in hospice care would be less likely to request euthanasia than patients in hospital settings, because, generally, they received higher quality care than patients in hospitals. Contrary to their assumption, the odds ratio for family members of patients in hospice care was 1.7 times higher than it was for family members of patients in hospital settings. In other words, family members of patients in hospice care indicated that it would have been better if the patient had died sooner. Moreover, the authors indicated that many of the patients themselves also expressed their desire for a hastened death. This finding indicates that the increased autonomy in hospice settings may counteract people's fear of dependence on medicine and lead them to assert their right to an assisted death (Seale & Addington-Hall, 1995).

Other research reveals that physicians ascribe differential levels of autonomy to nurses regarding their role in euthanasia. Research in the Netherlands by Muller,

Pijnenborg, Onwuteaka-Philipsen, van der Wal and van Eijk (1997) examined the experiences and attitudes of three physician groups: general practitioners (GPs), nursing home physicians (NHPs), and specialists regarding nurses' participation in euthanasia. Only a minority of GPs and NHPs (4% and 3%, respectively) indicated that nurses had administered a lethal injection while the corresponding figure for specialists was 21%. In addition, most GPs (94%) and NHPs (92%) and a significant number of specialists (72%) indicated that nurses should never be permitted to administer euthanasia or physician-assisted suicide. Despite these findings, Muller et al. (1997) suggest that physicians who are more socially distant from their patients (e.g. specialists) relinquish at least some control of patient care to other health care providers.

In some cases, physicians may promote "regressive intervention" when faced with dying patients and/or their families who refuse to become anonymous and maintain dependency on their physician. When death is certain, physicians attempt to stream patients toward palliative care or other supportive strategies and thus release themselves from obligation (Clair, 1990). Presumably, in these circumstances the role of other health care providers and social workers expands to cover the void left by the physician.

At the micro level, the role of non-physician health care providers in patient care is conditioned by the ongoing interactions occurring between them, the physician, the patient and his/her family. These relationships are embedded within the health care context and influenced by the dynamics in particular organizations (Benoliel, 1996). Arguably, "problem" patients – those who do not conform to the expectations placed on them by medical authority – may lead physicians to seek assistance from nurses or other non-medical professionals. Similarly, nurses may find themselves looking for support

from non-nursing professionals, like social workers. As the medical profession comes under closer public scrutiny, this phenomenon is accentuated by the lack of an interdisciplinary approach to education on death and dying in both medicine and nursing (Downe-Wambolt & Tamlyn, 1997) and social work (Neron, 1998). The lack of adequate training in dealing with death and dying presents a barrier to effective end-of-life patient care and is echoed by participants in Ogden and Young's (1998) survey on social workers and Young and Ogden's (1998) study on Canadian nurses working in AIDS care.

Thus far, research on patient self-determination/self-realization has been confined to the attitudes of physicians and nurses regarding euthanasia and assisted suicide (Anderson & Cadell, 1993; Bachman, et al., 1996; McDaniel, 1996; Searles, 1995; Leiser, Mitchell, Hahn, Slome, & Abrams, D., 1998; Young & Ogden, 1998). Leiser et al.'s (1998) research on nurses working in AIDS care in San Francisco found that slightly over half (54.8%) of the 206 respondents surveyed indicated that potential legal repercussions would prevent them from participating in an assisted death. With respect to morality, research on the effect of professed religious affiliation on the practice of euthanasia by physicians in New South Wales, Australia, indicates that doctors without a formal religious affiliation were more sympathetic towards euthanasia and more likely to have practiced euthanasia than doctors indicating a religious affiliation (Baume et al., 1995).

Although limited, research suggests that social workers support euthanasia and assisted suicide but feel that legislation is required to control death-hastening acts. As well, social workers want to be involved in discussions with patients considering a

hastened death as part of a care-giving team. They do not feel that physicians should be given complete responsibility for the decision to hasten a patient's death (Ogden & Young, 2003). This theme appears in the literature on physicians working with dying patients (Clair, 1990) and nurses regarding their role in euthanasia (Muller, et al., 1997).

The effects of these factors on attitudes/experiences of social workers have not been examined through qualitative research or tested empirically, but are considered important by stakeholders in both sides of the euthanasia/assisted suicide debate (see Callahan, 1994; Hadjistavropoulos, 1996; Neron, 1998). Given their relative position vis-à-vis physicians, it is assumed that social workers and nurses face many of the same issues in patient care. In addition, these factors may be intertwined with the four cardinal principles, or cornerstones of bio-medical ethics, that underlie decisions relating to euthanasia and assisted suicide. Latimer (1991) identifies these as autonomy, or self-determination, non-maleficence, beneficence, and social justice.

While not all cultures interpret these principles similarly, self-determination (patient autonomy) generally refers to one's right to choose the time and nature of their own death. In end-of-life research, non-maleficence and beneficence refer to the mutual obligation to minimize harm and at the same time promote the best interests of the patient. As a related concept, social justice implies that all persons have access to the same care, the right to accept or deny that care, and the right to choose (Werth, Blevins, Toussaint & Durham, 2002).

Finally, it bears mentioning that life factors besides religion can influence attitudes toward death and dying. Although not related to health care, research on the effect of life factors on college students' feelings about death reveals the importance of

two other life factor clusters: death of a significant other and personal near-death experiences (Franke & Durlak, 1990).

Table 3.2

**Factors Associated With Attitudes and Experiences
Toward Euthanasia and Assisted Suicide**

1. Practice setting (organizational context) (e.g. hospital, nursing home, hospice care, private home) (Addington-Hall & Karlsen, 2005; Seale & Addington-Hall, 1995).
 2. Influence of bio-medical model on health care (e.g. physician dominance and professional detachment) (Anderson & Caddell, 1993; Friedson, 1986; Muller et al., 1997).
 3. Relationship with physicians and other health care providers (Benoliel, 1996; Clair, 1990; Young & Ogden, 1998, 2000).
 4. Belief in self-determination and the factors affecting that belief (e.g. moral/religious beliefs and concern about legal repercussions) (Baume et al., 1995; Kitcheenr, 1998; Latimer, 1991; Leiser et al., 1991; Werth et al., 2002).
 5. Relationship with client and his/her family (Neron, 1998; Young & Ogden, 1998, 2000).
 6. Personal experiences with self, friends or family (Franke & Durlak, 1990; Ogden & Young, 1998, 2003).
-

Changing public attitudes on assisted death

This chapter concerns the attitudes of social workers and, to a lesser extent, the attitudes of other professionals in dealing with end-of-life issues. While comprehensive national or cross-national surveys of the public have not been undertaken, opinion poll research finds significant public support for assisted death in countries where the practice is currently illegal: Canada, the U.S., Australia, and the U.K.

Public approval of assisted death in Canada has been climbing since the 1960s. Gallup poll data show that 45% of Canadians supported legalized mercy killing in 1968. By 1977, 77% of Canadians endorsed physician-controlled euthanasia (Bozinoff and Turcotte, 1992). A 1997 Pollara study found that 70% of Canadians, including Catholics and Protestants, endorsed physician-assisted suicide (Culbert & Kennedy, 1997). In another survey, 73% of respondents suffering from cancer supported euthanasia (Branswell, 2000). A recent survey (August, 2003) indicates a decline in support for physician-assisted suicide with 50% supporting the act (Curry, 2003). This poll was taken in the absence of high profile cases in the media (e.g. Sue Rodriguez or Robert Latimer), which suggests public attitudes are influenced by sensational cases.

Similar to the Canadian trend, a national survey conducted by the Harris Poll in 2005 shows increased support for assisted death in the U.S. over the past two decades. Agreement with physician-assisted death increased from 53% in 1982 to 70% in 2005 (Taylor, 2005). In Australia, support for euthanasia increased from 47% in 1962 to 78% in early 1995 (World Federation of Right to Die Societies, n.d.). This figure had increased to 81% by late 1995 (Religious Tolerance, n.d.).

Support for assisted death is most prominent in the U.K. A poll conducted by NOP (National Opinion Polls) in 1997 revealed that 97% of people in England and Wales agreed that, "...terminally ill people have the right to die with dignity" (World Federation of Right to Die Societies, n.d.). Support for physician-assisted suicide England and Wales was high, at 82%. Approval of euthanasia was slightly lower, at 78% (World Federation of Right to Die Societies, n.d.), but up from 69% in 1976. Interestingly, public approval of assisted death held regardless of religion. Identical support for physician-assisted suicide, 82%, was found in Scotland (BBC News, 2004).

Summary: tacit support for assisted death?

The available research suggests that a significant number of social workers find assisted death ethical and acceptable in some cases. Social workers recognize the need to promote the best interests of their clients. However, the absence of clear guidelines and formal policies makes this obligation difficult to fulfill. Support for assisted death is also forthcoming from medical practitioners. The research shows that some physicians and nurses support assisted death in principle, but approval is not without question. Legislation, religion, adherence to professional ethics and practice context all influence support in principle of assisted death. A recent meta-analysis of nurses' attitudes toward euthanasia identifies the main issues affecting medical practitioners regarding support in principle of assisted death. As illustrated above, the same issues emerge in the literature on physicians' attitudes. On the one hand, dissatisfaction with current practice and legislative conditions, respect for patient autonomy and patients' quality of life bear directly on support for assisted death. Conversely, some medical practitioners view their

role as providing adequate pain control and palliative care for dying patients. Death is to be challenged until the very end and its control is to be left in the hands of God. Finally, fear of abuse and the slippery slope causes some to oppose assisted death, even if they support the notion of individual autonomy (Verpoort et al., 2004).

Many physicians and nurses favour legislative changes that would allow for assisted death in countries where it is currently prohibited. As suggested, the factors associated with medical practitioner attitudes toward assisted death in Table 3.2 may also affect social workers' attitudes toward legalization.

Given public approval of assisted death and death with dignity, more research is needed on influences that shape the attitudes and experiences of social workers regarding end-of-life decision-making. Whether the factors hypothesized as significant to medical practitioners can be extrapolated to social workers in the U.K. will be determined through the analysis in this dissertation. Unfortunately, the data used here do not provide information on social workers' relationships with medical practitioners (i.e. physicians) or their clients and/or family members. As well, given the dearth of empirical research on the attitudes and experience of social workers toward assisted death, the following hypotheses are more exploratory in nature than testable propositions.

Using the available research, the following hypotheses are applied to the quantitative data. First, that social workers working in medical settings are more likely to experience the trauma associated with life-prolonging treatment (Csikai, 1999b; Ogden & Young, 2003) and thus will be more supportive of assisted death. Second, social workers who play a major role in the lives of the terminally ill are less supportive of physician dominance in end-of-life issues and will be more supportive of assisted death. Third,

social workers who advocate for client self-realization believe people should be able to choose whether to live or die (Csikai, 1999a; Neron, 1996; Ogden & Young, 1999) and thus are more supportive of assisted death. Fourth, social workers holding religious beliefs will be less supportive of assisted death because they believe life belongs to God (Ejaz, 2000; MacDonald, 1998). Fifth, social workers who have had personal experiences with death and dying understand the anguish associated with dying and the problems associated with life-prolonging treatment and thus will be more supportive of assisted death (Ejaz, 2000; Franke & Durlak, 1990; MacDonald, 1998).

The quantitative findings will be compared with the written responses gleaned from the qualitative data. In addition, the qualitative data will be analyzed to determine the effect of the factors not covered in the quantitative analysis (3 and 5 in Table 3.2). The following chapter outlines the methods used to analyze and to test the stated hypotheses and analyze the qualitative data.

Chapter 4

Triangulation of Survey and Qualitative Data

This dissertation involves secondary analysis of quantitative and qualitative data initially collected on a population of registered social workers in England, Wales, Scotland and Northern Ireland (U.K.) in 1998. The choice of data was influenced by several factors. First, research on social workers' attitudes and experiences toward euthanasia and assisted suicide in the U.K. remains absent from the discourse on assisted death. Second, as set out below, my involvement in the original survey design and collection of the data affords me a level of familiarity with, and access to, the data. In this chapter, the advantages and disadvantages of secondary data analysis are discussed and the source and sample characteristics of the data are identified. The variables used in the quantitative analyses and their measurements are provided, as are the descriptive statistics relating to these variables. The method chosen to analyze the quantitative data involves cross-tabulation analysis. Assuming that social workers elaborated on issues raised in the survey, written comments collected at the end of the survey are also examined using a *specimen perspective* (Alasuutari, 1995). A frequency distribution of social workers providing written responses is noted, but analysis of these responses occurs in the following chapter. As Monette, Sullivan and DeJong (2002) observe, data triangulation¹ provides more confidence that the results of the survey questionnaire reflect the reality of the study population (i.e. social workers in the U.K.).

Secondary Data Analysis

For some time, the survey has occupied a central position of investigation in the social sciences. It is used in a variety of research domains requiring different kinds of data such as behavioral, attitudinal and demographic. With regard to empirical research, questions are formulated and a research design is developed based on the questions. If a survey method is selected, questions are developed with regard to the data needed. In the past there has been a tendency to equate original research with new knowledge. However, for a variety of reasons identified below, independent data collection has become increasingly difficult. At the same time, the potential for research based on secondary analysis has increased (Kiecolt & Nathan, 1985). Broadly defined, secondary analysis refers to further empirical analyses of one or more data sets, which produces knowledge or findings in addition to those presented in the original research (Hakim, 1982). Heaton (1998) elaborates on the nature of secondary analysis of data:

Secondary analysis involves the use of existing data, collected for the purposes of a prior study, in order to pursue a research interest which is distinct from that of the original work; this may be a new research question or an alternative perspective on the original question (Hinds, Vogel and Clarke-Steffen 1997, Szabo and Strang 1997). In this respect, secondary analysis differs from systematic reviews and meta-analyses of qualitative studies which aim instead to compile and assess the evidence relating to a common concern or area of practice (Popay, Rogers and Williams 1998). As will be shown below, secondary analysis can involve the use of single or multiple qualitative data sets, as well as mixed qualitative and quantitative data sets. In addition, the approach may either be employed by researchers to re-use their own data or by independent analysts using previously established qualitative data sets.

Researcher access to computers and statistical software programs, combined with the availability of data-bases from previous research, have contributed to the popularity of secondary research. Moreover, data from large surveys, like the General Social

Survey (GSS) conducted by the Canadian government, are conducted with secondary analysis in mind.

Advantages of Secondary Data Analysis

Secondary analysis is an affordable alternative to the expensive process of original-survey data collection. It offers economies of personnel, time, and money. Compared to the number of people required to conduct survey research, secondary analysis can be completed by an independent researcher. The time required to conduct secondary analysis is reduced to the time required to obtain the data set and prepare it for analysis (e.g. coding variables). When research budgets are constrained, secondary analysis provides a cost-efficient alternative to original survey research. With data previously collected, costs are reduced to the acquisition of the data set, usually nominal, and perhaps the computer and/or software involved for analysis (Kiecolt & Nathan, 1985).

Another advantage of secondary research is that it minimizes the need to repeat data collection on some topics. As Hakim (1982) observes, this point is crucial because, during the 1970s, public response rates in survey research started to decline from overuse. This issue has been somewhat addressed by more sophisticated sampling techniques, for example cluster sampling (Palys, 2003), but it remains a potential problem. Secondary research has an additional economic advantage in that it obviates potentially redundant and/or unnecessary research. If new knowledge can be gleaned from existing data, then there is no need to conduct additional research. In this vein, several research projects can be carried out with previously collected data. For example,

replication studies are frequently carried out using secondary data (Hakim, 1982).

Secondary analysis of existing data can be used to identify new aspects of research problems that require elaboration, measures that need improvement, hypotheses that need revision, and sampling issues (e.g. the need to over-sample certain populations) (Kiecolt & Nathan, 1985). In this sense, secondary analysis also serves as an exploratory method.

Combined with the degree of expertise required to design and implement a research project, the economic disadvantages of survey research severely limit access to important social science information. Secondary analysis allows individuals access to empirical information that heretofore tended to be the domain of fewer persons in select agencies (e.g. government agencies, privately funded research organizations and universities). Secondary analysis also removes the necessity that researchers be connected to the institutions they study, either politically or financially, which reduces the problems associated with access to information. Secondary analysis lends itself to a variety of analytical techniques and research methods (Hakim, 1982; Kiecolt & Nathan, 1985). Indeed, there are certain research topics that can only be researched with secondary analysis. Durkheim's (1951) study on suicide represents an early example of secondary analysis of aggregate data, which has expanded into other areas. In addition to the GSS, major empirical studies on health, labour, and poverty in Great Britain by the Department of Health and Social Security (1980) were based exclusively on secondary analysis.

Limitations of Secondary Data Analysis

The main problems with secondary analysis relate to data availability, data documentation, data quality, academic stagnation, and the misapplication of secondary analysis. These problems will be discussed below.

First, until recently, data sets on crime, drug use, and physical health were readily available, but data on specialized topics like mental health epidemiology were difficult to locate (Hakim, 1982). When they are available, researchers must negotiate their use with others who are frequently reluctant to share their efforts (Babbie & Benaquisto 2002; Kiecolt & Nathan, 1985). Not surprisingly, data sets on assisted death are difficult to locate. A related problem to data availability is inadequate documentation to accompany the data set. Although not a problem with large data sets from academic settings, smaller research firms and individual researchers frequently lack proper documentation (Kiecolt & Nathan, 1985). In some cases, this problem can be overcome by contacting the organizations and/or persons involved in the original research and by identifying the problems prior to conducting the analysis (Allan & Skinner, 1991).

The problems of data availability and adequate documentation are overshadowed by larger concerns about data quality. Problems related to poor sampling, poorly designed questionnaires, improperly conducted interviews, data coding and data entry errors pervade even the best survey research. Social desirability, or respondents' concern with providing answers that portray them in a positive manner, is a problem in survey research and can result in biased results of secondary analysis. If not identified and corrected before analysis, these problems are repeated in secondary analysis and may actually be magnified when the data are used in research for which they were not

originally intended (Allan & Skinner, 1991; Babbie & Benaquisto, 2002; Fowler, 1993). Moreover, most surveys do not contain all of the variables necessary for secondary research, and if they do, they may lack an adequate number of indicators of a concept for reliable measurement (Allan & Skinner, 1991; Kiecolt & Nathan, 1985). One approach to this problem involves using multiple surveys, or pooling of surveys with similar question sets, to test hypotheses. However, even assuming comparability between variables and measurement in surveys, which is unlikely, multiple surveys are not always available (Allan & Skinner, 1991; Hakim, 1982; Kiecolt & Nathan, 1985). If multiple surveys do exist, the other problems involved with secondary research are compounded with each additional survey. In short, secondary analysis frequently involves measures that do not precisely meet the demands of research.

The issues of academic stagnation and the misapplication of secondary analysis are closely related. Academic stagnation results when researchers repeatedly use the same data sets. Without the re-conceptualization of research problems and the development of new measures, the growth of scientific knowledge becomes frustrated. Similarly, using data to formulate research questions, commonly called “data-driven research” is a common criticism of secondary analysis (Allan & Skinner, 1991; Babbie & Benaquisto, 2002; Kiecolt & Nathan, 1985). Without a theoretical *a priori*, secondary analysis is nothing short of a data set in search of analysis. This approach can thwart scientific progress and will generate modest findings at best.

It is important to limit the application of secondary analysis to those research problems where databases are accessible.. Steps should be taken to obtain and even improve documentation on databases where it is lacking, or another source should be

considered. Data quality is essential to derive meaningful results. Although precise indicators of some variables may be impossible in secondary analysis, scales are frequently used in survey research. The validity of these scales is often tested and predetermined in other research, which strengthens the case for their use in secondary analysis.

Finally, in addition to researching problems not originally identified, secondary analysis can help to identify problems with existing research and chart directions for research in the future. When used appropriately, secondary analysis thus contributes to the body of scientific knowledge.

Secondary analysis and social workers' attitudes toward assisted death

In this dissertation, the advantages of secondary analysis far outweigh the disadvantages. In this exploratory research, I draw heavily on the primary data set gathered by Russel Ogden and myself, partly to bring forward the initial findings of the BASW-related project. This dissertation relies on a survey that was used in two previous studies co-authored by Russel Ogden and myself, which are available in peer-reviewed journals (see for example, Ogden & Young, 1998; Ogden & Young 2003) and other profession-related publications. Moreover, secondary analysis of the original data involves recasting of the original data and also integrating empirical findings with an updated literature search. Finally, key themes such as beneficence, non-maleficence and social justice are re-conceptualized to better understand assisted death in the social work context. Taken together, this dissertation provides otherwise unavailable research

findings from the original survey and complements the corpus of work undertaken by Ogden, myself and others researching end-of-life issues.

The theoretical *a priori*, or medico-ethical principles of autonomy, beneficence, non-maleficence and justice, driving this research make the problems with secondary analysis manageable. Given that the original survey was anonymous, social desirability will not be a problem. Respondents could not be identified and thus have little to gain or lose by attempting to bias their answers. Regarding data availability, this is the first analysis of the data set collected from research subjects drawn from the BASW population of social workers in the U.K. Although eight years old, the data form the foundation of research that has been virtually nonexistent since its collection. The exceptions are Ogden and Young's (2003) recent study on social workers in Washington State and studies about physicians' attitudes and involvement in assisted death. In contrast to academic stagnation, the data set provides a unique opportunity to study the attitudes of social workers to assisted death. All documentation on the survey is available, which allows for verification and correction of coding problems. Any shortcomings of the analysis can be used to improve the survey instrument and to chart future research on assisted death. For example, missing variables or inaccurate measurement can be identified and corrected. Further discussion of shortcomings in the survey occurs in Chapter 6, the conclusion. Finally, the triangulation of social workers' written responses with the survey data provides for more robust analysis and greater confidence that the results are valid (Lincoln & Denzin, 2000).

Data source, sample and measurement

The data for this research were obtained from a survey of BASW members conducted over the period of January 1998 – September 1998 by my colleague, Russel Ogden and me. The initial project received approval from BASW, as well as a small funding grant of approximately £3,500 for administration of the survey from the Voluntary Euthanasia Society. The research centred on social workers' attitudes and experiences toward euthanasia and assisted suicide. To ensure that the confidentiality and anonymity of participants were safeguarded, the proposal for the original research was also submitted to and approved by the Human Research Ethics Committee at the University of Victoria on January 14, 1998.

Data collection involved the administration of an anonymous postal survey questionnaire initially developed and used in other social work and nursing settings by Russel Ogden and me. Any differences in the versions of the survey relate to profession-based terminology and specific legal aspects of the countries involved. The survey has been used in research involving Canadian nurses in AIDS care (Young & Ogden, 1998) and Canadian social workers (Ogden & Young, 1998). More recently, a version of the questionnaire has been used on research with social workers in the U.S. (Ogden & Young, 2003). Although the use of the same survey limits the breadth and scope of data retrieved, this approach does allow for some cross-national comparison between professions. Approval of using the original BASW data for secondary research in this dissertation was obtained from the Office of Research Ethics at SFU on December 30, 2004, which deemed the project minimal risk.

