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Death and Dying: Basic Concepts, Disability, and Five Cultural Views

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This article reviews basic conceptions of death and dying in the context of people who have disabilities and chronic medical conditions. The authors take a developmental approach in discussing issues pertinent to the Rehabilitation Counseling profession and the role of the Counselor in providing services to clients on this subject. The second part of this article describes cultural views on death, dying, and disability from the viewpoint of five cultures.

I do not fear death. I had been dead for billions and billions of years before I was born, and had not suffered the slightest inconvenience from it. (Mark Twain)

Each night, when I go to sleep, I die. And the next morning, when I wake up, I am reborn. (Mahatma Gandhi)

Death is an indispensable part of human existence, of being born, and of human development through the lifespan. Rehabilitation Counselors will see some clients with disabilities who are nearing their final stages of life. It is essential to have knowledge of death and dying to provide appropriate services for these individuals. The first section of this article discusses basic concepts related to death and dying for people with disabilities. This subject is described through a developmental perspective. The second section views death and disability from the perspective of five cultures: Chinese, Middle Eastern, Native American, Latino/a, and African American. The authors describe the many similarities among cultural groups, as well as some distinctive cultural differences. For Counselors to provide appropriate services, they need to understand these cultural differences. This article offers both a reflection of the authors and also citations from the literature. When noted, the presented ideas are documented, with their applicable references. However, additional ideas not specifically referenced are reflective of the authors' opinions which are based on their knowledge of the subject.

Age-Related Ideas of Death and Disability

Infants do not comprehend the concept of death before the age of two; they also do not understand that disability can be permanent. At this early stage of human development, the person does not recognize either *being* or *not being*. Also, infants are unable to comprehend chronic illness and disability (Kail & Cavanaugh, 2014).

Between ages two and six, children begin to become aware of life and death, yet death is seen as temporary and reversible. Children at this age often compare death to the state of sleep. When material objects are moving, children may believe they are alive. When movement ceases, the objects may be seen as dead. It is noted that " . . . in infancy and early childhood, the disappearance or destruction of objects probably is experienced as a partial loss of the individual himself. In a sense, he disappears too, when his mother leaves the room" (Kastenbaum & Aisenberg, 1976, p. 407).

Children view permanent disabilities and chronic medical conditions as being temporary. It takes until ages six through nine to develop a clearer picture of what death and permanent disability mean. At about age nine, children recognize that death and permanent disabilities are final and irreversible. They begin to understand the difference between temporary (a broken arm or leg) and permanent (paralysis) disability (Kastenbaum & Aisenberg, 1976).

In middle childhood, children see death as irreversible, but not inevitable. Death begins to be understood as tangible, visible, and real. Youth who have disabilities that are severe or have terminal illnesses begin to

comprehend the seriousness of the situation they face. Once children become adolescents, they recognize the meaning of death, as well as severe illness and disability (Kail & Cavanaugh, 2014). Yet, they still engage in risk-taking behaviors and activities, believing death is something which only happens to the elderly while disability occurs to others, not to them.

By middle age, people develop an awareness of the aging of the body and that their lives are finite. During this time, concerns with dying become strongest. At this stage, terminally ill individuals frequently view death as similar to the end of interpersonal relationships. By late adulthood, they become realistic about approaching the end of life. Death and dying become more practical concerns. Individuals at this age are less concerned with death than they were during the time of middle age. There is a more pragmatic understanding of coping with the end of life. As people live into their late 60s and early 70s, there is a strong realization that life is coming to a final conclusion. Their parents and many of their friends and perhaps a spouse or partner have already died (Kail & Cavanaugh, 2014).

As per the opinion of the authors, for individuals with disabilities and chronic medical conditions, this situation is similar but more intense. As persons with disabilities age, they may approach the terminal stage of life with diminished health and at a younger age than those without disabilities. Kübler-Ross (1969) and Wright (1983) found that as people with disabilities age and their conditions begin to enter the life-threatening stage, the majority want to be told the seriousness of their condition, provided there is room for hope. Optimism for a favorable outcome is sustaining and helps people act in more practical and realistic ways, even though they are aware of the eventual outcome.

Maintaining Dignity

Although death is a natural consequence of life and living, it is not always a natural occurrence as seen many times with sudden death, or the onset of severe disability and chronic illness (Connor, 2014; Kübler-Ross & Kessler, 2005). People who do not die suddenly experience what researchers refer to as the terminal stage of life. This may occur as a consequence of aging, or when someone will die at an earlier age due to extended illness or a severe disability.

