END OF LIFE ISSUES

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Death. We do not say the word a lot. Speaking of dying may be the last taboo. We talk readily of sex – magazine articles highlight how women can please themselves and their guys in bed. We talk of money; Suze Orman and Dave Ramsey have given financial advice to millions. We talk politics. If you turn on Fox or MSNBC, the focus on political news is 24/7. But we don't say "he died". Even obituaries use euphemisms – he passed on, she went to her heavenly reward, he joined his beloved wife in the hereafter.

I. Introduction

Ernest Becker, the cultural anthropologist, asserted in The Denial of Death (1997) that fear of death is the primary motivator of human behavior, not sexuality as Freud had argued. Humans are the only animals who understand the inevitability of their own death. As a result, humans devote their lives to enhancing their perceived value, which may live on after them. Frequently, they embrace religions that assure immortality.

Psychologists Greenberg et al. (1986) have used Backer's death anxiety to develop Terror Management Theory. They assert that fear of death drives people to avoid thinking of their own deaths and to cope by working to establish their own importance: my work, my fame will live on (even when I do not). Yet there is a danger in overgeneralizing. Not everyone fears death. Many Latinx Americans celebrate the Day of the Dead in early November. They go to cemeteries to be with the souls of the departed. They build temporary shrines in their homes to honor family members who have died. They post pictures of the dead and eat their favorite foods to be with them in spirit.

Some older adults wish to die. Studies in European countries have found that 10 to 20% of older adults are ready to die:

- Some are clinically depressed and are experiencing suicidal ideation.
- Most are not depressed but have experienced a life of adversity and/or traumatic events and are ready to let go of this life. Some are believers in an afterlife who long to join a deceased spouse in heaven (Rurup et al., 2011).

Belvedere (2021), a psychologist who has worked with nursing home residents, has found that many older adults welcome the opportunity to discuss their deaths. They may share fears or hopes for the care they wish to receive in their final days. Some older adults strongly value these discussions because their own families are unwilling to talk about the coming death of their loved one.

Young adults think seldom of their future deaths; they are full of life and energy. They focus on building careers and enjoying the present. As time passes, some focus on finding a life partner to share intimacy and build a family. They have little reason to contemplate their own deaths.

Middle aged adults are maturing in their careers, becoming partners in their law firms, achieving tenure where they teach, becoming craftsmen in their trades and arts. Their children are growing older and are about to leave home for college, the military or youthful adventures. Wise middle aged adults are aware that good health habits in the middle years will often yield more time being healthy and independent as they age (Blackburn and Epel, 2017). They may not consider their deaths often, but focusing on healthy living can pay major dividends.

Older adults very greatly in their willingness to consider their own mortality, even in spite of a terminal diagnosis. Years ago, I worked with a widow whose husband denied he had cancer and refused to discuss his coming death. He had bone cancer which resulted in the loss of a leg. Yet he insisted his oncologist was in error about the cancer. He would not allow his wife to cry, share sadness or in any way say goodbye. She struggled for several years with processing her grief because of his denial.

Other older adults know that their death will eventually come. They may have some anxiety about loss of cognition or memory, about pain, about how their end will occur. They maintain positive relationships, a healthy diet and regular exercise to prolong quality years. They are not in denial. They have written wills and have advance directives. They do not spend a lot of time thinking about their own dying.

Some older adults seek out information about dying. They face their fear of death to be prepared for their inevitable end of life. Such adults are likely to value Advice for Future Corpses by Sallie Tisdale (2018), an informative, witty book by a palliative care nurse who has walked the last days with many of her patients. I will refer to her wise vignettes throughout this home study.

This paper will address

- the most frequent causes of death
- the psychological issues salient at the end of life
- communication with physicians and family

- the spiritual traditions about death and the afterlife
- caring for a dying person in their last days
- doing grief work
- the pros and cons of physician assisted death.

II How We Die

Death is more likely to come as our cells age and become less able to replicate. In most years, heart disease and cancer are frequent and common causes of death. Alzheimer's is the most frequent cognitive disorder; it slowly robs the person of new memories and eventually memories of the past. American physicians save lives daily with the most up-to-date diagnostics and treatments. Yet some physicians at the end of life are not trained to have sensitive discussions about how death will come and what the dying person's wishes are for their last days. Of course, not all those who die are elderly. Parents who lose their children need intense work to heal from such a devastating loss.

Death arrives at our doorstep at various times and in many forms. As young adults we may face death due to a car accident. In middle age death can be due to cancer of breast, colon or lung, or of alcoholism, drug abuse or suicide. In 2020, over 300,000 people died from Covid -19. Yet most Americans live to old age. If you are alive at 65, the odds are high that you will live about another twenty years (CDC, 2020). Research into cellular aging is helping us understand when we are likely to have many more years and when death is likely to be closer. Elizabeth Blackburn won the Nobel Prize for her research into telomeres and telomerase. We have more good years (healthspan) when our cells are able to divide; old cells die off, new cells replace them. Cells are able to divide a limited number of times (the Hayflick limit). That limit is governed by the length of the telomeres at the end of each DNA strand. Telomeres, which can break down from daily stress, are depleted as we age. When the limit of telomere division is reached, cells begin to break down and we are more prone to terminal illness (disease span). Blackburn discovered that we can add telomerase to the ends of DNA strands using good stress management, exercise, nutritious diet and other health related behaviors (Blackburn and Epel, 2017).

The Causes of Death

In 2018, the CDC (2020) reports the ten leading causes of death:

- heart disease (655,300)
- cancer (599,300)
- accidents (167,100)
- chronic lower respiratory diseases (159,500)
- strokes (147,800)
- Alzheimer's (122,000)

- Diabetes (85,000)
- influenza and pneumonia (59,100)
- kidney disease (51,400)
- suicide (48,300)

Clearly heart disease and cancer are the most frequent causes of death. Heart disease may involve heart attacks due to atherosclerosis (blocking of the arteries). Some die from arrhythmias like Afib (atrial fibrillation). Others have hearts that weaken slowly, and death comes from congestive heart failure. Heart disease can be kept at bay much longer with statins to reduce blockages, antihypertensives to reduce blood pressure and bypass surgery or angioplasty if necessary, allowing many Americans to live to their 80s (Nuland, 1995).
Rates of death from cancer have dropped almost 20% in the last 20 years, yet cancer remains a major cause of death. Lung cancer is decreasing, but remains the number one cancer that kills. The following cancers are lethal (from most frequent to less frequent):

- breast cancer
- prostate
- colon and rectum
- pancreas
- liver
- ovary
- leukemia
- non-Hodgkin lymphoma
- uterus (CDC, 2020)

Cancer can be prevented or postponed by healthy lifestyles:

- not smoking
- regular exercise
- the Mediterranean diet
- less red meat (especially processed meats)
- avoiding diabetes
- use of sunscreen
- informed use of medical care if cancer is identified at an early stage (Harvard Medical School, 2017).

People can die of accidents at all ages, e.g., motor vehicle accidents. Older adults are at risk from falls as they lose strength and balance. My father had Alzheimer's , but that did not kill him. He fell and developed an embolism which did end his life. Falls can be reduced by strength and balance training as well as environmental modifications, e.g., bath tubs with a door to allow easy entrance and exit (Jaret, 2018).

Chronic lower respiratory diseases include emphysema, chronic bronchitis and asthma. Chronic destructive pulmonary disease impairs the lives of many Americans and results in many deaths. Smoking is a major cause of these

disorders, but air pollution and occupational disorders like Black Lung disease (mining) can be deadly (Centers for Disease Control, 2020).

Strokes can be minor (TIA – Transient Ischemic Attack), temporary (Bell's Palsy), disabling (involving the middle cerebral artery), or can be fatal. Most strokes involve plaque blocking an artery in the brain. Notable symptoms include:

- **F**acial drooping on one side of the face
- **A**rm weakness
- **S**lurred speech.

