Chapter Fourteen

The Revival of Interest in Death and Dying

Sometimes we lie still and do not move. If air is still going in and out of our breathing holes, this is called sleep. If not, it is called death. When a person has achieved death, a kind of picnic is held, with music, flowers and food. The person so honoured, if in one piece, and not, for instance, in shreds or falling apart, as they do if exploded or a long time drowned, is dressed in becoming clothes and lowered into a hole in the ground, or else burnt up.

These customs are among the most difficult to explain to strangers. Some of our visitors, especially the young ones, have never heard of death and are bewildered. They think that death is simply one more of our illusions, our mirror tricks; they cannot understand why, with so much food and music, the people are sad.

But you will understand. You too must have death among you. I can see it in your eyes. (Atwood 1992:126)

We have much more information about the physical, psychological and social consequences of death in our culture, and others, than ever before in our history. Yet in spite of all of this information, we actually have relatively less knowledge, understanding or ease about our own mortality, or what it is like to die, than we ever had. It is as if the more we know about who dies, the causes of death, where and how people die, the less likely we are to think about our own death. We are a death-denying and a death-defying culture. Over the past twenty years, predominantly as a result of the hospice/palliative care movement, there would appear to be a revival of interest in matters related to death and dying. Figure 14.1 outlines some of the interconnections between the elements which contribute to this renewed curiosity.

Our awareness of death and dying has been revived in great measure by the work of two important women: Elizabeth Kubler-Ross and Cecily Saunders. Kubler-Ross, a Swiss psychiatrist living in the U.S., began in the late 1960s to call for a more humane approach to care for the dying. She and her colleagues interviewed thousands of dying people and her work has been published in many books. Initially, however, her findings were not well respected by the medical profession, which was threatened by her ideas. Kubler-Ross did not just produce academic work from her research with the dying, she also appeared on
Figure 14.1 Revival of Interest in Death and Dying

**LAW**
- Euthanasia
- AIDS treatment options
- Murder
- Court systems
- Living wills

**EUTHANASIA**
- Sue Rodriguez
- Nancy B.
- Jack Kvorkian
- Nancy Morrison
- Senate
- Committee
- Law

**POPULAR CULTURE**
- Books
- Television
- Radio
- Movies
- Plays
- Opera

**POLITICS**
- Euthanasia
- Palliative care
- Home care
- AIDS funding
- Access

**MEDICINE**
- Pain control
- Diagnosis
- Cryonics
- Technology
- Comfort measures
- Palliative care
- Holistic care
- Stages of death
- Definitions of death

**RELIGION**
- Morality
- Concept of “sin”
- Suicide
- Soul
- Euthanasia
- AIDS
- Abortion
- Reincarnation

**AIDS**
- “Guilty” vs.
- “innocent” deaths
- Women
- Homophobia
- Blood supply
- Cost of care
- Testing
television and radio talk shows taking her message to ordinary people.

While Kubler-Ross was reviving an interest and awareness of the needs of dying persons on this continent, Cecily Saunders, a nurse who later became a physician, opened St. Christopher’s Hospice just outside of London, England. This hospice was the first of its kind in modern times, and as a model of “care not cure” has influenced every other hospice or palliative care unit since. Today there are thousands of palliative care programs throughout the world. In Canada, in the last twenty years we have gone from 40 programs to 489 in 1997. Palliative care and hospices have helped to spark the revival of interest in death and dying. People’s stories about living and dying with diseases like cancer and AIDS were made visible in movies, music, books and TV shows, and this created a revival of interest in death and dying.

Presently in our culture we seem to be experiencing a type of “pornography” of death (Gorer 1965) with a whole slew of violent, popular movies showing people being killed for “fun.” Because of the increase in population, violent deaths on the street, in wars and at “home” have increased in a manner unparalleled in human history. Individuals like Sue Rodriguez, Nancy B, Jack Kevorkian and others involved in the Right to Die movement also raise awareness of death and dying. All of these factors, plus others, have increased medical, legal, religious, political and social discussion and debate about who should or will die, where, when, how and why.

Implicit in some of these discussions is the notion that there are “right” ways to die—at home, or at least in a hospice, surrounded by loving, open, family and friends. Like the midwifery movement which assured women it was better to have babies at home, hospice and palliative care philosophies tell the dying and their important ones that it is better to die at home. I have discussed earlier the arguments put forward by some practitioners in the palliative care field against legalizing euthanasia, who advocate instead that governments spend more money on palliative care. This debate is a political one in the fight over limited health care funding. It is possible for patients to want access to both palliative care and euthanasia.