The survey was attached to a mailing of a professional journal distributed by the British Association of Social Workers; a follow-up reminder card was not sent (Ogden personal communication, April 2, 2006). To the best of my knowledge, there were approximately 7,334 active members in BASW in 1998. Surveys were distributed to all registered social workers in Scotland, Wales and Northern Ireland. A random sample of 2,384 of the approximately 5,730 social workers in England also received the survey. The questionnaire included 25 items with a closed or forced-choice response set of “yes”, “no” or “undecided” used on the attitudes and experiences section of the survey. This approach produces a more definitive response than typical Likert-style scales (Fink, 1995; Schuman & Presser, 1981), but is known to result in a loss of subtlety of respondents’ opinion (Fink, 1995). To capture any additional thoughts and/or feelings on assisted death, social workers were also encouraged to respond to an open-ended prompt at the end of the questionnaire. A letter attached to the survey informed social workers they were not obliged to participate in the research, and that completion of the survey implied consent. Copies of the letter and survey are attached in Appendices A and B, respectively.

The typical completion time for the questionnaire was estimated to be between five and fifteen minutes. A total of 1,477 social workers returned completed surveys for a response rate of 37 percent. Although there is a potential for bias (e.g. responders are more likely to hold extreme views on assisted death), this rate is considered adequate for this kind of mail-out questionnaire (Fowler, 1993; Palys, 2003). In similar studies involving the attitudes of social workers toward euthanasia, this response rate is slightly higher than a study involving social workers in Washington state (34.5%) and lower than

a study of social workers in British Columbia (41.3%) (see, Ogden & Young, 2003; Ogden & Young, 1998). As indicated in Table 4.1, the response rate of social workers in Scotland was highest, followed by England, Wales and Northern Ireland. With regard to the qualitative results, the overall response rate of social workers providing written comments (57.8%) was noticeably higher than Ogden and Young's (2003) study of social workers in Washington State (48.7%). The response rates of social workers in Northern Ireland and Wales were higher than the response rates of social workers in England and Scotland (62.0%, 61.85%, 58.4% and 53.4% respectively).

To determine why social workers might not want to participate in the research, a non-response card was included in the mail out with the survey. Social workers could check any number of the reasons listed and/or provide their own. A copy of the non-response card is attached in Appendix C. Table 4.2 shows that 258 (6.5%) of social workers returned non-response cards. Although limited, this information can help identify shortcomings in the survey data.

Table 4.1

BASW Response Rate by Country

	Surveys Posted	Valid Replies	Replies with Comments
England	2384	898 (37.7%)	524 (58.4%)
Scotland	882	348 (39.5%)	186 (53.4%)
Wales	358	123 (34.4%)	76 (61.8%)
Northern Ireland	364	108 (29.7%)	67 (62.0%)
Total	3988	1477 (37.0%)	853 (57.8%)

Table 4.2

BASW Non-Response Rate by Country

	Surveys Posted	Non-Responders	Non-Response Cards Returned
England	2384	1486	168 (7.0%)
Scotland	882	534	48 (5.4%)
Wales	358	235	20 (5.6%)
Northern Ireland	364	256	16 (4.4%)
Total	3988	2523	258 (6.5%)

Data analysis

The following analysis of the quantitative data includes frequency distributions and descriptive statistics, including measures of central tendency of the variables. In the next chapter, cross tabulations are used to test hypotheses affecting social workers' attitudes toward assisted death. Quantitative analyses were carried out using SPSS 12.0®. The survey data were compared with the written responses collected at the end of the questionnaire. While this method of qualitative analysis does not elicit the type of rich data used to generate grounded theory (Strauss & Corbin, 1990), it does provide insight into social workers' perspectives on issues related to assisted death. Using a *specimen perspective*, the written comments were analyzed to identify themes relating to social workers' attitudes and experiences as they pertain to the survey responses. This perspective holds that "...data can always be studied as a reality in themselves, as a specimen, regardless of their relation to the outside reality they are supposed to tell about or reflect...language is the medium by which we convey information, so it is only natural to consider textual data from that perspective" (Alasuutari, 1995 p.61).

Triangulation of the qualitative data with the survey results can further enhance the conclusions derived from the qualitative source, a process Alasuutari (1995) refers to as *unriddling*. Combined with the quantitative analysis, triangulation allows for clarification of social workers' understanding of assisted death (Stake, 2000). Furthermore, it allows for identification of themes that give meaning to social workers' quantitative responses and their concerns regarding assisted death. The emerging explanations will not be generalizable to all social workers, but they can be tested and elaborated upon other social work contexts.

To assure consistency of social workers' responses, the following definitions of voluntary euthanasia (VE) and assisted suicide (AS) were provided to respondents.

Euthanasia: the administration of a treatment or an act by another person that induces death, at the request of the patient (e.g. a lethal injection).

Assisted suicide: the patient has been provided with the means (e.g. drug overdose) specifically for the purpose of suicide. The patient is the one who commits the final death-hastening act (e.g. swallows a lethal dose).

Frequency distributions and descriptive statistics

The frequencies of responses to the demographic items in the survey are presented in Table 4.3, as are the responses to demographic items with continuous responses. Similar representation of the dependent and independent variables used in the analysis appears in Table 4.4. As previously indicated, the items exploring the attitudes and experiences of social workers toward euthanasia and assisted suicide appear as closed or forced-response items. As such, they do not require further manipulation for analysis. Likewise, the categorical and continuous variables used in the analysis are not manipulated.

The majority of social workers were female (1040 or 70.4%). The mean age of social workers was 47.3 with a range of 19 to 89 years. Of those holding a single credential, most social workers held a Certificate of Qualification in Social Work (CQSW) (351 or 23.8%) followed by a Diploma in Social Work (194 or 13.1%), a postgraduate degree (132 or 8.9%), an undergraduate degree (102 or 6.9%) or a Certificate in Social Work (CSS) (55 or 3.7%). A significant number of social workers held multiple credentials, including a social work credential, and undergraduate degree

(377 or 25.5%), or a social work credential and a postgraduate degree (238 or 16.1%).

Only eight (1.5%) listed “other” educational qualifications.

The vast majority of respondents were members of BASW (1323 or 89.6%) and most (1147 or 77.7%) were employed in social work. The length of employment in social work ranged from newly employed to 60 years with a statistical mean of 17.23 years and standard deviation of 9.51 years. Most social workers were employed full time (1050 or 71.1%) or part time (256 or 17.3 %). Of the remainder, 68 or 4.6% were retired and 39 or 2.6% were students. The rest either did not specify their employment status or indicated that they were casual or unemployed. To reiterate, the response rate from social workers from Scotland was highest followed by England, Wales and Northern Ireland. However, the largest group of social workers in the sample comes from England, followed by Scotland, Wales and Northern Ireland (see indicated in Table 4.1).

Several questions in the survey measure social workers’ support for or opposition to assisted death. Questions that refer to legalization of assisted death serve as dependent variables in the analysis. The first of these is whether assisted death should be legal. Most social workers indicated that VE (1057 or 71.6%) and AS (1066 or 72.2%) should be legal. Support for the Dutch model of euthanasia as practiced before the new legislation was enacted in 2001 was also high (1010 or 68.4%). Finally, a minority, 380 or 25.7% of the sample, indicated that they would report a colleague whom they thought had been involved in a VE. Responses to the same question regarding AS were similar with 375 or 25.4% of respondents indicating that they would report a colleague. These variables were selected because they represent the strongest reaction to assisted death,

and perhaps the most serious in the case of reporting suspected incidences of collaboration.

The independent variables used in the analysis are derived from questionnaire items that relate to the factors noted in Table 3.1. Statistical frequencies of the independent variables appear in Table 4.4. With regard to practice setting (organizational context) many social workers reported working in child welfare (455 or 30.8%). Many worked in mental health (233 or 15.8%), medical settings (144 or 9.7%) or in private practice (54 or 3.7%). A significant number (506 or 34.3%) indicated that they worked in “other” settings while the remainder worked in community-based counselling, drug and alcohol rehabilitation settings or financial services. The majority of social workers (1077 or 72%) worked for government agencies. A noticeable number worked in unspecified “other” settings (156 or 10.6%). Several were self-employed (78 or 5.3%), worked for a private society (55 or 3.7%) or a health care facility (29 or 2.0%).

Direct measures that identify the influence of the bio-medical model on social workers were not available in the data set. Nevertheless, a majority of the sample responded positively to a question that asked if they should be involved in the development of social policy regarding end-of-life decision-making. For both VE and AS, 964 or 65.3% of social workers indicated that they wanted to be involved in this aspect of assisted death. While support for social worker involvement with a client’s decision to end his or her life was less forthcoming, almost half were willing to participate in discussions around assisted death (VE 726 or 49.2% and AS 719 or 48.7%), suggesting that the bio-medical model is not all pervasive or the exclusive model. Nevertheless, it is apparent that social workers’ perceived role in this area is equivocal as

many indicated that they were not sure about participating in such discussions (VE 477 or 32.2% and AS 481 or 32.6%).

Social workers were asked two questions related to self-realization, a measure of client autonomy. A majority (1126 or 76.2%) disagreed with the idea that it was their duty to respect their client's right to self-realization. A smaller majority of social workers agreed with the notion that the right to self-realization extended to assisted death (VE 902 or 61.1% and AS 930 or 63.0%). Whether God controls one's destiny—a tenet of many dominant religions and a variable related to self-realization—was determined by asking respondents to identify their own religion and level of religious commitment. Most social workers identified themselves as Protestant (691 or 46.8%), followed by Catholic (176 or 11.9%). A significant number of social workers indicated that they were not religious or had no belief structure about religion (224 or 15.2%) as compared to agnostic (160 or 10.8%) or atheist (116 or 7.9%). As suggested in Table 4.4, 61 social workers (4.1%) identified "other" as a religious category and only a few social workers identified themselves as adhering to Jewish, Hindu or Islamic faiths. Religious commitment was measured on a scale from 1 (not committed at all) to 7 (fully committed). The statistical mean and standard deviation of commitment were 4.18 and 2.098, respectively.

As indicated in Table 3.1, personal experiences may affect attitudes toward assisted death. A small number of social workers indicated personal experiences with VE (138 or 9.3%) and AS (117 or 7.9%). Slightly more had been consulted about VE (215 or 14.6%) and AS (197 or 13.3%). The data relating to both dependent and independent variables follow the demographic information in Table 4.3 below.

Table 4.3*

Demographic Variables for BASW Sample

*Missing cases are not included. Columns do not reach total sample size or percentages.

Continuous Variables

	<i>Range</i>	<i>Mean</i>	<i>SD</i>	<i>n</i>
Age (years)	19-89	47.30	9.705	1475
Employment (years)	0-60	17.23	9.514	1423

Categorical Variables

	<i>Frequency</i>	<i>%</i>
Gender		
Female	1040	70.5
Male	435	29.5
Total	1475	99.9
Education		
Diploma in social work	194	13.2
CQSW	351	23.9
CSS	55	3.7
Undergraduate degree	102	6.9
Postgraduate degree	132	9.0
SW and undergrad	377	25.6
SW and postgraduate	238	16.2
Other	22	1.5
Total	1471	99.6
Member of BASW		
Yes	1323	97.3
No	37	2.7
Total	1360	92.1
Currently Employed as a Social Worker		
Yes	1147	78.6
No	312	21.4
Total	1459	98.8

Table 4.3 Continued

Employment Status		
Full-time	1050	72.8
Part-time	256	17.8
Casual	19	1.3
Student	39	2.7
Unemployed	10	0.7
Retired	68	4.7
Total	1442	97.6
Country		
England	897	60.8
Scotland	348	23.6
Wales	123	8.3
Northern Ireland	108	7.3
Total	1476	99.9

Table 4.4*

Dependent and Independent Variables

*Missing cases are not included. Columns do not reach total sample size or percentages.

Dependent Variables

Forced Response

VE or AS should be legal in certain circumstances.

VE	Frequency	%	AS	Frequency	%
Yes	1057	72.2	Yes	1066	72.6
No	232	15.8	No	237	16.1
Undecided	175	12.0	Undecided	165	11.2
Total	1464	99.1	Total	1468	99.4

Dutch practice should be adopted in the United Kingdom?

	Frequency	%
Yes	1010	68.9
No	231	15.8
Undecided	224	15.3
Total	1465	99.2

Would report a social worker involved in VE or AS.

VE	Frequency	%	AS	Frequency	%
Yes	380	26.4	Yes	375	25.8
No	464	32.2	No	481	33.1
Undecided	598	41.5	Undecided	595	41.0
Total	1442	97.6	Total	1451	98.2

Table 4.4 Continued

Independent Variables

<i>Continuous Variables</i>	<i>Range</i>	<i>Mean</i>	<i>SD</i>	<i>n</i>
Religious Commitment	1-7 (likert)	4.18	2.098	1164

<i>Categorical Variables</i>	<i>Frequency</i>	<i>%</i>
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Practice Setting

Private/independent	54	3.7
Drug and alcohol	20	1.4
Mental health	233	16.2
Child welfare	455	31.7
Financial services	1	0.07
Community-based counselor	23	1.6
Medical setting	144	10.0
Other	506	35.2
Total	1436	97.2

Type of Employer

Government	1077	77.2
Private society	55	3.9
Self-employed	78	5.6
Health care facility	29	2.1
Other	156	11.2
Total	1395	94.4

Forced Response Variables

Social workers should be involved in policy development of VE and AS.

VE	Frequency	%	AS	Frequency	%
Yes	964	66.4	Yes	965	66.2
No	211	14.5	No	219	15.0
Undecided	276	19.0	Undecided	274	18.8
Total	1451	98.3	Total	1458	98.7

Social workers should be involved in discussions on client's decision regarding VE and AS.

VE	Frequency	%	AS	Frequency	%
Yes	726	50.1	Yes	719	49.6
No	247	17.0	No	250	17.2
Undecided	477	32.9	Undecided	481	33.2
Total	1450	98.2	Total	1450	98.2

Table 4.4 Continued

Right to self-realization extends to VE and AS.

VE	Frequency	%	AS	Frequency	%
Yes	902	62.6	Yes	930	64.3
No	246	17.1	No	234	16.2
Undecided	292	20.3	Undecided	283	19.6
Total	1440	97.5	Total	1447	98.0

Religious Affiliation

Protestant	691	47.2
Roman Catholic	176	12.0
Jewish	14	1.0
Islam	2	0.01
Hindu	5	0.3
Agnostic	160	10.9
Atheist	116	7.9
Buddhist	14	1.0
Not applicable	224	15.3
Other	61	4.1
Total	1463	99.1

Have had to cope with VE or AS in personal life.

VE	Frequency	%	AS	Frequency	%
Yes	138	9.5	Yes	117	8.0
No	1291	88.6	No	1313	90.2
Undecided	28	1.9	Undecided	26	1.8
Total	1457	98.6	Total	1456	98.5

Have been consulted regarding VE or AS.

VE	Frequency	%	AS	Frequency	%
Yes	215	14.7	Yes	197	13.6
No	1226	83.8	No	1244	86.1
Undecided	21	1.4	Undecided	23	1.6
Total	1462	99.0	Total	1444	97.8

With regard to the qualitative aspect of this research, the following prompt appeared at the end of the survey: *As a professional social worker, your comments about euthanasia and/or assisted suicide are invited and considered extremely valuable. Please feel free to add additional pages.* Using the *specimen perspective* referred to above, the written comments were analyzed for content that expands or clarifies social workers' views on assisted death. In addition, the data are examined for themes that may supplement the survey data. Analyses of social workers' responses to this prompt appear along with the quantitative analyses of the hypotheses in the following chapter.

Notes

1. Some qualitative researchers argue that “crystallization” should replace the concept of triangulation as the latter implies a two-dimensional interpretation of reality. For example, Richardson (2000) argues that there are multiple approaches to reality that reflect multiple dimensionalities of approaches to phenomena. However, Stake (2000) rightly observes that multiple perceptions (i.e. triangulation) help to clarify reality and meaning, which is one way of establishing accuracy in the research process. He adds that even the critics of triangulation seek accuracy in the interpretation phase of research.

Chapter 5

Social Worker Support of Assisted Death

Using a secondary analysis of the survey data, this chapter examines the relationships between social workers' attitudes toward legal aspects of assisted death, namely: legalization, support for the Dutch model of legalized euthanasia and the likelihood that social workers would report a colleague whom they suspected had participated in an assisted death. Assisted death refers to VE and AS, which are analyzed separately. Although the reasons for regional variation in responses cannot be determined using existing data, social workers' attitudes toward legalization, the Dutch model and the inclination to report a colleague, based on country of practice, were examined. Specific comments of social workers from various countries in the U.K. inform the analysis of the qualitative data. Restated, the hypotheses include:

- 1) social workers working in medical settings will be more supportive of assisted death;
- 2) social workers less supportive of physician dominance will be more supportive of assisted death;
- 3) social workers who advocate for client self-realization will be more supportive of assisted death;
- 4) social workers holding religious beliefs will be less supportive of assisted death; and
- 5) social workers with personal experiences in death and dying will be more supportive of assisted death.

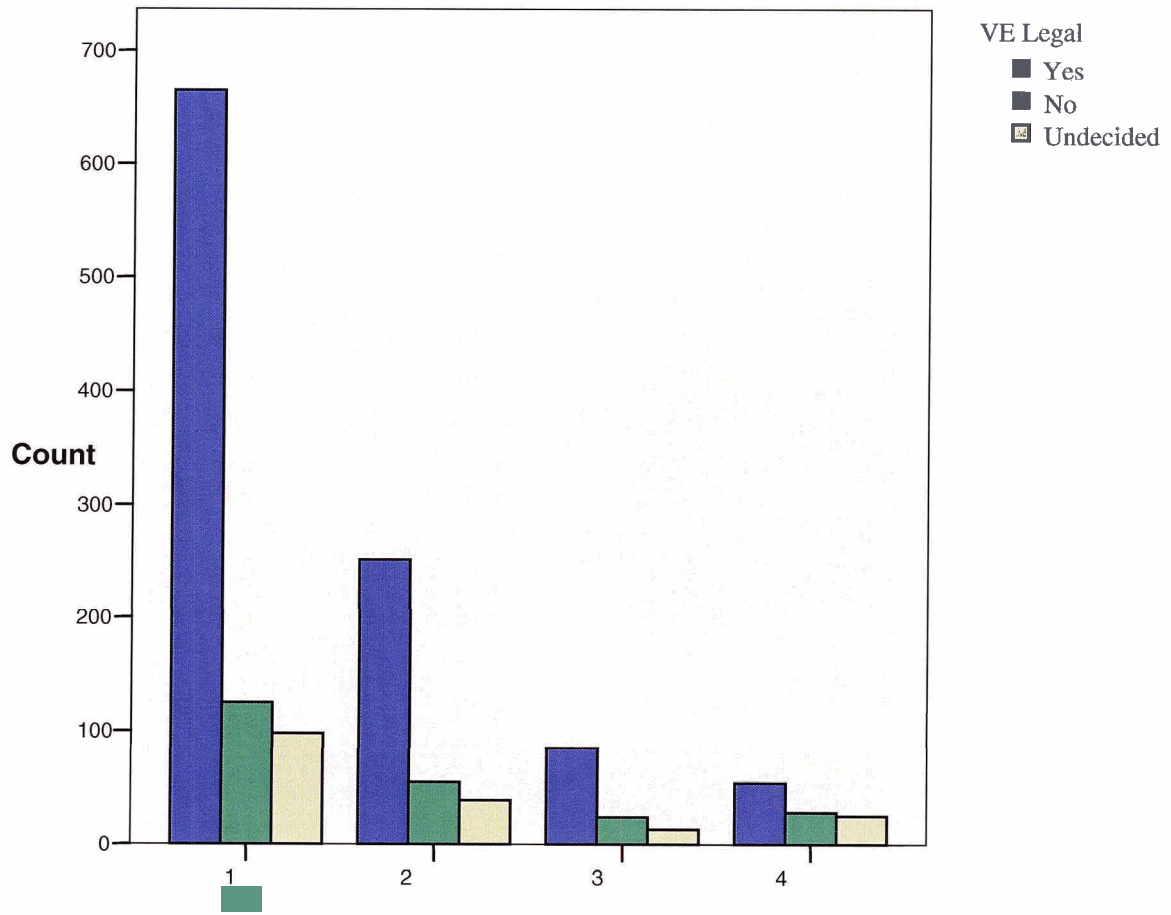
Given the constraints imposed by the forced response items on the survey, the hypotheses are tested using simple cross-tabulation analysis. For purposes of clarity, the results of analyses involving multiple categories are presented in graphic form using bar charts. These results are then supplemented with data from the written responses provided by social workers, with the intention of enhancing the validity of the survey data analysis. The qualitative data are also examined for information relating to factors identified in Table 3.1, but not covered in the quantitative analysis: that is, the effect of social workers' relationships with physicians, clients, and/or members of the client's family. Discussion of the implications of the results occurs in Chapter 6.

Support for assisted death by country

Analysis of social workers' attitudes by country reveals that social workers in Northern Ireland are the least supportive of VE (54 or 50.5%) and AS (61 or 57.0%) and are most likely to report a colleague they suspect of being involved in either act (VE 45 or 43.3%; AS 43 or 40.2%). Figures 5.1 – 5.5 show that social workers in England were the most supportive of legalizing VE (665 or 74.9%) and AS (679 or 76.3%) followed by Scotland, Wales and Northern Ireland. Support for the Dutch model of assisted death as it stood before the legislative revisions was strongest for England (637 or 71.6%) with Scotland, Wales and Northern Ireland following. Social workers in Wales were least likely to report a colleague for both VE (24 or 20.3%) and AS (25 or 21.0%) followed by England, Scotland and Wales.