Most people, if given the opportunity, choose to die with dignity, a feeling of worth, and self-respect (Teno & Connor, 2009). The hospice movement has improved the prospect of this occurring, especially for those who have medical conditions requiring hospitalization. An aspect that can be controlled, given the right circumstances, is the ability to die while maintaining one's dignity. Hospice is *a homelike setting which specializes in care of the dying*. It can keep a person from isolation within a hospital ward or nursing home, and from being faced with dying and death alone and away from loved ones (Connor, 2014). As opposed to hospice, hospitals typically treat dying patients with aggressive life-prolonging measures.

Dr. Arnold Beisser was a physician who lived the majority of his life with a severe disability. In his book, *A Graceful Passage – Notes on the Freedom to Live or Die* (Beisser, 1990), Dr. Beisser provides the following insights, which relate to both living with a disability and dying with dignity and grace.

- Being free to choose, or being forced to live [or die] with choices made for us.
- Being in control of life [or death], or being controlled by outside forces.
- Being useful, or feeling unnecessary.
- Finding that life has meaning, or feeling that it is an empty nothingness (p. 224).

Dying with dignity is especially crucial for people who have severe disabilities, as they often live their lives with less dignity than they would have chosen for themselves. However, there are several disability rights advocates who oppose the idea of allowing people who are terminally ill to choose when and how to die, as they see this as devaluing the lives of people with disabilities.

Often, people with disabilities have underprivileged status in employment opportunities, career advancement, educational pursuits, recreational activities, and social functions. As noted by Wright (1983), individuals with severe disabilities often have to struggle throughout their lives to gain self-esteem, respect, and dignity. Many are able to overcome societal stereotypes and develop a positive outlook and an optimistic personality. This is especially true for people who secure satisfying employment, are active within the community, and attend social events and/or recreational activities.

Mourning, Grief, Bereavement, and Funerals

Losing a loved one for any reason creates self-doubt, uncertainty, and emotional pain. "There is no typical death" (Connor, 2009, p. 11). People react differently to the impending death of a loved one, depending on various factors. They may feel avoidance, terror, anticipation, and have many other reactions. With the death of a loved one, a family member must first respond to the disequilibrium that is present. There may be a progression from protest to despair, to detachment, to resolution or integration (Bowlby, 1980).

People use a variety of ways to *protest* the reality of the loss. After protest, despair may occur followed by

detachment from the relationship. Slowly, the person integrates the relationship into his or her identity and goes on with life and living. Some individuals never detach themselves, but continue the relationship they had, but in new ways. This occurrence may be positive or negative. The dying person may have *set an agenda* for his or her death, thereby helping family members cope with the impending loss. This can occur in either an affirmative or harmful manner. It is hoped that the dying person will have helped family members cope with their future loss. Yet, all people die with some *unfinished business* (Teno & Connor, 2009).

According to Kübler-Ross (1969), there is a clear difference between grief and depression, although it is often difficult to discern. With grief, the pain of loss is recognized, whereas in depression, it is unrecognized and denied. In depression, there exists a pervasive disturbance in self-esteem, feelings of hopelessness, psychomotor retardation, and/or suicidal ideation which can affect social, educational, and occupational functioning.

Overall, how people grieve is related to their life experiences with loss; prior experiences of loss may establish a pattern of dealing with loss throughout one's life. Grief is not a fixed state but rather a process involving a succession of emotions, one psychological state affecting the next. Stages of grief have been discussed by Connor (2014) and Worden (2009).

Stage One – Numbness and little feeling; brief in duration.

Stage Two – Characterized by yearning and protest.

Stage Three – Disorganization and depression; apathy, loss of interest in the future.

Stage Four – Healthy resolution of the loss; emotional recovery. An ability to express anger, anxiety, and realistic guilt.

During Stage Four, memories of the deceased become pleasant ones. The person feels a commitment to life and a deeper appreciation of relationships with significant others. For an individual who has undergone a recent disability, the grieving process may be similar. There are feelings including numbness, anger, depression, apathy, and loss.

After a period of time, people begin to acknowledge what they still can do. Negative aspects are seen as manageable, life is again valued, and adjustment to the disability and consequent limitations occurs. The individual has learned to cope and adjust to disability in a healthy, productive way rather than simply succumbing to it (Wright, 1983).

