Chapter 19Death, Dying, and Bereavement

Death Itself

- **clinical death** refers to the few minutes after the heart has stopped pumping, when breathing has stopped and there is no evident brain function, but during which resuscitation is still possible.
    - **Heart attack patients are sometimes brought back from clinical death;**
- **Brain death** (referred to as *whole-brain death* in some jurisdictions) describes a state in which a person no longer has reflexes or any response to vigorous external stimuli and shows no electrical activity in the brain—essentially, irreversible failure of the cerebrum, cerebellum, limbic system, and brain stem.
    - **When the cerebral cortex, but not the brain stem, is affected, the person may still be able to breathe without assistance and may survive for long periods in a vegetative state or on life-support systems**.
- However, when the brain stem irreversibly ceases to function, no body functioning can occur independently, and, in Canada, the individual is said to be ***legally dead***
    - **Brain death most often occurs after a period of eight to ten minutes of clinical death,**
- **Social death** occurs at the point when the deceased person is treated like a corpse by others; for instance, someone may close the eyes or sign a death certificate.

End-of-Life Care

- majority of Canadians die in hospitals
- changing views about the process of dying means more families are turning toward an alternate form of end-of-life care for their terminally ill loved ones: hospice palliative care.

Hospital Care

- Almost **two-thirds of Canadians die in hospitals** rather than at home or in long-term care facilities
- **hospital death:**
    - **is more prevalent for older adults,** and somewhat more so for women than men
    - People with a terminal illness, such as cancer,
    - adults with terminal illness or chronic conditions

Hospice Palliative Care

- **hospice care**, a holistic approach to caring for the dying that embraces individual and family control of the process.
- Elisabeth Kübler-Ross, who emphasized the importance of a "good death," or a "death with dignity,"= patient and the patient's family have an active role in the process

- Many health care professionals, particularly in England, Canada, and the United States, believe that **death with dignity is more likely if the dying person remains at home, or in a home-like setting, in which contact with family and friends is part of the daily experience.**
- **Palliative care:** The emphasis is on controlling pain and maximizing comfort, not on invasive or life-prolonging measures.
- **hospice palliative care:** relief of suffering and the improvement of the quality of living and dying.
- **Hospice palliative care helps dying patients and their families to:**

1. address physical, psychological, social, spiritual, and practical issues and their associated expectations, needs, hopes, and fears.
2. prepare for and manage self-determined life closure and the dying process; and
3. cope with loss and grief during illness and bereavement

- **Model of Dignity**
    - shows that a loss of dignity is associated with increased levels of distress in the terminally ill
    - Subsequently, Chochinov developed the **Patient Dignity Inventory (PDI)** to **objectively measure dignity-related distress** in palliative care for the purpose of fostering psychotherapeutic interventions to help patients die with greater dignity
    - evidence suggests that **patients who participate in *dignity-based care*** report a **heightened sense of dignity, an increased sense of purpose, a heightened sense of meaning, better pain endurance, and an increased will to live**
    - the families of terminally ill patients were better prepared for the future.
- most communities in Canada provide some form of hospice palliative care
- no more than 4 out of 10 Canadians who are dying have access to quality hospice palliative care

Caregiver Support

- **Hospice palliative care providers now recognize that caregivers have needs as well**
- particularly important for the roughly 1 in 5 Canadians in their 50s and 60s who provide end-of life care for a parent, spouse, grandparent, or other family member or friend
- the majority of those caring for a dying loved one, particularly someone with cancer or dementia, induces a ***grief response*** both in anticipation of and following the death of their loved one
- For some caregivers, the grief response can be persistent and involve serious psychological disorders, such as depression, anxiety, PTSD, and/or substance abuse
- an important element of palliative hospice care is grief support for caregivers; often require support services because of the emotional strain involved in caring for patients who are terminally ill.

- caring for those who are dying is seen as an opportunity to address questions about the meaning and purpose of life which benefits them personally as well as their patient
- The Canadian Virtual Hospice enables palliative hospice care experts to interact directly with informal caregivers and palliative hospice care providers, provide access to a wide range of palliative hospice care services, and bring medical expertise to the home, and to rural and remote areas of Canada.

