Life Cycles and Spirituality
Spirituality, Religion, and Children

• Section Description
  – Spirituality is a dynamic, evolving process that begins in infancy and continues throughout life. The spiritual development in children is especially important because of its impact on the rest of the child’s life.
  – The goal of this course is to provide an overview of spiritual and religious development in children. The relationship between the phases of psychosocial development and spiritual development in all ages of children is explored. Characteristics of spiritual distress in children, methods of providing spiritual care to children, and specific care concerns for children with a chronic or terminal illness are also presented.
Learning Objectives

Upon completing this course, you will be able to do the following:

1. Describe the development of spirituality and religion in children.
2. Identify the relationship between the phases of psychosocial development and spiritual development in infancy according to Fowler, Piaget, and Erikson.
3. Identify the relationship between the phases of psychosocial development and spiritual development in toddlerhood according to Fowler, Piaget, and Erikson.
4. Identify the relationship between the phases of psychosocial development and spiritual development in early childhood according to Fowler, Piaget, and Erikson.
5. Identify the relationship between the phases of psychosocial development and spiritual development in middle childhood according to Fowler, Piaget, and Erikson.
6. Identify the relationship between the phases of psychosocial development and spiritual development in adolescence according to Fowler, Piaget, and Erikson.
7. Describe the process of spiritual assessment in children.
8. List the characteristics of spiritual distress in children.
9. Explain methods of providing spiritual care to children of various ages.
10. Describe specific care concerns for children with a chronic illness or for those who are dying.
Proud new parents gently hold their infant as their priest pours water over the child’s head. A congregation of friends and neighbors witness the baptism and welcome the infant into the Christian community. A Buddhist mother brings her child to a monk for consecration. On the eighth day after birth, a Jewish couple presents their son for his circumcision rite.

The acts described in the preceding paragraph represent specific rites of passage unique to a particular religious or faith community. While they often signify the beginning of a spiritual journey for the new family member, they do not guarantee that a child will follow that faith. In other words, as Carson (1989) writes, “Individuals may be born into a religious community but they are not born religious” (p. 25).

Just as the physical and emotional aspects of an individual need to be nurtured, the spiritual dimension of a person also needs care and “feeding.” This care and nurturance often begins during infancy or early childhood (Betz, 1981). Elisabeth Kübler-Ross (1983) writes, “. . . all human beings are different, even before they were here. And then they are here to share this world with us, and all human beings have different lives, different experiences . . . Has anybody ever thought about the trillions of possibilities that life offers each one of us?” (pp. xii–xiii). Through the support of family, friends, and a community of faith supporters, children are taught and guided as they travel on their own personal spiritual journey (Carson, 1989).
The development of personal spirituality is a dynamic, evolving process that occurs over a period of time. During this process, individuals become increasingly aware of the meaning, purpose, and values in their life. Faith, too, develops over time; it is an outgrowth of and a prerequisite for spiritual growth (Fulton & Moore, 1995).

An individual’s spiritual development can be horizontal or vertical. Horizontal development involves the individual’s relationships with the self, with others, with the environment or nature, or with spiritual activities. Vertical development involves transcendence and the individual’s relationship with a higher power (Carson, 1989; Fulton & Moore, 1995). Children, too, develop their spirituality in both a vertical and horizontal manner. Their relationship with their parents or a caregiver begins both their vertical and horizontal spiritual journey.

Children may or may not come from a religious or spiritual background. Those whose families possess a strong religious background may not question who God is or what he does, while those without a strong religious background may learn about spirituality through their world experiences (Fulton & Moore, 1995).

Spiritual integrity is a basic human need, since it provides every individual’s life with meaning. It influences values, relationships, and how people lead their lives. Spirituality in children is no different. Hart and Schneider (1997) state that spirituality in children is “the ability of a child through relationships with others to derive personal value and empowerment” (p. 263). Children’s relationships with others as well as their relationships with a supreme being or values lead to the development of that spirituality.
Development of Spirituality and Religion in Children

- Religious development, a component of spiritual development, involves the individual’s “acceptance of a particular system of beliefs, values, rules for conduct, and rituals” (Carson, 1989, p. 26). Religious development may occur along paths similar to that of spiritual development or it may not.

- Children, unlike adults, do not make clear distinctions between spirituality and religion. Yet even very young children may have clear, often fluid, ideas about faith, prayer, and divine experiences (Barnes, Plotnikoff, Fox, & Pendleton, 2000). Shelly (1982) states that “stories abound of very young children who made serious and lasting commitments to God” (p. 12).

- Religious and spiritual experiences can exert a powerful influence in the lives of children, influencing their moral development, their idea of social relationships, their way of perceiving themselves and their behavior, and their way of relating daily occurrences to a broader spiritual view (Barnes et al., 2000). A religious foundation in children has been associated with positive health-promoting and disease-preventing behaviors such as lower rates of adolescent pregnancy, suicide, delinquency, substance abuse, drinking, smoking, and violence. However, one potential negative effect of religious/spiritual involvement for a child is the risk of damage from a tradition that emphasizes guilt or the promotion of religiously sanctioned prejudice, hatred, or violence. In addition, a child may be considered at risk if the religion promotes a therapy that substitutes for medical treatment of an ill or injured child (Barnes et al., 2000).
• While the cultural and spiritual convictions of a child and his or her family need to be honored, difficulties can arise for health care personnel when those convictions are at odds with the alternative forms of therapies perceived to be “better” for the child by mainstream medicine. A further problem may develop when the health care provider from a more traditional biomedical culture is not familiar with the child and/or the family’s culturally based orientation and therapies and does not know how to relate to the family’s viewpoint. This can result in pressure being applied to the child and/or the family to comply with the biomedical caregiver and a potentially dangerous impasse that can potentially harm the child (Barnes et al., 2000).
Many theorists describe the relationship between psychosocial development and the development of religion and spirituality throughout the various phases of life. This course examines the work of three theorists: Erik Erikson, a leader in the field of psychosocial development; Jean Piaget, a leader in developmental psychology; and James Fowler, who developed the stages of faith development and was greatly influenced by both Erikson and Piaget.

Please note that all three of these theories are based on Western experiences and a Judeo-Christian perspective. While this perspective may be the most familiar to many American health care providers, the reader is encouraged to gain a broad insight into the role of various religions and cultures in the spiritual development of individuals from a wide range of backgrounds.
Phases of Psychosocial and Spiritual Development

Infancy

- While most people consider infants to be born without any defined spiritual self and without specific religious values, the time of infancy is a crucial one for developing faith, religious beliefs, and a personal spiritual dimension. This development is defined through the infant’s experiences with his or her caregivers and lays the foundation for the infant’s future spiritual beliefs (Carson, 1989).

- Erikson calls this period of psychosocial development (birth to 2 years) the stage of trust versus mistrust, when the foundation for hope and self-identity are established. At this stage, the infant’s understanding of God is vague and the infant responds most to a warm and loving environment in which diversion, rather than punishment, is used to correct wrongdoing (Hart & Schneider, 1997; Hitchcock, Schubert, & Thomas, 1999; Shelly, 1982).

- Piaget refers to this phase (birth to 2 years) as the sensorimotor phase, since the infant primarily relies on its senses, motor skills, and reflexes to explore the world and solve problems (Hart & Schneider, 1997; Hitchcock et al., 1999).

- Fowler defines this stage of faith development (infancy to 3 years) as stage 0 or undifferentiated, meaning that the infant does not have the ability to formulate ideas or communicate concepts about him- or herself or the environment (Betz, 1981). Infants have no sense of right or wrong and no religious or spiritual beliefs yet (Hart & Schneider, 1997). Their entire concept of self and the world is developed through the senses.
Phases of Psychosocial and Spiritual Development

- According to Shelly (1982), an individual’s need for meaning and purpose is present from infancy. The need for love and connectedness is the foundation for survival. Babies who are unloved fail to thrive and may even die. When infants are cared for by a loving, kind, tender mother who meets their needs, they begin to develop trust and ultimately faith, which can be described as “a confidence or trust in a person or thing” (Betz, 1981, p. 22).

- The infant’s earliest spiritual need is one of unconditional love, and this need is initially met through the infant’s relationship with his or her parents or primary caregiver (Hart & Schneider, 1997). Infants are completely dependent on their mothers (or primary caregivers) to meet their physical, emotional, and social needs, and these needs are met through touch and the senses. If their needs are met, infants develop a sense of trust. Through the process of trust, they begin to hope—hope that their needs will continue to be met in the future and hope that comfort will be provided by those closest to them. While the infant still has no concrete religious or spiritual beliefs (since they develop over time), trust and hope are the basis for the earliest development of both horizontal and vertical religious and spiritual development (Carson, 1989).

