Chapter One

Canadian Perspectives on Death and Dying

Introduction

Dying is a universal life passage that can be seen as natural: the final state of living. However, dying is also a major existential crisis for most people and usually represents a crisis point for both the dying person and for his or her family. (Latimer 1995: 362)

To be concerned with death and its celebration is not “morbid.” It is proper to reflect on a certainty of life. All healthy and vigorous civilisations of the past have apprehended the significance of death. (Curl 1993: 366)

Canadians have long been involved in both public and academic debates about matters related to death and dying. As part of the background research for the first edition of this book I reviewed over six hundred articles from the past twenty years dealing with this topic. These articles were found in publications in all of the health and social science fields as well as in ethics, geography, law, literature and multiculturalism. I also used numerous, but not as many, books, reports, monographs, newspaper and magazine articles and a small selection of video and audio tapes. Since that time, the number of Canadian publications and Internet sites on death are steadily increasing, especially in the area of hospice and palliative care, so it is clear to me that Canadians, like our U.K. and U.S. counterparts, are becoming fascinated with death.

As well as a vast array of Canadian literature on death and dying there are now more undergraduate, graduate and certificate courses being offered on these topics than ever before (Morgan 1986). In their 1977 article on death education amongst students in faculties of nursing and medicine in Canada and the United Kingdom, Barbara Downe-Wamboldt and Deborah Tamlyn note that:

If educators are to make significant improvements in the area of death education, systematic research is needed to determine which curriculum contents and approaches are most effective in prepar-
As more Canadian medical schools, including nursing faculties, introduce courses on death and dying into curricula, especially in institutions with palliative care programs, the demand for a more rigorous critical approach to styles of learning and teaching these complex issues will also continue to rise.

Several on-going events, which have been much discussed in the media, in health care and community-based settings and our families as we sit around our dinner tables at night are: euthanasia, also known as assisted suicide or mercy killing; palliative care and hospice, an alternative method for helping dying persons and their important ones deal with death in a holistic, patient-centred way; the high rates of suicide amongst young Aboriginal people; and the increased incidence of cancer amongst Canadians. Each of these topics will be discussed in more depth in later chapters of this book.

Since the first edition of this book was published in 2000, we have witnessed increased acts of terrorism on a global scale, as well as more hurricanes, tsunamis and other world disasters including wars and civil unrest and an ever growing number of deaths due to HIV/AIDS in Sub-Saharan Africa and elsewhere. These tragic, and often preventable deaths, are a daily reminder of the prevalence of the shadow of death in the midst of life.

Two important legal cases heard in Canadian courts are the most recent in a chain of events that have occurred here regarding the legalization of euthanasia. One case involved Robert Latimer, a Prairie farmer who, in 1993, ended his severely disabled daughter’s life in what he called a “mercy killing.” Tracy Latimer was suffering from cerebral palsy and her father pleaded guilty to causing her death. In early December of 1997, Justice Ted Noble heard Latimer’s appeal of his earlier conviction of second-degree murder and again found him guilty. He was sentenced to a minimum of twenty-five years in jail.

In March of 2006 Robert Latimer requested a second trial, arguing that in the original one the court had not adequately understood the condition of his daughter and the levels of care needed twenty-four hours a day, seven days a week from her family and others. He has appealed to the newly elected conservative government, under Prime Minister Stephen Harper for a re-trial of his case. At the time of writing he was awaiting word from the judicial system as to his request. (CBC 2006b)

Another euthanasia/assisted suicide case occurred in 2004, when multiple sclerosis sufferer Charles Farialla asked his mother to assist him to end his life. He was thirty-six years old at the time of his suicide in September of that year. In January of 2006 his sixty-year-old mother, Marielle Houle,
was found guilty of assisting in his suicide and was sentenced to three years probation for her part in his death.

Because of these events and others, both before the original text was written and presently, there is a revival of interest in matters related to death and dying in Canada and many other parts of the world. My intention in this book is to explore some of these topics and to analyze them in terms of what they tell us about the social changes that may occur in the Canadian environment as we now know it. Will we continue to be a death denying and death defying culture or will we embrace death as but another part of life, as part of the cycle of nature discussed by First Nations persons and others?