Health educators use the acronym FAST to help us remember the three above symptoms. If someone has any of these symptoms, it is **T**ime to call for assistance quickly. If a person has a stroke due to a blockage and is given the appropriate blood thinner, his life can be saved and disability can be minimized. Confirmation via MRT or CT scan can be lifesaving. However, a smaller number of strokes are due to an aneurysm, a bulging or tearing of a blood vessel in the brain. Aneurysms can be fatal unless surgery is done to stem the blood flow. If the medication for artery blockage is given to a person with an aneurysm, the result is likely to be death – it is clear that a brain scan is indicated at the time of a stroke (WebMD, 2019). Risk for stroke can be reduced by:

- use of anti-hypertensives for high blood pressure
- use of statins for high cholesterol
- not smoking
- the Mediterranean diet
- avoiding diabetes (Harvard Medical School, 2017).

Alzheimer's affects over 5,000,000 Americans and their families. Early Onset Alzheimer's is primarily a genetic disorder which devastates the lives of 200,000 adults with symptom onset before 65. More commonly, the memory loss and difficulty with daily living skills associated with Alzheimer's are more frequent as adults reach 80 (WebMD, 2019). Alzheimer's is feared because it robs the person of their recent memories initially and eventually their long-term memories, identity and personality. Alzheimer's Disorder (AD) changes the lives of family members who become caregivers, whether spouses or adult children. Adults with AD need 24 hour care eventually because they are unable to cook or clean for themselves. It is unsafe for them to leave home alone. They sometimes wander at night and need supervision so they do not injure themselves. It is not surprising that a popular book for AD caregivers is called The Thirty-six Hour Day (Mace et al., 2017).

AD is the most frequent neuro-cognitive disorder. Other disorders affecting memory and/or functioning include:

- Fronto-temporal disorders
- Lewy body disorder
- vascular dementia
- Parkinson's.

More information about AD and other cognitive disorders can be found at the National Institute on Aging (NIA.NIH.gov, 2019).

Much research has been focused on the prevention of AD. Heart-healthy behaviors also promote brain health:

- not smoking
- exercising regularly
- sleeping 7-8 hours each night
- avoiding high cholesterol
- avoiding high blood pressure
- avoiding diabetes
- avoiding head injuries
- meditating or praying regularly
- learning something new regularly (Harvard Medical School, 2017).

Diabetes impairs the lives of many Americans and can be fatal in older adults unless managed well. Adult onset diabetes is increasing in the US because of sedentary lifestyles and poor nutrition. Diabetes can prevented or delayed through:

- avoiding obesity
- regular exercise
- eating the Mediterranean diet
- getting enough sleep
- monitoring blood sugar levels carefully if diabetic (Harvard Medical School, 2017).

Some older adults die because of influenza, pneumonia and Covid-19. Adults with chronic conditions such as diabetes, COPD, obesity or heart disease are at higher risk from acute respiratory disorders. Low income and people of color have been decimated by Covid-19 because of pre-existing condition and jobs requiring regular contact with the public.

Chronic kidney disease is not well known. It is not curable and is treated via medications or dialysis. Signs of kidney disease are:

- fatigue, distractibility
- frequent urination
- blood in urine
- difficulty sleeping
- dry, itchy skin (WebMD, 2019).

Suicides have been increasing in the US in the last 20 years. It has become more frequent among youth, young adults, Blacks and Latinx, but the rate of suicide continues to be highest by white men over 80 who live alone (CDC, 2020).

Understanding how cultural differences can impact suicidality can assist clinicians have more insight into why a client may be suicidal. The highest rate

of suicide is among Native Americans and Alaskan natives. Poverty and inter-generational trauma may explain the hopelessness of many native Americans. The removal of Native Americans from their ancestral lands, the loss of their way of life, and forced assimilation via white-run boarding schools have left too many Native Americans feeling they lack control of their destiny. The suicide rate among white, male older Americans often is a function of loneliness or health problems. Historically, suicide has been rare among Blacks due to their use of spiritual resources and the stigma against suicide. Young Blacks may be at higher risk for suicide now because of heightened awareness of discrimination, e.g., the deaths of George Floyd, Breonna Taylor and Trayvon Martin. Mental health issues tend to be downplayed in Latinx families, but more Latina teens have become suicidal because of conflict between the generations. Less accultured fathers may expect Marianismo from their daughters: chastity, subservience and religiosity. More Americanized teenage daughters want the space to make their own decisions regarding dating, music, church attendance, etc. Some Latinx youth are traumatized by sexual or physical violence in their countries of origin or by separation from parents in this country. The suicide rate among Asian Americans tends to be low. Yet perfectionism, pressure to achieve and losing face can lead to depression or suicidal ideation in this group (Clay, 2018).

Women attempt suicide much more frequently than men do, but men often use guns. Family members can benefit from awareness of the warning signs for suicide:

- Talking about wanting to die
- Difficulty eating or sleeping
- Social withdrawal
- Writing a will/final arrangements
- Giving away pets or valued possessions
- Increasing drug or alcohol use (American Psychological Association, 2019).

Older adults who are depressed or anxious and are contemplating suicide can benefit from psychotherapy in general and brief CBT in particular (Bryan and Rudd, 2018). It is important to add that there are older adults who have received a terminal diagnosis and desire to control how and when they will die. If they are competent, not depressed and live in a state that permits physician assisted death, they may choose to end their lives on their own terms. This issue will be discussed further in the next section of this home study.

American Medical Heroics

American physicians are, for the most part, brilliant men and women who have dedicated their lives to improving the health of their patients. They are familiar

with the thousands of disorders that they may see on any given day. Nuland (1995) describes physicians as laser focused on solving the Riddle:

- what is the disease that explains the patient's symptoms?
- what is the medication, surgery or other intervention that will result in a cure?

Many of us have seen physicians in action, using modern technology and their diagnostic skills to make the correct diagnosis and offer successful treatment.

About five years ago I became ill when eating at a new restaurant. I have GERD (gastro-esophageal reflux disease), so I have experienced indigestion before. I felt tightness in my chest and indigestion; in worse episodes I experience nausea or vomiting. I take a daily medication which usually reduces my symptoms. On this occasion I did experience vomiting, so my wife and I decided we would not frequent that restaurant again. The next morning after breakfast I again experienced nausea and vomiting, which never happens. I wondered if I had food poisoning from the night before. I had the same symptoms after lunch and dinner. I assumed I would be fine the next day.

The following day my symptoms continued after each meal, although I ate bland foods (apple sauce and crackers). I called my sister, a retired nurse; she wondered if I had an ulcer. I decided to go to the emergency room of a local hospital that afternoon. My anxiety was increasing as my symptoms continued:

- Did I have severe GERD?
- Did I have an ulcer?
- I am aware that GERD can lead to esophageal cancer; was that the problem?
- a friend had died of colon cancer. Could that explain my symptoms?

The ER physician did an examination and had scans run on my entire digestive system. Cancer was not found, but my colon had twisted, blocking any food from passing through my body. A surgeon explained I needed surgery which would probably involve removing the twist and reconnecting my colon. I hoped my surgery could be scheduled early the next morning. No, my surgeon insisted, she would do the surgery at 10:00 PM that Sunday evening.

The surgery that evening was successful. I started eating soft foods the next day; I ate solids the day after that and went home healed and with minimal pain. I am aware that, if I had a similar problem 50 years ago, I may well have died. Our physicians are highly skilled at solving the Riddle!

Yet Nuland (1995) has described the downside of this laser focus on diagnostics and cure. Many physicians are not prepared to help their patients die well. Death is seen as defeat. Some physicians withdraw from their patients when they are near death. In a later edition of How We Die (2010), Nuland reports the development of palliative care and the hospice movement. This approach to the final days of a patient's life is more holistic and focused on improving the

quality of the patient's life, not the quantity of days . Yet he laments that too many physicians are still so focused on solving the Riddle that most patients are not referred to hospice care until the last two or three days of their lives.