- The development of trust is the foundation of a relationship with God because trust requires an openness and receptivity that are important characteristics of the relationship of an individual to a supreme being. If this foundation is not developed, individuals struggle with the ability to ever trust anyone other than themselves. Shame, doubt, and mistrust develop. If the foundations of trust, hope, and faith are developed, the infant possesses the basis for a relationship with God or an abstract being that is separate from self (Carson, 1989). The infant has a sense of belonging and self-worth and a solid foundation for spiritual development. Parents are usually the individuals who engender this hope and trust. Thus, parents are primarily responsible for the spiritual care of their children (Shelly, 1982).
Phases of Psychosocial and Spiritual Development

**Toddler-hood**

- The time of toddler-hood is characterized as a time of independence and the mastery of skills as the toddler begins to take advantage of his or her newly developing motor skills. In terms of spiritual development, this time is an important one. The toddler gains a sense of self and self-worth through the mastery of skills such as toilet training. According to Hart and Schneider (1997), faith is first experienced by toddlers as courage—often exemplified when they acquire a “will,” defy authority (usually the parents), and say “No!” Autonomy and assertion are important characteristics in the development of faith and a spiritual identity.

- Erikson views this time (from 1 to 3 years of age) as one of *autonomy versus shame and doubt* (Hart & Schneider, 1997; Hitchcock et al., 1999) and characterizes it as a time during which the toddler struggles with issues of assertion versus acquiescence (Carson, 1989). The toddler needs love balanced with consistent discipline (Shelly, 1982).

- Piaget refers to this stage (age 2 to 4 years) as *preoperational thought and the preconceptual phase*, when the toddler is extremely self-oriented, sees things from his or her own point of view, and judges things based on their outcomes or consequences (such as punishment or obedience) to the self (Hart & Schneider, 1997; Hitchcock et al., 1999).

- Fowler does not have a specific stage of development for this phase of life.
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Phases of Psychosocial and Spiritual Development

- Toddlers have difficulty conceptualizing a supreme being and do not have the ability to comprehend the significance of their own actions (Betz, 1981; Hart & Schneider, 1997). If there are no religious or spiritual beliefs in the family, toddlers will often create their own concept of a supreme being to explain the unexplainable.

- Toddlers cannot make a distinction between what is real or what is supernatural. Stories that explain faith or spirituality need to be simple. The use of illustrations is particularly helpful in getting the toddler to understand spiritual or religious concepts. The toddler often believes that supernatural beings are magical. For example, they may envision God as an angel or a “friendly person” with whom they can communicate (Betz, 1981).

- This stage lasts until the child enters school. If children do not develop a sense of self-worth, they may have difficulty recognizing the value of others. They may feel alienated, which can affect their ability to participate in religious or spiritual practices. If they do not feel loved, they may have difficulty believing that any other being (human or otherwise) could love them. This can influence both their horizontal and vertical spiritual development process. While the child at this stage does not think of this in logical, rational means, the perceptions created by this stage of development can result in misperceptions that persist throughout a lifetime (Carson, 1989).
Early Childhood

- The school-aged child is often a physically rowdy youngster who is quite active and demands the attention of others. This child is becoming increasingly proficient in both language and motor skills.
- Erikson characterizes this stage as one of initiative versus guilt (ages 3 to 6 years) since the child wins approval and recognition by solving problems and finishing simple tasks (Hart & Schneider, 1997; Hitchcock et al., 1999).
- Piaget calls this the stage of preoperational thought and the intuitive phase (ages 4 to 7 years) (Hitchcock et al., 1999). The child is learning to think but is not yet able to think rationally or systematically. He or she is self-centered and thoughts are subjective. The child will often fixate on one aspect of an event and ignore others, and is incapable of mentally reversing a series of events.
- Fowler calls this phase (ages 3 to 7 years) stage 1 or the intuitive-projective phase (Hart & Schneider, 1997). During this time, faith development mirrors the form of the child’s parents. The child is influenced by the actions of his or her parents, their religious behaviors (such as bowing their head in prayer), their experiences in church, as well as any religious stories and rituals that the family observes. Bedtime prayers, religious holidays, and mealtime blessings can have a profound influence on the child.
Phases of Psychosocial and Spiritual Development

- According to Shelly (1982), the child at this stage views God in terms of physical characteristics such as hair color, facial features, and clothing worn. The meaning of prayer is still vague, but rituals are important. The child understands simple Bible stories with clear singular themes. A conscience is beginning to emerge and the child fears punishment. As the child ages, the desire to please is strong and the child sees right and wrong as absolutes.

- School-aged children begin establishing new relationships outside the family, and their peer group becomes increasingly important. The desire to conform is strong. At the same time, these children are becoming independent, more skillful and productive, and developing a stronger sense of their own identity (Fulton & Moore, 1995).

- Children at this stage are attempting to learn how to balance what they want with what others want. The successful achievement of this task can impact horizontal and vertical spiritual development. Children at this age have a developing conscience and understand that God, or a higher power, is capable of rewarding or punishing specific behaviors. If children are taught that they are “bad” for disobeying strict rules, they may also view God as a strict “parent” who cannot possibly love them (Carson, 1989).

- During this time, children may increasingly verbalize their perceptions of God to their family. Others may, in their own unique way, ask God for something special (Carson, 1989). They may see God in a magical way and try to manipulate him through specific prayers that ask for something in exchange for good deeds. In this light, they turn to God only when they need something and they never really internalize their love of God (Carson, 1989).
Phases of Psychosocial and Spiritual Development

Middle Childhood

- The child between the ages of 6 and 12 years is characterized as one who is trying to become proficient at doing things.
- Erikson calls this the stage of *industry versus inferiority* (ages 6 to 12 years). This child is concrete in his or her thinking and is beginning to develop some logical reasoning skills (Hitchcock et al., 1999). If children are successful in this stage of development, they can feel worthwhile about their self-image. This can translate into successful participation in spiritual or religious activities and the ability to relate to others in a meaningful way (Carson, 1989).
- Piaget calls this the stage of *concrete operations* and believes that children in this stage (ages 7 to 11 years) have concrete thinking processes but are developing the skills of inductive reasoning and beginning logic (Hitchcock et al., 1999). Young children begin to acknowledge that God or a higher power is indeed how he has been presented by their family and community. If children experience a belief that differs from what they have been taught, they often dismiss that belief as “wrong” (Betz, 1981).
- Fowler calls this phase (age 7 to 12 years) *stage 2* or the *mythic-literal stage* and views it as one in which children are evolving in their understanding of what God “looks like.” Some children see God as an angry parent, a “bogeyman,” or a magical spirit in the sky.
Children at this stage are interested in understanding how God does what he does, since this is the age of skill mastery (Carson, 1989). They may be volatile or prejudicial in their behavior in an attempt to protect their belief systems from being challenged (Betz, 1981). Children at this stage may have a relationship with God that is based on the expectations of what God can, or cannot do, for them. For example, a child may state that God “answered my prayers by helping me in school” (Carson, 1989).