Much of this book examines the world of death and dying through a lens that sees these concepts as socially constructed practices engaged in by us as individuals moving about our everyday lives. From a sociological perspective death and dying are not clearly defined and articulated abstract concepts but an array of social behaviours, expectations, rules and obligations that occur in different cultures as the result of the end of an individual’s life.

According to information available from Statistics Canada (December 2005), the number of deaths has been on an upward trend for several years, the result of a growing and aging population. In 2003, 226,169 people died in Canada, up 1.2 percent from 223,603 the year before. In the same period, Canada’s population grew by 1.0 percent. As well, the number of deaths rose in every province and territory, except in Prince Edward Island, Quebec and the Yukon, where the number of deaths declined (Statistics Canada 2005a). The major causes of death in this country were as follows: Diseases of the circulatory system accounted for 74,824 deaths in 2001, about 34 percent of 219,538 total deaths in Canada. Of those deaths from circulatory system diseases, 55 percent were due to ischaemic heart diseases, which include conditions in which the heart muscle is damaged or works inefficiently because of an insufficient blood supply. Another 21 percent of the deaths due to diseases of the circulatory system were from cerebrovascular diseases, the vast majority caused by what is commonly known as a stroke (Statistics Canada 2005a).

**THE TEXT WITHIN**

Inherent in this book is a sub-text about my personal experiences with the subject matter at hand, a way of making visible my connections with the topic and of owning what I know—my “epistemology” as it is called in the social sciences. Epistemology refers to how we know what we know. From where, whom and under what social, cultural, historic and geographic circumstances do we gain our experiences and understanding of how the world works? What are the characteristics, limits and methods of ways to know something?
When we are able to identify these factors it helps us understand who we are. It also helps us make choices about which parts of our knowledge base we want to hold onto and which we can let go of or give up.

When we read most academic texts the author’s experience is hidden and, although they have a voice, one is never able to separate their experiences from their facts. I didn’t want to write that kind of book because part of my writing goals includes telling you who I am. Writing and reading are interactive processes; they represent a relationship.

You as reader and I as writer engage in a relationship of interaction. As students in the classroom you also engage with your peers and the instructor in a similar relationship. Therefore throughout the text I have included in-class assignments aimed at encouraging you to reflect upon and share your experiences with each other. I want to share mine with you too. So where appropriate I have included a section in each chapter called The Text Within. This will help you to understand who I am, where I am coming from and because of these experiences, why I write as I do.

My First Experiences with Death

I was born on March 19, 1945, in Essex, England. This date is significant for many reasons; I was baptized in the Roman Catholic faith. Those familiar with this religion may know that in England St. Joseph’s Day is March 19th and that Saint Joseph is the patron saint of a happy death. Although I no longer practise any organized religious activities I still like to think that my interest and work in death and dying was fated to be by higher forces!

My birth came shortly after the end of the Second World War, in a place called Braintree, Essex, which is in a rural part of the country. My family actually lived in London’s east end but due to the bombing pregnant women were sent off to have their babies outside of London. My mother had tuberculosis when I was born, a disease she probably contracted like so many others in England from sleeping in air raid shelters in the Underground. She died two years later in a hospice, a few days before my second birthday.

I grew up in Shoreditch in the east end of London, where death was a constant shadow looming over us. All of the children who I went to school with had lost family members in the war. We played on bomb sites that had once been people’s homes, factories and shops. Because our area had housed several factories it had been bombed many times. When I was a child, a favourite showing off spot, to friends and acquaintances (and as a very young child to the man who came to collect the football pools money!) was the hole in the downstairs hallway where a bomb had gone through the floor on its way to the cellar. Apparently the bomb was dropped in 1944 and had gone right through the window above the door and
landed on the hallway floor. The brown scorch marks on the wooden floor were a testament to what my parents always referred to as good old British luck. In the basement that was no longer used by any but the mice and the family cat that chased them, overhead windows were still painted black as part of the blackout procedures required during the war years.