Dr. Elizabeth Kübler-Ross authored 18 books on this subject, her last with Dr. David Kessler in 2005. One of her preferred thoughts, according to Kessler, is insightful and central to comprehension of the grieving process.

> *Listen to the dying. They will tell you everything you need to know about when they are dying. And it is easy to miss (p. xv).*

The word *funeral* comes from the Latin *funus*, which had a variety of meanings, including the corpse and the funerary rites themselves (Connor, 2009). In general, a funeral is a ceremony for celebrating, sanctifying, and remembering the life of a deceased person. For the deceased and the family, the funeral is a memorial service that provides the transition between life and death. It is the one last opportunity for those who survive the deceased to say their final *good-bye*. Funerary customs comprising the complex of beliefs and practices are used to remember and honor the recently deceased. Survivors perform the ceremonies which vary among cultures and religious affiliations within cultures. A traditional funeral in Western culture usually consists of a three-part ritual: viewing or wake (depending on religious beliefs), funeral, and burial service.

Rehabilitation Counselors, Disability, and End-of-Life Care

It has been suggested that "some Rehabilitation Counselors assist consumers with end-of-life issues" (Wadsworth, Harley, Smith, & Kampfe, 2008, p. 113). Working with a client during the end stage of life, a Rehabilitation Counselor assumes the responsibility to help the client assess end-of-life related situations and facilitates the decision-making process. Counselors can help clients with end-of-life issues related to coping with challenges deriving from the environment, facilitating interventions through social support systems, and advocacy. Issues to be addressed by the Counselor include unfinished business, meaning of existence, stages of loss, as well as planning and administration of the final exit. The Counselor can help the client with problem-solving related to impending death (Rolland, 1994). This also occurs for people who have severe disabilities and long-standing, chronic medical conditions.

Wright (1983), in discussing disability, stressed the significance of the environment to a person's attitudes, emotions, and behavior. She saw the individual's behavior as a property of his or her interaction with the surrounding environment. Indicators of a healthy, successful life involve an individual's ability to work and to love. Although people who are dying are usually incapable of work, they are not unable to love and be loved. Counselors can help ensure that the dying person's family stays intact, and the family remains involved with that individual (Kuhl, Stanbrook, & Hebert, 2010). The terminal phase of dying is a time when death is no longer considered uncertain, but inevitable. Hope for a cure and long-term survival must

be relinquished. This likewise occurs with long-standing, chronic illness during the terminal phase.

As noted by Rolland (1994) and Wright (1983), the key question in this phase is the amount of time left to prepare for death and survivorship issues for family members. The principle tasks for Counselors at this time are the following: minimizing their own assumptions, leaving aside their own beliefs and value system, and just *listening* to the client and family.

A summary of these issues includes:

- Completing the process of anticipatory grief and unfinished family business.
- Supporting the individual who is terminally ill, which includes helping the survivors and the dying family member to live together as fully and comfortably as possible during the time that remains.
- Beginning the family reorganization process including issues of control.
- Creating an environment where needs and feelings can be expressed without fear of causing resentment or disapproval.

Rehabilitation Counselors have the ethical responsibility to be knowledgeable about end-of-life issues (Wadsworth et al., 2008). On the other hand, according to the Commission on Rehabilitation Counselor Certification (2010), Counselors are not obligated to work with terminally ill clients who wish to explore their end-of-life options. They can offer appropriate referral information instead of providing services to clients in need of end-of-life care. Those who offer services to terminally ill individuals who are seeking physician-assisted suicide have the liberty of breaking or not breaking confidentiality on this matter, depending on ethical principles, state and federal laws, and the specific situation.

Five Cultural Views of Death and Disability

> *I have got my leave. Bid me farewell, my brothers. I bow to you all and take my departure. Here I give back the keys to my door – and I give up all claims to my house. I only ask for the last kind words from you.*
>
> *We were neighbors for long, but I received more than I could give. Now the day has dawned and the lamp that lite my dark corner is out. A summons has come and I am ready for my journey* (TAGORE, from Gitanjali, XCIII, p. 123).

Death is a taboo topic to discuss in most cultures. Overall, cultural beliefs and values influence treatment preferences for and experiences with end-of-life care among racial and ethnic groups (Kübler-Ross, 1975). Learning the traditions that emerge from various philosophical and religious backgrounds is important for Rehabilitation Counselors. Only then can they become able to meet the needs of dying consumers and their families from diverse cultural backgrounds. This article looks at the attitudes of five cultures towards dying, death, and disability.