Explanations about faith and religion need to be concrete and visual for the preadolescent, although they can be more sophisticated than those for the school-aged child (Betz, 1981). These children are able to reason inductively and deal with concrete, observable items. They have difficulty with abstract thinking but their ability to think is broadened by their interactions at school, which provides them with the opportunity to see other points of view and compare their ability to problem-solve and reason with other children (Ebmeier, Lough, Huth, & Autio, 1991).
Phases of Psychosocial and Spiritual Development

Adolescence

- Adolescence is a time characterized by rebellion against authority and conflict about previously held attitudes about personal values and beliefs. This is a time of great angst for most individuals.
- Erikson characterizes it as one of identity versus role confusion (Hart & Schneider, 1997; Hitchcock et al., 1999). This phase (ages 12 to 18 years) is characterized as a time of transition from childhood into adulthood. Adolescents begin to test their limitations, separate from their parents, and begin establishing their own unique self-image (including the clarification of their sexual identity). Peer relationships are very important and can influence their identity development. This is a time of intense conflicts that can center on who they are, what their life means, and what they hope to achieve in their life as an adult. Failure to achieve an identity results in confusion about who they truly are.
- Piaget refers to this phase as the formal operations phase during which abstract and deductive reasoning skills are developed (Hitchcock et al., 1999). Children must go through this process in order to develop a clear sense of who they are as individuals.
- Fowler calls this stage of faith development stage 3 or the synthetic-conventional stage. Adolescents realize that they are capable of separating facts about God and their world from their previously imagined perceptions of what God was like. They become aware of spiritual disappointment. If their perception of God is different from the perception presented by those in authority (such as their parents), they may often accept the authority’s perception. However, adolescents begin to question the standards set forth by their parents (Hart & Schneider, 1997). Children at this stage are interested in understanding how God does what he does, since this is the age of skill mastery (Carson, 1989). They may be volatile or prejudicial in their behavior in an attempt to protect their belief systems from being challenged (Betz, 1981). Children at this stage may have a relationship with God that is based on the expectations of what God can, or cannot do, for them. For example, a child may state that God “answered my prayers by helping me in school” (Carson, 1989).
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Phases of Psychosocial and Spiritual Development

• This is a time of paradoxes. Adolescents reject parental values and norms because they do not want to conform to their parents’ way of behaving. They want to experiment with peer group behaviors, yet the peer group also demands conformity. Teens may adopt a carefree, hedonistic behavior pattern or may completely give in to the requirements of their social group. This is a time when some teens totally reject organized religion because of what it represents to their parents, while others may find that organized religion provides them with a much-needed peer group and the promise of comfort and happiness. Those adolescents who were raised in a household where there was no strong religious identity may seek out a religion that was rejected by their parents (Betz, 1981; Carson, 1989).

• Adolescents seek answers to questions such as “Who am I in relation to God?” and “How do I fit in the universe?” Teens can, at this stage in their spiritual development, begin to understand that they are unique individuals with infinite value, and this understanding can satisfy their need for recognition. Adolescents sometimes experiment with new personas to see which one best suits them as individuals. They may even present themselves differently in different situations and among different people (Carson, 1989).

• If adolescents are hospitalized, they can experience extreme stress, intense psychological distress, and suffering. The intensity of their spiritual or religious needs often increases in proportion to the severity of the illness (Silber & Reilly, 1985). According to one study, most adolescents believe in God or a supreme being and almost half of those who were afflicted by a serious or fatal illness experienced a striking change in their spiritual concerns. The health care provider’s sensitivity to spiritual concerns can be crucial in providing compassionate care to adolescents during such a difficult time (Silber & Reilly, 1985).
## Phases of Psychosocial and Spiritual Development

### A Comparison of Psychosocial, Cognitive, and Faith Development Stages

<table>
<thead>
<tr>
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<td>Trust vs. mistrust (birth–age 2): the foundation for hope and self-identity are established</td>
<td>Sensorimotor (birth–age 2): the child relies on its senses to explore the world and solve problems</td>
<td>Stage 0, undifferentiated (infancy–age 3): the child has no religious or spiritual beliefs yet</td>
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<td>Autonomy vs. shame and doubt (ages 1–3): the child struggles with issues of assertion vs. acquiescence</td>
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<td>Preoperational thought/intuitive (ages 4–7): the child is not yet thinking logically and has a self-centered and subjective view of the world</td>
<td>Stage 3, synthetic-conventional: adolescents can separate facts about God and their world from previously imagined perceptions</td>
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<td>Identity vs. role confusion (ages 12–18): the child tests limits and begins to develop a unique identity and clarify life’s goals and meaning</td>
<td>Formal operations (ages 11–15): abstract and deductive reasoning skills are developed</td>
<td>Stage 1, intuitive projective (ages 3–7): a highly imaginative phase in which faith development mirrors the parents</td>
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**Spiritual Distress in Children**

- Children, like adults, can experience spiritual distress. If the spiritual assessment results in a suspicion of spiritual distress, the following information may be useful in confirming the diagnosis and determining a plan of care for the child and the family.

- Children may express a variety of behaviors indicative of spiritual distress, depending on their age and developmental level. School-age children, for example, may be angry, withdraw from interactions with other people, cry, or regress in their behaviors. They may have nightmares or be unable to sleep. Often these behaviors are observed at nighttime or at bedtime hours when they feel most vulnerable.
Spiritual Distress in Children

A summary of the most common types of behaviors observed in children with spiritual distress is presented below (Shelly, 1982).

- Bewilderment
- Anxiety
- A desire to undo, redo, or relive the past
- Crying
- Sleep disturbances
- Psychosomatic manifestations
- Depression
- Disturbing dreams
- Discontinued religious participation
- Self-destructive behavior
- Self-belittling
- Self-pity
- Fatigue

- Feelings of powerlessness
- Feelings of hopelessness
- Irritability
- Fear of being alone
- Feelings of uselessness
- Sense of abandonment
- Doubts about the compassion of a superior being
- Feelings of being spiritually empty
- Verbalizing that God seems very distant
- Verbalizing a desire to feel close to God
- Seeking spiritual assistance
- Displacing anger toward religious representatives
- Loss of affect
- Demanding behavior
Spiritual Distress in Children

Holistic care of the child in spiritual distress can be provided by many members of the health care team. For example, children may wish to talk to a spiritual care provider before they go to surgery; a child or family member may request a religious ritual such as a prayer or blessing before a particular procedure; or, if the client is an infant, the family may wish to have the child baptized or blessed before surgery or other procedures (Fina, 1995). The child or the family may ask for a quiet place for meditation or silent prayers or they may want to listen to music. They may also want to maintain spiritual rituals, such as bedtime or mealtime prayers, that provide them with a sense of constancy during times of stress.
• When providing spiritual care to children, health care providers should make every effort to deliver it in a manner that is congruent with the child’s developmental and psychosocial needs. Many children, because of their age or developmental stage, have limited ability to clearly and articulately communicate their needs and feelings in this area. Compassionate spiritual care should start with an understanding of the normal fears and concerns of children at their particular stage of development. Care should be presented in a way that the can child understand, and health care providers should be acutely sensitive to the child’s evolving spiritual needs. (Hart & Schneider, 1997).

• In addition to these general guidelines for pediatric spiritual care, several specific recommendations for certain age groups follow.
Providing Spiritual Care to Children

**Spiritual Care of Infants**

- When an infant is ill or hospitalized, spiritual care revolves around providing a normal, regular routine so the child’s sense of trust is not disrupted. Consistent care, consistent caregivers, and parental involvement in that care are crucial. Emotional comfort and stimulation can be provided to the infant through activities such as holding, cuddling, talking to, and playing with the child.

- The infant’s parents need to be supported in their parenting skills and listened to when they express concerns about the child. If they believe that their child’s illness is the result of some kind of punishment or that it is a religious omen, they may find it helpful to discuss their concerns with a spiritual leader or trained caregiver (Hart & Schneider, 1997).

- According to Betz (1981), spiritual care of the parents of an infant can be provided by:
  - actively listening to their concerns and fears,
  - providing reassurance about their parenting skills, and
  - supporting their religious and emotional support systems.
Providing Spiritual Care to Children

Spiritual Care of Children

• In order to provide spiritual care to children, the health care professional should understand how they grow physically, socially, emotionally, and mentally. The spiritual needs of children vary according to their particular stage of development. For example, a nurse will soon discover that providing a two-year-old with a detailed, clinical explanation of why he or she needs an injection is futile. The same is true about a child’s spirituality. Health care providers often expect very young children to understand complex religious or spiritual concepts and then act perplexed when they don’t understand what is being discussed (Shelly, 1982).

• The specific interventions that support the spiritual development of toddlers include helping them to focus on reality, relieving any feelings of guilt they have that their disease or condition is a punishment from God or a higher power, using their own support systems (such as parents) to help them understand that they are not “bad,” and continuing the use of any regularly used religious or spiritual rituals such as bedtime or mealtime prayers (Betz, 1981). While many children believe that their illness, their parent’s or sibling’s illness or death, or the injury or death of a friend is a form of punishment because they had “bad thoughts” or “did bad things,” other children find comfort in their relationship with God or a higher power (Ebmeier et al., 1991; Kübler-Ross, 1983). The feelings they experience are often a result of their level of cognitive development.
• Barnes et al. (2000) have suggested the following guidelines for health care practitioners interested in integrating spiritual and religious resources in the care of children:

  – Know that there will be spiritual and/or religious concerns when caring for children.
  – Understand your own spiritual history and perspectives and draw from that understanding when providing care.
  – Become familiar with a variety of spiritual, religious, and cultural worldviews.
  – Allow children and families to teach you about the specific practices integral to their perspectives.
  – Develop relationships with a variety of spiritual and religious resources and individuals.
  – Listen to clients and families as they express their spiritual needs or concerns.
Providing Spiritual Care to Children

Spiritual Care of the Child With a Chronic Illness

- Chronic illnesses often disrupt lives in many ways. A chronic illness experience can be one of the most stressful times in the life of a child and his or her family. The physical, social, emotional, and spiritual dimensions of a child can undergo alterations that often cause much despair.