Figure 5.1

Social workers' support for euthanasia by country

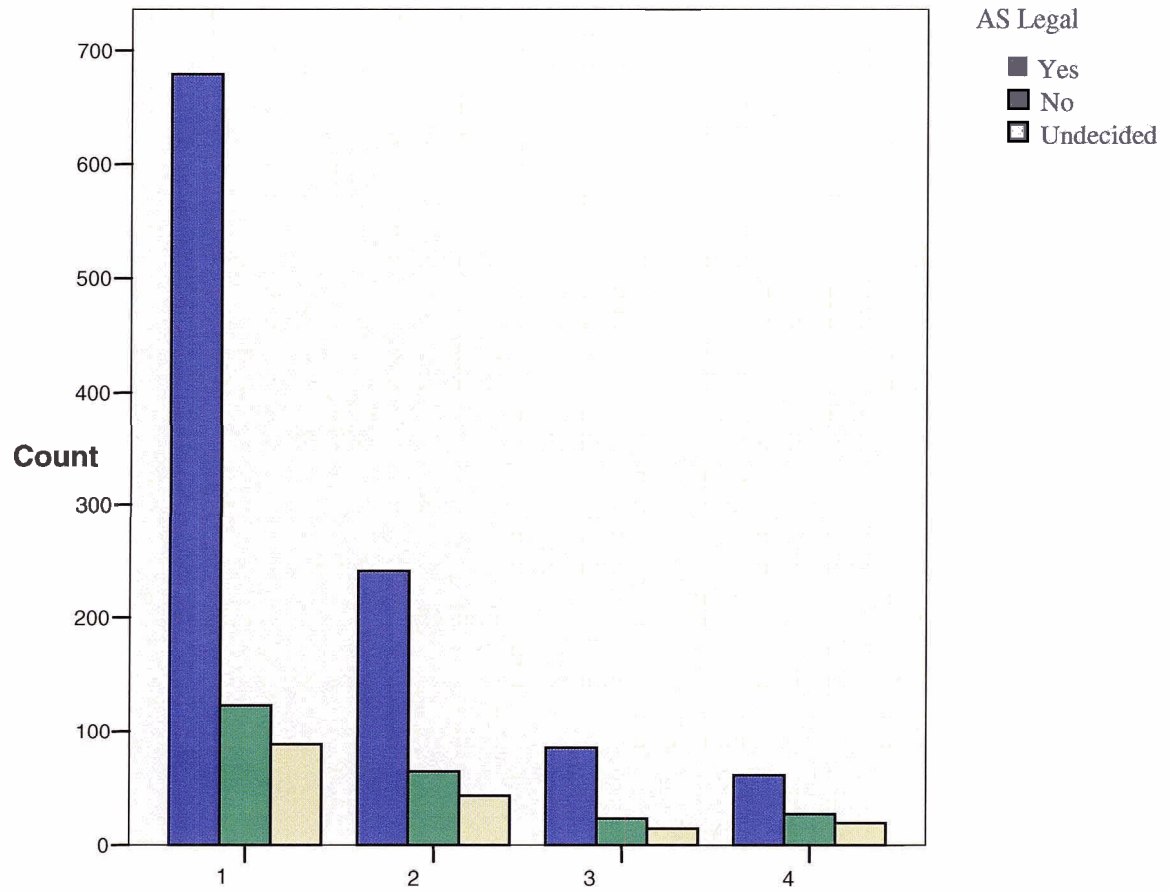


Country

1. England
2. Scotland
3. Wales
4. Northern Ireland

Figure 5.2

Social workers' support for assisted suicide by country

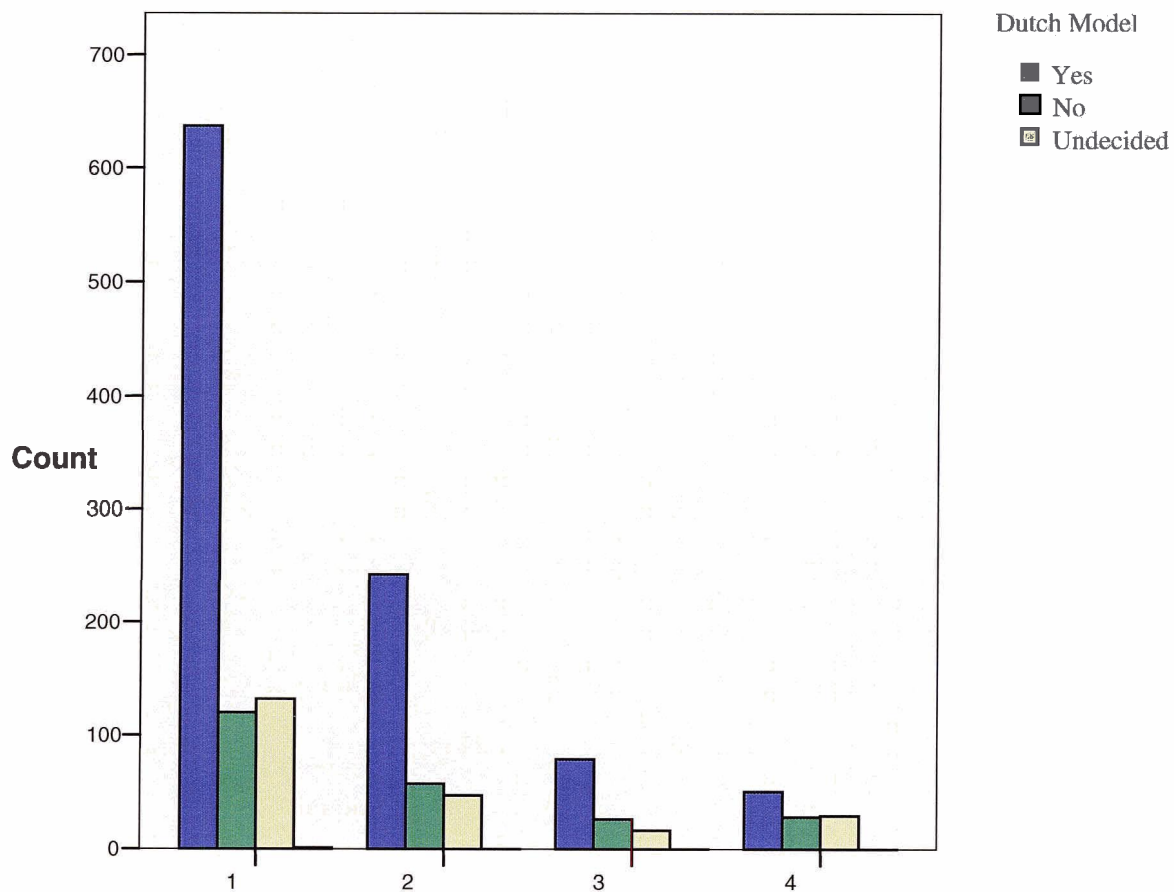


Country

1. England
2. Scotland
3. Wales
4. Northern Ireland

Figure 5.3

Social workers' support for Dutch model by country

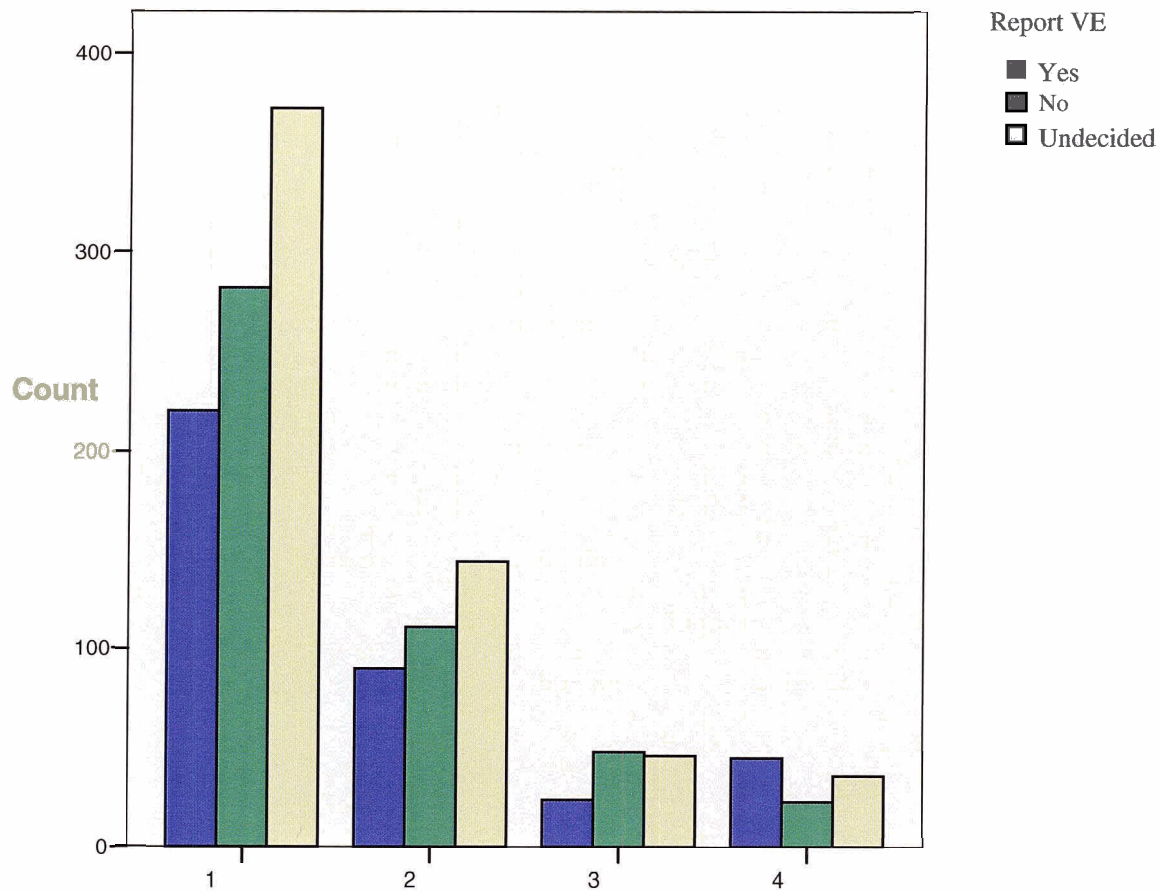


Country

1. England
2. Scotland
3. Wales
4. Northern Ireland

Figure 5.4

Social workers' decision to report a colleague for euthanasia by country

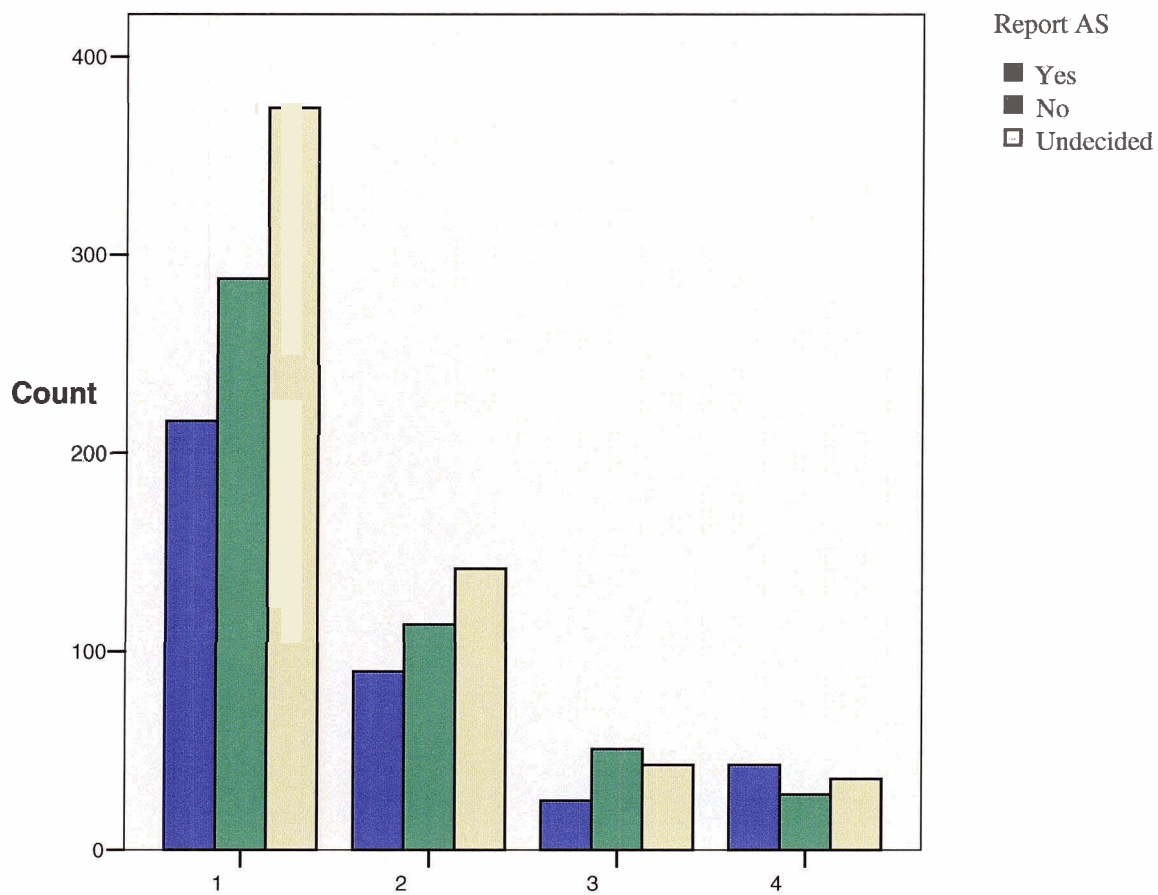


Country

1. England
2. Scotland
3. Wales
4. Northern Ireland

Figure 5.5

Social workers' decision to report a colleague for assisted suicide by country



Country

1. England
2. Scotland
3. Wales
4. Northern Ireland

Practice setting and legal aspects

Figures 5.6 – 5.10 reveal that across all practice settings, the majority of social workers support the legalization of VE (1025 or 72.0%) and AS (1035 or 72.5%). Thus, social workers do not appear to discriminate between VE and AS. In most cases, social workers in medical settings are no more likely to support VE or AS than their counterparts in other settings. Sixty-four percent of social workers in medical settings support both euthanasia and assisted suicide. With the exceptions of community-based settings (VE 52.2% and AS 47.8%) and the one social worker in a financial-based setting, social workers in non-medical settings are slightly more supportive of legalized VE and AS. While the sample size is small, those working in drug and alcohol rehabilitation settings are the most supportive of VE (85%) and AS (80%), followed closely by social workers in child welfare (VE 75.3% and AS 77.2%) and private practice (VE 75.9% and AS 72.2%). Interestingly, social workers in community-based settings are the least supportive and the most undecided regarding the legalization of both VE and AS.

Written responses regarding medical setting and support or condemnation of assisted death were rare. A hospice care social worker in England noted the dilemma with prolonging life from the perspective of a medical setting, but found it acceptable in some cases.

...I am acutely aware of the tremendous efforts of palliative care physicians to ease patients' pain and suffering. I have seen cases where patients felt that life was hopeless, only to change their mind when appropriate pain relief was given. However, I am also aware that sometimes it is not possible to relieve pain and suffering sufficiently. These are cases where I feel assisted suicide ought to be available and that voluntary euthanasia perhaps would be an option.

Referring to her experiences in hospitals and related health settings, another English social worker commented on her support for assisted death.

Having worked largely in hospital/health setting – with people with HIV/AIDS as well as with life-threatening conditions, having nursed 3 members of my immediate family through their terminal illness, these firmly held beliefs of mine...have evolved over many years of personal and professional experiences. My family is aware of my own views if I meet such circumstances.

Based on experiences in a hospital setting, a social worker from Northern Ireland,

...saw and observed patients dying a slow painful death on more than one occasion. I have always felt if a person wants to know all the facts about their medical condition and decide[s] to die by euthanasia or assisted suicide, they should be allowed to do so.

Also writing from experience in palliative care, a social worker from Wales stated that “[h]elping people to die at peace with themselves was part of social work”.

However, a Scottish social worker with experience in a health care setting came to the opposite conclusion.

I worked for many years as a medical social worker mainly with Acute Medical and Chronic Chest illnesses plus young adults who had cystic fibrosis. I feel that the practice of moving from curative to palliative treatment is sufficient given that palliative medicines often ease suffering but also ease patients out of life.

Practice setting and support for the Dutch model

Support for the Dutch model of assisted death is striking with 979 or 68.7% of social workers supporting the development of similar practices in the U.K. As noted, the Dutch model referred to in the survey endorses physician-assisted suicide and euthanasia. Figure 5.8 indicates that social workers in child and welfare settings are most supportive of the model (73.4%). While we must be cautious regarding other settings with small

sample sizes, support by social workers in child and welfare settings is highest followed by mental health, private practice, drug and alcohol, other, medical and financial service settings. Social workers in community-based counseling and in drug and alcohol settings are the most undecided, 27.3 % and 20%, respectively.

Despite numerous comments regarding the legal issues surrounding assisted death, few social workers took the opportunity to discuss the Dutch model. A Welsh social worker stated that "...the Netherlands have just about got it right..." while another supported the Netherlands' criteria provided that patient consent is verified by a social worker. The opinions of a social worker from Scotland suggested that finding meaning in the dying process often eliminates a patient's desire for hastened death. Skeptical of the Dutch model, this social worker noted,

I have worked with patients who, until they adjust from health to ill health would often express a wish to be "out of things", but, when they find a new role which confirms their importance to others, value their remaining days greatly. I have seen many people die within the hospice setting knowing they were valued. I feel this area needs to continue to grow and improve. I have little faith in the Dutch system which I did not feel is always as 'clean' as it seems.

A social worker from England commented on the potential problems with the Dutch model referring to an unspecified article that documented abuses of assisted death in Holland. Referring to the growing acceptance of assisted death, a Scottish social worker similarly documented the apparent problems relating to the Dutch model, which has been changed since the time of the survey. Referring to the slippery slope, this social worker accepted the arguments made by opponents of assisted death.

The relationship between doctor and patient is under threat. License a Doctor to kill, even under very restricted circumstances and we have changed the nature of the relationship. Residents in some Dutch nursing homes have already been found to fear that their lives may be ended contrary to their wishes...It has been shown that doctors there are prepared, not only to kill [via specific regulations] regarding

euthanasia, but also to terminate life, even in cases where the regulations do not apply...false certification of death, the use of euthanasia in patients who were not terminally ill, in patients who had made no request and given no consent, and in one current legal case, in a patient who was physically well but suffering from severe depression, have all been reported.

Another English social worker commented "...that the general conditions that apply to Holland's use of euthanasia or assisted suicide are a good basis to work from if it were to be introduced into Great Britain." Finally, highlighting the ongoing concern with end-of-life treatment, a Scottish social worker observed that,

Having known people whose quality of life and human dignity were impaired by their great suffering but who were also still rational enough to make a decision for themselves and seen them suffering more because those choices were not available to them I am convinced that we should move to the Dutch position.

Practice setting and the decision to report

The majority of social workers across all settings indicated reluctance or uncertainty about reporting a colleague whom they suspected of being involved in an assisted death. Slightly more than a quarter indicated a willingness to report VE (26.4%) and AS (25.9%). However, this finding may be misleading as a large number of social workers remain undecided about the decision to report euthanasia (585 or 42.0%) and assisted suicide (581 or 41%). The reluctance of social workers to report a colleague has not been the subject of any previous research. Even though assisted death is illegal in most countries, it may be argued that whistle blowing in the social work context may be infrequent, due to the absence of concrete ethical guidelines.

In the U.K., social workers in private practice were the most likely to report VE (39.2%), followed closely by social workers in other settings. Regarding AS, social workers in other settings were more likely to report (27.8%) followed by those in child

welfare (26.9%). In contrast to VE, social workers in community-based settings were the least likely to report AS (21.7%). The percentage of social workers uncertain about whether to report a colleague is notable, ranging from 29.5% of social workers in child welfare settings uncertain about VE to 45.1% in private practice uncertain about AS.

Analysis of the written comments highlighted how the reluctance experienced by social workers regarding the decision to report a colleague stems from conflicting obligations of respecting patients' wishes versus upholding practice guidelines and the law. An English social worker commented,

It is the lack of an accepted procedure that mainly causes my uncertainty...about whether I would report a situation that I became aware of. If I felt the social worker had acted as carefully as possible to be sure this was the person's consistent wish, that there was no acceptable alternative, and that their actions were solely directed to the person's welfare, I might not report it.

A social worker from Northern Ireland added,

...we are bound to report to doctor or line manager if a client has referred to suicide intent and we have concerns about this – we are not in a position to support the person's wish to commit suicide; in fact, we should be advising the opposite and often this presents a dilemma for us as it is at variance with the way we usually practice – [i.e.] to inform people of their rights and support them to exercise these rights but suicide is the exception and I feel we are not always satisfied with the way of practising but we have a fear if we don't follow the proper procedure and the person kills themselves we could be in serious trouble...so we do the right thing!

Identifying a further tension in social work practice, a social worker from Scotland observed the distinction between private and public life.

Working for the Criminal Justice Services leaves little room where knowledge of a criminal act exists. However, I would only report a colleague to my manager if a worker/client relationship existed. If the colleague acted in either manner in a private capacity then that is their business and outside the work setting.

Finally, social workers noted the discrepancy between law in the U.K. and the practice of assisted death. In the words of a social worker from England,

Personal beliefs about the nature of human existence are likely to guide social workers' attitudes. Social workers' response to the letter of the law has never been clear cut (e.g. reporting under-aged sexual activity between juveniles).

Referring to reporting an assisted death, a social worker from Scotland noted "I feel... obliged to report at the moment, but if the law were to change, the implications of reporting it would be different. (I would still report it)." Commenting on the apparent antiquity of the current prohibition against assisted death an English social worker wrote,

I do not think people may choose which laws to obey. If one chooses to challenge the law directly, the consequence is being reported to the Police etc. It is my view that a bad or out of date law should be openly challenged and questioned through debate and/or direct action.