Chinese Culture

Scholarly literature and educational materials on Chinese culture-specific death and dying rituals and practices are scarce. However, Chinese culture, as other cultures, has a particular perspective on dying and death. It is heavily influenced by Confucianism, Taoism, and Buddhism. Confucianism stresses the importance of family and therefore, ancestral worship. Taoism emphasizes longevity through nutrition and maintenance of health. Buddhism accentuates reincarnation and the belief of karma (Braun, 1997). Throughout the past four millennia, Chinese people have developed meanings about death in relation to religious beliefs, philosophical principles, and cultural practices. Families do not discuss issues of death and dying for fear of invoking bad luck; this includes not purchasing life insurance and not buying cemetery burial plots prior to the death of a family member. To avoid ill fate associated with death, Chinese men and women may try to prolong the dying person's life through every means possible (Sue & Sue, 2015).

In general, Chinese are taught to be kind and respectful, with a *must do good* attitude in the present life to be reincarnated to a higher level in the next life. It is believed that a bad person may be reborn as an animal or as a person who has a disability. Premature death is considered bad luck and thought to be a punishment resulting from evil deeds. The punishment may pass on to future generations (Chung & Wegars, 2005). In Yu's (2014) analytical research on Chinese high school students' attitudes toward people with disabilities, the author stated that the invisibility of disabilities in Chinese society reveals a pervasive avoidance. While it is shameful to be associated with negativity and wrong doings resulting in a member with a disability in the family, Chinese culture assumes the responsibility to take care of family members as a life obligation. It is uncommon for Chinese people to seek help because it signifies vulnerability and for some, they are too proud to receive charity (Hsi & Ebrey, 2014).

Traditional Chinese medicine has been around since 3000 B.C. and currently is utilized as one of the most popular alternative medicines for the Chinese population (Gu & Brodwin, 2014). In the face of death, Chinese may try other methods to prolong life. Using a mixture of traditional Chinese medicine and Western medicine is common in the United States while use of

certain traditions and religious rituals foreign to Americans are conventional in Chinese culture.

Advanced directives of funeral arrangements are considered taboo in traditional Chinese culture. As Chinese Americans become more westernized, advanced funeral planning and burial arrangements are becoming increasingly acceptable and popular (Hsi & Ebrey, 2014). Burial, memorial services, and bereavement traditions vary among provinces, villages, and tribes in China while the time for mourning varies by relationship to the deceased. At the funeral, family members wear white from head to toe. Symbolic paper money, paper clothing, and even paper servants, paper house, and paper car are burned for use in the next life of the deceased. Some families may follow the custom of burying jewelry, especially jade, inside the caskets (Sue & Sue, 2015). Most Chinese prefer to be buried instead of being cremated to keep the body intact. In the same light, organ donation is resisted because of the desire to die intact. The belief is that one's body is a gift from one's parents; giving up body parts is considered disrespectful. Some even believe that they will be missing the donated organ(s) in their next life (Braun, 1997).

In traditional Chinese custom, memorial services are usually held at home or in a temple every seven days for 49 days. Family members offer rice, favorite dishes of the deceased, burn incense, and pray. Annually, Chinese pay respect to ancestors by making offerings of food and paper money during the Ching Ming Festival in the month of April (Chung & Wegars, 2005). Over time, Chinese Americans are adopting Christian/Western philosophies and death-related rituals. Many changes have occurred including open discussions about death planning, euthanasia, and wearing black instead of white at funerals. The younger generation prefers simplified rituals and stresses the importance of convenience (Braun, 1997). As an example, memorial services of 49 days are more likely completed in 21 days.

Culture has a strong influence related to causes and treatments of disability. Chinese people with disabilities may avoid or refuse some services of vocational rehabilitation agencies. Negative issues within the family may not be shared beyond family members in the traditional Chinese family, as this may mean family failure. These issues are only shared within the family. Traditional values may view disability as a punishment from God for the family's sins, or even the sins of ancestors (Braun, 1997). The modern Chinese view is that disability is not due to past sins, but caused by genetic factors or diseases.