The Meaning of Death Across the Lifespan

Children's and Adolescents' Understanding of Death

- **preschool-aged children typically understand none of these aspects of death.**
    - They believe that death can be reversed, for instance, through prayer, magic, or wishful thinking; they believe that dead persons can still feel or breathe.
- young children's ideas about death are rooted in their lack of understanding of life
- teaching young children about the nature of biological life helps them understand what causes death and why it is irreversible.
- [when they start school] Children 6 to 7 years of age comprehend death as a biological event in which the heart ceases to beat, the lungs no longer take in air, and brain activity stops
- the child's specific experience seems to make a good deal of difference.
    - Experiences in which children discover a dead animal, lose a pet, or are exposed to a story in which a character dies (e.g., *Bambi*, *The Lion King*) can also speed up their understanding of death
- **Adolescents understand the finality of death better than children do.**
- in an abstract sense, they understand that death is inevitable
- [adolescents tend to overestimate their own chances of death] This phenomenon is most pronounced among teens who have personal experience with death, particularly those who live in high-crime neighbourhoods.
- Unrealistic beliefs about personal death also appear to contribute to adolescent suicide.
- Teens who attempt suicide claim to understand that death is final, (believe temporary escape from a stressful personal problem)
- some teenagers who attempt suicide believe that death is a pleasurable experience for most people who die
- suicidal adults typically think of death, even when it is desired, as painful and unpleasant.
- **the loss of someone close, such as a sibling, may lead an adolescent to re-examine critically her ideas about death**—both as a general concept and as something that is inevitable for herself

The Meaning of Death for Adults

Early Adulthood

- **young adults** have a sense of **unique invulnerability**—a belief that bad things, including death, happen to others but not to themselves.
- many believe that they possess unique personal characteristics that somehow protect them against death.
- many young adults engage in high-risk activities such as rock-climbing because succeeding at them reinforces invulnerability belief
- the loss of a loved one appears to shake a young adult's belief in unique invulnerability and, as a result, is often more traumatic for younger than for older adults
- such losses frequently lead to suicidal thoughts in young adults.
    - Young adults who have recently lost a loved one in an accident or because of a homicide or a suicide are about 5 times as likely to formulate a suicide plan as young adults who have not had such a loss, although most never follow through with their plans
- to maintain belief in their own unique invulnerability, young adults must come up with reasons why death came early to others but will not happen to them (celebrities = they elevate such figures to near-sainthood).