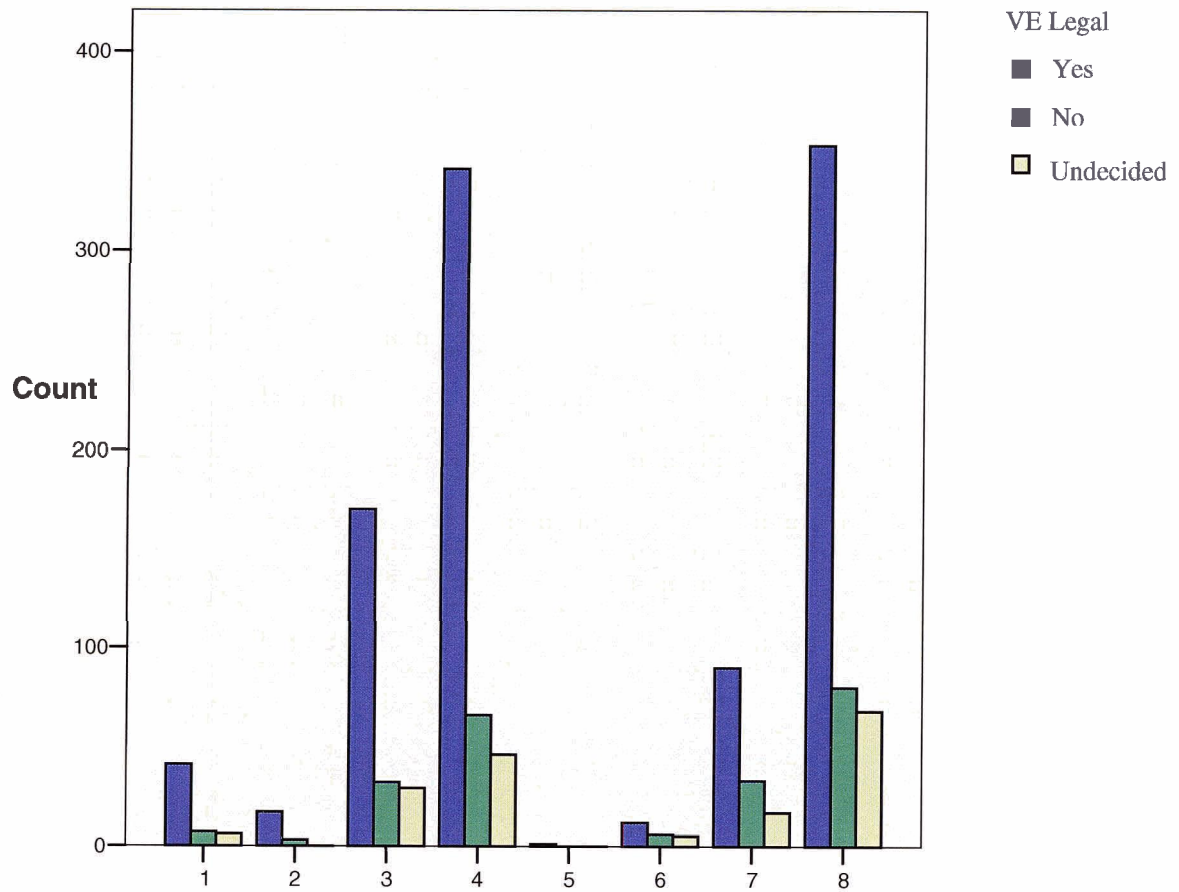
Summary: Support for assisted death and practice setting

The majority of social workers in most practice settings support assisted death, thus confirming the hypotheses. Analysis of the written comments reveals several issues that bear directly on the debate. The experiences of social workers in hospice settings led them to different conclusions about the value of human suffering and appropriateness of assisted death. This disagreement appears rooted in the distinction made by social workers between actions that can be construed as helpful or harmful. Support for the Dutch model of assisted death is apparent, but misgivings over apparent abuses in the Netherlands also cause some concern. Only a few social workers indicated that they would report a colleague whom they suspected of being involved in an assisted death. This finding suggests that personal value systems override organizational and legal requirements, an observation made about social workers in the American context (Csikai,

1999a; Holland & Kilpatrick, 1991). As stated by BASW (1996), in the interests of social justice, social workers are required to advocate for their clients. Not surprisingly, many social workers desire changes in legislation, which would have the effect of legalizing assisted death and thus removing the strain experienced by social workers who deal with end-of-life issues.

Figure 5.6

Social workers' support for euthanasia by practice setting

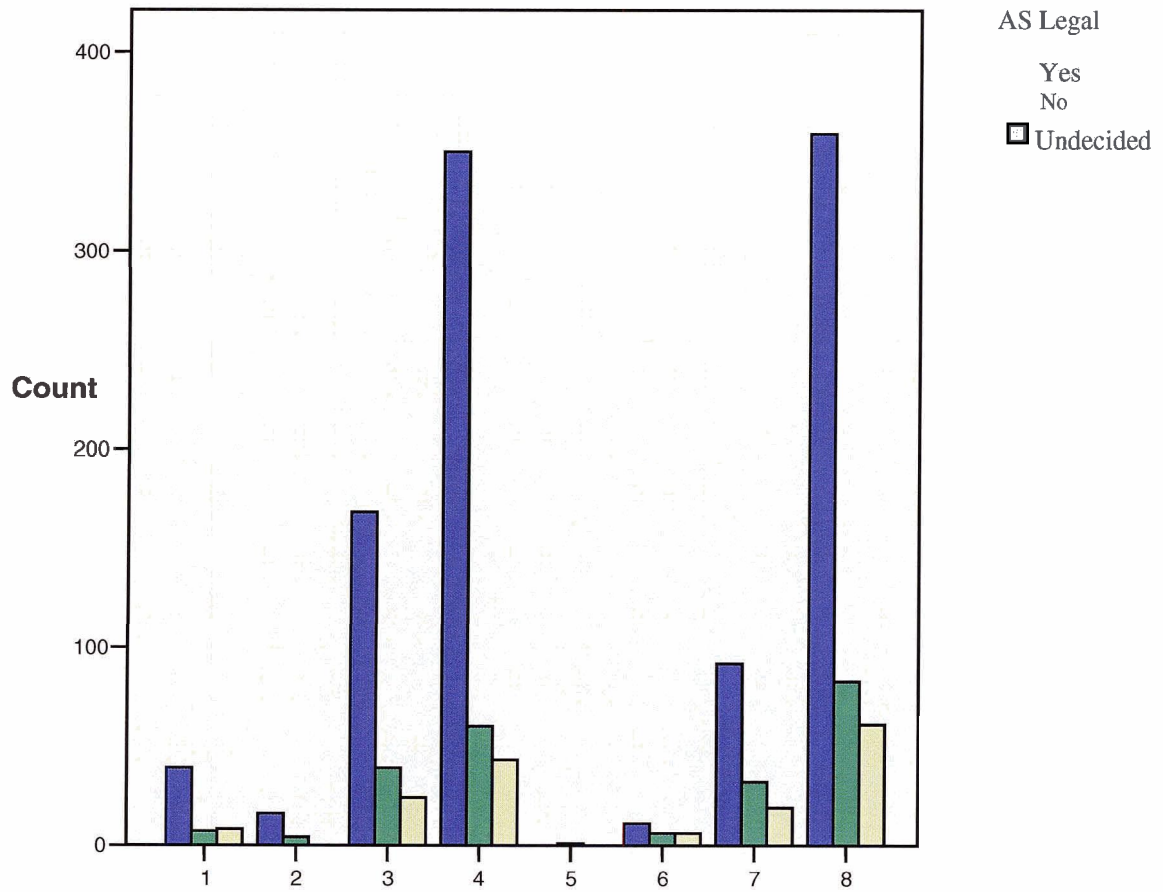


Practice Setting

1. Private/independent
2. Drug and Alcohol
3. Mental health
4. Child welfare
5. Financial service
6. Community-based counselor
7. Medical setting
8. Other

Figure 5.7

Social workers' support for assisted suicide by practice setting

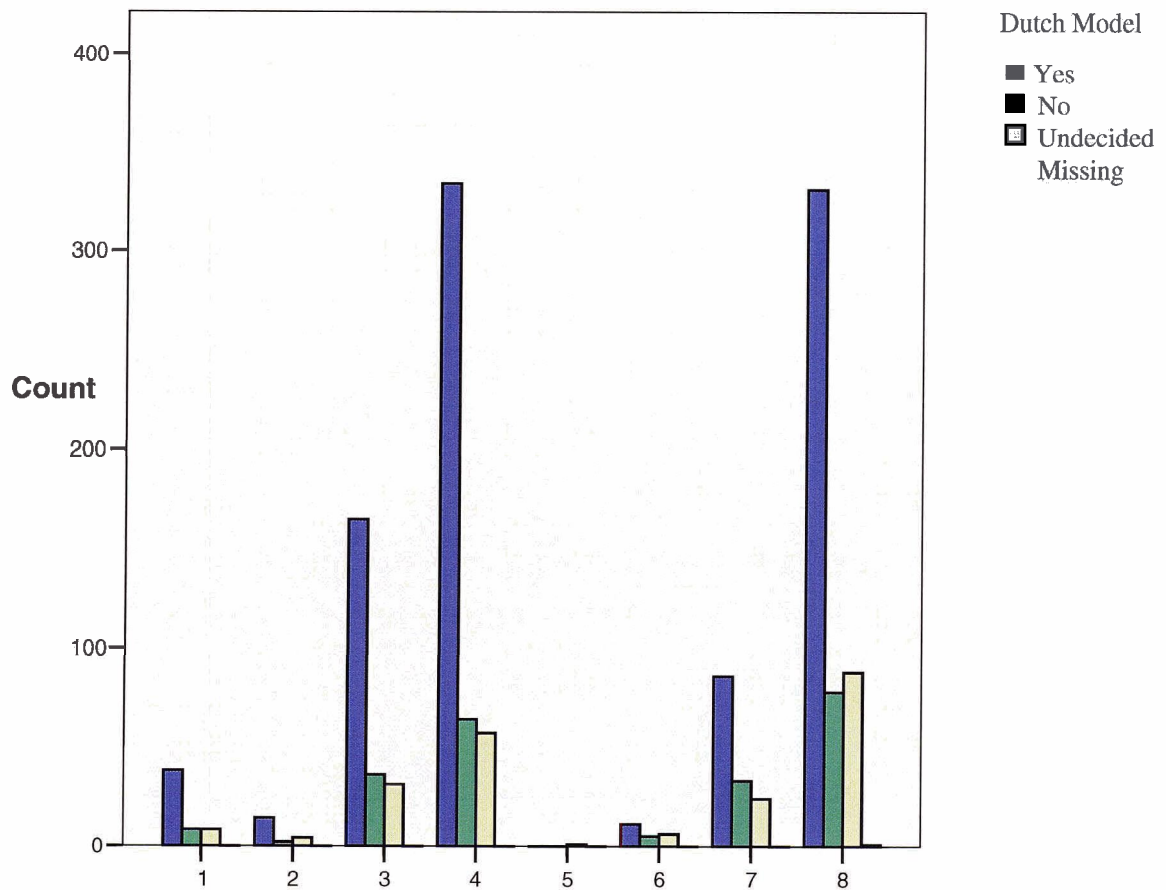


Practice Setting

1. Private/independent
2. Drug and Alcohol
3. Mental health
4. Child welfare
5. Financial service
6. Community-based counselor
7. Medical setting
8. Other

Figure 5.8

Social workers' support for Dutch model by practice setting

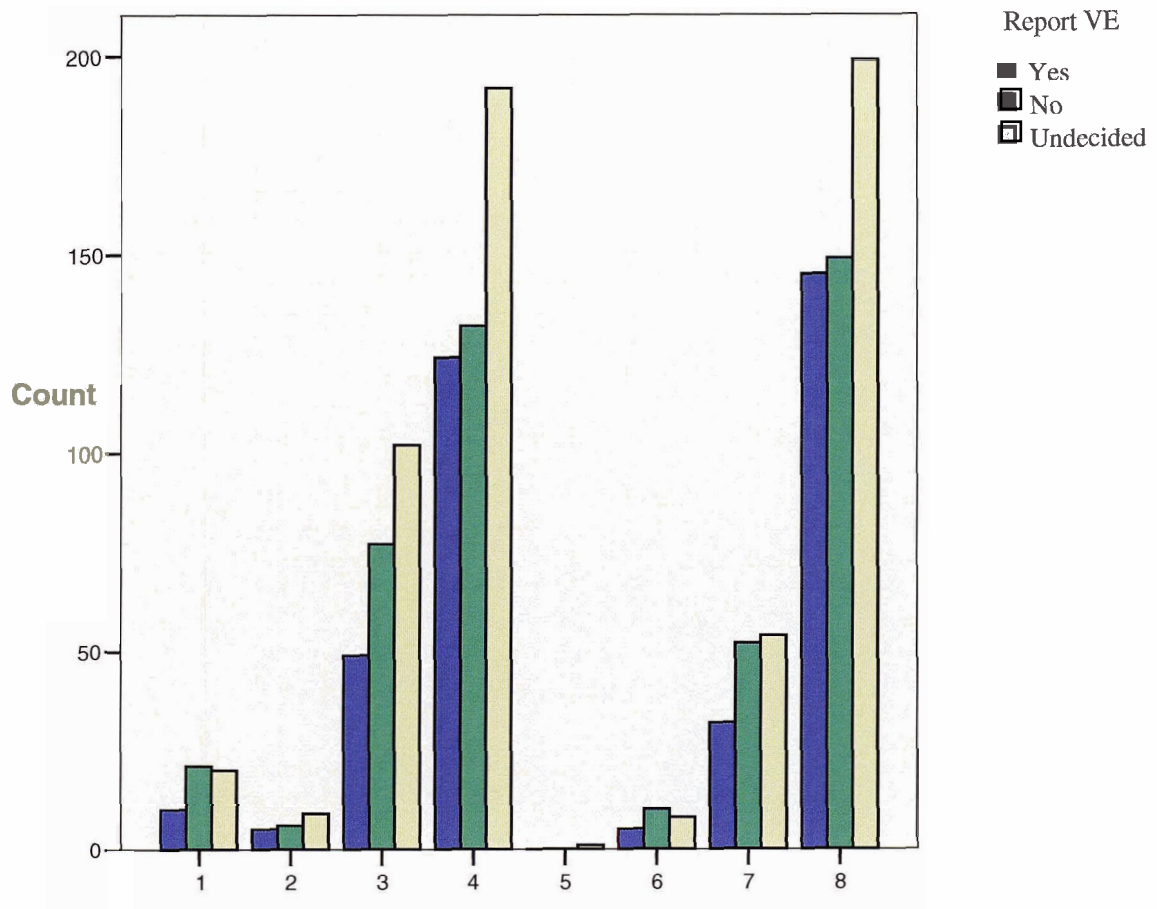


Practice Setting

1. Private/independent
2. Drug and Alcohol
3. Mental health
4. Child welfare
5. Financial service
6. Community-based counselor
7. Medical setting
8. Other

Figure 5.9

Social workers' decision to report a colleague for euthanasia by practice setting

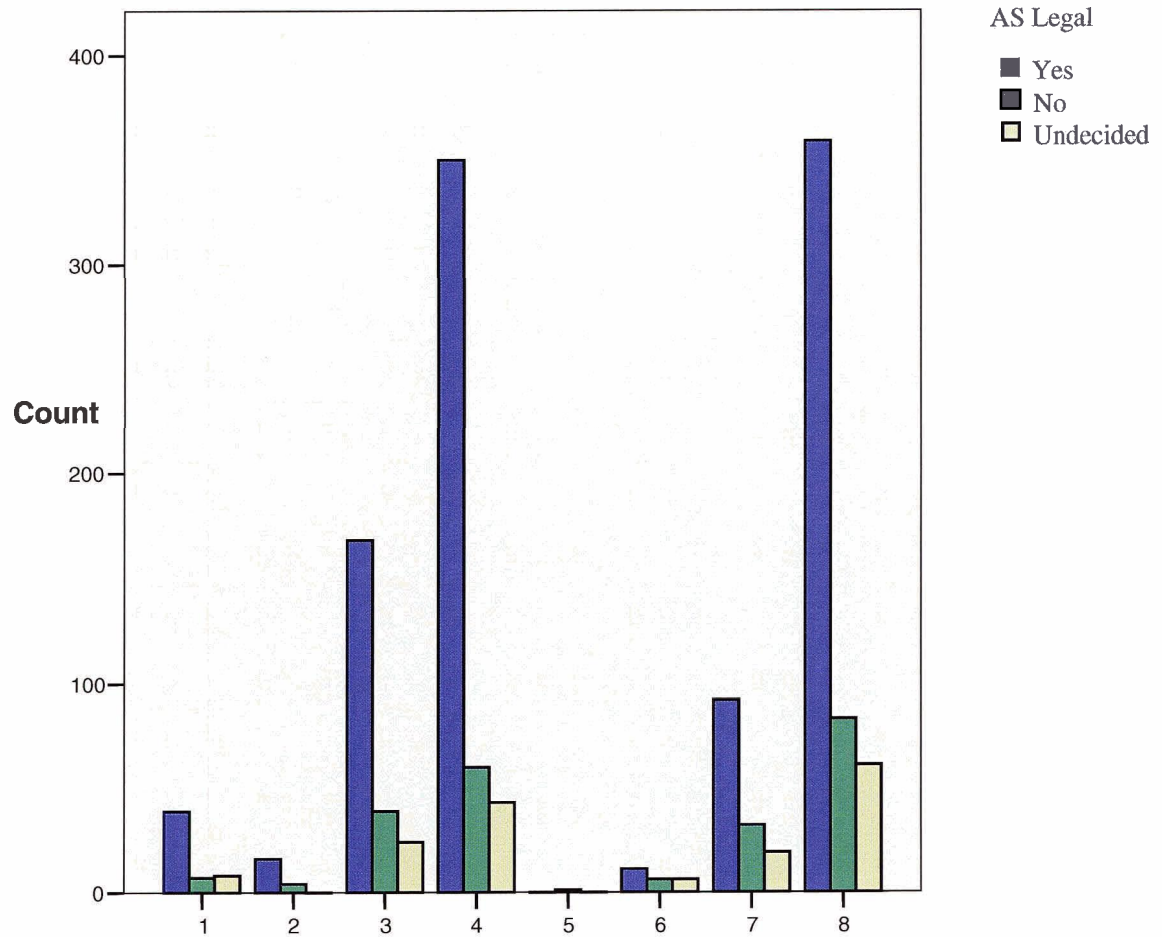


Practice Setting

1. Private/independent
2. Drug and Alcohol
3. Mental health
4. Child welfare
5. Financial service
6. Community-based counselor
7. Medical setting
8. Other

Figure 5.10

Social workers' decision to report a colleague for assisted suicide by practice setting



Practice Setting

1. Private/independent
2. Drug and Alcohol
3. Mental health
4. Child welfare
5. Financial service
6. Community-based counselor
7. Medical setting
8. Other

Bio-medical dominance of assisted death

As stated in Chapter 2, bio-medical dominance of assisted death refers to the medicalization of dying, or control of an event experienced by all people eventually. While there are no direct measures in the survey, two variables can serve as proxy variables of social worker support for bio-medical dominance of VE and AS: involvement in policy development and involvement in discussions with clients regarding assisted death. These variables were selected because they identify social workers' willingness to challenge the hegemonic role played by medical professionals in death and dying. Involvement in policy development implies that social workers have a voice on the issue and want to be recognized as equals in the debate on assisted death. As well, involvement in policy development suggests that social workers want to play a role in end-of-life decisions. Regarding involvement in discussions with clients, social workers may be serving in a role usually reserved for physicians, that is, discussions with clients regarding the choice of when and how to die.

Bio-medical dominance and social worker involvement in policy development

As indicated in the previous chapter, roughly two thirds of social workers wanted to be involved in the development of policies surrounding VE and AS (see Table 4.4). However, the cross tabulation between support for the legalization of VE and AS and those wanting to be involved in policy development is considerably greater. Table 5.1 shows that 772 or 80.3% of social workers who support legalization want to be involved in policy development of VE. Similarly, on another measure with a different number of respondents, 780 or 80.1% support legalization and want to be involved in policy

development of AS. Table 5.1 also shows that 732 or 76.2% of social workers who support VE endorse the Dutch model of assisted death. Likewise, 725 or 75.4% of social workers who support AS endorse the Dutch model. This finding is slightly higher than the 68% of social workers in Table 4.4 who indicated overall support for adoption of the Dutch model of assisted death in the U.K. Finally, Table 5.1 indicates that 221 or 23.4% of social workers who support policy development for VE indicated a willingness to report a colleague whom they suspected of being involved in VE. Roughly the same number of social workers who support policy development for AS suggest they would report a colleague for being involved in AS (215 or 22.6%).

The relationship between support for legalized VE and AS and social workers' desire to be involved in policy development suggests that not all social workers who support assisted death want to be involved in policy-making. In addition, the reduction in support for the Dutch model when policy-making is introduced indicates that not all social workers want to be involved in the policy process. Finally, there is a weak relationship between being willing to report a colleague and being interested in being involved in policy development. However, a significant number of social workers who endorse being involved in policy development are undecided about whether to report a colleague for VE (404 or 42.7%) and AS (404 or 42.5%). Accordingly, this result should be treated with caution and any conclusions drawn considered tentative.

A few social workers noted that social worker involvement in policies regarding VE and AS might be leading to the slippery slope of abuse. For example, a social worker from Scotland expressed concern that policy development might lead to a new eugenics movement. Others expressed the view that discussions about social policy were out of

place. For example, a social worker from Wales stated, “Changes in policy about euthanasia or assisted suicide have to follow changes in law.” Other written comments suggested that social workers in the U.K. lack guidance regarding issues surrounding assisted death. An English social worker cautioned that, “A clear precise procedure would have to be agreed upon by national policy makers to ensure that no client was pressured or encouraged to interact with a final conclusion to their life.” Another social worker from England observed,

Very clear safeguards would have to be built into any policy about euthanasia or assisted suicide to ensure that people did not feel pressured into going for one of the options – rather than be “a burden” on others.

Whether assisted death should remain under the purview of medicine was addressed by several social workers. A social worker from England noted,

I think these decisions/policies/changes should stay within the medical arena rather than the social one. I see social workers participating only when they have had or do have a significant role in the person’s life.

A social worker from Scotland added,

It should not be the place of social workers to debate/make policy on euthanasia/assisted suicide. They are not qualified. It is the place of those trained in medical ethics who would be involved in such decisions in actuality to examine issues.

Another English social worker commented that social work does not occupy “...a privileged position when policy is being considered.” Other social workers took the opposite position. Regarding the practice of assisted death, one social worker from Wales stated,

It is a complex issue and needs to be addressed so SWs can practice in a more meaningful way in this area. I would welcome developments in this area and agree social workers should be part of the policy making on this issue.

A social worker from England expanded on this approach.

I am unsure of the social work role but imagine that social workers with adult clients who may be terminally ill may have the appropriate relationship to support their clients through the decision making process. Therefore I feel that social workers should be involved in policy making.

An English social worker added a caveat to social worker involvement: “[s]etting up any group to look at developing policy needs to be done thoughtfully and with infinite care. Members of the group should have access to professional and personal support.”

Another social worker cautioned, “I believe only social workers who have extensive experience working with the terminally ill (and their families) should be involved in a policy that addresses euthanasia or assisted suicide.” A Welsh social worker proposed a unique solution to some of the issues surrounding end-of-life decision-making.

A clear policy and well documented policy is needed administered by a multi purpose and disciplinary team who can react to these situations. The team should be well trained in such matters. The team should consist of health, social services and others who work with a client. People should be allowed to make their wishes known in wills and before a situation occurs when they are unable to make rational decisions. The option is made available when the person is of sound mind.

Finally, an English social worker spoke directly to the issue of medicalization. For this social worker, the decision to die is up to each individual.

I am not in favour of these decisions being “medicalised” [and] professionalised”. Only each individual + perhaps close family and friends can make such decisions and I do question whether anyone in constant pain and despair should be taking such a decision – can it be “well-considered”? I also think that to put the responsibility of such decision-making onto medical practitioners or social workers is missing the point. I would have thought that it is a matter for each individual and his/her conscience.

Bio-medical dominance and social worker involvement in discussions

The other variable used to measure support for medical dominance of assisted death is social worker involvement in discussions with clients regarding assisted death. According to the data in Table 4.4, almost one half of social workers indicated a desire to be involved with discussions regarding VE (726 or 49.2%) and AS (719 or 48.7%). However, the data in Table 5.2 suggest that the proportion of social workers willing to be involved in discussions, and who support assisted death, is higher (VE 574 or 79.6% and AS 576 or 80.2%). Almost three quarters (539 or 74.4%) of social workers who support the Dutch model are willing to discuss VE with a client and 529 (73.7%) are willing to discuss AS. These statistics are slightly higher than the 1010 (68.4%) of social workers who supported adopting the Dutch model in the U.K. in general terms (see Table 4.4).