In Being Mortal, Atul Gawande (2014) reports that his medical training was also focused on saving lives. There was no discussion of how to help patients die well. He writes that:

> " . . . medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. . . . Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need" (p. 9).

Too many dying patients are receiving one last round of chemotherapy which has little likelihood of helping them, or they are hooked to numerous machines in ICU's that will only prolong their suffering. Multiple studies have shown that patients are ill-informed about the likelihood that their final treatment will save their lives. Only 5% of cancer patients accurately understood their prognosis well enough to make informed decisions about their care. In another study, 80% of patients with metastatic colon cancer wrongly thought their treatment was likely to result in a cure (Aleccia, 2019). Nearly one in three Medicare patients undergo surgery in the year before they die. The evidence shows that their quality of life generally does not benefit from that surgery (Szabo, 2018). The great irony about end of life treatment is that patients who are clearly informed about their treatment options and their likelihood of success are more likely to choose palliative care (focused on comfort and pain relief – but may also include cure-focused treatment) or hospice care (which does not include life-prolonging treatment). Patients receiving hospice care tend to live longer and with less pain at the end of their lives (Institute of Medicine, 2015). It is critical that dying patients and/or their families know the questions to ask to help them decide when to pursue curative treatment and when hospice care is the better path. Later in this home study, we will discuss the issues to cover with physicians to make the best end of life decisions.

Death at a Young Age

The primary focus of this paper is the death of older adults. Yet newborns die during childbirth or during their first year. Black babies die at more than twice the rate of white babies. Accidents are the number one cause of death for youth ages five to 19. Suicide and homicide are number two and three causes of death for teens 15 to 19 (CDC, 2010).

The loss of a child is tragic. The death of a child is often unexpected. Parents experience unspeakable pain. Siblings, grandparents, aunts and uncles mourn

too. Jerry Sittser lost his wife, his mother and his daughter Diane (age 4) in a horrifying car accident. He described his immediate pain as overwhelming. He was hardly able to function as a parent and minister. He wept; he prayed. Eventually he described the losses as an amputation. He healed, but he would never forget his wife, his mother, his precious child (Sittser, 1995). When we work with parents of children who have died, we need to be prepared to feel searing pain with them. Parents who lose their children/teens to suicide or homicide struggle with confusion, rage and guilt. They will need much support to recover from such tragic losses. In this paper we will address complicated grief which often accompanies unexpected deaths as well as the loss of children.

III Psychological Issues at the End of Life

The emotional issues most relevant to adults at the end of life are:

- *maintaining one's autonomy or having a surrogate to advocate for their last wishes*
- *feeling loved by one's family*
- *feeling satisfied with one's life, accepting both the triumphs and the regrets*
- *coping with whatever pain is present*
- *being ready to say goodbye.*

Most adults let nature take its course in terms of the timing of their deaths. Some choose their own end with physician assistance or by voluntarily stopping eating and drinking.

Autonomy/Control

Our health care system encourages dependence on the physician at the end of life (EOL). The doctor's decision-making can result in the patient feeling helpless – never a good place to be. Most patients want to impact how their last days will play out:

- Will they die at home, in hospice or in a hospital?
- Will they be resuscitated if they have a heart attack?
- Will they be kept alive with a ventilator?
- Will they be fed via a feeding tube?
- Who will be present?
- Will their spiritual wishes be honored?

Many older middle class adults have prepared a will with Advance Directives and a Medical Power of Attorney to think through these choices when they are of clear mind and can communicate their wishes in a legally binding way. Yet all health care facilities do not honor these legal boundaries. Many emergency rooms do not honor DNR orders (do not resuscitate). It may be valuable to know the laws of the state and norms of the hospital you are likely to use for your loved one.

Those who have done their legal preparation for the end of life have every reason to believe their wishes will be carried out as they desire. Their will, Advance Care Directives and Medical Power of Attorney are in place. Yet some of that confidence may unwarranted. In a study of about 350 veterans and their surrogates, 75% of their surrogates were confident that they knew end-of-life preferences of their loved one. However, when the veterans and their surrogates were presented with health care choices separately, only 21% of the surrogates actually knew what their family member or friend actually wanted (Sadick , 2019). This study highlights the value of adults having very specific discussions about DNR. ventilators, feeding tubes, etc. at the end of life.

Dying with Grace (Repka, 2011) tells the story of the last days of the author's father, a determined man who maintained control of his life to the end. Frank Repka was the son of immigrants from Czechoslovakia, born in the US in 1915. He cared deeply about his wife Helen and their eight children. He cared for Helen with attentiveness and compassion as she died from colon cancer. He neglected his own health as he attended to Helen. After she died, he went to his physician to address abdominal pain he was having. During surgery Frank was discovered to have a severed intestine; his body was septic, fighting a severe infection. Frank had acquired MRSA during his hospitalization. Frank was 92 and had been in good health before his sudden illness. His physician was honest, that Frank was very ill. He would need more surgery and months of antibiotics to have a chance of recovery. Frank called his adult children to his side. He informed them that he did not want the treatment his physician proposed. He did not want months of convalescence. He was ready to die on his own terms, with his children at his side, in his own home. Some of his children initially argued that he had more life to live. He silenced them; he said he loved them greatly, but he also valued his active lifestyle as a farmer. He had no interest in being bed ridden for months. His children reluctantly accepted his dying wishes. Frank died three weeks later at home in the embrace of his children, conscious until his final breath.

All would not choose the path Frank took. Our role as providers to or family members of the dying can be to help them clarify their last wishes. Enhancing the autonomy of the dying person is a great gift if the person is conscious and able to communicate; following the advance medical directives of a dying person who can no longer communicate is also greatly to be desired.

Family Relationships

As a parent nears the end of his or her life, a sense of crisis becomes stronger. Adult children may wish that the parent can live indefinitely so that they will always be present for them. Such is often true when parents are in their 50's or 60's and their adult children are in their 30's or 40's. That wish can be present when the adult children are in their 50's. I remember how shocked I was when I

learned my mother at age 80 was dying – I was not ready for that. I had never seriously considered that she would die. It was as if one of the foundations of my life was crumbling.

As a parent nears death, unfinished business becomes paramount. Old wounds may re-surface. If a parent had an alcohol or drug problem and was not the loving parent they had hoped to be, that parent may have a strong need to make amends with his/her children. If a parent was not present for their children due to divorce, alienation or remarriage, that parent may hope to re-connect with grown children to ask forgiveness. Ira Byock (2014), a palliative care physician, has written The Four Things That Matter Most for all families who want to have vital conversations at the end of life:

- Please forgive me.
- I forgive you.
- Thank you.
- I love you.

Sometimes adult children who engaged in years of acting out or rejected their parents want to make amends before the parent dies.

Most families yearn to share gratitude and love with each other at the end. Yet grieving is difficult. Some cope with the pain by blaming others. Families may benefit from brief therapy to deal with the death of a parent so that everyone's feelings and perspectives are honored.

Many people fear being alone at the time of their deaths. One of the tragedies of Covid-19 has been that some families have not been allowed to be at the side of a dying loved one. Such was truly tragic. Most hospitals now allow family to be at the bedside of a dying loved one.

Sometimes family secrets are shared when a parent is dying. Sharing those secrets may lead to a sense of closure.

Sometimes a parent writes a living will for their adult children, a document that highlights important values that the parent wishes to pass on to their children. Sometimes parents share their hopes and dreams for each adult child. Positive, realistic death bed wishes can live forever as last expressions of love.

Life Review/Acceptance

Some deaths come quickly and are unexpected – a first stroke or heart attack can end a life without warning. Neither the dying person nor their family members have time to prepare. Others may have several years to prepare for the end due to a terminal illness. This second group may embrace a life review, remember successes and failures, times of joy and times of disappointment.