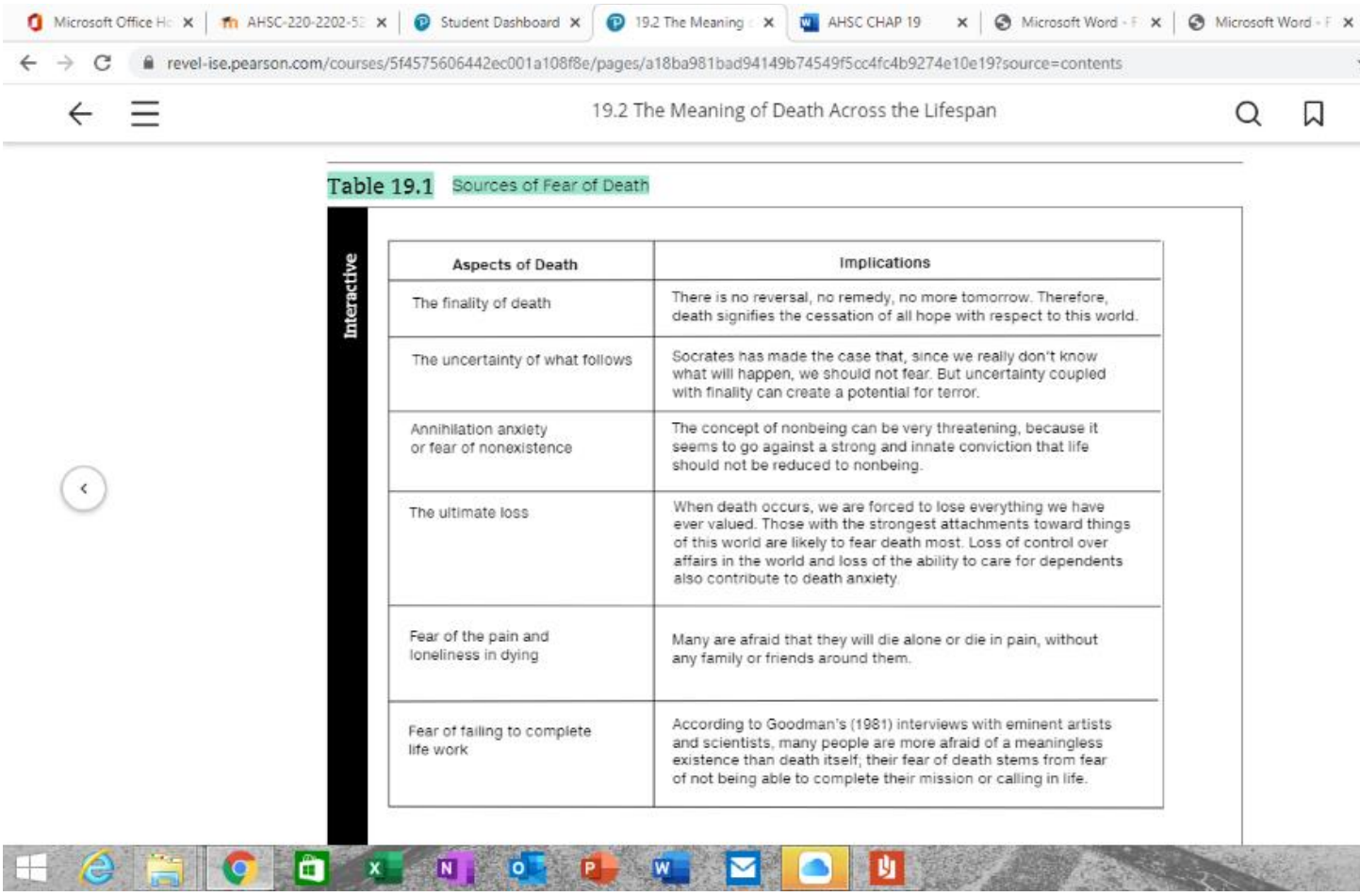
Middle and Late Adulthood

- when an elder dies, everyone else in that lineage "moves up" in the generational system
    - The death of a parent can be particularly unsettling for a middle-aged adult if the adult does not yet consider himself ready to assume the elder role.
- An individual's death also affects the roles of people beyond the family, such as younger adults in a business organization, who then can take on new and perhaps more significant roles.
- death brings many permanent changes in families and social systems.
- In middle age, most people exhibit a shift in their thinking about time, **thinking less about "time since birth" and being more aware of "time until death."**
    - One study of a group of **adults aged 72 and older found that only about half thought in terms of "time remaining"**
    - those who did think of death in these terms had less fear of death than did those who thought of their lives as "time lived."
    - **Middle-aged and older adults who continue to be preoccupied with the past are more likely to be fearful and anxious about death**

Death as Loss

- Young adults are more concerned about loss of opportunity to experience things and about the loss of family relationships
- older adults worry more about the loss of time to complete inner work.

- [if you were told you had 6 months to live]
    - Younger adults were more likely to say that they would seek out new experiences
    - older adults were considerably more likely to say that they would turn inward (disengagement theory)
- [Wong] our fear of death stems from six existential uncertainties



Fear of Death Across Adulthood

- **middle-aged adults are most fearful of death**
- For **young adults, the sense of unique invulnerability probably prevents intense fears of death.**
- In **middle age, though, belief in one's own immortality begins to break down, resulting in increasing anxiety about the end of life.**
- by **late life, the inevitability of death has been accepted, and anxieties are focused on how death will come about**.