Chinese are an underserved population for vocational rehabilitation providers to reach. They are less likely than Whites to apply for and gain access to the vocational rehabilitation service system. There is also a lack of bilingual providers to serve these individuals. Chinese are often seen as a *model minority* not needing rehabilitation services (Marini, 2012).

In traditional Chinese teaching, people are to avoid disclosing personal and familial information, to avoid participating in counseling, and to terminate any counseling early. Aside from traditional beliefs, another reason for this is that the Chinese community has been subjected to discrimination and anti-Asian sentiments. Therefore, there is a general distrust of White Counselors (Yan, 2014).

Middle Eastern Culture

The Middle East is a heterogeneous group of countries in Western Asia. The Middle East is comprised of 19 countries, though other definitions of the Middle East may include more countries, including some in parts of Northern Africa (CIA Factbook, n.d.). Citizens of these countries have many different ethnicities (including, but not limited to Arab, Azeri, Bahrani, Kurdish, Persian, and Turkish). There are a number of religions represented in the Middle East, including Islam, Judaism, and Christianity, among others, with Islam being the most common in the region (PBS.org, 2002). Given these varying countries, religions, and languages, the way that death is viewed in some parts of the Middle East may be vastly different from other parts of the region. This section will discuss death and dying from the standpoint of Arab Muslim cultures.

Generally, Middle Easterners do not speak of death (Meleis & Jonsen, 1983). For the Muslim majority, death is seen as the will of Allah, or in Allah's hands, and therefore many Middle Easterners do not prepare for death, nor anticipate it. When death is discussed, it is done so in a hypothetical manner, and should not be discussed in connection with an individual's life.

Families in Middle Eastern culture are very close, especially when a family member is critically ill or dying (Lipson & Meleis, 1983). When an individual is seeing a physician or is in the hospital, it is common for the person receiving medical care to bring family members to their doctor's appointments. Family members may ask many questions and be considered to be *overbearing* in their demands on staff during treatment as they shower their dying family member with care (Meleis & Jonsen, 1983). When a family member is near death, it is considered essential that he or she has the support of family and the community. Middle Easterners believe that a person should never have to suffer dying alone and should die surrounded by family (Lipson & Meleis, 1983). It is preferable in Middle Eastern culture that people die in their own homes.

Middle Easterners have a negative opinion of life support. Yet, if a person is placed on life support, family members will likely be unwilling to terminate the life-support. If a physician or the medical team proposes that the person be removed from life support,

the family will likely be incredibly offended or angered by the suggestion (Meleis & Jonsen, 1983).

Before the individual has passed, the family is expected to be supportive but stoic. Grieving or mourning pre-death is looked down upon. Once the individual has died, mourning becomes both loud and public. Family members will sob and yell; both men and women may beat their chests or heads while crying loudly to show their grief. After death, the individual's eyes are closed and the face is turned towards Mecca. The arms and legs are placed together and clothes are removed by an individual of the same sex as the deceased. The body is then washed and draped in a white cloth (again, by a member of the same sex) (Gatrad, 1994). Burial occurs as soon as possible, preferably without a coffin; however, in many Western countries, this is not allowed. As stated before, grief after death is loud and visible. The length of time for mourning varies depending on the specific culture but initially lasts three days. Memorial services for the deceased are typically large and attended by family, friends, and acquaintances.

Disability is prevalent in the Middle East, as it is in other regions of the world. There is no singular definition of disability that exists, and the topic of disability is not widely discussed (Hasnain, Shaikh, & Shanawani, 2008). The most common causes of disability in the region include disabilities occurring during birth, chronic illnesses and communicable diseases, lack of access to health care, nutrition, and violence and accidents. There is discrimination against people with disabilities in the Middle East; social stigma against people with disabilities is prevalent (Hakim & Jaganjac, 2005).

According to Lipson and Jaganjac (2005), people with disabilities in the Middle East often live in poverty. Similarly, individuals from poverty-stricken families are more likely to have or acquire a disability. This, coupled with barriers to education and work, often ensures that an individual with a disability will likely remain below the poverty line for life. However, a number of countries in the Middle East are working to improve these outcomes, by promoting both inclusive education and inclusive environments through policy initiatives and disability legislation.

Native American Culture

There are 562 different Native American tribes which are federally recognized in this country; although they are culturally diverse, they share many beliefs. The ten largest tribes in number are the Navajo, Cherokee, Sioux, Chippewa, Choctaw, Apache, Pueblo, Iroquois, Creek, and Blackfeet (National Congress of American Indians, 2013).