Those who are depressed may become preoccupied with their losses or failings. These individuals may benefit from processing their pain and letting it go. Some may benefit from griefwork, Brief CBT or an antidepressant.

Losses and regrets are part of life for most people. It can be helpful to reflect on one's relationships and successes in life. Healthy life review includes both the good times and the bad times. Years ago I worked with a brilliant college professor near the end of his career. He became preoccupied with the students who did not benefit from his humanistic approach to life. His father had been a successful jazz pianist. The professor wondered if he had taken the wrong road in his life, if he should have followed his father's path, becoming a musician. There was an obsessive quality to his negative thoughts. First we processed his regrets that all his students did not gain from his open minded approach to life. Some were convinced Evangelicals who believed they had the answers to life's questions. The professor agreed that even great teachers do not open the minds of every student. I asked him if he experienced some students as open to his less dogmatic approach to life. He recounted lively class discussions when it was clear that his students were gaining new insights. He also remembered students he met over the years who approached him as adults to thank him for his opening their eyes to more possibilities. The professor did play the piano for himself and friends visiting his home. He played well and received kudos. Yet as he reflected on the question of his career choice, he decided it was preferable to play the piano for entertainment and have the stability of his teaching career while having a wife and family. A second-tier musician often has to live out of his suitcase, being absent from his wife and children for many days a year – his father was often absent when he was a child. He ended at a place of valuing his career and the choices he had made.

One of the advantages to patients learning that their situation is terminal is that they have time to work through the loose ends of their lives. It was mentioned above that physicians often are not clear with patients that their conditions are terminal. Physicians tend to over-estimate the time left. Kasi-Godley et al. report that the average patient enters palliative care three weeks before death. The average hospice patient enters that care two to three days before their death (2019). So many patients and families do not benefit from the psychological, spiritual and physical services of palliative and/or hospice providers as much as are available.

Coping with Pain

A major concern some of us have about the end of life is: How much physical pain is part of the dying process? The answer of course varies greatly. Those who die quickly of a stroke or heart attack may experience brief pain before they lose consciousness. Those with COPD may experience discomfort in

breathing which is relieved through administration of oxygen and perhaps relaxation training. Some cancers can be quite painful, but use of opiates can diminish the pain significantly.

My sister worked as a nurse in a small rural hospital in Nebraska. She assisted thousands of patients in the dying process over a forty year career. She reports that most of her patients had little pain and were not taking opiates (Holthaus, 2021). Likewise, Tisdale (2018), a palliative care nurse, assisted many patients in the months or days before their death. She reports that severe pain near death is rare. Minimal pain is much more common and can be relieved with OTC acetaminophen, meditation or cannabis (where legal). Those patients with more significant pain can be given opiates such as hydrocodone or oxycodone. Addiction is not a concern because the person is dying. Opiates are sedating. As the dose is increased, the patient is less alert. That may be welcome for some and unwelcome for others. An effective physician will work with her patient to get the pain/sedation balance right.

I oversimplify in writing about pain as if physical pain is distinct from emotional pain. All pain has physical and emotional aspects. For some patients, existential issues are central to their pain:

- a diminished sense of self
- spiritual angst
- a crisis of faith
- questions of meaning
- guilt
- isolation
- readiness for dying (Kasi-Godley et al., 2019).

Palliative and hospice services include a spiritual component. Many nurses, social workers and chaplains have pastoral care training and are able to help the patient and/or family explore questions of meaning or faith. In a later section we will review the major beliefs and rituals around death that may be helpful for those working with dying patients and their families.

Grief work may also be valuable to patients and their families who are hurting, angry or in turmoil.

Grief work

It may be important that the person dying and/or his family be able to process losses as they are occurring or are about to take place. As was noted above, the dying person may need to process sadness, guilt or anger about losing her roles, losing dignity (helplessness, enuresis, incontinence, etc.), or losing meaning in her life. Family members may vary greatly in their readiness to let go of a spouse or parent. Interpersonal Therapy (IPT) has a helpful module to draw from when intervening with the dying person, her spouse or adult children.

In IPT, grief work is normalized; the client is encouraged to feel the sadness of loss, to be angry, whether at God, the physician, or unsupportive family. Sometimes the spouse is angry at their dead mate for leaving them behind. Tears are encouraged as well as reaching out to supportive siblings, adult children or friends. The IPT counselor encourages discussion of the dying process:

- Did medical staff tell you your spouse was dying?
- Did she seem to be in pain?
- What was it like for you to care for, to clean up, your spouse?
- Did he speak?
- Was he in and out of consciousness?
- Were you there when he died? (Heinrichson et al., 2010).

Normalize the client's experiences. Grief can be like a 20-foot wave crashing down on you. "Feel the pain and let it go". Over time the waves of pain are less violent; they even become gentle. I encourage clients to explore feelings of guilt and let them go. All relationships have some conflict; sometimes hurtful things are said. One need not see a spouse as all good; it is equally important not to see a spouse as all bad (even a chronic alcoholic with a history of infidelity). A wise professor of mine once said, "You can't bury saints; you can't bury demons" (MacDonald, 1973). Help clients work through any need to idealize or vilify dead spouses.

Grief work usually helps a client progress through their pain unless complicated by tragedy such as a suicide, a murder or sudden and unexpected accident. Complicated grief is more severe and extended; "it is marked by broad changes to all the person's relationships, a sense of meaninglessness, a prolonged yearning or searching for the deceased, and a sense of rupture of personal beliefs" (Kersting, 2004). Many of those suffering complicated grief can be diagnosed with Major Depression and Post Traumatic Stress Disorder. Not surprisingly, early research is showing that standard IPT grief work when complemented by modified exposure work is more effective than IPT alone (Shear et al., 2005).

Standard griefwork often involves working through the five "stages" of mourning:

- denial
- bargaining
- sadness
- anger
- acceptance.

David Kessler has clarified and expanded Kubler-Ross' description of grief (2020). A simplistic understanding of the "stages" is misleading. The five points are not a road map; the progression is not linear. Some people never bargain. Others explode in anger and have difficulty letting themselves feel the vulnerability of

depression. Many alternate between anger and depression for months or even years. People grieve the way they grieve. It is important that we not judge others in whether they are grieving "correctly"! Kessler has added a sixth "stage" – finding meaning. We must experience the pain of grief. There is no shortcut around it. Yet as we live in acceptance, we may find a meaning in the loss:

- My mother's life was a gift to her family and the entire community.
- My divorce was terribly painful, but I learned if I marry again, it will be to someone who can be my partner in solving problems.
- I mourned the loss of my administrative job, but I am called to be a clinician, not a manager.

Healing often involves finding meaning.

Euthanasia/Death with Dignity

The question of physician assisted death is highly controversial. Sometimes older adults who receive a terminal diagnosis embrace death and want to take the matter into their own hands. Is the person suicidal or are they maintaining control over their lives?

If the person is clinically depressed, highly anxious or traumatized, and he desired to end his emotional pain by suicide, almost all providers would want to offer treatment and attempt to dissuade the person from taking their own life.

Oregon, California, Colorado, Hawaii, Maine, New Jersey, Vermont, Washington and the District of Columbia have passed legislation permitting death with dignity. The OR criteria are:

- The person must be 18 years or older.
- The person must be a resident of OR.
- The person must be competent, capable of making and communicating such a decision.
- The person must have been diagnosed with a terminal diagnosis with a life expectancy of six months or less.

Some choose physician assisted death because of physical/emotional suffering or fear of suffering. It is important that dying adults have access to palliative care or hospice services to offer them appropriate treatments for their pain. Severe pain that is not responsive to available treatments is rare (Tisdale, 2018).

For others with terminal conditions, the issue is autonomy. Some find incapacity unacceptable. They choose not to be if they are unable to meet their own daily living needs. The APA takes a values-neutral position on death with dignity, and has identified issues for involved providers to consider:

- Does the individual have the capacity to make informed consent?
- Is the person being influenced because of financial considerations?