- Chronic illnesses are estimated to affect 7.5 million children in the United States each year. They can involve physical, physiological, and developmental states that can fluctuate from acute exacerbations to periods of stability during which individuals and family members collaboratively support one another in an effort to manage the condition (Fulton & Moore, 1995).

- Children with chronic illnesses such as cancer are at a high risk for spiritual distress. They may experience depression, feelings of isolation, helplessness, inadequacy, guilt, and a variety of fears related to their changing body image. Weight loss, alopecia, loss of body parts, and the fear of a premature death are all experiences that can contribute to a spiritual crisis (Hart & Schneider, 1997).

- According to Ebmeier et al. (1991), concern over body image is especially distressing during illnesses that occur in middle childhood or adolescence. For school-aged children, the most feared health care experiences include having surgery, receiving an injection, having a finger pricked for a lab test, being away from family, and worrying that someone else might “catch” their illness. Children experiencing chronic illnesses may not be able to develop or maintain relationships with their peers. They may compare themselves to their peers and focus on their differences or the changes that have occurred because of the illness. This can lead to intense feelings of inadequacy, leading to a loss of self-worth and hope. Ultimately, these feelings can greatly affect the child’s ability to heal and can result in spiritual distress (Fulton & Moore, 1995).
Providing Spiritual Care to Children

- Children with chronic illnesses who are hopeful, who believe they have a future, or who are optimistic or have a positive attitude or expectations, may experience the ability to maintain, regain, or support their health condition. Spirituality and/or religious affiliations may provide a structure for these children so that positive coping strategies are developed. For example, spirituality can help children cope with the following types of issues (Barnes et al., 2000):
  - Nighttime fear
  - Hospitalization
  - Cancer
  - Terminal illness
  - Death of a family member
  - Racism
  - Trauma
  - Sexual abuse
  - A sibling’s illness or death
  - Substance abuse
  - Psychiatric problems
Children with chronic illnesses who are hopeful, who believe they have a future, or who are optimistic or have a positive attitude or expectations, may experience the ability to maintain, regain, or support their health condition. Spirituality and/or religious affiliations may provide a structure for these children so that positive coping strategies are developed. For example, spirituality can help children cope with the following types of issues (Barnes et al., 2000):

- Nighttime fear
- Hospitalization
- Cancer
- Terminal illness
- Death of a family member
- Racism
- Trauma
- Sexual abuse
- A sibling’s illness or death
- Substance abuse
- Psychiatric problems
Providing Spiritual Care to Children

- Spirituality provides children with the ability to hope, and this hopefulness helps them accept the limitations of their current illness or provides them with the ability to accept that they may be dying. While hopefulness in children and adolescents is similar in many ways to that of adults, adolescents, in particular, have expressed a greater intensity and range of hopefulness than adults (Hinds, 1988).

- Fulton and Moore (1995) consider chronic conditions to be multidimensional experiences. Interventions should reflect the child’s developmental level, the type of condition the child is experiencing, the child’s coping strategies, and the family’s unique psychosocial and economic variables. Holding, comforting, play therapy, adequate pain control, and allowing parents to participate in the child’s care are examples of important interventions, since they support the child’s and the family’s spiritual life (Hart & Schneider, 1997). Other effective avenues of care include bibliotherapy (the use of poems, anecdotes, metaphors, storytelling, and journal writing) appropriate for the particular developmental stage of the child, as well as biographical scrapbooks and literature that the child finds meaningful. Finally, health care providers can use themselves as a powerful healing tool.

- In caring for the child with chronic illness, health care providers should also be sensitive to the needs of the child’s family. Siblings may experience many different outcomes as a result of their brother or sister having a chronic condition. They may develop higher levels of self-esteem as they help the family with responsibilities and activities around the home. They may develop greater empathy and maturity as they strive to cope with the impact of the chronic illness on their sibling. Conversely, siblings may also experience jealousy or resentment about the special attention the sick sibling receives. They may also experience sadness, loneliness, anxiety, or guilt if they feel they somehow contributed to the sibling’s illness (Fulton & Moore, 1995).

- Health care providers can help the various family members (including the siblings if their age warrants it) to understand these feelings by educating them about the wide range of emotions that may be experienced. By their caring presence, health care providers can be a “safe place” for the child and family members to express their emotions and vent feelings that might be uncomfortable or unacceptable if they were expressed to other family members. Health care providers can provide counseling services (depending on their expertise and training) and they can also provide family members with spiritual care resources as well as community resources that may help the members cope with these emotions.
Providing Spiritual Care to Children

Spiritual Care of the Dying Child

- In modern society, children are expected to outlive their parents. Yet, according to the American Academy of Pediatrics (2000), approximately 53,000 children in the United States each year die from trauma, lethal congenital conditions, extreme prematurity, genetic disorders, or acquired illnesses. These causes are quite different from the causes of death in adults. However, the same basic components of compassionate spiritual care provided to adults should be provided to dying infants and children.

- Holistic palliative care is concerned with the physical, psychosocial, and spiritual care of the child at every stage of the illness. This growing concern for the holistic palliative care of the dying child comes from studies showing that “many children with cancer experience substantial physical suffering in the last month of life and that, in the memory of their parents, attempts to control the child’s symptoms are often unsuccessful” (Collins, 2002, p. 657).

- Competent and compassionate care, including palliative care, places paramount importance on respecting the dignity of the child and the family. Health care providers need to support the family’s and the child’s expressions of disappointment, anger, grief, and suffering. Fears of abandonment and isolation are great, and the parents and child need reassurance that the health care team will continue to provide support and caring throughout the child’s death and thereafter (American Academy of Pediatrics, 2000).
Providing Spiritual Care to Children

- Spiritual support for the dying child and his or her family includes communicating with the child about death. This is often a taboo subject in many cultures, and many families as well as health care and spiritual care providers avoid it to avoid facing a frightening reality. However, many children are quite aware that they are dying, and open communication can reduce their feelings of isolation and anxiety (Collins, 2002). Elisabeth Kübler-Ross (1983) writes that, “Every person, big or small, needs one person in which to confide. Children often choose the least expected person: a nurse’s aide, a cleaning person, or at times a handicapped child who comes to visit them in a wheelchair . . . and since they have gone through the windstorms of life at an early age, they know things that others of their age would not comprehend . . . They become stronger in inner wisdom and intuitive knowledge” (p 2).

- Families and siblings need much support during the dying process and after the child’s death. Survivor guilt, suicidal thoughts, inconsolable grief, withdrawal, and self-accusations are common and may require formal counseling, since the intense grief reactions may remain for at least four years. Siblings cope in a variety of ways depending on their developmental stage. Shock, anxiety, and resorting to familiar activities (such as play) are common (Collins, 2002). Siblings are also keenly aware of their parents’ or family’s pain and worries and cannot be fooled. If they are allowed to share in the sorrow, they can often provide support in the form of a hug, a smile, or an insightful comment. Sharing feelings with them makes the loss easier to bear and helps prevent them from feeling guilty or as though they are the cause of all the anxiety. Healthy children should be allowed to laugh, giggle, bring friends home, or watch television (Kübler-Ross, 1983).

- Health care professionals often do not feel equipped to provide the type of care needed by dying children and their families. Lack of formal training, time constraints, lack of reimbursements for the time spent with the families, and the often extremely difficult emotional challenges of providing care are just some of the barriers to providing optimum holistic care (Wolfe, Friebert, & Hilden, 2002).