I have also noted that some health care providers in Canada, the U.S.A., and the U.K. argue that such care is “Cadillac service” for a few. This argument suggests that all dying persons should receive quality holistic care, with high nurse-patient ratios and adequate pain and symptom relief. Palliative care should not be accessible only to a minority. The principles of palliative care include an ideology that suggests it is better for patients and their important ones to be open about death, to communicate their fears and feelings fully and to attend to their unfinished business. This ideology underpins the effectiveness of palliative care and may create a set of value judgments to which patients and their loved ones may not adhere.

Recently there have been more movies with death as a main theme. Ever since Love Story we have seen other films such as Terms of Endearment; Phila-
delphia; Beaches; Ghost; Truly, Madly, Deeply; Phenomenon; Four Weddings and A Funeral; Outbreak; It's My Party; Jeffrey; And The Band Played On; Long Time Companion and so on. Many of those listed deal with the subject of AIDS, and others present a basically unrealistic plot line where once an individual receives a terminal diagnosis, apart from their demise, everything ends happily. As well as movies there are also numerous books which deal with the topic, ranging from revised editions of classics like the Tibetan Book of the Dead (Rinpoche 1993) to novels, children’s books, works of non-fiction and plays.

The news media in particular has focused on radio and television broadcasts covering contentious issues like euthanasia and mercy killings centred around people like Robert Latimer, Sue Rodriguez and Dr. Nancy Morrison. Dr. Jack Kvorkian in the U.S.A. has also provided the broadcast media with many news stories on the use of his “death machine,” and there is an internet site devoted entirely to Dr. Kvorkian. The deaths of Diana, Princess of Wales, and Mother Teresa of Calcutta brought the subjects of death, grief and bereavement into millions of homes around the world. A very interesting component of these deaths, as with those of Elvis Presley, Marilyn Munroe, Janis Joplin, John Lennon, Sonny Bono and other celebrities is that the general public was able to express outpourings of grief in a communal manner while not necessarily being able to do so for people they knew and loved.

Throughout the television coverage of Princess Diana’s funeral, those in attendance along the route and surrounding Westminster Abbey made statements like, “I never cried so much even after my dad died,” or “I’ve never felt such pain as this no matter who had died.” Michael Traber notes that death “as part of a spectacle of violence, is the staple face of the mass media” (1992:3). Death or mourning of ordinary persons, unless the death occurred in tragic, newsworthy circumstances is, totally excluded from public view. As Traber notes, the invisibility of “real deaths” and the proliferation of newsworthy ones obscures some of the real human tragedies in our lives and allows us to confuse movie, soap opera, cartoon and other contrived deaths with the real thing. Trabor states,

This is the century of the Holocaust, the century of mass starvation and infants’ death, and a century of seemingly never-ending genocides and wars. It all fits into the general framework of the Western value system, expressed and reinforced by the mass media, that life on earth is cheap, that it can be disposed of easily, and that life is annihilated according to specific patterns related to status and power. (1992:5)

Demographics
Due to the increase in an aging population, with Canadians in general dying much later in life, there is a revival of interest in death and dying issues among
older persons. How cultures deal with an ever-increasing number of elders and the diseases which affect them is also a contemporary topic. The AIDS epidemic, hepatitis, and the re-emergence of tuberculosis also creates a revival of interest in this topic.

As the world population continues to grow, concern is heightened regarding the use of land for burial rather than shelter or food production, as well as the pollution caused by funeral pyres, placing remains in rivers and crematoria waste. There is a renewed interest in what happens to the physical and material world as a consequence of people dying.

**Politics**

Politics is involved in all levels of decision making and we see this clearly regarding euthanasia, the death penalty, and funding for palliative care, home care and AIDS treatment. In spite of the notion that health care is accessible to all Canadians, with recent cut-backs to health care programs across the country we see that the smaller provinces, i.e., those in Atlantic Canada, already geographically marginalized, are hit hardest when it comes to hospital closures. As well, there appear to be greater hardships for those in rural communities than those in larger population centres with greater tax revenues and political clout.

Those who provide services to the dying and their important ones at home normally utilize programs offered by the Victorian Order of Nurses, the Red Cross and provincial home care agencies. These organizations, usually funded through provincial ministries of social and community services, are also experiencing funding cut-backs. Although governments pay lip service to the care of the dying, few provinces in this country provide adequate resources to assist this group of citizens. Providing adequate care to the dying and their important ones is not politically a high priority, possibly because the dead do not vote!