- older adults do not become less preoccupied with death, and most would prefer to extend their lives
- To an older person, particularly one who has a strong sense of having lived for some higher purpose, death is highly important, but it is apparently not as frightening as it was at mid-life
- older adults are more likely to fear the period of uncertainty before death than they are to fear death itself
    - They are anxious about where they may die, who will care for them until they do, and whether they will be able to cope with the pain and loss of control and independence that may be part of the last months or years of life

Religious Beliefs

- adults who are deeply religious or who regularly go to their place of worship for spiritual reasons are less afraid of death than those who describe themselves as less religious or who participate less regularly in religious activities
- both those who are deeply religious and those who are totally irreligious report less fear of death.
- the most fearful may be those who are uncertain about or uncommitted to any religious or philosophical tradition.
- **Religious beliefs may moderate fears of death** = religious people tend to view death as a transition from one form of life to another, from physical life to a spiritual one.
- **the belief that God exists increases with each age group**
- **belief in life after death decreases with age**
- [Dorothy Ley and Harry van Bommel] the spiritual search for meaning in our lives is often intensified by the reality of death.
- religious beliefs provide adults with death stories that help them cope with both their own deaths and those of loved ones
    - for example, Jewish scriptures, the Christian Bible, and the Muslim Quran all contain many stories that convey the idea that death comes when one's purpose in life has been fulfilled.
- death is portrayed as a necessary part of the transfer of responsibility from one generation to another.
    - This kind of philosophical approach to death leads believers to focus on the contributions to family and community that they have made during their lives rather than on the losses they will experience at their deaths.

Personal Worth

- Feelings about death are also linked to one's sense of personal worth or competence
- Adults who feel that they have achieved the goals they set out to achieve, or who believe that they have become the persons they wanted to be, are less anxious about death than are those who are disappointed in themselves

- Adults who believe that their lives have had some purpose or meaning also appear to be less fearful of death, as do those who have some sense of personal competence
- Adults who have not been able to resolve the various tasks and dilemmas of adulthood face their late adult years more anxiously, even with what Erikson described as despair.

Preparation for death occurs on several levels.

- **At a practical level,** regardless of age, **most adults agree that it is important to prepare for death**
- issuing advanced care directives regarding end-of-life care, often called a **living will.**
- **health-care power of attorney** specifies who can make decisions for an individual in the event that he or she becomes unable to do so.
- most people agree that advance funeral planning can help bereaved family members deal with the many decisions they must make in the hours and days following the death of a loved one.
- older adults are far more likely than younger adults to have made such preparations

Terminal Decline

- **At a somewhat deeper level, older adults may prepare for death through some process of reminiscence.**
- those nearer to death became increasingly more conventional, docile, dependent, and non-introspective, a pattern that did not occur among those of the same age who were further from death.

The researchers set out to identify and describe well-being at the end of life.

- They found:
  - sharp declines in life satisfaction, commencing in the four years prior to death.
  - individuals dying at older ages spend more time in the terminal period of life satisfaction decline than individuals dying at younger ages.
- A Canadian research team has observed a pattern of change in mental functioning that is characteristic of a **terminal decline**—there tends to be a gradual, but accelerating, decline in overall cognitive functioning over the course of roughly six years
- not all cognitive abilities decline at the same rate
- a sudden, steep drop in crystalized intellectual ability seems to signal that death is imminent

The Process of Dying

- Elisabeth Kübler-Ross (1926–2004) was a Swiss-American psychiatrist who studied the experiences of the dying and their loved ones.
- In the 1960s, she formulated a model that asserted that those who are dying go through a series of psychological stages.

- In Kübler-Ross's early writings, she proposed that those who know they are dying move through **a series of steps, or stages, arriving finally at the stage she called *acceptance*.**