- Providing a family-centered approach to the spiritual care of dying children and their families is an effective way to meet the special needs of these situations. Through the unique skills of a caring staff and a multidisciplinary team, the entire family unit can be supported and cared for during this most difficult time.
Two little boys, Jason, age 4, and Matthew, age 6, were playing a game of ball in the street when a speeding car hit and severely injured Jason. Matthew ran into the house screaming that Jason had been hit, and his mother, who was inside the house at the time of the accident, called 911. Although Jason received immediate care at the scene and was rushed to the hospital, his injuries were too severe and he died several hours later. During his last moments, his family was allowed to be with him, touch him, and talk to him so that he “wasn’t alone.” While he was not fully conscious during this time, his family knew that he was aware of their presence as they prayed and held him one last time. The hospital staff asked his family about their spiritual and religious preferences and contacted their clergy to support them during their ordeal. Although grievous and distraught, they felt that Jason was loved and cared for during his time of greatest need.
Spiritual integrity, whether it concerns children or adults, is a basic human need since it provides life with meaning. Spiritual development in children is dynamic and evolves over time, although some theorists have proposed that faith and spiritual development progresses along a specific continuum of phases. Children, like adults, may experience spiritual distress, and the care provided depends on the child’s developmental and psychosocial needs as well as family-centered issues. Through the unique skills of a caring staff and a multidisciplinary team, the entire family unit can be supported and cared for during this most difficult time.
1. There are several theorists whose theories help explain the role of faith development in children: Fowler, Erikson, and Piaget are among the most well known.
2. The time of infancy is a crucial one in developing faith, a religious belief, and a spiritual dimension.
3. Toddlers have difficulty conceptualizing a supreme being and they do not have the ability to comprehend the significance of what they are doing.
4. During early childhood, children view God or a higher power in terms of physical characteristics such as hair color, facial features, and clothing worn. A conscience is beginning to emerge and the child fears punishment.
5. During middle childhood, children have concrete thinking ability and are beginning to develop logical reasoning skills.
6. Adolescence is characterized by rebellion against authority and conflict about previously held attitudes about personal values and beliefs. Teens realize that they are capable of separating facts about God or a higher power and their world from their previously imagined perceptions, and they become aware of spiritual disappointment.
7. Children with chronic illnesses are at high risk for spiritual distress. Spirituality and/or religious affiliations may provide a structure for these children so that positive coping strategies are developed.
8. Support of the dying child includes support of the parents and siblings during the dying process and after the child’s death.
Questions for Reflection

1. A health care provider’s beliefs about a child’s ability to understand spiritual matters can have a powerful impact on the type of care and communication provided. Take a few moments to examine your beliefs about children’s abilities at various ages. What do you think a 5-year-old understands about death and dying? A 10-year-old? A 15-year-old? Do your beliefs coincide with the developmental phases presented in this course?

2. Sammy is an 8-year-old boy with terminal cancer. His family has decided not to tell him about his prognosis, because they think he’s too young to understand. One night during the night shift, Sammy tells you he knows he is dying and wants to talk about it. What do you do?
Spiritual Dimensions of Aging

• Section Description
  – Aging presents unique challenges to an individual’s spiritual growth, development, and expression. This course examines the process of spiritual development in the aging individual. It explores the relationship between loss, hope, love, sexuality, religion, health, and spirituality in the older adult. In addition, it discusses the roles of spirituality and religion in helping the aging adult cope with personal difficulties, stress, surgery, chronic disease, and cancer. Finally, it considers the importance of cultural wisdom and spiritual elders.
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Learning Objectives

Upon completing this course, you will be able to do the following:

1. Describe the unique spiritual challenges of aging.
2. Describe the process of spiritual development in the aging individual.
3. Explain the relationship between loss, hope, spirituality, and aging.
4. Describe the relationship between love, sexuality, and spirituality in the older adult.
5. Explain the relationship between religion, spirituality, aging, and health.
6. Identify how spirituality and religion help the aging adult cope with personal difficulties, stress, surgery, chronic illness, and cancer.
7. Describe cultural wisdom and the role of spiritual elders.
Introduction

• The second half of life is a turning point—a time in which personal, social, and cultural goals are quite different from those of the first half of life. Creating a new self-image, adjusting to physical and mental changes of aging, adapting to a simpler lifestyle, and seeking quality of life become important objectives that can be realized through the dynamic, integrative process of spirituality (Mcfadden & Gerl, 1990; O’Brien, 1999). A little more than 100 years ago, these goals were only dreams, since most human beings did not live long enough for issues related to the “second half” of life to be important.

• As people live longer into old age, the human race is moving toward an unprecedented phenomenon. Only a century ago, the average life span was 45 years. Today, that life span has almost doubled (O’Brien, 1999). During the 1980s, age 40 was considered “over the hill” by many; today, more than 108,000 individuals in the United States are over 100 years old (Adler, 1995). By the year 2020, more than 52 million Americans will be aged 65 or older, and by 2030 almost one in five will be over 65 (Fischer, 1998). With an individual maximum life span that is now thought to be between 80 and 120 years of age, the “face of aging” is truly changing. The “third age” or “young old” now begins around age 75 to 80, and the “fourth age” or “old old” begins at age 80 to 85 (Baltes & Smith, 2003).
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As longevity increases, society is becoming more and more concerned about issues such as extended life, ethics, and aging. People struggle with questions like, “Is it ethical to remove elders from their homes when they are no longer able to care for themselves?” or “Does a 95-year-old deserve the same medical interventions as a 45-year-old with a similar condition?” As life expectancy increases, there is a great deal of interest in what it means to live longer and age well.

Everyone is aging, and nearly everyone has older siblings, friends, and parents, causing these issues to take on personal importance. Research has produced a greater understanding of the physical, emotional, economic, spiritual, and social aspects of this phase of life. But for many, the concept of aging remains ambiguous. Is it an ascent or a decline? Despite the varied opinions about aging, one question remains: How can people continue to live longer and enjoy a life filled with meaning and joy?
The Unique Spiritual Challenges of Aging

- For many people in the United States, aging is viewed simply from a physiological perspective. Aging is depicted as a time of deterioration, a time when body systems “fall apart” and minds “weaken.” Aging individuals often lose or deny their mind-body-spirit connection and do not want to be associated with their aging body, especially when a particular body part has lost its youthful capacity (Becker, 2002). Many Americans are deeply worried about living for many years in a nursing home once they become physically or mentally frail or suffer from a long-term illness (Koenig, 1999).

- In addition to physical concerns, the aging process also involves spiritual concerns. Many older Americans believe that their spirituality is central to who they are as a person and that spirituality is a vital component of their entire well-being (Davenport, 2003). While many people talk about aging gracefully, “growing younger,” or emphasizing the positive aspects of aging, others dwell on the losses and negative facets. In Winter Grace, K. Fischer (1998) addresses these apparent differences of opinion: “The fact is that aging is both a descent and ascent . . . Aging is a paradox, the unity of apparent contractions . . . Emptiness can somehow be fullness, weakness can be strength, and dying can lead to new life” (p. 8).
The Unique Spiritual Challenges of Aging

• Spiritual concerns in later life are often driven by these paradoxes. Enrichment can result from the achievement of many of life’s major tasks—creating a family and watching one’s children grow and become independent, achieving a career goal, paying off a mortgage, or succeeding in a personal, creative project. Yet losses are also a part of the paradox. With the independence of children and freedom from responsibilities of child rearing comes the “empty nest.” With an abundance of free time comes the loss of independence, friends, and partners. With the wisdom of age comes the depletion of energy or physical strength, regardless of the individual’s luck or genes (Davenport, 2003).

• Spirituality is a critical component of health and well-being for the aging individual and it becomes more important as a person grows older. A key element of that spirituality is a realistic perspective of what is involved in the aging process so the realities are neither over- nor undervalued.
In the United States, late adulthood (the time from age 65 to death) is more prone to negative stereotyping than any other stage of life (Hitchcock, Schubert, & Thomas, 1999). This is due, in part, to the cultural emphasis on youth and beauty and anxieties about aging and death. Since the extension of life is a relatively “new” human experience, many aging individuals have no positive role models, and very few aging individuals have been provided with any real direction about how to deal effectively with end-of-life issues. Fewer still have a “road map” for their spiritual journey as they age.

Among most cultures, however, the aging journey is revered as a time of hope, a time of discovery, and a time of maturity that is to be embraced. Spirituality is encouraged and expected with aging. The aging Hindu Brahman, for example, is given special status and is expected to retreat from active family and social life so that he or she may “obtain spiritual self-realization through renunciation and contemplation” (Blazer, 1991, p. 61). Aging is seen as symbolic of the beginning of a new life task.