As reviewed by Josephy (1991), Native American religions (spirituality) are diverse due to different tribes being spread out across the country and throughout North America. They evolved different beliefs, due to the distance from one another. There is a profound connection to the spiritual world. Different than other religions, their religion is not institutionalized, but is considered a process or journey more than a religion. Native American beliefs have a strong affinity to spirituality for all that is created and believe they have a relationship with all that has been created.

They believe that the souls of people who have died are passed into a spirit world; this world influences all facets of life. Native American culture observes various death customs and beliefs. There is a central belief in an afterlife. The rites used for those who have died center on helping those who are deceased in their afterlife (Garbarino, 1976; Josephy, 1991).

Although burial customs and death rituals vary among the Native American tribes, there are profound commonalities. These commonalities were outlined by Garbarino (1976):

1) The medicine man or spiritual leader leads the ritual.
2) Deceased ancestors are asked to join in the rituals.
3) A belief that the spirit of the person never dies.
4) Gifts are buried with the deceased.
5) Pipes are smoked during the rituals.
6) The circle is symbolic in the ritual, as in the circle of life.
7) Nature is revered; death is part of nature.
8) The burial is often at a special site either close to or away from the deceased's home.
9) Death is believed to be a journey to another world.

According to Turner-Weeden (2011), Native Americans believe that when people die, they pass over into the spiritual world, at which time they meet their ancestors who have passed on before them. Their spirit continues into the future. Native Americans are raised to not hold onto material things; to do so is considered greed. Turner-Weeden's mother would tell her "you come into this world with nothing and you will go out with nothing" (p. 1). When a person is near death, the emphasis is to help them find serenity and contentment during these final days.

Native Americans do not have a word for disability or handicap. They put little emphasis on a person's disability or abnormality. Rather, a person's sameness within the community defines an individual. The difference a person with a disability has becomes only one element of the individual's existence, but not the defining element. The worth of the person is not diminished due to physical or mental variance. Attention is centered on community – restoring balance between the individual and his or her community (Sue & Sue, 2015). All people are seen as integral parts of

their communities. Native American belief is that the equality of value extends to all beings regardless of differences (Lovern, 2008).

As noted by Pengra and Godfrey (2001), people who have physical differences are seen as ordinary variations of the human condition. Because the full spectrum of intelligence is considered normal, Native Americans feel there is no impairment of intellectual functioning. The underlying philosophy is that people within the community take care of each other. If the society fails to support all its members, the society is considered impaired. Disability, therefore, is considered to be the inability of the society to provide the resources and assistance needed by all the members of the community.

Latino/a Culture

The Latino/a population consists of over 50 million people that make up 16.3% of the nation's total population (United States Census Bureau, 2011a). Latino/a Americans reside in the United States but may share a variety of national backgrounds ranging from Mexico, Puerto Rico, Cuba, Dominican Republic, and most Central and South American countries with different histories and cultural practices. There are regional and ethnic dialect differences and preferences for group labels among Latino/as living in the United States. Most Latino/as are Christian with the majority belonging to the Catholic Church. Different groups may have diverse affiliations and some descendants from Caribbean nations and Mexico practice blends of Catholicism and African indigenous folk medicine (Sue & Sue, 2015). For purposes of this article, the term Latino/a American is used to refer to the broad culture of non-European Latino/a people living in the United States.

Latino/a culture is people oriented and collectivistic in nature. Understanding these cultural values helps contextualize the belief systems and practices related to death and dying for Latino/a Americans (Santiago-Rivera, Arredondo, & Gallardo-Cooper, 2002). High value is placed on relationships with others, and the maintaining and nurturing of these relationships.

The concept of *Familismo* is a strong and salient factor involved in Latino/a culture. *Familismo involves deep feelings of loyalty, reciprocity, and attachment within families* (Soriano, 1991). Maintaining close relationships with extended family members is expected and highly valued. The nuclear and extended family frequently includes non-blood relatives. This concept permeates the culture in daily beliefs and practices.

The immediate and extended family plays a major role when it comes to death and dying within Latino/a culture (Doran & Downing-Hansen, 2006). The concept of *familismo* serves as a way of coping in that the large family network provides comfort and practical aid while grieving. This is reflected in the before and after death rituals of the culture. An example of this is when Latinos/Latinas spend days rotating prayer vigils by the bedside of a family member (Shapiro, 1994).