- Is there family pressure to die or to remain alive?
- Are there cultural or religious issues that need to be addressed?
- Are family members aware of the individual's preferences? How are family members reacting?

End of Life Issues and Care is a detailed paper highlighting the ethical and clinical concerns important at the end of life (APA Working Group, 2002).

Physicians differ as to whether they will assist a patient to die, overtly or covertly. Proponents of physician assisted death see their participation as an extension of their obligation to respect patient autonomy and relieve suffering. This group will prescribe medications that will end the person's life as permitted by the laws of their state. A second group of physicians is open to prescribing progressively higher doses of opiates and/or barbiturates for pain, knowing that the person will expire at some point. A third group of physicians oppose any action that would lead directly or indirectly to a patient's death. They cite the physician's obligation to do no harm and fear the slippery slope of eventual acceptance of involuntary euthanasia (Zugar, 2017). It is important that a patient with a terminal illness have a physician whose values line up with their own.

Oregon keeps a log of residents who choose to obtain a prescription for medications to end their lives. One of three who use this option do not use the prescription to obtain the needed drugs. In the end, they found the dying process to be acceptable.

An end of life option that some may find acceptable is voluntarily stopping eating and drinking. A person with a terminal illness whose end is near may decided to stop eating and drinking. The person will benefit from ice chips to avoid discomfort from a dry mouth. If the person chooses this option, it is important that they take in minimal fluids because fluids can only prolong life for weeks or months. The advantage of this option is that the person is in control; they can stop the process at any time, and there is minimal discomfort. After some hunger the first day, most individuals feel little or no pain. As the fast continues, the person tends to spend increasing time sleeping until their death. If the person is weakened from a terminal illness, death may come in days to several weeks (Compassionate Choices, 2015).

IV Societal Issues at the End of Life

The high rates of death of Black and brown persons from Covid 19 have made many Americans more aware of health disparities between the various ethnic groups. White and Asian Americans tend to have more wealth, better medical coverage and jobs that involve working from home. Black Americans are more at risk for earlier death because of pre-morbid health issues like diabetes, heart disease or obesity. Black and Latinx Americans are more likely to work in service jobs that require

contact with the public. Gender and sexual minorities may have more health issues as they age in part due to coping with years of discrimination. Clinicians need to be aware of cultural differences that are significant at the end of life.

Minority Health Disparities

The pandemic has highlighted the dramatic differences that wealthy white Americans experience in terms of death and disease in contrast to low income Americans, especially those who are Black and brown. Preliminary data suggest that Blacks are dying of Covid-19 40% more often than whites (Latinx 22% more often) (The Atlantic, 2021). Ethnic minority groups have less access to health care and health insurance. They are more likely to work at jobs with close contact to the public or other workers, e.g., farms, factories, food processing or groceries. They are more likely to have pre-existing conditions that make them more vulnerable, e.g., obesity, diabetes, heart disease (CDC, 2020).

Currently Blacks die on average three and a half years younger than whites in the US (National Vital Statistics System, 2019). In some cities the difference in life expectancy between a wealthy white suburb and an inner city minority area can be as much as 20 years (Kazan, 2018). Payne documents the correlation between wealth and health; the death rate in the poorest zip codes in the US is 40% higher than in the richest zip codes (2017). If you are working with low income, Black or Latinx clients, it is essential to be aware of the health issues they face. They may need assistance to access quality health care.

Some LGBT adults struggle as they get older. Some have health issues secondary to smoking, substance abuse or HIV. Sexual minorities are more likely to live alone and not have children to assist in their care (Choi et al., 2016). Gays are more likely to experience difficulty in securing assisted living or nursing home care. Clinicians working with gender and sexual minorities are encouraged to be aware of health issues and discrimination and encourage them to develop families of choice if they are not close to their families of origin.

Cultural Differences

Ethnic differences can be impactful at the end of life. One family gathers as soon as possible at the bedside of the seriously ill, even if that means coming from all parts of the country. In contrast, an Anglo-Saxon with a terminal illness may never talk about the illness or seek comfort from her family (Tisdale, 2018).

Black families tend to seek more aggressive treatment at the end of life. Some are suspicious of physicians neglecting their loved one as occurred in the Tuskegee Study many years ago. They may not be aware that a patient may

benefit from palliative care to make the dying more comfortable while they are also receiving life prolonging care (APA, 2019).

There are East-West differences when adults consider death. Many Europeans and white Americans tend to be linear in their approach and, given the Christian influence, tend to believe in an after-life. Asian Americans, comfortable with paradoxical thinking, may be less likely to focus on an after-life and more likely to embrace living life well when thinking of death (Ma-Kellams et al., 2012).

We will discuss the five major world religions and death later in this paper.

V Communication at the End of Life

> *Many physicians have little or no training in communicating about a terminal diagnosis. Some see a patient's death as a sign of their own future. The more that physicians can be clear and sensitive in communicating about approaching death and the pros and cons of various treatment options, the better the dying person and/or their loved ones can make informed decisions. As approaching death is often highly emotional, families can benefit from learning how to communicate clearly and with sensitivity to the emotions of all involved.*

Physicians, Patients and Families

As discussed earlier, medical heroics have added to the length of life for countless Americans. CPR, brain or heart surgery, and chemotherapy have added many healthy years to the lives of Americans. Yet the desire to intervene at all costs may make the end of life more disrupted than is necessary. Not everyone wants to spend their last days in ICU with IV medicines prolonging their lives.

The key questions are:

- Why is this test being recommended?
- What treatments are likely to prolong the life of this patient?
- What will be the quality of the remaining life?
- What are the side effects of the suggested treatments?
- What are the goals and wishes of the patient?
- Where does the patient want to die?

There are no one-size-fits-all answers. Different individuals will have different goals/wishes. Their preferences may change over time, so the communication about goals and options needs to occur repeatedly.

Some physicians have little training or willingness to have these end-of-life conversations. Gawande (2014) and Byock (2014) highlight the importance of

the conversations between seriously ill patients, their families and t heir physicians. If a physician is unable or unwilling to address these concerns, the patient is encouraged to find a different physician. Some seriously ill patients are not alert or able to process complex information – hence the importance of Advance Care Directives and having a family member or close friend who has Medical Power of Attorney (legal authorization to make decisions on the patient's behalf).

Ideally, physicians know the patient's condition well. They have shared the diagnosis(es). They are able to discuss the costs and benefits of treatment options. For example, a 60-year-old woman with stage 2 breast cancer (cancer in breast and lymph nodes) has an 80% to 90% chance of cure with a lumpectomy, lymph node removal and chemotherapy. A 75-year-old woman with breast cancer that has metastasized to her spine and brain has less than a 20% survival rate with chemotherapy. It is the first woman who can straight-forwardly choose the treatment options. The second woman may decline chemotherapy and opt for palliative care to make her last days less difficult, but only if her physician clearly offers her the costs and benefits of various treatments.

Gawande (2017) has developed the Serious Illness Conversation Guide to facilitate these difficult conversations:

- The physician asks the patient (or Medical Power of Attorney) if this is a good time to discuss important decisions.
- If so, the physician shares the prognosis with treatment options.
- The physician gives the person time to reflect, share emotions and ask questions.
- The physician explores the person's
    - fears
    - goals
    - sources of strength.
- The physician helps the patient understand the trade-offs with each treatment option.
- The physician determines if the patient is ready to make a decision as to how to move forward or if she needs time to reflect on her options with significant others in her life.
- When decisions are made, they need to be documented in the medical record and communicated to the other providers involved.

Prediction is not an exact science, so Gawande recommends that the future be discussed with appropriate tentativeness:

> It can be difficult to predict what will happen with your illness. I hope you have more time, but I worry that your time may be short (days, weeks, months?)