Here in America, only during the last few decades of the 20th century has an emphasis on spirituality shifted the focus of aging to include the dimension of life. According to Fischer (1998), rather than stereotyping the elderly, health care providers can view the later years as a time when diversity and true individuality can evolve. If this perspective is adopted, then every stage of life can be viewed as part of a journey toward that unique evolution as a spiritual human being. In the face of the paradoxes of aging, people can find amazing resources. Wisdom, reflection, strength, a sense of purpose, inner peace, and transcendence can result.
According to Missinne (1990), human beings, as they age, have three fundamental needs. All three needs are equally important and interrelated in different forms and degrees. Each human being needs the following:

1. Biophysical exchange—the need to be in contact with the physical environment in order to live and to fully develop as a unique individual
2. Psychosocial exchange—the need, through psychosocial contact with others, to develop and nourish our unique personality
3. Spiritual integration—the need to “maintain and to illuminate ourselves beyond our existence” (p. 46).

For the older adult, spirituality can provide the following elements essential to a healthy life (Fischer, 1998):

- Spirituality promotes acceptance of the past, contributes to enjoyment of the present, and provides hope for the future.
- Spirituality meets a basic human need.
- Spirituality helps during stressful life events, increases an individual’s understanding of the meaning of life, and helps in preparing for death.
- Spirituality provides support during phases of multiple losses and during the grieving process.
Aging and the Human Spirit

Benefits of Spirituality in Aging

• The elderly population is highly spiritual and highly religious (Heintz, 2001; Isaia, Parker, & Murrow, 1999). Spirituality can provide comfort during times of loneliness or distress, bring relief from anxiety, and provide a sense of meaning, purpose, productivity, and self-integration. It can provide the older individual with the ability to adapt to a changing environment such as the shift from a familiar home environment to that of a hospital or long-term care facility. Spirituality provides as sense of self-esteem, and it is an important resource for coping with illness and in preparing for death (Fehring, Miller, & Shaw, 1997; Isaia et al., 1999; Levin, Taylor, & Chatters, 1994).

• Even though physical functioning may decline as an individual ages, spiritual functioning does not necessarily decline with age. Isaia et al. (1999) report that there is “no evidence that the spirit succumbs to the aging process, even in the presence of debilitating illness” (p. 16). Spiritual awakening and development with aging can provide the individual with wonderful opportunities for growth and the release of old patterns and beliefs that are no longer relevant (Leetun, 1996). Faith provides the aging individual with the inner strength needed to transcend physical disabilities associated with aging and to develop the emotional resilience needed to achieve longevity (Koenig, 1999).

• The aging process is an important step in an individual’s spiritual journey and spiritual growth. Spiritual individuals strive to transcend the many changes as well as the losses that accompany aging and achieve a higher understanding of their life and meaning.
The Inner Journey of Aging

- Aging involves an intense inner journey: an examination of life and accomplishments, of relationships, challenges, dreams, and insights. Aging is a time of assessing and evaluating how one’s life was lived and preparing for the end of life. Older people may be less distracted and freer to “think without boundaries” than at any other age. This can result in a significant breakthrough in the individual’s ability to reach new spiritual heights (Seeber, 1990).

- As the years pass, individuals often consider their physical and mental decline. This can lead to depression and spiritual despair, bitterness, negativity, and over-reliance on others. For some, a serious or chronic illness, or the threat of death, can give their life transcendent meaning and help them view their lives from a larger perspective. For others, these life situations can challenge their spiritual beliefs and a spiritual crisis can result, leaving them to question their beliefs and their faith. Faith can, however, provide individuals with a sense of meaning and a broader perspective from which to view their lives and relationships (Koenig, George, & Siegler, 1988).
Spiritual Development in the Aging Individual

- Spiritual growth involves developing a sense of identity, creating and sustaining meaningful relationships with others and a higher being, appreciating the natural world, and developing an emerging realization of transcendence (McFadden & Gerl, 1990). Spiritual development starts early: “Beginning with the first cry at birth, the human psyche yearns for integration” (McFadden & Gerl, 1990, p. 35).

- The spiritual goals of children, adolescents, and young adults are focused on acquiring skills and knowledge so they may become productive and fulfill their personal goals. The second half of life involves a different spiritual journey. Spirituality in the second half of life involves an ability to think abstractly, tolerate ambiguity and paradox, experience emotional flexibility, and commit to values that are more universal in nature (McFadden & Gerl, 1990). Not everyone, however, can achieve this state of integrity. Aging, alone, does not mean individuals can achieve integration with themselves, others, or the natural world, or achieve transcendence.

- The developmental tasks of aging involve finding meaning and fulfillment in life and exploring the positive aspects of life. They also include the following (Hitchcock et al., 1999):
  - Recognizing and accepting the limitations of self
  - Planning for safe living arrangements
  - Practicing healthy lifestyles
  - Continuing warm relationships with family and friends
  - Establishing affiliations with individuals in the same age group
  - Facing the inevitability of death and the death of loved ones
Psychosocial development authority Erik Erikson refers to the developmental tasks of this stage of life as ego integrity versus despair. These tasks involve the integration of all the elements of the past and an acceptance that this is the only life to be lived. The goal of this time in life is to be able to look back on life as meaningful and fulfilling. The positive aspects of life need to be explored and individuals strive to review the contributions they have made to others and the world around them (Carson, 1989; Hitchcock et al., 1999). Facing one’s own mortality is a major life task (O’Brien, 1999). If individuals fail to achieve these tasks, they face a sense of futility and hopelessness that failed to accomplished what they wanted to in life. Anger, resentment, and feelings of inadequacy and worthlessness may result (Hitchcock et al., 1999).

James Fowler, who developed the stages of faith development, describes the stage of spiritual development of the older adult as one of universalizing faith (O’Brien, 1999). This phase represents the culmination of all the work of the previous faith stages and is manifested by a feeling of absolute love and justice toward all humanity. An individual in this stage of faith development is one who can “sacrifice himself or herself to meet the needs of others” (Berggren-Thomas & Griggs, 1995, p. 8). This stage of faith development is difficult to achieve and few people ever attain it. The individual who is truly at this stage of development answers to a higher authority than the world recognizes and is often seen as a subversive individual (Berggren-Thomas & Griggs, 1995). Health care providers should remember that chronological age may not fully indicate what stage of faith development an individual has achieved.
Loss in middle and old age can occur in many forms. It may include the loss of a spouse or partner, health, friends, a work identity, social relationships, a beloved pet, economic stability, or independence. Bereavement, the outward manifestation of loss, usually does not permanently affect the health of an individual but it may cause many psychological symptoms. While some losses produce negative health consequences, some may result in positive changes. Increased support from family and friends, more social interactions, or the making of new contacts and the broadening of life interests may occur as a result of loss (Hitchcock et al., 1999).

Losses such as retirement, the death of a spouse, or a terminal illness can complicate the older adult’s spiritual journey (Berggren-Thomas & Griggs, 1995). Death is one of the greatest spiritual challenges in the life of any person (Kremer, 2002). For aging individuals, an approaching death may create a need for forgiveness as well as an opportunity to review their life and acknowledge their accomplishments. Religious persons fear death less than nonreligious individuals but they still may fear the dying process. Many older adults turn to spirituality and religion to cope with illness, the death of a loved one, or the anticipation of their own deaths. If dying individuals cannot reconcile their life and struggles, or cannot ask for the forgiveness they need, they may experience a spiritual crisis (Berggren-Thomas & Griggs, 1995). Personal contact can help alleviate loneliness and provide an opportunity to address the issues of spiritual distress that may result from the losses of aging (Malcolm, 1987).
The Role of Transcendence in Aging

- Spiritual well-being in the aging individual means confronting suffering, loss, forgiveness, and death. Not all individuals want to enjoy or participate in the opportunity to grow spiritually or become self-actualized, but many find spiritual meaning in these struggles. For those who do, feelings of harmony and connectedness can be achieved through self-transcendence. Ellermann and Reed (2001) define *self-transcendence* as “a person’s capacity to expand self-boundaries intrapersonally, interpersonally, and transpersonally, to acquire a perspective that exceeds ordinary boundaries and limitations” (p. 699).

- *Gerotranscendence*, the final stage in an evolution toward maturation and wisdom, is a form of transcendence unique to the aging individual. It is normally accompanied by an increase in life satisfaction and it involves characteristics such as a connection to earlier generations, little or no fear of death, an acceptance of the mystery of life, the discovery of hidden aspects of the self (both positive and negative), a shift from egotism to altruism, and a rediscovery of the child within (Wadensten & Carlsson, 2003).