1. Kübler-Ross's model predicts that most people who are confronted with a terminal diagnosis react with some variant of "Not me!" "It must be a mistake," "I'll get another opinion," or "I don't feel sick."
    a. Reactions = forms of ***denial*,** a psychological defense that may be highly useful in the early hours and days after such a diagnosis.
    b. Denial of this kind may be helpful in insulating a person's emotions from the trauma of hearing such news.
    c. Keeping emotions in check in this way may help an individual formulate a rational plan of action based on "What if it's true?"
2. Kübler-Ross thought that these extreme forms of denial would fade within a few days, to be replaced by ***anger*.**
    a. The model suggests that anger among the dying expresses itself in thoughts such as "It's not fair!" but a dying person may also express anger toward God, the doctor who made the diagnosis, nurses, or family members.
    b. The anger seems to be a response not only to the diagnosis itself, but also to the sense of loss of control and helplessness that many patients feel in impersonal medical settings.
3. ***Bargaining*** follows anger in the Kübler-Ross model.
    a. In this form of defense, the patient tries to make "deals" with doctors, nurses, family, or God: "If I do everything you tell me, then I'll live till spring." Kübler-
    b. Bargaining may be successful as a defence for a while, but the model predicts that, **eventually, bargaining breaks down in the face of signs of declining health.**
4. At this point, Kübler-Ross's theory predicts, the patient enters the stage of ***depression*.** According to Kübler-Ross, depression, or despair, is a necessary preparation for the final stage of *acceptance*.
5. To reach **acceptance**, the dying person must grieve for all that will be lost with death.

<u>Criticisms and Alternative Views</u>

- Kübler-Ross's model has provided a common language for those who work with dying patients, and her highly compassionate descriptions have, without doubt, sensitized health care workers and families to the complexities of the process of dying.
- Many new programs for terminally ill patients are clearly outgrowths of this greater sensitivity to the dying process.
    - Kübler-Ross's basic thesis—that the dying process necessarily involves these specific five stages in this specific order—has been widely criticized.
    - small sample raises questions about the generalizability and cross-cultural relevance of her findings.
    - Centers on the issue of stages

- not all dying patients exhibit these five emotions, let alone in a specific order.
- Of the 5, **only depression seems to be common among Western patients.**
- **thanatology** (the scientific study of death and dying)
- [Edwin Shneidman] argues that people who are dying display a wide range of emotional responses and do not all have the same needs.
    - **Shneidman suggests that the dying process has many "themes"** that can appear, disappear, and reappear in any one patient in the process of dealing with death.
    - themes include terror, pervasive uncertainty, fantasies of being rescued, incredulity, feelings of unfairness, a concern with reputation after death, and fear of pain.
- **"task-based" approach suggested by Charles Corr (1991/1992)**
    - oping with dying is like coping with any other problem or dilemma (You need to take care of certain specific tasks)
    - Corr suggests **four such tasks for the dying person:**
        - Satisfying bodily needs and minimizing physical stress
        - Maximizing psychological security, autonomy, and richness of life
        - Sustaining and enhancing significant interpersonal attachments
        - Identifying, developing, or reaffirming sources of spiritual energy, and thereby fostering hope
        - Corr argues that for health professionals who deal with dying individuals, it is more helpful to think in terms of the patient's tasks, because the dying person may need help in performing some or all of them.
- no common patterns typify most or all reactions to impending death.
    - Common themes exist, but they are blended in quite different patterns by each person who faces this last task.
- **Canadians prefer to focus on comfort more so than aggressive technologically based interventions**

Responses to Impending Death

- [study involving 26 terminally ill men] researchers found that many of the men believed that they could avoid entering the process of actively dying by continuing to engage in their favorite hobbies
    - **Such findings raise questions about whether attitudes and behavioural choices can influence the course of a terminal disease.**
- [Steven Greer and his colleagues] followed 62 women diagnosed with early stages of breast cancer in the 1970s.
    - **Three months after her original diagnosis, each woman was interviewed at some length and her reaction to the diagnosis and her treatment was classed in one of five groups:**

- ***Denial (positive avoidance).*** The person rejects evidence about diagnosis; she insists that surgery was just precautionary.
- ***Fighting spirit.*** The person maintains an optimistic attitude and searches for more information about the disease. These patients often see their disease as a challenge and plan to fight it with every method available.
- ***Stoic acceptance (fatalism).*** The person acknowledges the diagnosis but makes no effort to seek any further information; or, the person ignores the diagnosis and carries on normal life as much as possible.
- ***Helplessness/hopelessness.*** The person acts overwhelmed by diagnosis; she sees herself as dying or gravely ill and as devoid of hope.
- ***Anxious preoccupation.*** Women in this category had originally been included in the helplessness group, but they were separated out later. The category includes those whose response to the diagnosis is strong and persistent anxiety. If they seek information, they interpret it pessimistically. They monitor their body sensations carefully, interpreting each ache or pain as a possible reoccurrence.