Some individuals will not consider nursing home care and strongly desire to die at home. Palliative or hospice care may be indicated. Some are comfortable with being in a nursing home, but would not want to continue life in a demented state. Nuland (1995) described a patient with a terminal heart condition who wanted to go home and have one more party with his friends before his death. He loved entertaining and it was his one last wish. He greatly enjoyed the time at his party and he died at home about a week later.

Patients, Families and Friends

Coping with death and dying is stressful for most of us Discomfort with the topic can lead family and friends to make comments that are not helpful:

- Things could be worse.
- You have to stay positive.
- If it's meant to be, it's meant to be.
- You look so good (for someone who is dying).
- You should have exercised more.
- You should have eaten less red meat.
- Speaking to a cancer patient about friends who have died from cancer.
- Is your colostomy paper or plastic?
- You're going to be fine.
- You'll be dead in three months or so.
- This is a blessing in disguise.
- God has a plan for you. (Gawande, 2014: Kalick, 2005)

What communication is helpful? Words are not as important as presence. Sometimes friends or even family members cannot cope with a terminal diagnosis (Kalick, 2005); they disappear. Some men divorce their wives if the wives are diagnosed with cancer or with a terminal diagnosis (Kalick, 2005). Being present to the dying person is the greatest gift. Being quiet is an important gift. The wise visitor does not attempt to cheer up the dying person. Space for reflection is a gift. Touch is a gift. Maybe the dying person shares his fears or unfinished business. Perhaps he wants to share a family secret. Maybe she wants to share a regret or a hope for the visitor. Acceptance of whatever the patient shares is important – anger, sadness, fears, hopes. Earlier in this paper I noted The Four Things That Matter Most:

- Please forgive me.
- I forgive you.
- Thank you.
- I love you. (Byock, 2014).

Byock now adds a final statement for family and friends:

- Goodbye.

Sometimes dying patients hang onto life because they believe a beloved son, daughter, etc., is not ready to accept their passing. As the end nears, it can be

important for both the dying patient and the loved one to say "Goodbye". Death is not final. Memories of the beloved last forever.

Familiarity with the world religions can be an important resource for those professionals who comfort the dying and/or their family.

VI Religious Traditions and Death/Afterlife

> *Religion offers many of us a way to find meaning at the end of life. Jews sit shiva. Christians and Muslims hope for peace and joy in heaven. Hindus expect karma will determine their fate through reincarnation. Buddhists are mindful, letting go of pain and leaning into more acceptance of death as part of the circle of life.*

Religions offer a set of beliefs about the cycle of life and death. They also offer practices or customs that guide families in how they can best honor the dead.

Judaism

The oldest people of the Book are the Jews, dating back to Abraham, the patriarch who lived about 1800 BCE. The Torah are the essential books of Judaism, the first five books of the Hebrew Scriptures. The Torah details:

- the Creation by God
- God's choice of Abraham to begin a new nation
- Jacob's sons going to Egypt during a famine in Israel
- Moses leading the Hebrews from slavery in Egypt to the edge of the Promised Land in Canaan
- God giving Moses the Ten Commandments as well as all the laws contained in the Torah.

Judaism honors the cycle of life, from circumcision at birth to burial at death. Judaism is divided into the Orthodox, who follow the law most strictly, Conservatives who walk a middle path between the Torah and modern beliefs, and Reform Judaism which is more humanistic, Some Reform Jews do not believe in God, do not practice traditional Jewish ways, e.g., eating Kosher, yet do identify as Jews and see themselves as followers of the prophets who preached social justice (Falcon et al., 2001).

Judaism does not have a single approach to the issue of an afterlife. Orthodox Jews are most accepting of an afterlife; Reform Jews are less so. The focus in early Israel was on being God's chosen people. The goal was prospering for generations in the land of Israel. The ten tribes of the North were not faithful to the Lord; they were defeated and disappeared after being conquered by the Assyrians. The two Southern tribes were conquered by Babylon; they returned to Israel after the Exile. The first notion of an afterlife in the Hebrew Scriptures is

after 200 BCE in the Psalms and the book of Isaiah. Today some Jews do not believe in life after death. Others believe that the bodies of the dead will be resurrected on the Day of the Lord in the unknown future.

Life and death are honored in Judaism. Suicide and euthanasia are strongly discouraged. When a religious Jew dies, members of her synagogue gather to cleans the body and wrap it in a white robe. Jews are often buried simply, with no casket or in a pine box, within one or two days after the death. Jews tend not to embalm or cremate the dead. A funeral service may be held at the synagogue by a rabbi, at the grave side or at the funeral home.

Judaism is most respectful of the grieving family. Friends and extended family sit shiva with the family of the deceased during the week after death. It is a time of silence and respect for the dead and his family. Prayers (kaddish) are said repeatedly during that week. Family members in mourning are not expected to socialize for a year after a parent's death (Berkson, 2016).

Insights from Jewish rabbis abound:

- Death is a time of hesed. God's loving kindness is present to the dying and all those present.
- Create a circle of love of family and friends around the dying.
- Make room for joy. Of course there is sadness at the death of a loved one. Let there also be gratitude for all that life/God has given the dying and for all the dying have given to us (Paashe-Orlow, 2021).

Christianity

The central events in Christian belief are the death and resurrection of Jesus Christ, the Son of God. Christians see the resurrected Christ as confirmation that they too will experience life after death.

There are hundreds of Christian sects, but the three main branches of Christianity are Roman Catholics, Protestants, and the Orthodox. Roman Catholics see the Pope, the Bishop of Rome, as the human head of the Church. Traditional Catholics see life as a gift of God and oppose abortion, euthanasia and a government imposed death penalty. Catholics see the end of life as a special time to make peace with one's Creator; a special rite available is the Anointing of the Sick. Most Catholics see purgatory as a temporary place/time of cleansing to prepare for heaven. Heaven is eternal happiness with God and all who have lived throughout history. Hell is eternal punishment for those who have rejected God. Pope John Paul II described heaven and hell as states of the soul rather than physical places (Berkson, 2016).

The Protestant branch of Christianity broke off in the 1500's with Luther's denouncing the Church's granting indulgences to those suffering in purgatory

for financial gifts to the Church. He rejected the notion of purgatory because it had no basis in Scripture. Luther highlighted the centrality of the Bible as the source of Christian belief. Calvin, Henry VIII, and Wesley went on to found Calvinism (Presbyterianism), Anglicanism and Methodism. Protestants do not accept purgatory, but do believe in heaven and hell. Liberal Catholics and Protestants see a loving God welcoming all people of love into heaven after their deaths. More conservative Catholics see God reserving heaven for faithful Catholics only; more conservative Protestants likewise see heaven as being reserved for Christians who accept Jesus as their Lord and Savior.

The Orthodox branch split from Catholicism in 1066 due to differing beliefs about the Trinity and East-West cultural differences. The most important Orthodox patriarchs are in Greece and Russia. The Orthodox embrace mystery more than Catholicism does. Heaven and Hell are accepted. Orthodox would hope for God's mercy in deciding who is welcomed into heaven.

Richard Rohr, a Franciscan priest, writes:

> In the last few decades, I have faced my own mortality on several occasions through cancer and a heart attack. Each time I have experienced an outpouring of love and care from others and from God. The sky and the whole world take on a nostalgic and fleeting tone. God seems inside, closer than my own skin. I can hear the messages:
>
> - Listen to your body.
> - Slow down.
> - Live in the precious now.
> - Love all that is.
>
> We learn to befriend death and prepare for its arrival. We accept our losses. . . . We make peace with all that is in and around us (2019).

<u>Islam</u>

Muslims are the third people of the Book. Mohammed received inspiration for the Quran in seventh century Arabia. He had some knowledge of Judaism and Christianity. Abraham is viewed as the father of Muslims. Jesus is seen as a holy man and prophet. The central belief in Islam (surrender) is:

> There is no god but Allah (Arabic for God),
> and Mohammed is his prophet.

There are two main branches of Islam, the Sunni and the Shia. They do not differ significantly in their beliefs and practices about death and the afterlife.