- Transcendence is an important predictor of mental health and well-being among middle-aged and older adults (Ellermann & Reed, 2001). Healing and hope are often the result (Leetun, 1996).
Hope, Spirituality, and Aging

• Dossey, Keegan, and Guzzetta (2000) describe hope as “a desire accompanied by an expectation of fulfillment” (p. 98). It is future oriented, involves something the individual wants, and goes beyond merely wishing or believing. Hope involves envisioning the desired circumstances to become a reality (Burkhardt & Nagai-Jacobson, 2002; Carson, 1989). Hope is linked to trust and is strengthened by strong religious and moral values (O’Brien, 1999). Erikson describes it as the outcome of a balance between trust and mistrust and thus as the first developmental task of life (Carson, 1989).

• Positive, healthy relationships with others and with a higher power provide the basis for hope. Without these connections, a sense of loneliness and isolation can lead to a spiritual crisis. According to W. R. Miller (1999), hope has two components: willpower or will, and wayfulness. Willpower involves the desire to live, to survive, to recover, or to learn, while wayfulness refers to the object or person in which one hopes, or in which the person places their trust and confidence.

• Hope is a vital element in healing, but hope is not the same as the promise of a cure. Having hope is also related to spiritual well-being (Burkhardt & Nagai-Jacobson, 2002). Spirituality and the faith it entails can provide the aging adult with a positive outlook on the particular life situation experienced. The aging person engaged in life struggles may, for example, hope for a resolution, hope for a closer relationship to a higher power, or hope for forgiveness. Spirituality and the intrapsychic strength of the aging individual can provide a source of help when coping with stressful life events. This can take the form of intrinsic religiosity (prayer, a sense of meaning and purpose, and transcendence) or extrinsic religiosity (social support) (Fehring et al., 1997).
Hope has a horizontal dimension (oriented toward earthly goals and relationships) and a vertical dimension (oriented toward eternal goals and relationships) (Carson, 1989). In Spanish, the verb for hope is *esperar*, which also means “to wait.” This dual definition seems appropriate, since hope can involve the process of waiting for clarification about what is to come (Miller, 1999).

According to W. R. Miller (1999), research on the effects of hope and health have found that hope results in
- a greater number of goals being set by an individual,
- more difficult goals chosen,
- more personal happiness,
- less distress,
- better coping skills when dealing with difficult life situations, and
- faster recovery from physical illness and injury.
• Miller (1999) further states that one of the health care provider’s first duties to a client is to inspire hope through the development of a therapeutic relationship and the provision of appropriate and accurate health education and information.

• Closely tied to the loss and hope experienced by older adults are the spiritual needs of forgiveness and reminiscence. According to O’Brien (1999), the process of forgiving oneself and others, especially in the face of a serious or terminal illness, can be difficult and involve a long and complex process of healing. Reminiscing about past events can often give rise to the need to forgive. While it may be hard for the individual to let go of past transgressions, forgiveness can help elders reframe their self image and make peace with the past.
Love is personal, universal, and the source of all life. It prompts each person to live from the heart, it encourages each person to choose, it underlies compassion and courage, and its relationship to health and healing is unexplained and wonderful (Dossey, Keegan, & Guzzetta, 2000).

Individuals love in many forms. Children love their parents and grandparents, their favorite toy, or a beloved pet. As they grow, they experience their first infatuation or love of another person and all the emotions that go along with that experience. But as individuals age, certain aspects of love are unique to growing older. These aspects include a love of self, others, and a higher power that can only be experienced after the many “trials and tribulations” of a life journey have been experienced (Fischer, 1998).

For aging individuals who have lost friends, family, loved ones, or a life partner, loneliness and isolation are common. They may celebrate their birthdays without cards, presents, family, or friends. They may not have experienced touch in a long time (Strong, 1990). This has been due, for the most part, to society’s portrayal of what it means to age. American culture often views the aging American as unattractive, asexual, slow, and nonproductive (Reed, 2002). Yet, as Kübler-Ross (1983) so eloquently states, “We need the touching until we die . . . Old people would be less likely to drift into senility if they could rock a needy child . . . tell them stories or build dreams together. The little hands would explore old wrinkles and find them interesting and lovable” (p. 71).
Without a love for others or a love for a higher being, spiritually would not exist. Sulmasy (1997) writes that “spirituality is a relationship of love” (p. 13). The love people have for others and for God or the Ultimate Being is a spiritual relationship. Fischer (1998) theorizes that human love “enables us to trust that God actually loves us; it embodies that love, making it visible and tangible in our lives” (p. 88). Seeber (1990) adds, “To love with the whole soul is to love with all of the elan vital or the life-force within” (p. 49). The agape experience is one characterized by spontaneous, altruistic love that is achieved when the self is shared with others with no thought of reward. It is rarely achieved but is considered a spiritual virtue (Strong, 1990). Lasting love, whether it be from others, from God, or from some transcendence, allows individuals to fully experience their own wholeness. True healing and new life are the result (Leetun, 1996).
The following example illustrates this type of love and spiritual essence.

An Act of Love

Madeline is an 82-year-old widow whose 86-year-old husband recently died of cancer. During the last years of his life, Madeline took care of her husband. She spent many days in the hospital with him, dressed and bathed him, and helped with his care. She believes these acts demonstrate her caring and love for a man she was married to for over 50 years. While it was emotionally draining for her at times, Madeline believes she is blessed. She has three children, seven grandchildren, and two great-grandchildren. She knows that by taking care of her husband, she passed on God’s love and support through her love and support of him.

Madeline is one example of how spirituality can be expressed in older age. She has been able to reflect back on her life and find the purpose behind her existence. By reflecting on the past and believing in the future, Madeline finds meaning in the present.
• For many people, spirituality is also reflected in sexuality and the physical expressions of love. Sexuality embodies the physical and emotional intimacy shared between people (Reed, 2002). It is an important part of who people are as individuals and it impacts how they interact with others as well as how they view themselves. While it does involve the physical act of intercourse, sexuality also involves the full and deep interactions with and connections to another person and with the universe. Love and sexual expression are often part of the respect and honor one person shows for another. Spirituality is an extension of that love and can be demonstrated through the caring, honor, and devotion that one person has for another.

• Many individuals erroneously assume that sexual desires diminish with age, so the physical and sexual needs of aging individuals are often overlooked. However, stereotypes about sexuality and aging are beginning to change. Most research now indicates that while older adults may experience normal, age-related changes in their sexual systems and responses, sexual patterns persist throughout the life span. Most people maintain sexual interest and activity well into advancing age (Fischer, 1998; Reed, 2002).
Many older adults report that sexuality results in a higher quality life and it provides love, passion, affection, self-esteem, and affirmation of who they are as individuals (Lueckenotte, 2000). The older adult sees sexuality as a deep form of communication, and its expression may be more fully developed in the older adult than in the younger individual. Slower paced and more intimate concerns of empathy, nurturance, and deep joy may replace the more performance-oriented patterns of youth (Fischer, 1998). Health care providers should remember that the norm for sexual behavior in younger individuals should not be used as the norm for sexual behavior in the older adult (Fischer, 1998).

Spirituality means acknowledging the uniqueness of an individual. If older individuals are confined to a long-term care facility, tied to a wheelchair, and taken to places they may not wish to go, is their spirituality being honored? What if they are told when they were going to eat, be bathed, or put to bed? What if a couple in a long-term care facility is never given any privacy to express their feelings for each other? Providing holistic care means honoring the spiritual, physical, emotional, psychological, and sexual dimensions of the individual.
Many individuals, especially older adults, express their spirituality through their religion and religious practices and behaviors. Religion and associated activities are common among older adults; nine out of ten older adults rate religion to be important in their lives and say that its importance increases with age (Ebersole & Hess, 1998; Hunsberger, 1985; Mull, Cox, & Sullivan, 1987). They rate religious groups as the third most important source of support to older adults, following families and the federal government (Blazer, 1991).

While a fair amount of study has shown that church attendance is a fairly standard example of religiosity in young individuals, the same cannot be held true of the aging adult. Church attendance is often affected by environmental and personal resources as well as physical function and physical or social limitations of the aging person, such as changes in mobility. Thus, church attendance among aging adults may more accurately reflect physical health, activity level, and mobility than a level of religiosity. As individuals age, decreases in church attendance are often offset by increases in listening to religious programs on the radio or in private Bible reading (Ainlay & Smith, 1984).
Spirituality is an important dimension of well-being for the elderly. A fair amount of research defines the complex connections between religious and spiritual beliefs and practices and an individual’s physical and psychological health.