<u>Responses to Impending Death</u>

- Greer then checked on the survival rates of these five groups after 5, 10, and 15 years:
  - **Only 33% of the women whose initial reaction had been a fighting spirit had died of cancer 15 years later, compared with 76% of the women whose initial reaction had been denial, stoic acceptance, anxious preoccupation, or helplessness/hopelessness.**
  - **coping strategies more generally affect the likelihood of disease in the first place.**
  - [subsequent study] Greer reported that the **link between the fighting spirit and cancer survival was likely to have been due to an absence of an anxious or hopeless approach to the disease**
  - having a fighting spirit does not necessarily increase a cancer patient's chances of survival, but an anxious or hopeless attitude reduces it.
- [Canadian cancer psychologist Alistair Cunningham and his colleagues] wanted to look at how much better each person did than expected, and how this correlated with their engagement in the self-help work.
  - 1/3 of patients who became most engaged in self-help lived much longer (about 3 x on average) than the 1/3 who were least engaged,
  - 10 of 22 patients with medically incurable cancers outlived their prognosis from 2.2 to 12.5 years
  - 2 of the patients had complete remission of their disease—the difference being that those with the higher survival rates displayed a much higher degree of early

involvement in their psychological self-help than did most of their non-surviving peers.
    - Long-term survivors also saw their lives as having changed profoundly: They came to understand what was important and meaningful to them (authenticity); to exercise freedom of choice in determining how to live their lives (autonomy); and they exhibited greater "acceptance," evidenced by enhanced self-esteem, greater tolerance for and emotional closeness to others, and an affective experience described as more peaceful and joyous.
- suffering can be lessened while survival can be prolonged by psychological interventions
- research shows that, along with the body's own healing mechanisms and medical treatment, **mental state and attitude are associated with healing and can cause people to live longer in some cases**

The Experience of Grieving

- **In virtually every culture, the immediate response to a death is a funeral ritual.**
- **grieving**—the emotional response to a death—which may take months or years to complete.

Psychosocial Functions of Death Rituals

- Funerals, wakes, and other death rituals help family members and friends manage their grief by giving them a specific set of roles to play: these include both expected behaviours and prohibited or discouraged behaviours.
- In Canadian society, depending on one's ethnic or religious background, the rituals prescribe what one should wear, who should be called, who should be fed, what demeanour one should show, and far more.
- Death rituals also bring family members together as no other occasion does (apart from weddings).
- Such occasions typically inspire shared reminiscences and renew family relationships that have been inactive for a long time
- death rituals can strengthen family ties, clarify the new lines of influence or authority within a family, and "pass the torch" in some way to the next generation
- A death can become an important organizer of experience that separates the past from the present: dividing time in this way seems to help survivors cope with grief
- Death rituals are also designed to help the survivors understand the meaning of death itself, in part by emphasizing the meaning of the life of the person who has died.
- By telling the story of a person's life and describing that life's value and meaning, others can more readily accept the person's death.
- death rituals may give some transcendent meaning to death itself by placing it in a philosophical or religious context

Age of the Bereaved

- **Children express feelings of grief very much the way teens and adults do**
- children demonstrate grief through sad facial expressions, crying, loss of appetite, and age-appropriate displays of anger, such as temper tantrums
- most children resolve their feelings of grief within the first year after the loss.
- knowing that a loved one or even a pet is ill and in danger of death helps children cope with the loss in advance, just as it does for those who are older
- **teens may be more likely to experience prolonged grief than children or adults.**
- Adolescents may also grieve longer than children or adults for lost siblings; in some cases, teens continue to have problems with grief-related behaviours, such as intrusive thoughts about the deceased, for as long as two years after the death of a sibling
- adolescent girls whose mothers have died run a particularly high risk of developing long-term, grief-related problems
- Teenagers may also be more likely than adults to experience grief responses to the deaths of celebrities or to idealize peers' suicides.
- Adolescents' grief responses are probably related to their general cognitive characteristics.
- Prolonged grieving among adolescents may be rooted in their tendency to engage in this kind of "what if" thinking
    - may lead teens to believe that they could have prevented the death and, thus, cause them to develop irrational guilt feelings