The number of social workers willing to report a colleague involved in assisted death, and who desired to be involved in discussions with clients, is roughly 50% lower than the number who would report for VE and AS alone. Only a minority of social workers who wanted to be involved in discussions regarding VE and AS would report a social worker they suspected of being involved with VE (179 or 25.3%) and AS (174 or 24.6%). Presumably, this minority of social workers would want to counsel clients against death-hastening acts. As with the relationship between social worker support of VE and AS and the desire to be involved with policy development, this conclusion should be treated with caution. As Table 5.2 shows, significantly more social workers who want to be involved in discussions with clients would not report or were undecided about whether to report.

Analyses of the written comments reveal that social workers' decision to report a colleague are linked to the wellbeing of the client. An English social worker commented that the question about reporting a colleague "...can only be answered accurately if the exact circumstances are known; there might be instances when it would be correct to report a S/W for such an act." Another social worker from England added,

If I felt the social worker had acted as carefully as possible to be sure this was the person's consistent wish, that there was no acceptable alternative, and that their actions were solely directed to the person's welfare, I might not report it.

Another social worker indicated that their client's best interest might involve reporting.

For this English social worker,

Euthanasia/assisted suicide is an individual choice – I would help a client to discuss this openly. I would report such a conversation to my supervisor (Team leader). If I felt that the client had not exhausted all the medical options or was mentally ill (sectionable) I would wish to consult their medical advisors.

Some social workers also feel inadequate about their own abilities vis-à-vis client wellbeing. A social worker from England observed,

Social workers may become involved in discussions of this issue with their clients but I believe their role should be one of liaison and passing on their knowledge of their client's wishes to medical clinicians involved in their client's care. I believe social workers have insufficient medical knowledge to make judgements about irreversible conditions and treatments available to alleviate suffering.

Finally, the words of another English social worker underscore the obligation many social workers feel toward discussions regarding end-of-life decisions.

I feel that voluntary euthanasia and assisted suicide should be permitted under very clearly defined circumstances, particularly taking into account the nature of their medical condition and a comprehensive assessment of their mental state. I feel that social workers may under certain circumstances help to facilitate discussion with the patient, their family and involved professionals.

Summary: bio-medical dominance of assisted death

The results of the analysis show support for the hypothesis that social workers who challenge physician dominance are more supportive of VE and AS. The relationship between policy development and approval of VE and AS is approximately 15% higher than the overall support social workers hold for both VE and AS identified in Chapter 4 (66%). The same support for the Dutch model is apparent. As noted in Chapter 4, overall, roughly 50% of social workers indicated support for the Dutch model and legalization of VE and AS, whereas over 74% of social workers indicated support for the Dutch model and being involved in policy development regarding VE and AS. Only 15% of social workers who support AS and VE would report a colleague they suspect of being involved in VE or AS. The remainder were unsure or unwilling to report further implying that personal value systems override organizational and legal constraints (Csikai, 1991; Holland & Kilpatrick, 1991). However, the large number of social workers who were undecided, 42% for both VE and AS, suggests that this result should be treated cautiously. To ensure that social justice is achieved, one social worker thought that clients' best interests could be served through a multidisciplinary team developed specifically for the purpose of developing policy for end-of-life decisions.

The number of social workers who support assisted death and are willing to be involved in discussions with clients regarding assisted death was less than 40% for both VE and AS. Similarly, less than 40% of social workers who supported the Dutch model were willing to be involved in discussions with their clients, substantially less than the 68% that indicated support for the Dutch model. Approximately 25% of social workers who would discuss VE or AS with a client would report a colleague, but the percentage

of undecided social workers in this category was high, over 40% for both VE and AS. For some social workers, the written responses imply that the reason for reporting turned on the issue of beneficence. If the client's best interests were being met, there was no need to report. Likewise, although professional protocol caused some concern, the decision to report appears to be motivated by concern for clients' wellbeing, not social workers' desire to follow the letter of the law. An English social worker said,

I believe individuals have a right to determine their own well being even if this results in earlier death – how this tallies with responsibilities such as sections under Mental Health legislation where an individual's rights are overruled in his/her own interest or for the protection of others, I am not sure.

Table 5.1^{1,2}

**Cross-tabulations
Policy Involvement with Legalization, the Dutch Model and Reporting a Colleague**

<i>Policy in VE</i>	<i>VE legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	772	80.3	94	9.8	95	9.9	961
No	83	39.5	91	43.3	36	17.1	210
Undecided	192	70.8	39	14.4	40	14.8	271
Total	1047	72.6	224	15.5	171	11.9	1442

<i>Policy in AS</i>	<i>AS legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	780	80.9	96	9.9	88	9.1	964
No	84	38.5	97	44.5	37	17.0	218
Undecided	195	72.2	38	14.1	37	13.7	270
Total	1047	72.6	224	15.5	171	11.9	1442

<i>Policy in VE</i>	<i>Dutch Model</i>						Total
	Yes	%	No	%	Und	%	
Yes	732	76.3	97	10.1	131	13.6	960
No	77	37.0	91	43.8	40	19.2	208
Undecided	191	69.5	36	13.1	48	17.5	275
Total	1000	69.3	224	15.5	219	15.2	1443

Table 5.1 Continued

<i>Policy in AS</i>	<i>Dutch Model</i>						
	Yes	%	No	%	Und	%	Total
Yes	725	75.4	100	10.4	136	14.2	961
No	88	42.3	84	40.4	44	21.1	208
Undecided	191	69.5	41	14.9	41	14.9	275
Total	1004	69.2	225	15.5	221	15.2	1450
<i>Policy in VE</i>	<i>report a colleague for VE</i>						
	Yes	%	No	%	Und	%	Total
Yes	221	23.4	321	33.9	404	42.7	946
No	101	49.5	40	19.6	63	30.9	204
Undecided	54	19.9	93	34.3	124	45.8	271
Total	376	26.5	454	31.9	591	41.6	1421
<i>Policy in AS</i>	<i>report a colleague for AS</i>						
	Yes	%	No	%	Und	%	Total
Yes	215	22.6	331	34.8	404	42.5	950
No	104	48.4	45	20.9	66	30.7	215
Undecided	51	18.9	98	36.3	121	44.8	270
Total	370	25.8	474	33.0	591	41.2	1435

1. Missing cases not included.
2. Und refers to undecided.
Columns may not total 100% due to rounding.

Table 5.2^{1,2}

**Cross-tabulations
Involvement in Decision-Making with Legalization,
the Dutch Model and Reporting a Colleague**

<i>Decision in VE</i>	<i>VE legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	574	79.6	92	12.8	55	7.6	721
No	106	43.3	92	37.6	47	19.2	245
Und	362	76.2	41	8.6	72	15.2	475
Total	1042	72.3	225	15.6	174	12.1	1441
<i>Decision in AS</i>	<i>AS legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	576	80.2	86	12.0	56	7.8	718
No	109	44.0	99	40.0	40	16.1	248
Und	367	76.8	43	9.0	68	14.2	478
Total	1052	72.9	228	15.8	164	11.4	1444
<i>Decision in VE</i>	<i>Dutch Model</i>						Total
	Yes	%	No	%	Und	%	
Yes	539	74.4	92	12.7	93	12.8	724
No	107	44.0	87	35.8	49	20.2	243
Und	353	74.2	44	9.2	79	16.6	476
Total	999	69.2	223	15.5	221	15.3	1443

Table 5.2 Continued

<i>Decision in AS</i>	<i>Dutch Model</i>						
	Yes	%	No	%	Und	%	Total
Yes	529	73.8	95	13.2	93	13.0	717
No	116	47.2	84	34.1	46	18.7	246
Und	354	73.8	44	9.2	82	17.1	480
Total	999	69.2	223	15.5	221	15.3	1443
<i>Decision in VE</i>	<i>report a colleague for VE</i>						
	Yes	%	No	%	Und	%	Total
Yes	179	25.3	244	34.5	285	40.3	708
No	102	42.3	65	27.0	74	30.7	241
Und	90	19.1	152	32.3	228	48.5	470
Total	371	26.1	461	32.5	587	41.4	1419
<i>Decision in AS</i>	<i>report a colleague for AS</i>						
	Yes	%	No	%	Und	%	Total
Yes	174	24.6	247	34.9	286	40.5	707
No	108	44.1	71	29.0	66	26.9	245
Und	84	17.6	160	33.6	232	48.7	476
Total	366	25.6	478	33.5	584	40.9	1428

1. Missing cases not included.
2. Und refers to undecided.
Columns may not total 100% due to rounding.

Assisted death and self-realization

Two variables were used to assess the effect of self-realization on attitudes toward assisted death: social worker's belief in self-realization and religious affiliation. Previous research on this topic has explored the concept of self-determination—a cornerstone of social work practice—and social workers' attitudes toward assisted death in North America. At the core, self-realization refers to the development of one's full potential. Whether self-realization and self-determination are similar concepts is debatable because the former places more constraints on personal achievements by recognizing the limitations of individuals due to social and economic barriers (BASW, 1996). Indeed, the choices individuals make are influenced by several factors, not the least of which include the quality of interpersonal relationships involving family and friends and socioeconomic status. While somewhat ambiguous, both concepts provide some measure of social workers' beliefs in client autonomy or, choice, and, as such, are treated the same here for comparative purposes. As predicted, Table 5.3 shows that most of the social workers who believe that self-realization should extend to VE agree that VE should be legal (867 or 96.3%). The same holds for social worker agreement with, and the legalization of AS (885 or 95.6%).

Social workers belief that self-realization extends to assisted death

A majority of social workers who believe self-realization extends to assisted death also support the Dutch model of assisted death (VE 829 or 92.0% and AS 822 or 88.8%). A minority of social workers who believe self-realization extends to assisted death would report a colleague (VE 160 or 18.1% and AS 154 or 16.8%). Although

small, this number suggests that not all social workers are willing to violate policy or legal prohibitions to assisted death. This conclusion may be erroneous as many social workers are undecided about reporting a colleague whom they suspect has been involved in an assisted death (VE 368 or 41.6% and AS 390 or 42.4%).

For some social workers, the concept of self-realization is problematic because the profession lacks guidelines about how it is to be achieved and because it interferes with practical considerations of social work. A social worker from England observed,

Self-realization is a vague concept and has to take into account that most people are not alone in this world and a decision of this magnitude may have far-reaching effects on family and friends. Nevertheless it is right to look at ways to alleviate suffering, both for patients and for carers, some of whom find themselves torn between doing what is legal and what is right.

Other social workers cautioned that self-realization could be used inappropriately with vulnerable persons. In the words of a social worker from Northern Ireland,

On the whole this issue suffers from many other factors impinging upon it. People with learning difficulties for example and their understanding of all the facts. The elderly [are] confused also. Some people need to be protected more than others and therefore within that the...of self-realisation gets blurred somewhat.

Another social worker from Wales commented,

I feel comfortable with the concept of assisted suicide but less so with voluntary euthanasia because of the involvement of, at the point of administering, i.e. a fatal injection, of a third party. I fear this is open to abuse and my experiences of the prescriptiveness of medical practitioners and lack of awareness of rights to self-realisation cause me to fear influence by the medical profession where death may be in their interest [i.e.] shortage of beds; cost of keeping someone alive.

Other social workers noted the conflict between their own value systems and self-realization. According to an English social worker,

The difficulty in answering the questions relates to my own value of preserving life, at the same time an individual should have self-realisation. It is a conflict I

do not feel I am able to resolve. This is why I feel that nobody is qualified to make decisions of this kind because [their] own values influence the situation.

Personal value systems based on religion also come into play with self-realization. A social worker from Scotland observed,

I totally disagree with the idea of euthanasia or assisted suicide, from my deeply held Christian views. My problem arises where professionally I am committed to [a] client's self-realisation and self-determination but personally I am totally opposed to the taking or assisting in taking away a human life. This problem exists in the area of abortion also where there can be a conflict of personal and professional values.

Religious beliefs and support for assisted death

Belief in God and attitudes toward assisted death can vary depending on the religion in question and the level of commitment held by individuals. Religion is often associated with negative attitudes toward VE and AS, as the Scottish social worker above describes. Figures 5.11- 5.15 show that, compared to other religions, Protestants and Catholics are more opposed to the legalization of assisted death: Protestant (VE 155 or 22.7% and AS 152 or 22.2%), Catholic (VE 43 or 24.8% and AS 44 or 25.3%).

However, a significant number of both agree that assisted death should be legalized: Protestant (VE 434 or 63.5% and AS 451 or 65.7%), Catholic (VE 103 or 59.5% and AS 98 or 56.3%).

An overwhelming majority of non-Protestant and non-Catholic social workers supported the Dutch model of assisted death. Compared to their Protestant counterparts, Catholic social workers were slightly more opposed (Catholic 44 or 25.3% and Protestant 150 or 21.9%). The majority of other social workers were reluctant to report a colleague whom they suspected of being involved in assisted death. Protestants were almost equally split with the decision to report VE (212 or 31.2%) and AS (206 or 30.2%).

Protestants were almost identical regarding the decision not to report VE (206 or 30.3%) and AS (206 or 30.2%), with a significant number undecided (262 or 38.5%). Catholics were more likely to report VE (58 or 34.7%) and AS (61 or 35.5%) than not report (VE 38 or 22.8% and AS 42 or 24.4%). The findings regarding the decision to report should be treated cautiously as many social workers from several religions were undecided about the decision to report a colleague. The decision to report is influenced by several factors, not the least of which is the obligation to respect client self-realization, a point noted by the Scottish social worker above. A social worker from England observed,

As a social worker I adhere to having values of service users and do not feel I have the right to play God with them. My religion opposes euthanasia and I would struggle with my faith to end my life. Over many years I have seen patients in hospice and their families and I thought I could not put my family through this. Once I knew I would discuss it logically with them I feel sure they would respect my wishes to die with dignity.

For other social workers, the decision to end life cements professional hegemony (Freidson, 1986) in life and death matters, particularly bio-medical dominance. For an English social worker, decision-making around end-of-life this should be a shared process.

The burden of involvement must be shared among the range of professionals who may be participating (as may be set out in guidance) e.g. medical, legal, social work, religion – so that no one individual has sole responsibility.

One social worker from England agonized over the issue of religious beliefs and assisted death.

I cannot agree with making either euthanasia or assisted suicide legal. I just can't. I've thought about this for weeks before responding... whilst I am not religious, I do not subscribe to organised religion, I have deeply held spiritual beliefs and the right of all to live until it is their natural time to die.

Summary: assisted death and self-realization

Clearly, self-realization and religion interact to influence social workers' attitudes toward assisted death. Dominant religions in the U.K. appear less accepting of VE and AS (see Collange, 2003; Religious Tolerance.org, n.d.). Yet, in contrast to the hypothesis that religion predicts practice, social workers do not always adhere to religious tenets because they advocate for or at least respect their client's rights to self-realization. In doing so, they are willing to set aside religious beliefs for professional codes of conduct. Not surprisingly, the hypothesis that social workers who support client self-realization are more accepting of assisted death was confirmed.

Table 5.3^{1,2}

Cross-tabulations
Self-Realization with Legalization, the Dutch Model and Reporting a Colleague

Self-realization VE VE legal

	Yes	%	No	%	Und	%	Total
Yes	867	96.3	13	1.4	20	2.2	900
No	32	13.3	185	76.8	24	9.9	241
Und	136	47.2	27	9.4	125	43.4	288
Total	1035	72.4	225	15.7	169	11.8	1429

Self-realization AS AS legal

	Yes	%	No	%	Und	%	Total
Yes	885	95.6	12	1.3	29	3.1	926
No	22	9.5	191	82.3	19	8.2	232
Und	143	50.7	30	10.6	109	38.7	282
Total	1050	72.9	233	16.2	157	10.9	1440

Self-realization VE Dutch Model

	Yes	%	No	%	Und	%	Total
Yes	829	92.0	16	1.8	56	6.2	901
No	32	1.3	176	73.3	32	13.3	240
Und	129	44.6	35	12.1	125	43.3	289
Total	990	69.2	227	15.9	213	14.9	1430

Self-realization AS Dutch Model

	Yes	%	No	%	Und	%	Total
Yes	822	88.8	24	2.6	80	8.6	926
No	40	17.4	160	69.6	30	13.0	230
Und	133	47.3	44	15.7	104	37.0	281
Total	995	69.2	228	15.9	214	14.9	1437

Table 5.3 Continued

Self-realization VE report a colleague for VE

	Yes	%	No	%	Und	%	Total
Yes	160	18.1	357	40.3	368	41.6	885
No	136	57.6	41	17.4	59	25.0	236
Und	77	26.7	56	19.4	155	53.8	288
Total	373	26.5	454	32.2	582	41.3	1409

Self-realization AS report a colleague for AS

	Yes	%	No	%	Und	%	Total
Yes	154	16.8	375	40.8	390	42.4	919
No	138	60.1	39	17.2	50	22.0	227
Und	78	27.9	60	21.4	142	50.7	280
Total	370	25.9	474	33.2	582	40.8	1426

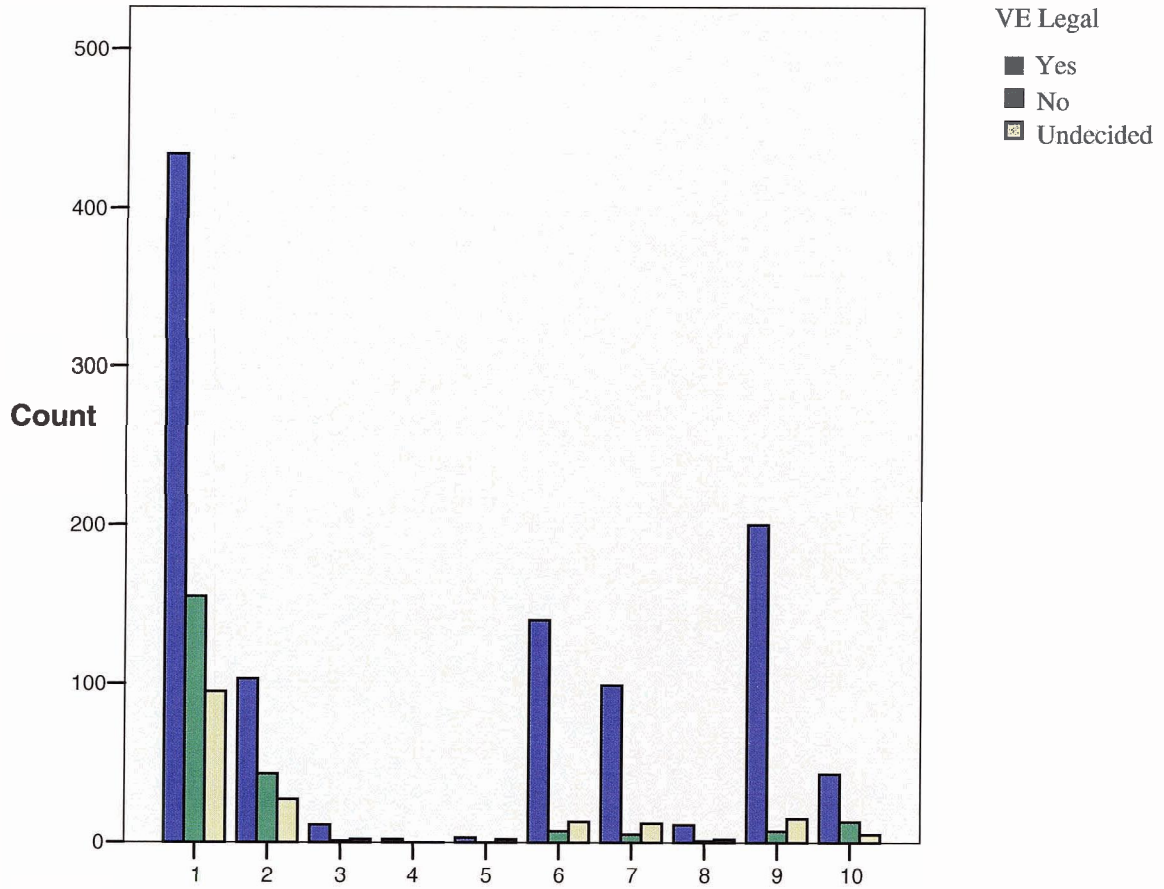
1. Missing cases not included.

2. Und refers to undecided.

Columns may not total 100% due to rounding.