According to Schoulte (2011), general beliefs about how to deal with death and dying are prevalent in Latino/a culture. Rituals and practices facilitate the grief process. Expression of grief is an accepted practice. Crying and wailing are common and the intensity of the expression may indicate the importance of the deceased to the person, or how much he or she was loved. Crying can be seen as a sign of respect and love for the deceased. It is frowned upon for men to show demonstrative acts of grief such as crying or wailing. Instead, men are expected to grieve in a more reserved manner.

As a relationship-oriented culture, there is a focus on attachment, as opposed to detaching from the deceased in order to process grief. This is in contrast to Eurocentric models of a universal grieving process. Latino/as hold a general belief that there is a continued relationship between the living and the dead resulting in rituals that honor this relationship. Common themes in grieving patterns reflect the concept of spiritual continuity and continuing relationships with the deceased (Doran & Downing-Hansen, 2006).

Death rituals in the Latino/a culture are highly influenced by religion and spirituality beliefs (Sue & Sue, 2015). Catholic beliefs are a focus and dictate how Latino/as process death. Before-death rituals in the Latino/a culture include the practice of calling a priest for last rites or baptism when a loved one is dying or prayer rituals at the bedside. Based on cultural values described, this may involve a few or many family members at the bedside. After death occurs, the continued relationship is fostered through spiritual rituals such as prayers and visits to the grave. A pervasive belief is that of the soul of the deceased leads Latino/a families to perform rituals and customs that foster passage of the soul to God, heaven, *the light*, or another life.

Latino/a views on disability are connected to the values of the culture. A family with a special needs child relies heavily on family members as a support system. Often aunts, grandparents, or cousins attend school meetings or conferences with parents and participate in childcare and childrearing (Harry, 2002). Disabilities are often understood from a religious, spiritual, or supernatural perspective, especially by the more traditional or less acculturated. Disabilities and behavioral issues are often regarded as the work of *God's hand* or fate. Usually, mothers accept the child as a gift or blessing from God and assume the position that they have been found worthy enough to have been given this child. Older more traditional individuals may believe that mental retardation or developmental disability is a punishment for the sins of the par-

ents. Modern parents perceive disability as a mere reflection of individual differences in children. For others, disabilities may be viewed as having a supernatural origin. Disability and mental illness can be taboo subjects. There are stigmas that are associated with having children with severe disabilities (Pena, Silva, Claro, Gamarra, & Parra, 2008).

Latino/a parents value education. They want to be involved in the educational decision-making process of their children, but may feel marginalized, intimidated, unable to navigate the system, or feel as if their voice is not heard (Salas, 2004). Barriers such as language, cultural beliefs, lacking of familiarity with the school system, and citizenship status also impact the parent's involvement in obtaining services for their child. Hughes, Valle-Riestra, and Arguelles (2008) found that families talked about wanting to treat their child like a *normal child* regardless of the child's unique needs, but acknowledged that their level of involvement with their child was different compared to raising their other children. They understood their child who has a disability was different but did not want him or her to be treated as such. Most families want their children with disabilities to reach a level of independence similar to what most families want for their children.

African American Culture

African American culture is a large and growing minority group in the United States that constitutes approximately 14% of the United States population with an increase of 12% in the last ten years totaling 39 million people (United States Census Bureau, 2011b). Variations and differences among groups within the African American culture exist due to the diversity of ancestry within the culture. These differences can impact practices related to grief and mourning as influenced by spiritual beliefs, social class, geographic location, family influences, and political contexts (Schoulte, 2011). The African American population experiences higher death rates from heart disease, cancer, and diabetes than any other racial group in the United States. They also experience the highest rates of homicide and unintentional fatal injuries (National Center for Health Statistics, 2007).

Culture and traditions focusing on religion and spirituality play an important role for African Americans. A high reliance on strong religious beliefs and coping is common. Religion is seen as an answer to help better understand the loss, accept it, and to be able to create a new bond with their deceased loved one (Schoulte, 2011). Death is viewed not as an end of life, but a beginning to a different type of life. Some believe that one's current life should be lived in preparation for death. Physical death is seen as a transition to the spirit world. Spirits of the dead are considered to be active and in touch with the living. Family members may talk about hearing or seeing the spirits in their dreams or feeling their presence. Their belief system allows them to grieve while also maintaining a connection with the deceased (Lobar, Youngblut, & Brooten, 2006).