In Islam, Allah is Creator and Judge; he is all powerful, generous and merciful. God expects correct beliefs and correct practices. Allah gives life and only Allah can take it away, so suicide and euthanasia are forbidden. When martyrs die, they go straight to heaven. Everyone else after death goes to an intermediate place where they wait/sleep until Judgment Day. Allah then sends

the just with their resurrected bodies to heaven and condemns idolators to hell (those who "worshipped" anything but Allah).

Heaven is a garden with flowing water and physical delights. Married couples enjoy physical intimacy there. The unmarried join beautiful companions. Hell is described as a place of fire, where humans suffer and regret their bad choices.

After death, Muslims are washed with reverence and wrapped in a white shroud. Bodies are not embalmed but are buried as soon as possible. Funeral prayers comfort family and friends of the deceased. The body is buried directly in the ground, with the head toward Mecca. Mourning is encouraged for forty days after the death; then family is encouraged to accept the will of Allah (Berkson, 2016).

Muslims remember that Allah is in charge. Death is not the end of life, but the continuation of life in another form.

- From Allah we came, to him we will return.
- Every soul will taste death. You will enter heaven or hell on the Day of Resurrection.
- What is the life of this world but the enjoyment of delusion.
- Do not speak ill of the dead. Respect Muslims, Jews and Christians (Abdulla, 2020).

Hinduism

The earliest Hindu scriptures are the Vedas, believed to have been written in India around 1500 BCE. Hinduism accepts innumerable gods, yet emphasizes the unity of all things. Hindus believe that humans are divided into castes, with Brahmins being the highest caste. Brahmins are priests, rulers and leaders. Dalits, the lowest caste, are referred to as untouchables. Dalits are to step aside if a Brahmin is walking toward them (Wilkerson, 2020). Hindus believe in karma. Those doing good things experience blessings in this life and are reincarnated to a higher level of being in their next life. Those who are selfish or destructive gather bad karma and are reincarnated to a lower level of life, even to becoming insects.

Hindus strive to be freed from this cycle of suffering via the four yogas:

- karma yoga – selfless acts
- jhana yoga – wisdom
- raja yoga – meditation
- bhakti yoga – devotion to God

Engaging in these forms of yoga liberates the self.

Hinduism is an Indian religion. The Ganges River is seen as holy Mother Ganges. Varanasi is a city on the Ganges and is beloved by the god Shiva. Dying in

Varanasi and being cremated on a boat in the Ganges can short circuit the cycle of reincarnation and lead directly to nirvana, union with Brahman the divine.

As a Hindu approaches death, family members are encouraged to chant mantras, the names of God, or passages from the Bhagavad Gita, one of the sacred books. Followers of Shiva pray for a peaceful death and passage to a better life. At death the body is cleansed, wrapped in cloth and adorned with flowers. The body is cremated as soon as possible.

At the end of life, Hindus are encouraged to become more spiritual, focus on the divine, and let go of all earthly possessions. In the Bhagavad Gita, there is tension between dharma (duty) and karma (destiny).

- The human body will die, but the soul is eternal. The spirit is unborn and eternal.
- Through meditation, the Higher Self is seen.
- Brahman (the ultimate reality/God) shines forth – vast, luminous, inconceivable. He is far beyond what is far, yet is very near at hand.
- He who knows Brahman becomes Brahman (Ohesion, 2020).

Buddhism

About 600 BCE, Siddhartha Gautama was a young prince in Nepal whose father had protected him as a child from pain and suffering. When he left the palace, he encountered an old man, a sick man and a corpse. He was shocked by all the suffering in the world and devoted his life to find freedom from pain. He discovered what we now call mindfulness meditation and became awake (Buddha). Buddha was aware of the polytheism of Hindus which he rejected. Some would say Buddhism is more psychology than theology, as many Buddhists do not believe in God. Buddhism is not a historical religion, so there is little focus on how the world began or how it will end.

Buddha taught the Four Noble Truths:

- Life is often out of balance; suffering is a part of life (dukka).
- The causes of suffering are greed, anger or illusion (negative thoughts).
- All is impermanent – both pleasures and pain will pass.
- The Eightfold path makes enlightenment possible.

The Eightfold Path includes developing:

- mindfulness
- letting go of negative thoughts and addictions
- a career focused on integrity and making the world a better place
- kindness toward self and others; compassion
- flexibility; life is always changing
- wisdom, acceptance

(Berkson, 2016; Tirch et al., 2016).

Some Buddhists believe in reincarnation; many do not believe in an afterlife. Death is the best teacher, so Buddhist teachers may encourage their students to think of death:

- letting go of grasping
- letting go of possessions
- letting go of anger, grudges
- letting go of relationships
- letting go of self.

The great insights of Buddhism are

- that much pain is self inflicted
- being fully in the present means letting go of the past, letting go of worries about the future
- all is impermanent, change is the only constant
- letting go of ego or self brings peace
- death is not a medical failure, but a sacred transition that awaits us all (Chitwood, 2020; Tirch et al., 2016).

There are many variations of Buddhism, with no fixed dogmas or rituals, other than all is impermanent and mindfulness is the path to contentment.

VII Final Weeks, Last Days

Death may come quickly in a stroke or heart attack. Death via cancer may be slow. Most Americans want to be close to their loves ones in their final moments.

Tisdale (2018) has much wisdom to share about the end of life from her years of experience as a palliative care nurse. Deaths can differ greatly. My grandfather was seemingly in good health until he died instantaneously of a heart attack. There was no time for goodbyes. Others may fight cancer for years. For most families there are signs that the end is nearing. This can be a highly emotional time. There are tears. Some may lash out in anger. Some are fearful of losing their loved one.

Physicians tend to over-estimate survival time. Patients on average enter hospice care <u>three days</u> before they die. After the patient's death, the family remembers the last walk, the last bedtime, the last meal. The patient is usually quite fatigued, sleeping more than usual.

As the end nears, people eat and drink less. It is important not to push the patient to eat. They may have difficulty digesting food. They may lose control of their bladder and bowels. Their skin may become thinner. They may need to be turned carefully to avoid bed sores. Tube feeding at the end may be tortuous.

Dying people who are conscious often prefer soft lighting; some appreciate soft, relaxing music. TV or radio may be jarring. Loving touch is often welcome. Introverts may prefer the company of one or two people at a time, or may desire periods of quiet. Extroverts may appreciate more people being present (NIA, 2017). What unconscious people experience varies greatly. It is wise to speak and act as if the dying person has some awareness of their surroundings. Some of those who have had near death experiences tell us they could hear the conversation and feel the presence of their loved ones even when they could not communicate.

The person's breathing may be slow or labored. They may not be able to converse. Silent presence can be a gift to them at this time. Sometimes the dying speak in metaphor, about travel, about going home. The person may become delirious or speak to dead relatives. A minister friend of mine says the curtain between heaven and earth becomes permeable near death.

Most people are not in significant pain as they die. Those who are in pain can be given OTC meds (Aleve, Tylenol) or opiates. More opiates will cause more sedation. They may benefit from quiet or soft light music.

Death is often a long moment. The person's heart rate and breathing speed up or slow down. Then it all stops. In death there is freedom and peace.

When Great Trees Fall
Maya Angelou

When great trees fall,
rocks on distant hills shudder,
lions hunker down
in tall grasses,
and even elephants lumber after safety.

When great trees fall
in forests,
small things recoil into silence,
their senses eroded beyond fear.

When great souls die,
the air around us becomes
light, rare sterile.
We breathe, briefly.
Our eyes, briefly,
see with
a hurtful clarity.
Our memory, suddenly sharpened
examines,
gnaws on kind words
unsaid,
promised walks
never taken.

Great souls die and
our reality, bound to
them, takes leave of us.
Our souls,
dependent upon their
nurture,
now shrink, wizened.
Our minds, formed
and informed by their
radiance,
fall away.
We are not so much maddened
as reduced to the unutterable ignorance
of dark, cold
caves.