Mode of Death

- **How an individual dies also contributes to the grief process of those who are in mourning.**
- widows who have cared for spouses during a period of illness prior to death are less likely to become depressed after the death than those whose spouses die suddenly
    - Grief-related depression seems to emerge during the spouse's illness rather than after the death.
- a death that has intrinsic meaning, such as that of a young soldier who dies defending his country, is not necessarily easier to cope with but does provide the bereaved with a sense that the death has not been without purpose
- mourners have a **built-in cognitive coping device**—a rational explanation for the death—that allows them to grieve but also protects them from long-term depression.
- **Sudden and violent deaths evoke more intense grief responses**
    - one study found that 36% of widows and widowers whose spouses had died in accidents or by suicide were suffering from post-traumatic stress disorder (PTSD) symptoms (e.g., nightmares) two months after the death, compared with only 10% of widows and widowers whose spouses had died of natural causes
    - almost all those whose spouses had died unnaturally and who had PTSD symptoms were also depressed.

- **Death in the context of a natural disaster is also associated with prolonged grieving and development of symptoms of PTSD**
- the most frustrating aspect of the grieving process for people who have lost a loved one through a **violent crime** is the inability to find meaning in the event
    - In the initial phases of the grief process, survivors protect themselves against such frustration through cognitive defenses, such as **denial,** and by focusing on tasks that are immediately necessary
    - survivors often channel their grief and anger into the criminal justice process through which they hope that the perpetrator of the crime will be justly punished.
    - survivors eventually become involved in organizations that support crime victims and survivors of murdered loved ones or those that seek to prevent violence
- suicide is associated with a unique pattern of responses among survivors
    - family and close friends of someone who commits suicide experience feelings of rejection and anger.
    - their grief over the loss of the loved one is complicated by the feeling that they could or should have done something to prevent the suicide.
    - a source of shame.
    - suicide survivors may be more likely than others who have lost loved ones to experience long-term negative effects.

Widowhood

- bereaved parents often report that their health is poorer after a child's death than it was before the death, and many parents continue to experience intense feelings of sadness for several years
- children who lose a sibling sometimes worry that thoughts produced by sibling rivalry, such as wishing a brother or sister would die, caused the death
- the most difficult death to recover from is that of a spouse

Widowhood and Physical Health

- The experience of widowhood appears to have both immediate and longer-term effects on the immune system
    - Investigators found that the widows' immune systems were suppressed somewhat immediately after the death but in most cases had returned to normal a year later.
    - widows' immune responses continued to differ from those of married participants seven months after the spouses' deaths, even though psychological differences (such as feelings of sadness) between the two groups had disappeared
- **Widowhood** applies to both men and women
    - **widow** refers to women
    - **widower** to men

- the association between death of a spouse and ensuing illness in the surviving partner may be the **result of the effects of grief on the body's defenses against disease agents such as viruses and bacteria**

Widowhood and Mental Health

- mental health of older adults whose spouses have died may differ for several years following the death from the mental health of peers whose spouses are still alive
- **declines in mental health follow bereavement**, but how long such effects last may be highly variable.
    - One such factor is **mental health history.** Older adults who enter widowhood with a history of depression or poor health are more likely to experience depression after the death of their spouse
    - Depressive symptomology, anxiety, and somatic complaints were predicted by a combination of risk factors, including lower age, shorter duration of widowhood, lack of social support (both actual and perceived), more physical illness/disabilities, and a lower sense of mastery (i.e., their perceived sense of influence over outcomes).
- the **quality of the relationship of the widow or widower with the deceased spouse is related to depressive symptoms.**
    - Widows who report **high levels of marital satisfaction are more likely than less satisfied widows to experience depression**
- **Economic changes accompany the loss of a spouse and add to the overall stress involved in the transition to widowhood.**
    - **women suffer greater economic losses** after the death of a spouse than men do, usually because they lose their husbands' income or pension
    - the degree to which an individual's economic status changes as a result of a spouse's death is probably another factor that contributes to individual differences in the long-term effects of bereavement.