Figure 5.11

Social workers' support for euthanasia and religion

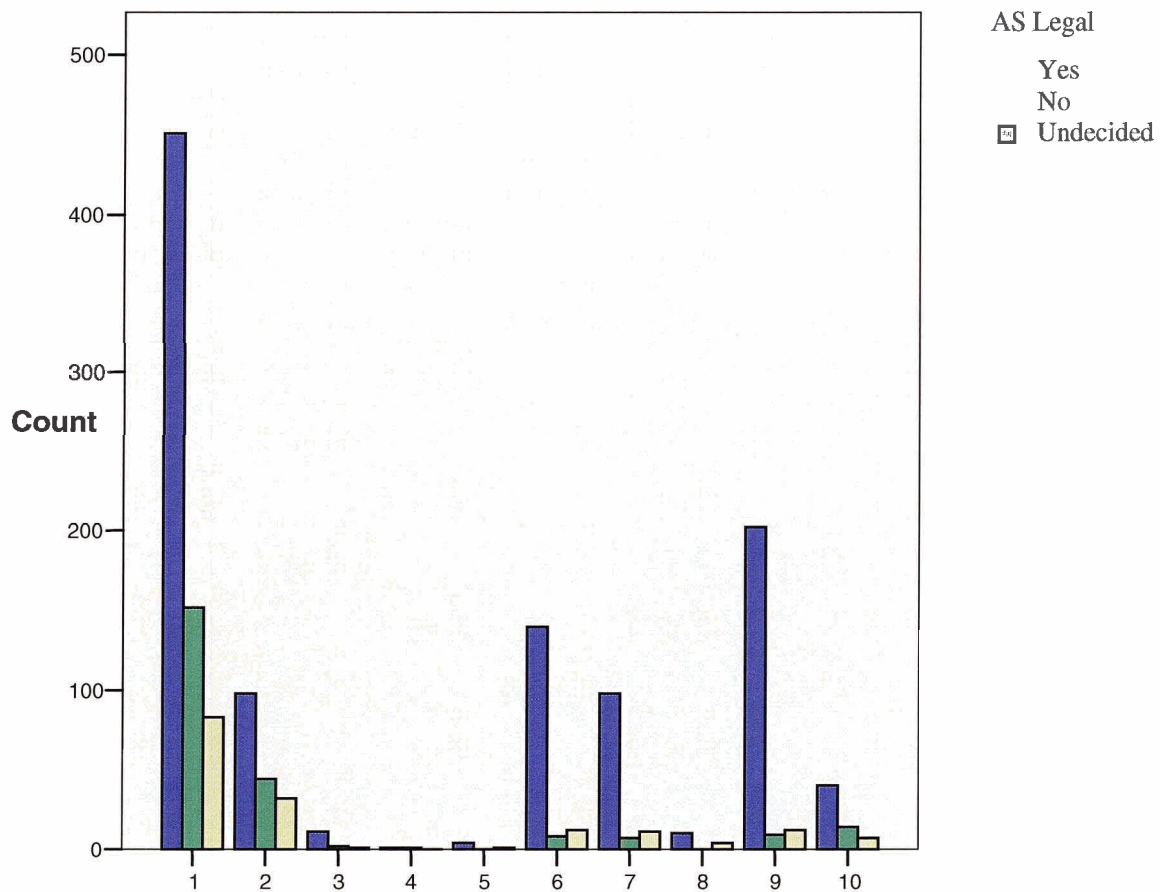


Religion

1. Protestant
2. Roman Catholic
3. Jewish
4. Islam
5. Hindu
6. Agnostic
7. Atheist
8. Buddhist
9. Not Applicable
10. Other

Figure 5.12

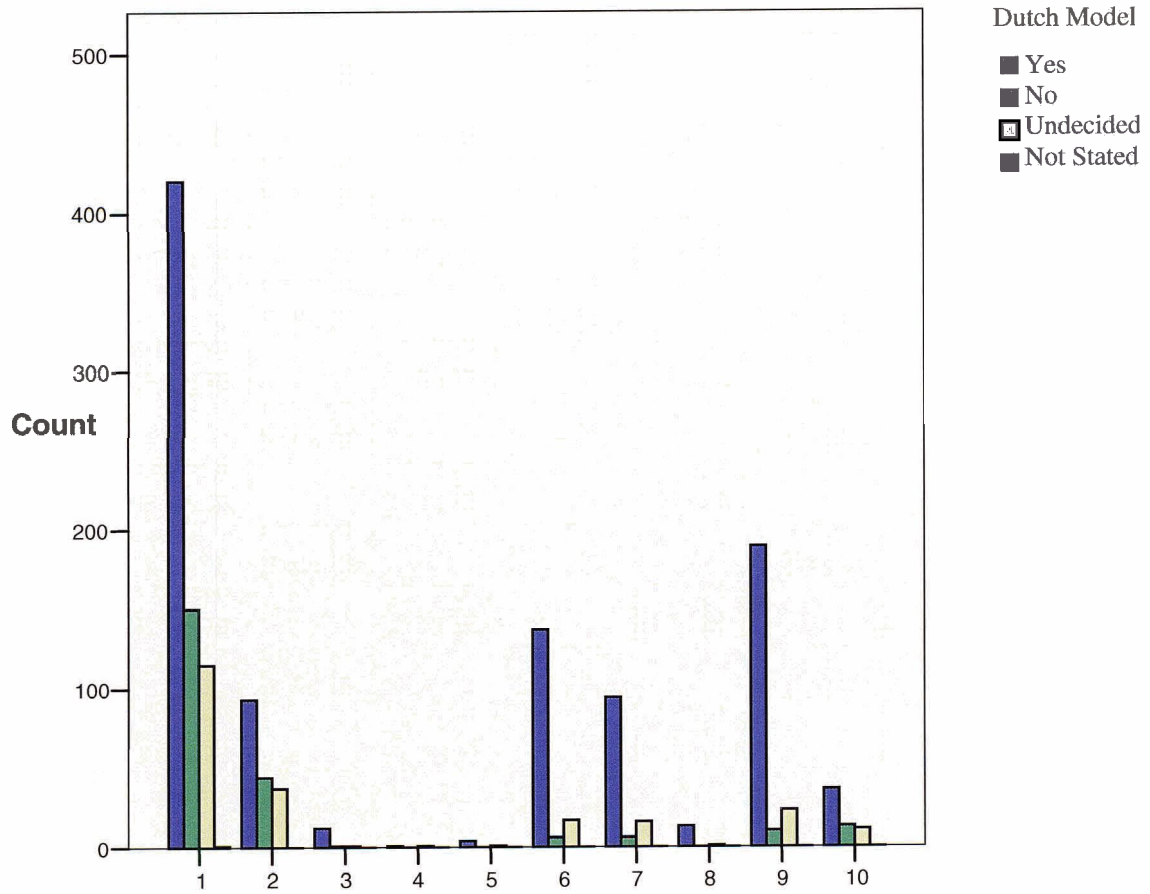
Social workers' support for assisted suicide and religion



Religion

1. Protestant
2. Roman Catholic
3. Jewish
4. Islam
5. Hindu
6. Agnostic
7. Atheist
8. Buddhist
9. Not Applicable
10. Other

Figure 5.13
Social workers' support for Dutch Model and religion

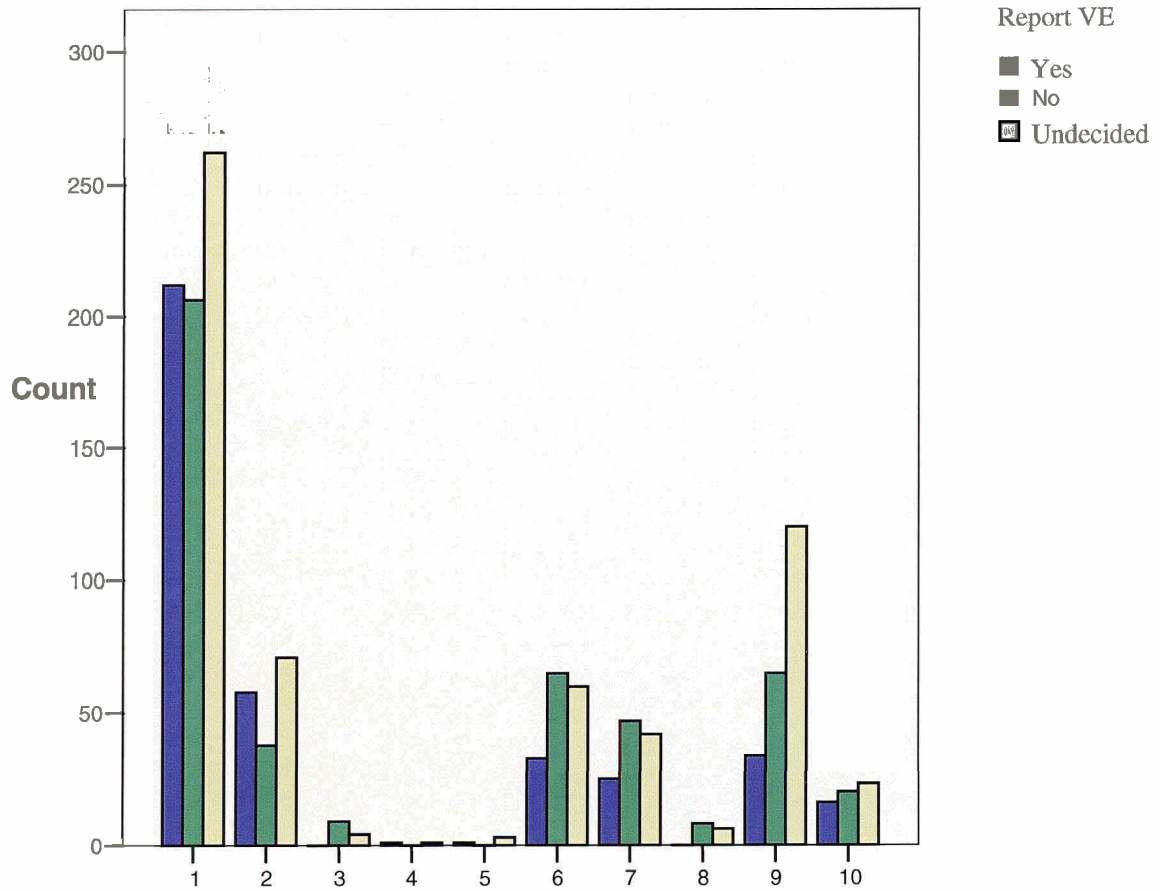


Religion

1. Protestant
2. Roman Catholic
3. Jewish
4. Islam
5. Hindu
6. Agnostic
7. Atheist
8. Buddhist
9. Not Applicable
10. Other

Figure 5.14

Social workers' decision to report a colleague for euthanasia and religion

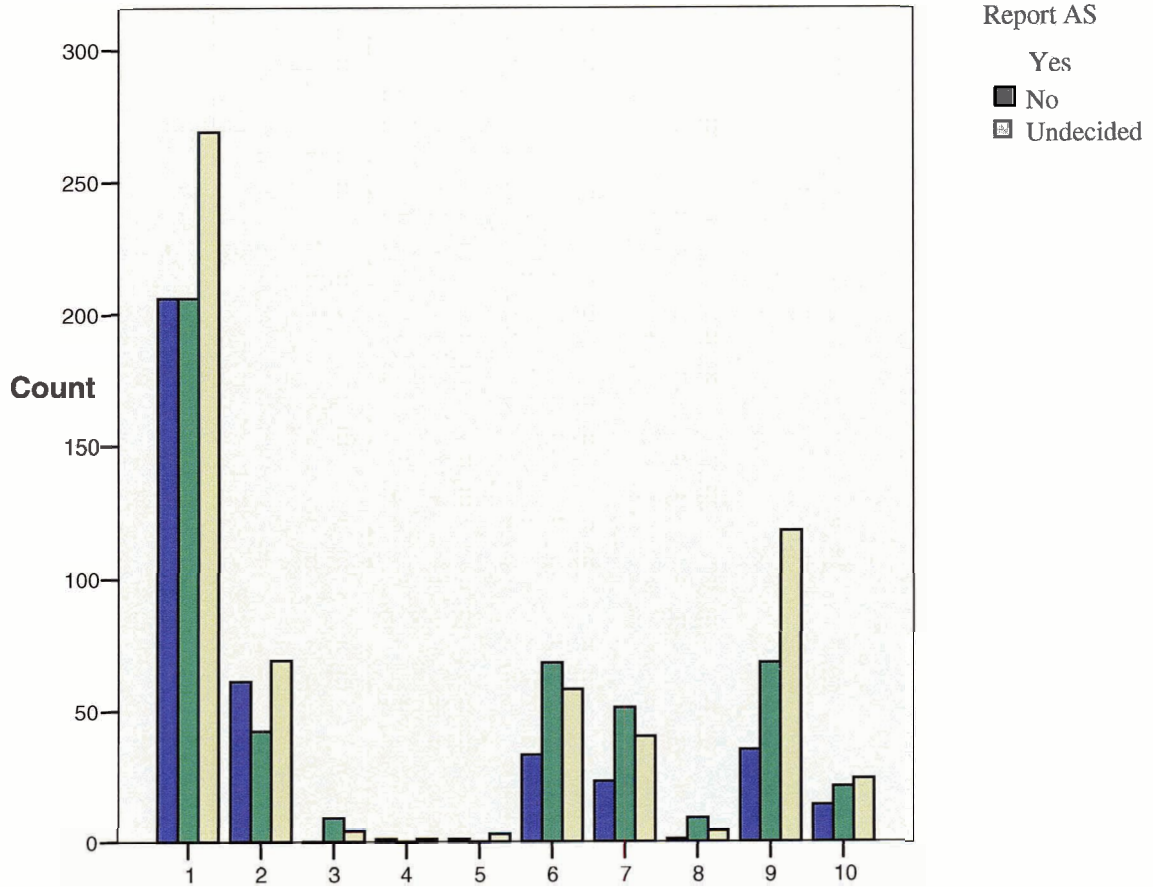


Religion

1. Protestant
2. Roman Catholic
3. Jewish
4. Islam
5. Hindu
6. Agnostic
7. Atheist
8. Buddhist
9. Not Applicable
10. Other

Figure 5.15

Social workers' decision to report a colleague for assisted suicide and religion



Religion

1. Protestant
2. Roman Catholic
3. Jewish
4. Islam
5. Hindu
6. Agnostic
7. Atheist
8. Buddhist
9. Not Applicable
10. Other

Assisted death and experience

Whether it involves friends or family members of clients, experience dealing with people at end-of-life is thought to affect attitudes toward assisted death because it sensitizes social workers to the issues associated with death and dying. From a humanistic perspective, social workers may support VE and/or AS for terminally ill patients in great physical pain. Unnecessary suffering is considered abusive and of little value. On the other hand, social workers who believe that all human life is precious or the dominion of God may not endorse a patient's assisted death, regardless of the quality of life experienced by their patients (Csikai, 1999a). Two variables were used to determine social workers' experiences and attitudes toward assisted death: whether social workers had to deal with VE and/or AS in their personal lives (personal experience) and whether they had been consulted regarding VE and/or AS in their professional lives.

Personal experience and assisted death

Table 5.4 shows that most social workers with personal experience with someone dying support legalization (VE 112 or 81.8% and AS 91 or 77.8%). Likewise, support for the Dutch model among social workers with personal experience was high (VE 106 or 76.8% and AS 85 or 73.3%). A minority of social workers with personal experience indicated that they would report a colleague for VE (37 or 27.4%) or AS (37 or 32.2%). The remaining social workers were either unwilling or uncertain if they would report, which implies that any conclusions derived from this analysis should be treated tentatively.

As predicted, Table 5.5 reveals that most social workers who were consulted about assisted death also support legalization of VE (157 or 73.0%) and AS (141 or 71.9%). Support for the Dutch model from social workers who have been consulted was also high (VE 150 or 70.4% and AS 138 or 70.8%). With regard to reporting a colleague for suspected involvement in an assisted death, most social workers were either unwilling to report or undecided (VE 158 or 75.6% and AS 142 or 73.9%). Only 51 (24.4%) of social workers were willing to report for VE and 50 (26.0%) were willing to report for AS. Like the other analyses involving a high percentage of undecided responses, conclusions based on these findings should be treated cautiously.

Whether they support VE or AS, the written comments provided by social workers reveal concern for a dignified death. A social worker from England emphasized how at end-of-life procedures can be profoundly important for the dying person and others.

My response is conditioned by my personal experience of the death of my Father some years ago from cancer. He died a very undignified death at home in extreme distress and pain. The medical care and response to his plight were totally inadequate and incompetent and as a result he suffered enormously and unnecessarily. In my view euthanasia would have been a merciful and welcomed release from this suffering – in many ways I regret that I did not have the courage to intervene myself.

An English social worker emphasized that the right of choice extends to loved ones and other clients.

My terminally ill son died from a brain haemorrhage but I have evidence to suggest that the brain haemorrhage was caused by an overdose of morphine which he took himself and [he] was helped by a member of the nursing staff. I have not reported this evidence because it was my son's wish to die and I am pleased that he died free from pain. These personal experiences have a bearing on my professional judgement and opinion and I feel that all human beings should be able to make decisions about their own deaths and that persons aiding them should not be convicted for doing this. We professionals should respect the wishes of people in our care.

Other English social workers made similar comments about the impact of lived experience on their beliefs regarding death and palliative care. One social worker stated:

A personal family experience taught me that it would be more appropriate and moral for both options particularly the assisted suicide method to be considered with patients prior to becoming incapably ill to avoid a possible chaotic and painful method [of death] by use of syringe drivers, morphine etc. time lapses and incompetent GPs managing the end crisis at the patient's home – (with inadequate back up). This contributed considerably to the distress felt by the patient. Even if all had gone well the present methods are not sufficient to alleviate pain and unbearable psychological stress felt by the person that is dying and therefore (sometimes) seems cruel and barbaric.

Another social worker similarly commented,

...I worked for five years in an oncology unit. I witnessed death many times and was sad to observe that on far too many occasions doctors would prolong someone's life even when they were in extreme pain and they knew they would not survive...It was also not unusual for patients to continue to be given chemotherapy treatment up to the day of the patient's death. There was no dignity, no honesty with the patient about the reality of how near death was and for the relatives too often last memories of loved ones sickness and pain.

Finally, recounting several experiences, a social worker from England expressed concern about the balance between prolonging life and invasive treatment.

My mother would have welcomed death a lot earlier, than the time it came to her. All her life she was a very active human. At 82 years she suffered a severe stroke. From that time until her death 1 year later she could no longer walk or talk. From her attitude and apathy it was very clear she would welcome death...My stepfather remained deeply unconscious following an extensive abdominal operation at the age of 76 years. The surgeon stated even if he recovered consciousness his quality of life would be very poor. Despite this he was resuscitated twice when his heart failed. After consultation with the surgeon, he accepted he should make it known to the I.T. [intensive treatment] staff this was not to happen again...If I had been given the prognosis, and discussion with an informed person re their quality of life, I would probably have agreed to euthanasia...Maybe I did, and I certainly asked the surgeon to listen to what my stepfather's body was saying and not resuscitate further...My daughter aged 15 years suffered a severe head injury following a riding accident. She was

unconscious for a considerable time. She went on to make a full recovery and is now four times a mother. This bodes the need for caution...Very often, social workers are pressured by health professionals into acting to keep a person safe and well, when the person concerned wants to be left alone, whatever the consequences...They should be allowed to choose to stay at home and die with dignity.

For some social workers, adequate pain management through palliative care is sufficient for a dignified death. A Scottish social worker observed,

In my experience of working in hospital and witnessing the deaths of patients, and [seeing] my father suffering from cancer I have yet to see people being allowed to suffer 'unbearable pain'. Modern methods do allow people to die comfortably.

An English social worker recounted:

I have witnessed 3 members of my immediate family [die], 2 from painful cancers. I was also involved in nursing them. We were fortunate to experience excellent palliative care which made the slow death dignified and self-realising. I believe that in the vast majority of circumstances avoiding active intervention (anti-biotics etc.) and highly skilled pain control can make most terminal illness bearable.

A social worker from Northern Ireland summarily stated,

I have been present at a number of deaths and have been part of a team to ensure a peaceful and painful death...We have now sufficient knowledge and expertise about pain control to ensure pain free or [a] pain controlled death...to adjust to death by offering pastoral care, opportunities in counselling, time to review life, carry out wishes etc. are very important and effective...I see assisted suicide or euthanasia as a "disposable" "quick fix" remedy which does not enable a patient to have peace within himself or enable the family/carer time to adjust to the process which aids grieving.

In contrast, the experience of another social worker from Northern Ireland contradicted the palliative care approach.

It would have to be the most extreme situation before I would feel able to assist in a patient's suicide. Having said that, I watched my mother-in-law die in agony from cancer and I was greatly relieved when the doctor gave her a dose of

morphine “for pain” which I know hastened her inevitable death. I feel that he did us, the family, as well as the patient, a great kindness.

Another social worker from England agreed and noted,

...I know I am influenced by the current status quo [to prolong life]. However, I bring to this questionnaire the experience of my mother’s death last year when she had a long lingering death and I know that if I had had the means at my disposal and it was practicably possible I would more than likely have assisted in ending her life as it had become so utterly degrading.

The written comments also highlight the strain experienced by caregivers and the need to help family and friends with the dying process. A social worker from Scotland noted:

As the manager of a Carers’ Centre I am only too aware of the burden of caring but I do feel that individuals and families can find untapped resources within themselves, with support, to cope. It is the social workers’ task to help them find these resources and to offer and create support.

Another English social worker highlighted the tension between extending life and medical abuse in the form of heroic measures and the use of technology for technologies’ sake.

There has to be some balance between a dignified death and the technological advances we have made in medicine. Now there that is the ability to keep people alive almost indefinitely I cannot believe that this is what most people want – certainly in general conversation with clients, the idea of a ‘time to go’ and a ‘proper ending’ are still strong beliefs.

Being consulted regarding assisted death

Several social workers answering the survey indicated that they had been consulted about VE and AS, but few made any reference to assisted death in the written comments. With respect to patient choice, an English social worker stated,

...I have not been consulted – clients have discussed this with me. Views vary and some are against intervention of this type in any circumstances. Many however would welcome the right to choose and should be permitted this.
(Emphasis original)

Writing about being consulted in her personal life, the experience of a Scottish social worker summarize the issues associated with caring for a dying loved one or patient: support, dignity, palliative care, and choice.

In the course of my professional life – until 3 years ago – I have never been consulted on assisted suicide or voluntary euthanasia. My views...have, however, been held by me for the past 40 years. They have been confirmed personally by my father's death 2 years ago this month. Having, over the period of 17 years, twice had successful treatment for carcinoma of the larynx and mouth, he elected to have no further treatment when diagnosed for the third time 2½ years ago, to have carcinoma of the larynx. He asked me to provide him with the necessary information [on] voluntary euthanasia. What was available to me seemed little and unsatisfactory. He would have been greatly reassured to have had a clear and legal choice to end his life should he so have decided.

In the event, good palliative care by his GP, allowed him to survive completely pain free and in full command of his faculties until his death – in his sleep; he was fortunate in this but [he] dreaded helplessness and pain. To have been in a position to control his last days in dignity – as he was lucky enough to be able to do, and in his own home – would have made contemplating death easier for him. It would also have been easier for his family to know that a man who had decided to allow his illness to take its course, could make final decisions by himself about his own person, on his own terms. I would wish no less for myself or any other member of my family. Counselling and support from the MacMillan nurses was invaluable – once he accepted it – social workers might well be able to provide a similar service (but I think additional training could be required!).

Summary: assisted death and experience

According to the survey results, a small portion of social workers indicated personal experience or being consulted for VE or AS. As predicted, of those with experience, most support legalization of VE and AS. As well, support for the Dutch model of assisted death among this group is high. Very few are likely to report a

colleague for being involved in VE or AS. Several social workers made reference to the necessity of honesty with dying patients and the provision of options to ease the dying process. The comments of a social worker from Northern Ireland illustrate this point.

Before working in social work, I worked in a hospital, I saw and observed patients dying a slow painful death on more than one occasion. I have always felt if a person wants to know all the facts about their medical condition and decide to die by euthanasia or assisted suicide, they should be allowed to do so. I also feel I would consider dying by euthanasia or assisted suicide in the event of having a terminal or incurable illness.

These comments are echoed by an English social worker who wrote,

[m]y work was individual and group counselling with patients. Although very ill if the choice had been theirs some would have opted for assisted suicide. Obviously others fought to the end and would never have considered it...Although practice within hospitals is improving, the aggressive model of treatment even in the terminal stage still continues. I believe strongly that honesty is imperative – a true choice for patients on their death and manner of IT should be legally considered.