**Religion**

The role of denominational religious institutions, for example, the Canadian Council of Catholic Bishops, in the euthanasia and abortion debates has also increased an awareness of death and dying issues. Religions have also imposed notions of morality and sin, especially concerning the AIDS pandemic.

Berger (1967) has noted that religion has always been involved in matters relating to death, particularly the notions of leading a “good” life until death, what happens after death and the very meaning of life and death. As organized religions grapple with issues such as abortion, reproductive technology, euthanasia and assisted suicide, this creates a revival of interest, debate and discussion of the topic of death and dying.

**Law**

As well as in the political realm, the euthanasia debate takes place within the legal profession, as we have seen with prominent cases like those of Robert
Latimer, Sue Rodriguez and Dr. Nancy Morrison. Living wills and medical directives are also funnelled through legal jurisprudence.

Corr, Nabe and Corr note that the law is involved in issues related to death and dying in three important ways. They are: (1) prior to death in legal matters such as “advance directives for the treatment of the dying”; (2) those that arrive with death itself, the “definition, determination and certification of death”; and (3) “those which may have been initiated prior to death, but whose real force is exerted after death, such as organ, tissue or body donation, and broader questions concerning disposition of one’s body and property” (1997:436).

In Canada, as discussed earlier in the chapter on euthanasia, legal issues most prominently contribute to a revival of interest in death and dying through various court challenges regarding those who have been accused of committing euthanasia, assisted suicide, or mercy killing.

**Medicine**
The field of medicine clearly plays a pivotal role in public awareness and the revival of interest in death and dying. Pain control, diagnostic abilities, comfort measures, and definitions of death all fall within the public discourse of the medicalization of death. There is more awareness in Canada today that dying is a natural process which need not be medicalized or legalized. McCue (1995:1039) notes that, “Medicalizing dying deprives individuals of their autonomy.” Medical advances with the ability to create life through reproductive technology, prolong and maintain it through life-saving machines like dialysis, or end it via lethal injection all have an impact on public perceptions of how, where, when and if people die. The field of cryonic suspension also raises interesting notions of immortality and a different kind of life after death.

**AIDS**
The fear of AIDS/HIV has taught us many lessons about dealing with the dying. It has also created, especially in the media, a two-tiered system of morality where homosexuals, drug users or “promiscuous” individuals are categorized as “guilty” victims of AIDS, whereas those who contracted the disease due to tainted blood products are viewed by some in society as “innocent” victims of the disease. This guilty/innocent dichotomy became most visible in the media during the compensation hearings of the Randy and Janet Connors case and during hearings of the Krever inquiry (Vacon 1991).

The AIDS/HIV tragedy also publicly raised other issues about testing procedures, confidentiality and homophobia. As well, it taught us that medicine is not gender blind when it comes to diagnosing women.

**Euthanasia**
No topic has touched the hearts and minds of Canadians over the past twenty years as has euthanasia or mercy killing. Television and radio talk shows have
focused on the pros and cons of assisted suicide, both in Canada and the U.S.A. As well, individuals like Sue Rodriguez and Robert Latimer have placed a human face on the consequences of euthanasia.

All of these issues have sparked an awareness and renewal of interest in death and dying in Canada today. What used to be a matter of private grief has now become part of the public discourse of ethics, morality and law.

As we struggle towards a culture of individualism, the “Death with Dignity” movement encourages what Tony Walter (1996) terms the “doing it my way” approach to dying. As the popular media covers stories of persons who choose to die based on their vision of the good death, these images cause Canadians to rethink human concerns with death and dying. All of these interconnected events raise a public awareness of death and dying in our culture. No long-standing questions are answered, such as why we die, what is the purpose of life, or how we will die, but certainly the topics of death and dying are taking front stage in public and private discussions across the country.

Suggested Readings

Discussion Questions
1. Where do you hear, see or observe a revival of interest in death and dying?
2. How have views about death changed since your parents’ and grandparents’ times?
3. Why do you think we grieve publicly over the deaths of celebrities?

In-class Assignments
1. Look up newspaper accounts of the death of a celebrity of your choice. What sorts of themes emerge from these stories?
2. Make a list of celebrities who have died in your lifetime. Rank them based on age, gender and cause of death. What impact did these deaths have on your life?
3. Which death of a famous person has most impacted on your life? Why?
4. Count up the number of movies you have seen with death as a main theme. What sorts of images were portrayed? Have others in the class do the same for pop songs and videos and compare your responses.