I grew up then in a time of mourning, as many of my Jewish friends did whose families still relived the Holocaust on a daily basis. My family was Lithuanian on my mother’s side and French Canadian on my father’s. All of my family members longed for a past that they could not return to in their lifetime. So death was a part of my life at a very young age and has been with me ever since.

My public school was St. Monica’s in Hoxton, a fifteen-minute walk from my home. There were no buses or trains going there from my house because there were no such things as school buses in England. The school was across the street from a small park that had once been the burial pit for victims of the Black Death and the bubonic plague, which swept across Europe killing hundreds of thousands in the fourteenth century.

When I was fifteen and still active in the church I became a volunteer at St. Joseph’s Hospice in London, working predominantly with dying children whose mothers had been prescribed the drug thalidomide during pregnancy. It was during this time that my interest in work with the dying was sparked and even then I was convinced that we needed to provide more sensitive care to the dying and their important ones and that we couldn’t do this work very well in hospital settings.

Within the traditions of my families of origin it was normal and appropriate for people to die in their own homes rather than in hospitals or nursing homes. Friends and relatives came to the family home to pay their last respects to the old ones. Daily life was going on around them as Lithuanian cabbage soup cooked on the stove, my brother listened to his records, my parents were glued to the latest episode of the Archers (a popular nightly radio show in Britain, then and now) and I was downstairs reading. Grandparents, aunts and uncles were waked in our living room and these elderly relatives had died in their own beds.

Death was very much part of life, always visible and present, not hidden as it is today in the majority of people’s homes. Children were always present at funerals and invited to kiss the dead relatives before the coffin lid was closed down. We attended the wakes afterwards and learned that although death was a sad event within the family, it was also a time to celebrate life and to remember the good times we had shared.

My two children used to think that deaths only happen in hospitals. They have never seen a dead person, or witnessed a funeral, although we
have lovingly buried several cats and a dog. They have, however, been inundated with deaths on television, in the movies and in many of the video or computer games that they used to play. They live in a time when death is said to be conquered either by medicine, by game wizards or by positive thinking. They have trouble believing that they or I will die.

Growing up in the particular time and place that I did, in a country steeped in thousands of years of history and mourning for its many dead, caused me to wonder about the role of death in our lives, the kind of work that death makes necessary for the living, as well as the social changes that death brings about not just for immediate family and friends but for entire communities, cultures and regions.

When someone we love dies, we engage in a process through which we try to make sense of that death. That death, whether we knew the person or not, as in the case of the death of the Princess of Wales or, as part of my own history, the famous English pop singer Dusty Springfield, causes us to reflect on and remember our past. Death re-connects us to a string of memories and relationships; it takes us into our pasts and helps us come to terms with the passing of the years. In this sense death provides psychological work for us to do to come to terms with the loss.

In this book I want you to imagine that you have received a parcel marked “Death and Dying.” Our task is to unpack this box. Each section of the book represents a package within the parcel, and only when we have opened and explored the contents of each, as social detectives, will we be familiar with the many perspectives on death and dying.

One of the reasons we wish to delve into these topics is because we will all die, so when we study these phenomena we study not “them,” the unknown data providers or “informants,” those other than us typically learned about in university and college courses, we also learn about ourselves, our own feelings, thoughts and fears about death. In this way we can integrate our experiences, fears and knowledge into our learning experiences.

Throughout the text I have included suggested readings for each section, some personal reflection sheets to be used for in-class or group discussion, and suggested discussion questions.

Why Study Death and Dying?

The end of life is a complex and difficult subject. While media stories on the end of life are common, final decisions around death and dying are personal and shaped by the cultures in which we live. There are many reasons to study these topics. Some include the following, and you could add your own to the list too.
Personal Reasons
Many of us study death and dying due to our personal experiences, infatuation with and interest in the topic. Here are some reasons why we want to study these topics:

- to be better informed about what options exist for the dying and their important ones;
- to heal a loss that has not been resolved, resulting in unfinished business;
- to come to terms with the fear of death;
- to be able to help others deal with death;
- to be aware of the social activities that recognize a death has occurred and the consequences of it;
- to become self-reflective about how we feel about death and dying and all of the feelings/reactions/opinions associated with them;
- to understand how we respond to the news of deaths of celebrities, in comparison to those closer to us;
- to understand how we relegate the deaths of people from other countries in televised news broadcasts as somehow less important than those closer to home. (This is clearly evident in the reaction of the West to the AIDS pandemic in Sub-Saharan Africa);
- to understand how we react, individually and as a culture, to deaths due to natural disasters such as tsunamis, hurricanes, tornadoes and so on;
- to understand how we react to deaths as a result of wars, murders, mercy killings, etc.