Table 5.4^{1,2}

Cross-tabulations

Personal Experience with Legalization, the Dutch Model and Reporting a Colleague

<i>Experience in VE</i>		<i>VE legal</i>						
		Yes	%	No	%	Und	%	Total
Yes		112	81.7	17	12.4	8	5.8	137
No		911	70.9	211	16.4	150	11.7	1284
Und		18	64.3	3	10.7	7	25.0	28
Total		1041	72.0	231	16.0	174	12.0	1446
<i>Experience in AS</i>		<i>AS legal</i>						
		Yes	%	No	%	Und	%	Total
Yes		91	78.0	17	14.5	9	7.7	117
No		942	72.1	216	16.5	149	11.4	1307
Und		18	1.2	235	16.2	164	11.3	1450
Total		1052	72.9	228	15.8	164	11.4	1444
<i>Experience in VE</i>		<i>Dutch Model</i>						
		Yes	%	No	%	Und	%	Total
Yes		106	76.8	19	13.8	13	9.4	138
No		872	68.0	209	16.3	201	15.7	1282
Und		16	57.1	2	7.1	10	35.7	28
Total		994	68.6	230	15.9	224	15.5	1448
<i>Experience in AS</i>		<i>Dutch Model</i>						
		Yes	%	No	%	Und	%	Total
Yes		85	73.3	21	18.1	10	8.6	116
No		894	68.4	208	15.9	204	15.6	1306
Und		16	61.5	1	3.8	9	34.6	26
Total		995	68.7	230	15.9	223	15.4	1448

Table 5.4 Continued

<i>Experience in VE</i>	<i>report a colleague for VE</i>						
	Yes	%	No	%	Und	%	Total
Yes	37	27.4	50	37.0	48	35.5	135
No	336	26.6	339	26.9	527	41.8	1262
Und	6	21.4	7	25.0	15	53.6	28
Total	379	26.6	456	32.0	590	41.4	1425

<i>Experience in AS</i>	<i>report a colleague for AS</i>						
	Yes	%	No	%	Und	%	Total
Yes	37	32.2	48	41.7	30	26.1	115
No	331	25.6	421	32.6	541	41.8	1293
Und	3	11.5	10	38.5	13	50.0	26
Total	371	25.9	479	33.4	584	40.7	1434

1. Missing cases not included.

2. Und refers to undecided.

Columns may not total 100% due to rounding.

Table 5.5^{1,2}

**Cross-tabulations
Being Consulted with Legalization, the Dutch Model and Reporting a Colleague**

<i>Consulted VE</i>	<i>VE legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	157	73.0	38	17.7	20	9.3	215
No	874	71.8	191	15.7	152	12.5	1217
Und	17	85.0	1	5.0	2	10.0	20
Total	1048	72.2	230	15.8	174	12.0	1452
<i>Consulted AS</i>	<i>AS legal</i>						Total
	Yes	%	No	%	Und	%	
Yes	141	71.9	36	18.4	19	9.7	196
No	900	72.7	197	15.9	141	11.4	1238
Und	18	78.3	1	4.3	4	17.4	23
Total	1059	72.7	234	16.1	164	11.2	1457
<i>Consulted VE</i>	<i>Dutch Model</i>						Total
	Yes	%	No	%	Und	%	
Yes	150	70.4	37	17.4	26	12.2	213
No	837	68.7	189	15.5	192	15.8	1218
Und	14	66.7	2	9.5	5	23.8	21
Total	1001	68.9	228	15.7	223	15.4	1452
<i>Consulted AS</i>	<i>Dutch Model</i>						Total
	Yes	%	No	%	Und	%	
Yes	138	70.8	30	15.4	27	13.8	195
No	849	68.7	196	15.9	191	15.5	1236
Und	16	69.6	2	8.7	5	21.7	23
Total	1003	69.0	228	15.7	223	15.3	1454

Table 5.5 Continued

<i>Consulted VE</i>	<i>report a colleague for VE</i>						
	Yes	%	No	%	Und	%	Total
Yes	51	24.4	82	39.2	76	36.4	209
No	323	26.9	372	31.0	505	42.1	1200
Und	2	10.0	4	20.0	14	70.0	20
Total	376	26.3	458	32.1	595	41.6	1429

<i>Consulted AS</i>	<i>report a colleague for AS</i>						
	Yes	%	No	%	Und	%	Total
Yes	50	26.0	71	37.0	71	37.0	192
No	321	26.2	401	32.7	504	41.1	1226
Und	1	4.5	4	18.2	17	77.3	22
Total	372	25.8	476	33.1	592	41.1	1440

1. Missing cases not included.

2. Und refers to undecided.

Columns may not total 100% due to rounding.

The effect of relationships on social workers' attitudes toward assisted death

Whether it involved physicians, clients' relatives, or their own family, in most cases social workers' relationships had a profound impact on their attitudes toward VE, AS, and end-of-life. Notably, the treatment of respondents' relatives was often used by social workers to discuss concerns related to assisted death. These concerns centred on respect for the dignity of dying persons and ensuring that adequate care is provided, but not to prolong life to the point where it harms to the patient. The comments of a social worker from England exemplify this concern.

I feel euthanasia and suicide (assisted or otherwise) should be one of a range of solutions to an insolvable [sic] and physically/mentally degrading/painful problem. I do not feel either of these are solutions to social or psychological problems, palliative care and...TLC [tender loving care] have their place in care of the dying, but in a few cases there is distress and loss of dignity for all involved – patients, carers, families, friends, “professionals”/volunteers and so on...The way of dying in most hospitals is one of pain, confusion, loneliness, aloneness, degradation...and downright horror.

The issues of abuse and exploitation, as they apply to VE and AS, were raised by many social workers. A social worker from England wrote:

I have heard that, what I consider to be reliable information, that the Dutch system is abused and that the safeguards are not always observed. Shortcuts are made. I consider that, if legalised, many vulnerable, sick, elderly people would feel obliged to consider euthanasia or assisted suicide.

As well, the competing interests of patient self-realization and protecting persons at risk from abuse were made apparent by another English social worker who said:

Social workers have a duty both to further...the client's right to self determination but also to protect vulnerable members of society, sometimes with the use of statutory powers. There can also be conflicts of interest involved, e.g. burden of caring on the family; financial costs of care on Health and Social Services.

With the exception of reference to the Dutch model, however, not one social worker documented personal experiences suggesting that VE or AS *were* being practiced in such a way that was abusive or exploitive. Fear of the slippery slope of assisted death was the most prevalent comment made, but examples of this phenomenon were not presented. The dominant theme emerging from social workers' comments on the role of physicians, and indeed medicine generally, was the double effect of managed pain control and hastened death. As a social worker from England documented:

In both work and family situations I have known occasions when Doctors have either given or withdrawn treatment, in so doing easing pain and hastening death (the "double effect"). In my experience I have not found them willing deliberately to administer or to provide the means specifically to bring about death. I have also known and worked with many situations e.g. in the Hospice movement where pain relief and palliative care have helped patients and their families approach death without euthanasia or assisted suicide.

Regarding experience with physicians, a social worker from Scotland recounted suspicious cases involving intravenous drug users (IDU). Although opposed to VE and AS, this social worker accepted the potential double effect of medication.

Most of my experience with people who have contemplated euthanasia was incurred while working with people with AIDS. Almost without exception they expressed the view that they would end their own lives before 'things got too bad'. Many were heroin users and knew only too well how to do this – for themselves – Of those who became terminally ill and subsequently died – none carried out their intention despite appalling suffering and loss of all independence. By then they had grown to trust the staff and we had grown to love them. The suffering was often terrible and mistakes in care were made which sometimes made things worse. I cannot be sure that death was not hastened by the physicians but, if it was, it will have been at that point where the level of medication required to alleviate suffering is actually a fatal dose which the doctor chooses to administer. I am sure that this [alleviation of suffering] was the case with my own father for which I am truly grateful.

Similarly, an English social worker indicated support for VE by documenting personal experiences involving the hastened death of her husband through the double effect.

I find that my answers have been strongly influenced by my experience of my husband's death from cancer 7 years ago. He was clear that he might reach a point where his suffering was unbearable, and told his GP that he had no wish in these circumstances for any attempt to be made to keep him alive. I was also clear that he did not want to suffer unduly. When, some hours before he died, the pain was clearly very bad, I had no hesitation in insisting that the nursing staff in the cottage hospital where there was no resident doctor, phoned his GP, who authorised a further dose of morphine, which I think probably ended his life as well as relieving pain. I might previously have been more unsure about some of my answers in this survey. However, having been so sure when faced with the situation I have described, I have answered accordingly.

Although not involving VE or AS, a social worker from England noted that the decision to hasten death by withholding treatment to a terminally ill child was the correct course of action.

I was actively involved in lengthy discussions with parents of a terminally ill 8 year old as to whether they should continue to revive him following repeated heart attacks – both were nurses, and were nursing the child at home. Following increased suffering [of their son], and following discussions with their GP in which I was also involved, they made a decision not to administer oxygen following his next severe heart attack. He died peacefully in the arms of his parents. The doctor issued a death certificate stating death was due to heart failure. This situation caused great anxiety and soul-searching on the part of all concerned – but with hindsight I am convinced it was the 'right' decision.

On the advice of a physician to increase the dosage of medication, another English social worker noted the double effect of medication on hastening death and implicit approval of VE.

My mother, when aged 72, was terminally ill with cancer...Despite diamorphine she was in a lot of pain. The day before she died she felt nauseous. Her doctor advised that to deal with that, she would have to be asleep and it was not likely she would come round. My sister and I agreed and sat with her. My mother agreed to this. She died early the next day, with my sister and I still sat with her on her bed...I don't think it was euthanasia, though we knew she wouldn't come round, but it was similar. Until three days before her death she was up and about. 1 week before she died we took her out for the day – in a wheelchair, all wrapped up. She was able to say goodbye to all her grandchildren, her sister and her daughters and son in law...She died in her own bed, in my sister's home. It struck me as civilized and dignified, we made her last weekend "special"...It was

important to my family that we treated this situation in a way that we all felt comfortable with. My mother was scared of dying when the cancer was diagnosed but not at the end. She asked not to be left alone and she wasn't. Her last meal was a piece of cake – her choice.

Regarding clients' relatives, social workers' attitudes toward assisted death were shaped by the tension between sanctity of life and the desire to end suffering. Referring to the double effect, a social worker from England concluded that assisted death was a positive option in some cases.

My father was nursed by my mother and I for several months and at one point we were given a dose of morphine to give him if we felt he needed it. He was in the final stages of heart failure and I often wonder whether we would have been helping him on his way if we had given it to him at that time...I feel that there are...instances with those with progressive illnesses where it would be nice to be able to work with a doctor and give them reassurance that death could be peaceful and comfortable rather than a frightening process...

While not endorsing assisted death, other social workers commented that current methods of palliative care made patients' last days more comfortable. In addition, an English social worker commented that social attitudes toward the dying needed to change so that dying should not be considered undignified.

...there is... enormous need for a change in attitudes which recognises that major and increasing impairment does not necessarily mean a diminishment of 'self' – it can lead to expansion – also that helplessness and dependency are not states to be ashamed of or 'undignified' etc.

On the other hand, a social worker from Wales noted that improvements to palliative care options were needed.

A member of my family suffered a long, terminal illness. What I personally learnt from this experience was that to the very end life is very precious and it is not for people to decide when it ends. Much of the onus to administer powerful medication is placed on the family members when a patient is still at home...Pain is often not effectively controlled. There is a shortage of hospice care and the home hospice service struggles to deal with the shortfall...we as a society should

deal first with palliative care for [the] terminally ill patient before we get into the realms of legalising euthanasia or assisted suicide.

This social worker's comments highlight the political economy of health where death and dying are subject to market considerations and not just humanistic ones (Light & Levine, 1988).

Other social workers indicated support for, and the obligation to provide, assisted death. As a social worker from Scotland observed, medicalized death is often impersonal and potentially paternalistic and demeaning. Referring to the study of dying—thanatology—(Kübler-Ross, 1975), this social worker had

...been involved with the deaths of a considerable number of close friends and family members over the last nine years. I have always come to the conclusion that it is our last responsibility to the person to help them die. And that often in our society the pressure or expectation is that we walk away and leave it “to medicine and technology” and strangers...In all the circumstances I have been in the need has been to provide care and support to the dying and to accept this is the time to allow death to occur. Only a few weeks ago the responsibility fell to me and my whole family concerning the care of my father who was unconscious. We agreed to remove all supports keeping him alive as a result of which he died quickly – within hours. (emphasis in original)

Acting according to conscience, another Scottish social worker recounted a personal experience involving assisted death. This social worker had

...been directly involved in administering diamorphine by pump, releasing extra doses which hastened the death of my mother who was in the final stages of cancer and who was suffering. My mother died relatively comfortably, with family at home, as was her wish...This circumstance was controlled by myself and sister whose primary and overriding concern was for our mother.

Summary: The effect of relationships on Social workers' attitudes toward assisted death

Whether their relationships led them to accept or reject assisted death, it is clear that social workers in the U.K. advocate dignity in death and dying. Those opposed to

legalizing VE or AS frequently documented concern about abuse, such as involuntary euthanasia. In particular, some social workers fear that health rationing will result in a slippery slope of hastened deaths in the U.K. at the expense of appropriate palliative care. The problem appears rooted in the interests of those involved with the dying person. For a social worker from England,

...practical 'education' of the process is surrounded with complication. Central to this issue is that of confused impartiality of those involved. In particular the emotional pressures on members of the family of the person concerned and of those caring can lead to false perceptions about what is desired by all concerned. Furthermore, a result of the above has in my experience led to the...person believing that they would be serving those around them best if they were to die.

The indignity of prolonged suffering is frequently experienced by those associated with the dying person. Not surprisingly, the double effect of pain management resulting in death was welcomed by many social workers with experience of dealing with dying loved ones and patients. Acknowledging the desire to help end suffering, an English social worker wrote that,

Family members are often traumatised by watching those they love suffering either emotional, spiritual or physical pain. Many would gladly help to end this suffering, and regret for a long time that they were unable to do so.

Similarly, the pain experienced by those close to the dying person leaves many people feeling helpless. The idea of an assisted death complicates matters for many. A social worker from England commented,

Both euthanasia and assisted suicide leave relatives, friends, professionals involved with enhanced guilt factors in the normal grieving process...my own father, who was a doctor, tried to commit suicide when terminally ill but I still feel very guilty at having failed him...[and]...guilty at denying him the right to self-realisation and control of his own life/death.

Yet, other social workers felt obliged to respect the choices of others wanting a dignified death. An English social worker commented that the guilt surrounding death and dying can be managed through one's preparation.

I believe it to be the humane and dignified way for any person to have the right to determine when and if to terminate their life. If it were possible I would have a legal document drawn up, expressing the terms and conditions to end my life – therefore taking any responsibility and guilt feeling away from my family – Also should I become mentally frail or demented, my wishes would be recorded and hopefully my instructions adhered to.

For social workers directly involved with dying persons, end-of-life decisions are fraught with personal, ethical and practical concerns. The implications of legalized VE or AS are often greeted with suspicion and skepticism because both have the potential to be abused. This said, *not* assisting dying persons leaves social workers in a conflicted position—while following professional codes of conduct and legal obligations—of being remiss or ineffective in their duties to promote their clients' best interests. Advocating assisted death may lead to wrongful deaths, but not doing anything is potentially associated with prolonged suffering for dying persons.

Clearly, the results show that social workers are involved in end-of-life decisions and have much to contribute to the debate on assisted death. Moreover, as a profession, social work has an obligation to take a leadership role regarding assisted death. The implications emerging from the preceding analyses are discussed in the following and concluding chapter. Some limitations of the dissertation and possible future research considerations are also identified for the profession.

Chapter 6

Social Work and the Right to Die with Dignity

Men fear death as children fear to go in the dark; and as that natural fear in children is increased with tales, so is the other. (Sir Francis Bacon)

I have argued that social workers play an important but often unacknowledged role in end-of-life decisions. At a time of increased emphasis on individual autonomy, social workers are increasingly involved in discussions related to choices at end-of-life (Neron, 1996; Werner & Carmel, 2001). In the context of medical advances, the salience of social worker participation in end-of-life decision-making becomes more apparent when specific groups such as elderly persons and PLWHIV/AIDS are considered (see Neron, 1996, 1998; Werth, 1999). The need for policies and training of social workers dealing with clients at end-of-life was raised 25 years ago (Holland Kilpatrick, 1991). While suicide prevention is universally praised and social workers are trained to deal with such issues social work organizations have universally sidestepped the development of policies related to assisted death (Csikai, 1999a). The exceptions are broad statements that reaffirm social workers' role in advocating for client rights at end-of-life (see NASW, 1994, 2003). This leaves social workers in a position of dealing with VE and AS on an ad hoc basis, a situation further complicated by legal decisions that neither support nor fully condemn VE or AS, particularly in the U.K. VE and AS are illegal, but withholding and withdrawing treatment are common practice (Dimond, 2004; Griffiths, 1999).

In the absence of defined policies, social workers in the U.K. apply basic medico-ethical and social work principles to decisions regarding their practice. Self-realization, beneficence, non-maleficence, and justice serve as road signs to social workers' attitudes

on assisted death and guide them somewhat in end-of-life decisions. The dearth of research on social workers' attitudes toward assisted death in the U.K. required the extrapolation of research from other social work and practice contexts. In addition to social work, the hypotheses examined in this research also reflected the research on attitudes toward VE and AS in medical settings. This chapter explores the implications of the results for social workers and social work practice. As well, the limitations of this study are examined and suggestions for future research are discussed herein.

The limited research on social workers' attitudes toward, and experiences with, assisted death suggests that social workers in the U.K. support legalizing VE and AS (72.0% and 72.5%, respectively). Comparative research by Ogden and Young (2003) found similar support among social workers in Washington State for VE (72.4%) but slightly higher support for AS (77.6%). As well, social workers in B.C. were supportive of legalizing VE (75.9%) and AS (78.2%) (Ogden & Young, 1998). Other researchers in Oregon reported that the majority of social workers in medical settings (95%) supported a patient's right to choose an assisted suicide under the *Oregon Death with Dignity Act, 1995* (Miller et al., 2004).

Almost 69% of social workers in the U.K. supported physician-assisted suicide as defined in the Dutch model before legislative changes in the Netherlands refined the practice. Similar support for self-realization (self-determination) in North America reveals that roughly two-thirds of social workers in B.C. (Ogden & Young, 1998) and Washington State (Ogden & Young, 2003) also favoured the Dutch model as defined prior to 2002. Finally, in this dissertation, approximately 25% of social workers U.K social workers in this study believe that they would report a colleague who they

suspected was involved in an assisted death. This rate is high compared to B.C. where 13.7% of social workers would report VE and 12.3% would report AS (Ogden & Young, 1998). The U.K. rate is also higher than Washington State where 16% of social workers would report a colleague for VE and 14.2% would report for AS (Ogden & Young, 2003).

Although not empirically testable with the data in my dissertation, the written responses suggested two themes that influenced the decision to report. First, social workers concerned about abuse of assisted death--non-maleficence--are more likely to report. Second, religiosity appears to be related to punitive attitudes, but regardless of religion, a majority of social workers were undecided or ambivalent toward assisted death. Those at the extreme end of commitment to religion tended to view assisted death with less tolerance. Although the data do not allow for such comparisons, it may be that social workers in Northern Ireland hold stronger religious beliefs than their U.K. counterparts. They were less supportive of legalizing VE and AS, less supportive of the Dutch model of assisted death, and more likely to report a colleague for engaging in VE/AS.

The factors influencing social workers' support of VE and AS, endorsement of the Dutch model, and reluctance to report colleagues suspected of being involved in VE or AS were examined using survey data and the written comments of social workers themselves. The question of the influence of practice setting on the dependent variables--beneficence and justice--emerged as a key theme in the study. The hypothesis that social workers in medical settings would be more supportive of VE and AS was not supported. Instead, social workers in non-medical settings were more supportive of VE and AS.

Comparative research on the relationship between practice setting and support for VE or AS among social workers is meagre. Csikai (1999b), however, found that, compared to their U.K. counterparts, social workers in American hospital settings were less supportive of legalizing assisted death (VE 57% and AS 47%). Roughly 64% of social workers in medical settings in the U.K. supported legalizing both VE and AS. In contrast to other medical practitioners, social workers in medical settings were least supportive of assisted death. Whether these social workers have more insight into death and dying because they deal more with clients, their families and other professionals at end-of-life, or some other reason, is unclear. It appears that social workers lack direction and clarity about their role in assisted death, a finding confirmed in other social work contexts (Csikai, 1999a; Neron, 1996; 1998; Ogden & Young, 1998; 2003). Nevertheless, that clients are treated justly and receive needed care was emphasized by social workers in the written responses.

A similar conclusion can be drawn regarding the decision to report a colleague and practice setting. The lack of clear policies and practice guidelines is evident in the decision not to report, and the indecisiveness about reporting was manifested in social workers' responses. In the face of end-of-life decision-making, social workers struggle with doing what is best for their clients—beneficence and non-maleficence—especially as it relates to quality of life (Dworkin, 1998; Hermerén, 2003). Thus, the notion that social justice, the argument that formal equality provided in law does not necessarily imply substantive equality (Burtch, 2003), is key to social workers who predominantly advocate for self-realization of their clients. These social workers demonstrate respect for life, an essential aspect of decision-making (Magnusson, 2002) and ensure that their

clients are treated fairly according to fundamental notions of right and wrong, based on cultural beliefs. Importantly, a non-medicalized approach to end-of-life is sought by many social workers who want a broader array of people involved in end-of-life decisions, thus moving death away from the professionalized corporate imperative model described by Light and Levine (1998).

Analysis of bio-medical dominance in assisted death on social workers' attitudes was undertaken by examining social workers' desire to be involved in policy development and discussions with clients regarding VE and AS. Previous research in North America shows that social workers want to be involved in policy development. Roughly 80% of social workers in British Columbia (Ogden & Young, 1998) and Washington State indicated that they wanted to be involved in policy development on VE and AS. Similarly, upwards of 70% of social workers in British Columbia (Ogden & Young, 1998) and 75% of social workers in Washington State (Ogden & Young, 2003) wanted to be involved in the decision-making process with clients. A smaller, but significant percentage of social workers in the U.K. also wanted to be involved in policy development surrounding VE and AS (65.3% for both). Considerably fewer social workers in the U.K. indicated a desire to be involved in the decision-making process with clients (VE 49.2% and AS 48.7%). On the one hand, the reluctance of social workers in the U.K. to get involved in policies and discussion regarding end-of-life decision-making may indicate support for bio-medical dominance of assisted death. Indeed, a few social workers wrote that assisted death was a medical responsibility. Alternatively, by taking a "hands off" approach U.K. social workers may accord more value to patient autonomy or self-determination compared to their North American counterparts.