And when great souls die,
after a period peace blooms
slowly and always
irregularly. Spaces fill
with a kind of
soothing electric vibration.
Our senses, restored, never
to be the same, whisper to us.
They existed. They existed.
We can be. Be and be
better. For they existed.

Maya Angelou wrote this tribute, contemplating the death of Martin Luther King, Jr. There is greatness in most lives that can be celebrated by their loved ones.

VIII Grief Work, Self Care

Loved ones may have begun grieving years before the death of their spouse/parent, etc., if the person has dementia or some cancers. Unexpected death can lead to post-traumatic reactions. Some family members will benefit from psychotherapy; others may find great assistance in support groups for care-givers. Providers who regularly work with the dying and/or other family members need to use self-care resources to maintain their resilience and compassion.

The patient has died. There is silence. If death has been quick, family members may be numb, in shock or overwhelmed with affect. If the march to death has been slow, much grieving has already been done. There will be more to do. If the patient had dementia, family has seen the personality of the patient slip away for years. Death may be a relief.

In an earlier section of this home study I described using modules from IPT to assist the patient or family with grief work and cope with changing roles. Those interventions may also be most helpful now to the surviving family members. I also described complicated grief and how often those PTSD-like reactions can be treated with a mix of IPT and PTSD interventions such as Prolonged Exposure or Cognitive Processing Therapy (Foa et al., 2007; Resick, et al., 2017).

Using Dialectical Behavior Therapy for Intense Emotions

Clients with baseline vulnerability (poor emotion regulation, low self-esteem and impulsivity) are at risk for being overwhelmed with affect and unable to problem solve. Stuntz and Linehan (2021) have written a self-help book for cancer patients, detailing how to use DBT skills to cope with intense emotions. These same skills can be life-saving for vulnerable family members who have just lost a loved one.

DBT teaches:

- acceptance of all feelings
- self-awareness
- identifying the trigger
- cognitive restructuring
- using the wise mind to decide on appropriate action
- paced breathing, relaxation.

Stuntz and Linehan describe overwhelming affect like driving in a storm. It is pouring rain. You can barely see well enough to stay on the road. Your GPS stops working. The waters are rising around your car. You are about to drown. Life can feel like this nightmare for some dying patients and some family members before or after the death of their loved one.

DBT therapists never shame the person about the intensity of their feelings. Self awareness and acceptance of feelings are the starting points of DBT. Yet DBT therapists do not accept victim thinking – I'll never feel better; I just can't cope. They teach emotion regulation skills, problem solving and assertiveness. Self-injurious behavior, substance abuse, and suicide are discouraged as not being products of a wise mind. Distress tolerance is encouraged through skill building. These skills can be life-saving for vulnerable clients.

Wise Self-care

Walking with a client or family member who is dying may be draining. Empathizing with family members who have just had a loved one take his own life is equally painful. It is at the core of our work that clinicians walk through hellish places with their clients and truly feel their pain. It is equally essential that clinicians are centered so that they do not become overly distraught in working with the most difficult clients.

It is critically important that clinicians not be Lone Rangers. Those who go it alone miss the constructive feedback and insightful support of wise colleagues. In my experience as an investigator for my Psychology Board, the psychologists most prone to mental breakdown, substance abuse and/or serious clinical errors were loners who did not consult with wise colleagues. They frequently did not belong to their national or state professional associations; they risked losing their clients, their reputation or their licenses.

Working with clients in great distress is draining. Compassion fatigue is "the cost of caring". If clinicians are not distressed at times walking with their clients, their boundaries may be too firm. A danger in doing clinical work is to burn out, to start going through the motions without investing in the affective life of clients. The alternate danger is to have boundaries that are too permeable, to be overwhelmed by the adverse events in our clients' lives.

Clinicians who work with clients who have experienced severe trauma are at risk for secondary trauma symptoms. After mindful listening to episodes of unexpected death, suicide or other trauma, we may experience secondary PTSD symptoms:

- Hyperarousal
- Intrusive imagery, e.g., nightmares or flashbacks
- Numbing, walling off pain
- Somatic complaints
- Insomnia
- Impairment of day-to-day functioning.

It is critical that clinicians doing trauma work have a strong support system as well as professional and personal skills to maintain resilience and the ability to care about the pain of our clients. Dutton et al., (1995) and Norcross and Burnett (2009) offer a helpful range of recommendations for stressed clinicians to consider. They begin with work related strategies:

- Having one or more colleagues for consultation on difficult cases, for the purpose of venting and problem solving as well as receiving constructive feedback.

- Knowing how many trauma clients you can serve well at one time; having a range of clients with different needs that pull from different parts of your psyche.
- Doing some professional work that does not require direct contact with traumatized clients, e.g., supervision, consultation, research or writing.
- Maintaining appropriate professional boundaries, e.g., having clear rules about emergency calls, setting aside at least an hour a day for handling urgent or emergency clinical situations.
- Creating a comfortable, safe, nurturing work environment for yourself.
- Maintaining curiosity and interest in learning in every stage of your career.
- Valuing the difficult, but transforming work of therapy; not being rattled by demanding clients or managed care staff who do not appreciate what we do.

These authors also recommend good self-care:

- Regular exercise, relaxation and time in nature,
- Healthy diet and preventative medical care,
- Having a supportive circle of friends,
- Maintaining a healthy work-life balance,
- Getting personal psychotherapy when you need it,
- Having engaging hobbies or interests that are both challenging and renewing,
- Devoting time to religious or spiritual growth to maintain meaning and optimism when working with even the most difficult clients

Hanson (2009) has brought together Buddhist wisdom, positive psychology and the findings of neuroscience in Buddha's Brain. He writes that pain is inevitable in life, but suffering is optional. We may feel sadness, fear, anger or anxiety intensely, but, if we are mindful, we can let these intense feelings pass. Developing the ability to stand back from pain, observe it and let it go is central to an inner sense of peace. Being able to dive deep in a storm to the quiet waters below can be life saving. Developing relaxation and mindfulness skills will "truly increase your contentment, kindness and insight" (p. 63).

Germer (2009) has written The Mindful Path to Self-Compassion, a wonderful resource for bright clients and clinicians for personal renewal. He writes from the loving kindness branch of Buddhism on how to step off the hedonic treadmill, compulsive pursuit of pleasure to reduce pain, nurture yourself, and let it go. Self-compassion involves learning to listen to your body, to accept whatever pain, stress or discomfort is present, and to breathe calmness and caring into your body and your spirit. The mantras of loving kindness are healing:

- May I be safe.
- May I be happy.
- May I be well in mind and body.

- May I live at ease (in peace).

Germer would encourage us to extend lovingkindness to a person you care deeply about (spouse, child, grandchild, best friend, etc.):

- May he be safe.
- May he be happy.
- May he live at ease (in peace).
- May he be well in mind and body

He would encourage us to wrap our most difficult client in lovingkindness:

- May she be safe.
- May she be happy.
- May she be well in mind and body.
- May she live at ease (in peace).

When we have peace and love in our hearts for the clients who trouble us most, we are more likely to avoid irritability or impatience and more likely to make possible healing moments in their lives.

Finally, to keep balance in our lives we need to retain our sense of humor. Life is full of absurdity. The world is a wonderful and wounded place. Humor enables us to experience tragedy and not be overwhelmed. All is impermanent.

Her Journey's Just Begun

Don't think of her as gone away
her journey's just begun,
life holds so many facets
this earth is only one

Just think of her as resting
from the sorrows and the tears
in a place of warmth and comfort
where there are no days and years.

Think how she must be wishing
that we could know today
how nothing but our sadness
can really pass away.

And think of her as living
in the hearts of those she touched . . .
for nothing is ever lost
and she was loved so much.

Written by Ellen Brenneman, revised with a female focus.

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