Scientific Reasons
All branches of science are involved with the study of death and dying, from laboratory based experiments in biology and medicine to pharmacological studies of drugs to alleviate pain and symptoms, to in-depth interviews with the dying and their important ones in sociology and anthropology and the need for an understanding of the religious and spiritual needs of the dying on the part of pastoral care counsellors and others in the field of theology. While science is involved in a variety of examinations of issues related to death and dying, many are concerned with the prolongation of life. However, medical advances that prolong life also create ethical, legal and practical dilemmas about how, when and who should end the life of another. Some of the topics scientists, in all disciplines, are interested in include:

- the desire to know more about causes of death, types of death, pain and symptom management and control;
- prevention of deaths due to accidents, suicide, preventable illness;
- reactions to death and ways to assist with coping techniques;
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- medical interventions, treatment options and “cures”;
- the most appropriate settings for deaths due to terminal illnesses to occur;
- the most appropriate training techniques needed to prepare care-givers to assist the dying, as well as others in the “helping professions”:
- to understand changes in life expectancy, mortality rates, chronic and acute pain;
- to understand the lifestyle implications of disease related illnesses.

Institutional Reasons
Many institutions are involved in care for the dying and deceased, ranging from those involved in medicine, ethics, law, spirituality and religion, the counselling professions, social workers and the funeral industry. The types of issues these professionals pursue include:

- the emotional, physical, economic and spiritual costs of prolonging life;
- end of life issues such as euthanasia, assisted suicide/mercy killings;
- legal issues in the above;
- types of facilities needed to care for the dying;
- end of life decisions and services;
- final disposition of the dead;
- cultural, spiritual and religious values concerning death and dying;
- ways to assist the dying and bereaved;
- deciding on the most appropriate levels of care for people of different ages and health conditions.

Who Studies Death and Dying?
Many people choose to study death and dying, either for personal reasons such as their own mortality or that of those they love, or because their profession, vocation or field of academic inquiry requires it. Although all citizens may be interested in death and dying for personal reasons, scientists normally engage in a more rigorous and systematic examination of the topics. Others are just fascinated with knowing more about what happens when we die. Scientists and others who chose to study the dying process and death include the following:

- sociologists;
- gerontologists;
- medical professionals;
- social planners and policy developers;
- journalists;
- funeral directors;
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- anthropologists;
- psychologists;
- social workers;
- spiritual and religious advisors;
- archeologists;
- criminologists and police personnel;
- coroners and medical examiners;
- lawyers;
- ethicists;
- philosophers;
- holistic health practitioners;
- nursing home administrators and their staff;
- safety equipment manufacturers.

Where Is Death and Dying Studied?

Death and dying are studied in a variety of laboratory, medical, legal, university and colleges, scientific and everyday settings, some of which include the following:

- in classrooms;
- in the “field,” e.g. in archeology and anthropology;
- within people’s own homes;
- within hospices, palliative care units and nursing homes;
- in pharmaceutical companies and laboratories;
- in coroners’ and medical examiners’ offices;
- within military establishments;
- within the media in all its forms;
- in a variety of medical settings;
- in crime laboratories.

How Is Death and Dying Studied?