Traditions including prayer and meditation help the dead transition to the afterlife and spirit life. The ease of this transition is believed to depend on the family preparing food and clothing, singing, and praying to ancestral spirits to ensure the entrance of the dead into the spiritual world. When death is unexpected, these transition practices cannot be made and can contribute to increased distress on the family. As with many cultures, African Americans attend funerals of loved ones to demonstrate respect for the deceased and their family. Traditions may vary by region, but some more traditional customs may have the corpse at the house the evening before the funeral where friends and family are able to come together and help out.

The nuclear and extended family play a prominent role. African Americans similarly grieve the loss of both nuclear and extended family members with both causing significant distress on family members. Grief is freely expressed, particularly by women and children. Psychological distress can take the form of a *falling out* in which the person may experience somewhat of a dissociative reaction, dizziness, or fainting spell. This is considered to be a culture-bound syndrome and a reasonable social response to the death of a loved one (Jackson, 2006). While they may experience high levels of grief and distress, African Americans tend to use less mental health care services compared to other cultures, possibly due to negative perceptions of mental health care providers. They are more likely to seek help from clergy than health care professionals (Lobar et al., 2006). There is a high reliance on religious and spiritual coping with much of the perceived levels of support coming from the immediate and extended family, and external resources. These resources play a significant role in grief recovery.

The poverty rate for African Americans who have disabilities is 37%, compared to 19% for African Americans without disabilities. Overall, this group has the highest disability rate, 21%. Learning disabilities are likewise overrepresented in this population. When considering all ethnicities, there is less accommodation and greater societal stigma surrounding disability (Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010).

Approximately 14% (one in seven individuals) of working age African Americans have disabilities. There is more unfavorable employment, lesser education, and poorer rehabilitation outcomes for African Americans with disabilities. A smaller per cent are employed (16%) when compared to others (26%). African American males under the age of 24 have the highest death and disability rates due to crimes of violence (Marini, 2012). Overall, this culture experiences a greater disproportion

of disease, injury, and disability. Prevalence of disability is highest within this culture, and there is a higher rate of many chronic illnesses which lead to impairments and resulting disabilities (Balcazar et al., 2010).

Religion is highly valued and is a priority. Family is considered first before individual needs. Interdependence on one's family, family values, and strong religious beliefs give the person and the family strength to adapt to disability. African Americans need culturally appropriate vocational rehabilitation services. Schoulte (2011) stated that access to and utilization of these services are not as available within the community. Many of these services are provided by White Counselors who lack the knowledge and understanding of other cultures.

As noted by Yan (2014), "as people from across the globe become educated about disability and disability-related issues, traditional ideas should be gradually replaced by more respectful and supportive perceptions" (p. 7).

The Final Finale

Death is an indispensable part of human existence, of being born, and of human growth and development throughout the lifespan. As an integral part of every being's life, it helps provide meaning to our existence. Through the knowledge that our lives are finite, it gives people the opportunity to accomplish something productive within the limited time they have. In the perceptive words of Braga and Braga in the forward of Kübler-Ross' (1975) book, *Death – The Final Stage of Growth*,

> *If you can begin to see death as an invisible, but friendly companion on your life's journey – gently reminding you not to wait till tomorrow to do what you mean to do – then you can learn to live your life rather than simply passing through it (p. x).*

Death can offer a context for living, its meaning, and a key to growth and development. In the words of Kübler-Ross (1975),

> *LIVE, so you do not have to look back and say: God, have I wasted my life (p. xix).*

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Editorial Comments: Over the span of a year I would estimate that 60 articles are received for review. Among the articles approximately 30 are immediately rejected. Approximately, six months ago I received an article by Dr. Brodwin concerning an article on death and dying. My initial impression, admittedly, was to reject the article. After all, the purpose of the profession is to assist in the rehabilitation of persons with disabilities, and death, respectfully, represents avoidance by the profession. Unfortunately, at the time of receipt of the article, a client had died. I began thinking across the span of my career that several clients had died, with some dying as a result of acquired injuries and other as a result of natural causes. Within the span of processing the death of the client, I opted to reconsider the article. I contacted Dr. Brodwin and accepted the article. Then, I contacted Dr. Brook Breaux, as I knew she had previously completed research on the linguistics of death. Across both articles quality presentations have been offered on this timely topic.

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