As predicted, social workers who want to be involved in policy development are more supportive of assisted death practices of legalizing VE and AS, and are more likely to endorse the Dutch model as it existed before 2002. As well, social workers who want to be involved in discussions with clients regarding VE and AS are more likely to support assisted death practices and legalizing VE and AS. Social workers wanting to be involved in discussions and to advocate for social justice are less likely to report a colleague whom they suspect of being involved in an assisted death; however, this finding should be treated cautiously as a significant number of social workers were undecided. That a significant number of social workers were unsure or unwilling to report, implies further evidence that personal value systems override organizational and legal constraints (Csikai, 1991; Holland & Kilpatrick, 1991). Whether for or against involvement in policy development, social workers cautioned that safeguards were needed to protect vulnerable persons. This theme is apparent in the limited research on end-of-life decisions and the role of social workers (Callahan, 1994; Csikai, 1999a). Indeed, the lack of guidance in the BASW (1996) Code of Ethics contributes to the confusion and misgivings experienced by social workers in the U.K. regarding assisted death. The U.K. is not unique in this situation as ethical codes of conduct in Canada and the U.S. have very little to say in this regard (see Csikai, 1999b; Ogden & Young, 1998; 2003).

It is difficult to speculate on the findings pertaining to social workers' attitudes toward bio-medical dominance given the lack of research in this area. Nevertheless, it is clear from the written comments that social workers are caught in an ethical bind regarding their obligations to uphold the law and organizational policies on the one hand

and to do what is best for clients on the other. Whether they lean toward or away from bio-medical dominance, social workers' respect for dignity of the person is beyond question. Beneficence and non-maleficence are interpreted differently by social workers, but the goal is still to act in the best interests of their clients.

While ambiguous, the guiding principle of self-realization inherent in social work in the U.K. is a driving force in social workers' attitudes toward assisted death. The majority of social workers agree that self-realization should extend to VE (61.1%) and AS (63%). Regarding its North American equivalent, research reveals similar support for the claim that self-determination should extend to assisted death in Canada and the U.S. A majority of social workers in B.C. agreed when asked if self-determination should extend to VE (70.2%) and AS (73.1%) (Ogden & Young, 1998). Slightly fewer social workers in Washington State agreed with a similar question (VE 65.2% and AS 70.8%) (Ogden & Young, 2003). Not surprisingly, U.K. social workers in agreement with extending self-realization to assisted death were more supportive of its legality, more likely to endorse the Dutch model of assisted death, and less likely to report a colleague whom they suspected of being involved in an assisted death.

In contrast, the relationship between religion and attitudes toward assisted death was more complex. The majority of social workers who mentioned a religion identified a dominant belief system that places decisions about life and death in the hands of God. Although the small number of respondents who noted a religious affiliation precludes any definite conclusions about the attitudes of social workers from those faith communities the responses relating to two of these religions are interesting nonetheless. Jewish and Buddhist social workers indicated more support for VE, AS and the Dutch model than

other believers.. As well, they were less likely to report a colleague who they suspected had been involved with an assisted death. As expected, social workers who identified themselves as agnostic, atheist or non-religious were more supportive of VE and AS than Catholics or Protestants.

Surprisingly, a majority of social workers from the two dominant religions, Catholicism (over 50%) and Protestantism (over 60%), supported assisted death (VE and AS) and the Dutch model of assisted death. Nevertheless, of those who provided a definitive response, social workers were more equally split on the decision to report a colleague, but many were undecided making it difficult to draw conclusions. Research on the relationship between religion and measures of social workers' attitudes toward assisted death does not appear to have been undertaken. However, multivariate analysis of social workers' attitudes in Washington State found that Catholic and Protestant Christians were more likely to find VE immoral than members of other faiths. However, the relationship between religion and AS was statistically significant only for Catholics (Ogden & Young, 2003). It is apparent that social workers' personal value systems are set aside in favour of professional ethics and the pursuit of beneficence and non-maleficence. Research on social workers in Canada (Ogden & Young, 1998) and the U.S. (Csikai, 1999b) reports similar findings. The lack of clear guidelines constrains social workers' efforts to help their clients achieve self-realization, a problem inherent in North American social work contexts (Csikai, 1999b; Leszczynska, 1997).

A small percentage of U.K social workers have had to cope with assisted death in their personal lives (VE 9.3%, AS 7.9%) and have been consulted regarding VE (14.6%) and AS (13.3%). Research on social workers in North America identifies a similar

pattern. In B.C. a slightly higher percentage indicated personal experience (VE 18.1%, AS 12.7%) and being consulted (VE 21.4%, AS 21.6%) (Ogden & Young, 1998).

Research on social workers in Washington State found similar results for personal experience (VE 18.0%, AS 14.4%) and being consulted (VE 21.4%, AS 22.9%) (Ogden & Young, 2003).

The relationship between U.K. social workers' attitudes toward assisted death and experience confirmed the stated hypotheses. Social workers who have had to deal with assisted death in their personal lives were more supportive of VE (112 or 81.8%) and AS (91 or 77.8%), were more likely to endorse the Dutch model (VE 106 or 76.8%, AS 85 or 73.3%), and less likely to report a colleague who they suspected had been involved in an assisted death (VE 37 or 27.4%, AS 37 or 32.2%). Similarly, social workers who had been consulted were more supportive of VE (157 or 73.0%) and AS (141 or 71.9%), more likely to endorse the Dutch model (VE 150 or 70.4%, AS 138 or 70.7%), and less likely to report a colleague (VE 51 or 24.4%, AS 50 or 26.0%). As the data from the other analyses show, results about the decision to report should be treated cautiously because a significant number of social workers were undecided, upwards of 30% in all cases.

The written comments underscore the breadth of issues related to personal experiences. Concerns for death with dignity, adequate palliative care, support for caregivers, and patient choice were highlighted. Protecting patients from abuse—a cardinal obligation of social work—is also important (Callahan, 1994; Latimer, 1991). Some social workers expressed concern that the dying may become disposable and subject to premature death, a concern voiced by Csiaki (1999a). Alternatively, social

workers cautioned that unnecessarily prolonging life for the dying is tantamount to medical abuse, a conclusion reached by Dworkin (1998) in his critique of assisted death policies and practices in the U.S.

Overall, the results suggest that social workers in the U.K. support assisted death. The concerns voiced over abuse and exploitation on the one hand are balanced by concern for patients' right to self-realization on the other. As the written comments and survey results attest, the guiding principles of beneficence, non-maleficence and justice are never far from social workers in their day-to-day lives. Even those who oppose assisted death advocate dignity in dying. Therefore, it is not surprising that the double effect of pain management in the U.K. is not treated as skeptically as it might be. The double effect that results in premature death can be construed as dignified by both proponents and opponents of assisted death.

The double effect was established as a non-culpable cause of death in *R v. Bodkin Adams* (Griffiths, 1999). In that case, the trial judge stated that a doctor's obligation is to relieve pain and suffering, even if the measure taken inadvertently shortens life. Under ideal circumstances, it is doubtful that the slippery slope of unwanted deaths through the double effect will occur, especially if access to quality palliative care is available (Keizen, 2004; Kirchner, et al., 1997). Still, social workers remain concerned about medical hegemony regarding death and dying and the lack of education available to those intimately involved with patients at end-of-life. Social workers' relationships appear restricted to patients and their families, with little interaction with other health care providers. The necessity of training and organizational guidelines emphasized in other research (Neron, 1996; Ogden & Young, 1999) was repeated in social workers'

comments here. Only then can the questions pertaining to quality of life and the right to choose death be adequately addressed. Beneficence and non-maleficence and respect for life must be considered along with the right to individual autonomy (Hermerén, 2003; Latimer, 1991). Counter to the argument that the right to choose VE or AS threatens the common good (Callahan, 1997), respect for choice at end-of-life reaffirms an individual's significance as a member of society able to think and act according to their personal convictions. In most cases, social workers in the U.K. already demonstrate this belief by setting aside personal value systems in favour of clients' wishes.

As argued, there is a noticeable power differential between medical practitioners, especially physicians, and social workers. Yet, there exists a considerable degree of overlap between the two professions with regard to the factors that inform those attitudes. The factors can be categorized as personal or contextual. Personal influences refer to value systems, which may or may not be related to professional association. In this dissertation, Catholics were less supportive of assisted death, but this varied depending on level of professed religiosity. Likewise, Catholic physicians (Anderson & Caddell, 1993) and Australian nurses (Aranda & O'Conner, 1995) with stronger religious beliefs were less likely to view assisted death favourably. As well, whether or not they approve of assisted death, some social workers in this dissertation viewed suicide as a rational act, as do psychiatrists in the U.K. (Shah et al., 1998).

Context influences attitudes in several ways. Social workers in the U.K., like physicians in the Netherlands, are guided by legal constraints (Anderson & Caddell, 1993; Cormack, 2006). The same can be said of nurses in Canada working in AIDS care (Young & Ogden, 2000). Although challenged by some, there is belief among physicians

and nurses that adequate pain management renders assisted death unnecessary (see, Addington-Hall & Karlsen, 2005; Searles, 1995; Young & Ogden, 2000). In addition, physicians and nurses working in palliative care, or otherwise caring for those at end-of-life, (e.g. those working in oncology) are less supportive of assisted death (Dickinson et al., 2005; Verpoort et al., 2004; Young & Ogden, 2005).

Finally, like physicians and nurses, social workers identified the need for checks and balances in regard to end-of-life decisions and assisted death. Nurses in the Netherlands caution that assisted death may become another bureaucratic exercise with tasks to be accomplished and forms to be completed (Verpoort et al., 2004). Social workers in this study express a similar sentiment. However, the checks and balances seem necessary as abuses of assisted death have been documented in the Netherlands where it is legal (Onwuteaka-Phillipsen et al., 2003), and Australia where it is not (Cormack, 2006).

Limitations

Using a secondary analysis, including attention to qualitative data, this exploratory research has examined a crucial aspect of social work in the U.K. Admittedly, the results are not generalizable to other social work settings, particularly North America where self-determination has more influence. Although adequate (n=1477), a larger sample size and higher return rate would provide more confidence that the results were valid and reliable. Particularly, larger samples of social workers from Northern Ireland and Wales would benefit the analysis involving cross-cultural, national and religious differences, which could involve a more sophisticated statistical analysis.

While the results reveal a spectrum of social workers' attitudes, they are not the same as behaviors. The use of forced response items in the survey was employed to mitigate this issue. However, the high percentage of social workers undecided about whether to report a colleague whom they suspect had been involved in an assisted death underscores the observation that life and death decisions are hardly black and white. In hindsight, the inclusion of vignettes in the survey may have resulted in fewer undecided responses. As well, Likert-style questions might have allowed respondents more flexibility to respond to the questions, thereby reducing the number of undecided responses. This approach may also have resulted in a higher response rate.

Although the written comments add a lived experience aspect to the research, the inability to probe social workers on their responses is another limitation of this research. Indeed, the comments reveal that social workers frequently behave differently when confronted with real life situations involving end-of-life decisions. In-person interviews and participant observation may provide additional information on social workers' attitudes and experiences regarding assisted death. Social workers' reluctance and/or indecisiveness to report a colleague involved in ostensibly illegal activities is an example of the contradiction between beliefs and behavior which might be captured using an ethnographic approach.

Future Research

Given their involvement with clients, social workers can and do play a key role in end-of-life decisions. Although not all agree with VE and/or AS, a statistical majority of social workers support a version of legalized assisted death. Moreover, those at odds

with VE and/or AS typically place client interests above their own values. Clearly, further research is needed on the role of social workers in end-of-life decisions. This dissertation can serve as a springboard to future research. Three main issues are highlighted for further inquiry. First, given their unique position with clients and their families, the factors affecting social workers' attitudes toward VE and AS require further investigation. Much of the theoretical knowledge emerging from social work practice is generated in practical settings. As Scott (1990) points out, quantitative methods are often difficult to employ in social work settings. This point is made more poignantly by Verpoort et al. (2004) who argue that research involving end-of-life issues requires at least a qualitative component. Using participant observation, the practice wisdom developed by social workers dealing with clients and their families is one method that could be used to develop a broader understanding of social workers' attitudes. In-depth interviews could be used to supplement this type of observational research and provide the type of "rich" data inherent in ethnographic research methodologies (Denzin & Lincoln, 2000). This knowledge would contribute greatly to the development of policies for social workers dealing with clients and their families at end-of-life.

The second implication concerns bio-medical dominance of death and dying and the proposal for a multidisciplinary and/or holistic decision-making team for clients at end-of life. The call for further dialogue among disciplines regarding assisted death is documented in the literature (Azzarto, 1986; Ogden & Young, 1999; Young & Ogden, 2000). The substance of this dialogue and how it might be undertaken needs further exploration. Depending on the practice context, dignity, self-realization (self-determination), beneficence, non-maleficence and justice may take on different

meanings. Whether diverse professions can collaborate to determine that “enough is enough” for dying patients while protecting against abuse of death versus abuse of life requires investigation. Equally important is the question of whether or not guidelines—developed to guard against abuse of assisted death or abuse of treatment—can satisfy all of those involved with clients at end-of-life. Comparative research of social workers in different social and political contexts would add to the dialogue regarding the role of social workers in assisted death. As this research demonstrates, the results are comparable with other research on the topic along several dimensions (see Csikai, 1999a; Ogden & Young, 1998; Ogden & Young, 2003).

Finally, future research should examine the content of medico-ethics education in the social work curriculum. While varied, opinions on the question of legalized VE or AS pointed toward legalizing VE and AS. The diversity and indecisiveness of opinions regarding the decision to report a colleague for his/her involvement in an assisted death illustrates a lack of clarity and/or guidance for social workers. While stated policies are necessary, consistency in the application of ethical principles is also required. Research into the need, content, delivery and application of such training is essential if social workers hope to be effective with clients at end-of-life. The scope of this education must go beyond the social work community and include medical practitioners.

An education model that emphasizes collaboration between social workers and other health care providers could be developed. Abramson and Mizrahi (2003) identify three collaborative strategies used between physicians and social workers in health care settings: traditional, transitional and transformational. Traditional physicians and social workers view the social work role as providing concrete services. With this model, little

attention is given to the psychosocial issues that may affect patients. Social workers follow physicians' directives and physicians are unaware of social workers' counseling role, which is usually not provided.

In contrast to their traditional counterparts, transitional physicians understand the social work role to include counseling. While these physicians engage in discussions with other health care providers, including social workers, they prefer communication based on physician priorities. Transitional social workers tend to separate their roles into counseling and the delivery of concrete service. These social workers participate in care teams, but often avoid direct communication with physicians.

Compared to other physicians, transformational physicians and social workers are more alike than their traditional and transitional counterparts. Both professions emphasize the need for counseling patients and support for families going through difficult times. Physicians and social workers alike believe that responsibility for caring for patients and their families is shared. Arguably, a transformational model of practice based on collaboration could be developed and applied to social workers dealing with assisted death and other end-of-life issues. Collaboration could be expanded to include nurses and other health care providers such as volunteers in hospice settings. That a small, but growing number of medical practitioners and social workers value such arrangements suggests that further education may improve the contributions of social work (Abramson & Mizrahi, 2003). Moreover, integrating the expertise of physicians with the breadth of services provided by social workers and other health care practitioners stands to improve the level of treatment of those at end-of-life. This will

benefit all professionals involved regardless of their attitudes toward assisted death and the values espoused by individual professions.

As with birth and other weighty issues, dying is much a social as medical event. Whether legal or not, social workers can and do play a role in end-of-life decision-making regarding assisted death (Csikai, 1999a). Their proximity to clients, friends and family and other caregivers places social workers in a key position to contribute to the debate on assisted death. Along with collaborative education, policies and practice guidelines are needed for social workers involved in end-of-life situations with clients. Frequently, social workers are the ones supporting clients and their families in the transition from life to death (Wood et al., 1993 in Neron, 1998). That policies and guidelines be developed from the ground up is essential for social workers to be effective in their dealings with clients at end-of-life. To ignore social work practice wisdom in policy formulation and the development of practice guidelines (Scott, 1990), results in inconsistent care of clients and places social workers in seemingly unnecessary ethical dilemmas. Moreover, failure to engage assisted death and the issues concerning end-of-life care condemns social work to being the mute handmaiden of medicine.

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Appendix A

EUTHANASIA AND ASSISTED SUICIDE SURVEY QUESTIONNAIRE

Please check (✓) each response that you give.

1. What is your gender? Female Male
2. What is your age? _____ years
3. What is your highest level of education? (check all that apply)
 Diploma in Social Work
 CQSW
 CSS
 undergraduate degree (specify) _____
 postgraduate degree (specify) _____
 Other (specify) _____
4. What is your current religious affiliation?
 Protestant
 Roman Catholic
 Jewish
 Islam
 Hindu
 Agnostic
 Atheist
 Buddhist
 Not applicable
 Other (specify) _____
5. How would you rate your level of commitment to your religion, if applicable? (circle)

	1	2	3	4	5	6	7	
Not at all Committed								Completely Committed
6. Are you currently?
a) employed as a social worker Yes No
b) a member of the BASW Yes No
7. What is your primary employment status?
 Full-time
 Part-time
 Casual
 Student
 Unemployed
 Retired

8. What best describes your practice setting?
- Private practice
 - Drug & Alcohol
 - Mental Health
 - Child Welfare
 - Financial Services
 - Community based counselor
 - Medical setting (e.g. palliative/hospice, acute/long term care, etc. specify) _____
 - Other (specify) _____
9. What is your current type of employer?
- Government
 - Private society
 - Self-employed
 - Hospital/Ambulatory health care facility (e.g. extended care)
 - Other (specify) _____
10. How many years have you practiced social work? ____ years

Instructions & Definitions

Please place a check mark (✓) beside each response that you give. Some questions allow for more than one response, so please check all that apply. For the following questions, euthanasia and assisted suicide are defined as:

- **Voluntary euthanasia: the administration of a treatment or an act by another person that induces death, at the request of the patient (e.g. a lethal injection).**
- **Assisted suicide: the patient has been provided with the means (e.g. drug overdose) specifically for the purpose of suicide. The patient is the one who commits the final death-hastening act (e.g. swallows a lethal drug dose).**

11. Do you feel that voluntary euthanasia or assisted suicide are immoral?
- a) assisted suicide is immoral Yes No Undecided
- b) voluntary euthanasia is immoral Yes No Undecided
12. When a competent, informed patient has an incurable or terminal illness that from their point of view is causing unbearable suffering, do you feel that he/she should be legally permitted to request and receive voluntary euthanasia or assisted suicide?
- a) assisted suicide Yes No Undecided
- b) voluntary euthanasia Yes No Undecided

13. Euthanasia and assisted suicide are illegal. If you knew that a social worker had been involved in an act of euthanasia or assisted suicide, would you report it?
- a) assisted suicide Yes No Undecided
- b) voluntary euthanasia Yes No Undecided
- c) to whom would you report it?
- to a colleague
- to BASW
- to my employer
- to the police
- I would not report it
- Not sure
14. Do you feel voluntary euthanasia or assisted suicide should be legal in certain circumstances?
- a) assisted suicide Yes No Undecided
- b) voluntary euthanasia Yes No Undecided
15. Do you feel that the law should be changed to allow physicians to take active steps to bring about a patient's death in some circumstances?
- Yes, in certain carefully defined circumstances
- No
- Not sure
16. Should social workers be involved in the development of social policy that addresses euthanasia or assisted suicide?
- a) assisted suicide Yes No Undecided
- b) voluntary euthanasia Yes No Undecided
17. In the Netherlands, physicians are now virtually certain not to be prosecuted if they end the life of a patient under the following general conditions:
- a) this is the patient's well-considered wish;*
- b) the patient has an irreversible condition causing protracted physical or mental suffering which the patient finds unbearable;*
- c) there is no reasonable alternative (reasonable from the patient's point of view) to alleviate the suffering;*
- d) the doctor has consulted with another professional who agrees with his or her judgment.*
- Do you feel it would be a good thing if such a situation were to exist in the United Kingdom?
- Yes
- No
- Not sure

18. Is it a social worker's ethical duty to respect the client's right to self-realisation?
- Yes, always
 Yes, in certain circumstances
 No
 Not sure
19. Should the client's right to self-realisation extend to the right to voluntary euthanasia or assisted suicide?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
20. If voluntary euthanasia or assisted suicide were legal, would you consider either as options for yourself if you were terminally ill?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
21. If voluntary euthanasia or assisted suicide were legal, would you consider either as options for a terminally ill family member?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
22. Have you ever had to cope with euthanasia and assisted suicide issues in your personal/family life?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
23. If voluntary euthanasia or assisted suicide were legal, should social workers be involved in the decision making process with clients?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
24. In the course of your social work practice, has a patient/client ever consulted with you about euthanasia or assisted suicide?
- a) assisted suicide Yes No Undecided
b) voluntary euthanasia Yes No Undecided
25. Have you ever assisted the death of a patient? (check all that apply)
- Yes, by euthanasia
 Yes, by assisted suicide
 No
 Not sure

Appendix B

Research: Social Worker Attitudes Concerning Voluntary Euthanasia and Assisted Suicide

Dear Member of **BASW**,

The attached survey is designed to explore anonymously the issues of voluntary euthanasia and assisted suicide. It is part of an independent, ongoing social work project in Canada and the United States.¹

Please fill in the survey as soon as possible and return it in the FREEPOST envelope. You are encouraged to answer as many questions as you can, but retain the right to refuse to answer any of the questions. Return of the survey constitutes your consent to participate.

To ensure your confidentiality, distribution of the 4,000 copies of this questionnaire is controlled by BASW; the researchers do not have access to the BASW membership list. Please do not write identifying information on the questionnaire, so that your confidentiality is protected.

Your participation is valuable to the ongoing discussion about voluntary euthanasia and assisted suicide and will provide important data for education, policy development and legislative analysis. This is the first comprehensive effort in the UK to collect data on social workers' attitudes toward assisted death issues. Data obtained in this study will be compared with research in Canada and the USA.

Thank you for your assistance in this important study. We will offer a summary of the survey results for publication in the BASW magazine, **Professional Social Work**.

Sincerely yours,

Russel Ogden, BGS, BSW, MA, PhD(candidate)	Michael Young, BA, MA, PhD(candidate)
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¹ Russel Ogden and Michael Young have conducted social work surveys on the memberships of the BCASW in British Columbia, Canada and the WANASW in Washington, USA. They have also conducted research on Canadian nurses working in HIV/AIDS. These projects are independent from their university research programmes.

Queries about this survey may also be made to your BASW representative, Sally Arkley, 16 Kent Street Birmingham, B5 6RD.

Appendix C

Non-Response Card

Non-response Card

If you have chosen to not respond to this survey, we are interested in learning from your reasons. Please check all that apply:

- (insufficient time to complete the survey
- (never participate in postal surveys
- (no longer in social work practice
- (concern about protection of confidentiality
- (not interested in the topic
- (personal views about the topic
- (concern about the purpose of the investigation
- (do not feel the questions are appropriate

Other _____

It would help us if you would indicate your:

age ____ gender ____

Thank you. Please insert this card in the postage paid reply envelope.