When death and dying are studied, regardless of whether the methods used are qualitative (such as observation, case studies, ethnographies and so on) or quantitative (through the use of surveys, questionnaires and such), in all cases our understanding and awareness of these processes are enhanced. As a result of these studies different treatment options may be available, we may become more aware of the options facing those with life limiting illnesses in terms of where they might chose to die and we may assess and evaluate care of the dying in our own communities and within our own homes. Some of the ways in which death and dying processes are studied include the following:
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• through observation, talking with the dying and their important ones;
• through digging in archeological burial sites;
• through attitudinal surveys and questionnaires on specific topics, e.g., euthanasia, AIDS, hospice care;
• through an examination of history, literature, cross-cultural material;
• through an examination of cadavers to understand causes of death and the disease processes;
• through laboratory experiments on non-human subjects;
• through non-fiction, film and video representations;
• through examinations of military strategies and recovery efforts after local and global disasters and pandemics;
• through assessments and evaluations of programs and services targeted towards the dying and their important ones, and with those who provide services and programs to them. These would include complementary as well as traditional programs;
• through the observation and recording of death and mourning rituals in diverse cultures, and among different racial and ethnic groups within them.

Different Disciplinary Approaches to Death and Dying

Within the realm of academia a wide of disciplines are concerned with the topics of death and dying. Whether these courses and programs are provided within specific schools, such as nursing, medicine or social work, or in more general programs, such as arts and the humanities, the social, environmental or biological sciences, each discipline approaches the topics from a unique perspective. Sometimes there is an overlap between disciplines, and this assists in being able to examine an issue or topic from a variety of different perspectives, thus providing a more detailed and thorough account of the phenomenon. Below are just some of the disciplinary approaches to the study of death and dying.

Psychological Studies

Psychology is both an academic discipline and an applied field of research and treatment involving the study of the mind, brain and behaviour in both humans and non-humans. Psychology is also interested in a variety of human activities, including the ways in which people deal with the challenges of everyday life and the diagnosis and treatment of mental illness. Psychologists are primarily interested in the mental processes and behaviours of individuals, whether alone or in groups. Death possesses many faces and meanings, and perceptions of it vary across cultures and in different historical time periods. It is obviously too intricate to be the special province of any one discipline. Nevertheless, psychology’s contributions to the topic have
succeeded in increasing understanding of coping with death and bereavement. “Our future mandate is to extend our grasp of how death can serve life” (Fiefel 1990: 538).

In 1959, U.S. psychologist Herman Fiefel was the first in his field to publish a series of articles dealing with the meaning of death from a psychological perspective. Later, in 1990, Fiefel noted that:

Except for a few sporadic forays… the place of death in psychology was practically terra incognita and an off-limits enterprise until the mid-twentieth century. (1990: 538)

From a psychological perspective, questions are raised about how individuals face their own deaths through a developmental framework moving through childhood, adolescence and into adulthood. As well, psychologists analyze death anxiety issues and the role of psychoanalysis in helping individuals cope with the loss of all they hold dear as death approaches. Psychologists involved in grief counselling work also assist the bereaved in dealing with and moving on after loss.

**Death Anxiety**

Most of us experience anxiety over our own death and those of the people we love at some time in our lives. How we manifest this in our daily lives is of interest to psychologists and those who provide care to the terminally ill and their loved ones. “Mortophobia” is the term used by some psychologists and counsellors who work with and for persons dealing with the loss of self and loved ones to explain the excessive and incapacitating fear of death of others or the self.

In a 1996 article appearing in *Death Studies*, Robert Loo and Leisa Shea of the University of Alberta reported on the Collet-Lester Fear of Death and Dying Scale. This scale is used extensively by psychologists interested in measuring death anxiety. Four main aspects of attitudes are measured: fear of death of the self, fear of death of others, fear of dying of the self and fear of dying of others. The authors found that this scale is a useful tool to stimulate people’s self-discovery of views related to death and dying and then to help them identify potential directions for attitudinal and behavioural change. As the authors note, the practical application of such scales is “with fire-fighters and police officers who deal with death and dying as part of their jobs. This scale could be appropriately used during recruitment or basic training and later in supervisors’ training” (1996: 586).

In a U.S. study also utilizing death anxiety testing, Andrew Dattel and Robert Neimeyer (1990) note that sex differences have emerged in many studies using these scales. They conclude that women display greater death concern than do males. They analyze these findings to relate “women’s