- Religiousness, or an individual’s belief in a supernatural being, has been linked to recovery from and positive coping with breast cancer (Mickley & Soeken, 1993).
- Men and women coping with cancer who viewed religiousness as a major force in their lives and attempted to live according to the tenets of their faith reported less anger and hostility and greater transcendent meaning related to the disease than those individuals who practiced religion as a means to achieve personal goals (Mickley & Soeken, 1993).
- Individuals with ambivalence about religion or a lack of strong beliefs were shown to have more headaches, loneliness, worry and anxiety, and other mental health symptoms (Mull et al., 1987).
- Women tend to be significantly more religious than men in both their activities and their attitudes. Since widowers are less likely to participate in religious activities than married men, it is hypothesized that women serve as the social contact and religious “link” for their husbands (Cobb & Robshaw, 1998; Isaia et al., 1999; Mull et al., 1987).
As people age, their feelings of self-worth may diminish. What factor prevents older adults from experiencing these feelings when dealing with declining health or retirement?

• Religion provides individuals, especially the elderly, with effective strategies for coping with personal difficulties and stress. Religious coping strategies include obtaining personal strength or support from God or a higher being, using prayer to help cope with difficulties and stress, and seeking the guidance of a higher being when making important decisions (Krause, 1998).

• Attendance at religious services, prayer, Bible study, or listening to religious radio or television programs elicited “good feelings” and provides comfort to aging individuals. Prayer, in particular, provides the individual with a sense of power—to pray for friends in need, for health, and for strength during difficult times (Young, 1993).

**Spirituality, Religion, and Surgery**

• Spirituality becomes very important for most older adults during the stress of hospitalization, health care procedures, or surgery. During this time, individuals reflect on suffering, death, and their relationships with self, others, and a higher power in order to make meaning of their life.

• In addition, the most important and commonly used coping strategy in the acute care setting is prayer. Religious beliefs and practices have been linked to the survival rate among surgical patients.
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Spirituality, Religion, and Chronic Disease

- Due to rapid advances in health care technology, individuals can now live into old age with heart disease, Parkinson’s disease, diabetes, multiple sclerosis, and other chronic diseases. As the burden of chronic illness grows, the importance of addressing how to care for individuals living with chronic illnesses also grows.

- Clinical studies are beginning to clarify how spirituality and religion contribute to the coping strategies of many clients with severe, chronic, and terminal conditions (Post, Puchalski, & Larson, 2000). Chronic illness can lead to a renewed faith in or relationship with a higher power, or it can have a devastating impact on an individual’s spiritual growth and sense of wholeness. Those with chronic illnesses often perceive themselves to be different from others, and they may experience intense feelings of loneliness. Chronic illness often signals the end of one way of life and a need to use a different set of skills to adapt to the changes presented by the illness (Young, 1993).
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Healthy friends of the chronically ill person may withdraw because of their discomfort about the illness or their wish to minimize the discrepancy between themselves and the ill person. Chronically ill individuals may experience conflict about whether to suffer alone or share their fears and concerns with those closest to them. Individuals with neurological disorders such as stroke or Parkinson’s disease often find their sense of isolation compounded by their inability to communicate with others in a socially acceptable manner (Miller, 1985). Loneliness can lead to a loss of self-esteem, negativity, depression, self-loathing, and spiritual distress or a spiritual crisis.

Spirituality may play an important part in the well-being of the chronically ill. It provides individuals with an ability to cope with their condition, thereby improving their physical and mental health. It can also counteract negative feelings and promote a feeling of productivity. Spirituality allows the person to “reconcile with the past, accept the present, maintain a positive view of life, and achieve life satisfaction” (Young, 1993).
Spirituality, Religion, and Cancer

- Spirituality and religious beliefs are central to coping with cancer and helping individuals find a meaning in their having the disease. Older adults with cancer often experience guilt, fear, anxiety, and resentment. Having faith in a higher power often helps them reaffirm the value and meaning of their lives.

- Health care and spiritual care professionals can play a major role in providing spiritual care to people with cancer. A multidisciplinary approach is usually the most effective. Although many institutions provide clergy visits, nurses, in particular, spend a great deal of time with their clients. Individuals should be cared for in a way that preserves their uniqueness and their religious or spiritual beliefs. Ministers, priests, or other religious advisers should be included in the client’s health care program. Privacy should be afforded and respected so the client can discuss confidential matters (Leuckenotte, 2000).

- Older adults may have personal items with them such as a Bible, a Koran, a crucifix, a religious medal, a prayer shawl, handkerchiefs, small bottles with oil, or other religious or spiritual items that should not be tampered with or thrown away. If the client wishes to meditate, privacy should be maintained.

- If a health care provider is uncomfortable with providing spiritual care to a client, assistance from another care provider may be necessary. Addressing spiritual and religious beliefs is an integral dimension of survivorship (Leuckenotte, 2000).
Spiritual Interventions for the Aging Adult

As with every other age, interventions for the older individual should be specific to each client’s spiritual needs. Organizations can help individuals find meaning in life and enhance their spirituality through the following methods (Ebersole & Hess, 1998):

- Provide gerontological education to clergy in seminaries as well as training to existing religious and health care staff.
- Develop outreach and visitation programs to homebound elderly.
- Create prayer circles.
- Provide telephone reassurance programs.
- Televise religious services.
- Provide devotional readings.
- Create parish nurse programs in which nurses within congregations identify and develop a practice that includes home visits to older adults within the church family.
When an individual ages, physical and mental deterioration may necessitate the adaptation of spiritual practices and interventions to meet their unique needs. For example, according to Richards (1990), all aspects of life, including the spiritual, are altered when dementia affects a person, but this does not mean that spiritual needs disappear. The attitude that spiritual needs no longer matter to a person who is confused, suffers from memory loss, or is unable to communicate effectively is inappropriate. Interventions for the confused person can include touch, pictures, faith symbols, and music. These interventions can reach an emotional level that may not be immediately apparent in the traditional sense.
Spiritual Elders

- Blazer (1991) describes spiritual elders as people who “are perceived to ‘understand the nature of things’ and to have magic powers” (p. 61). Spiritual elders focus on beginnings and endings, and they create rituals that recognize and celebrate transitions and transformative experiences. For example, they may develop rituals to welcome a child into the world, celebrate the wisdom of the post-menopausal woman, or honor the end of a relationship with a partner or substance.

- Healing themselves and others through holistic techniques such as massage, therapeutic touch, and a holistic approach to life that emphasizes positive well-being, spiritual elders often provide natural healing knowledge in a broad, spiritual context that is often a metaphor for self-transformation (Miller, 1995). These are powerful forces that should be recognized and understood, since they can be extremely effective tools for healing.

- In Western society, aging individuals who have reached a level of spiritual maturity, or gero-transcendence, will often exhibit different behaviors from their less-spiritual contemporaries. Spiritual elders will be more likely to discuss topics other than their health or physical limitations. They often have a different perspective of time, and they might prefer to discuss adventures of the past, the dying process, or how their experiences have shaped their lives. Meditation, solitude, or peaceful reflective times might be more important than at earlier stages of their lives (Wadensten & Carlsson, 2003).
Cultural Wisdom

- Culture and spirituality are closely related concepts. M. A. Miller (1995) explains that they are often so closely related that it is difficult to distinguish between those aspects of a cultural belief system that arise from a sense of religion/spirituality and those that stem from the ethnic/cultural heritage. Spirituality may be determined entirely by cultural norms, it may be opposed to cultural norms, or it can be influenced by both cultural norms and individual experiences. For example, 75% of Haitians practice voodoo (declared to be the cultural heritage of Haiti by President Aristide in 1991), yet many have converted to Protestant Christianity (in opposition to cultural norms) and have moved to the United States where new experiences temper their beliefs (Martsolf, 1997). All cultures use some form of communication with a higher being and may incorporate meditation, prayer, contemplation, or rituals in their spirituality.

- For a wide variety of ethnic elders, religion and a sense of spirituality provide support in daily living as well as in times of adversity. However, there are differences among the ethnic and racial groups when it comes to religious involvement. For example, older blacks reported a higher degree of religious involvement than did older whites (Koenig, 1999). The latter may be due to the fact that women’s roles in religious practices typically involve social activities, caregiving, and nurturing (Isaia, et al., 1999). The aging African American woman’s spirituality is often closely tied to personal experiences, interpersonal relationships, and the maintenance of community (Lauver, 2000). Within the African American community, religion is a powerful personal and institutional resource for managing the unique life circumstances, history, and stressors that negatively impact this group (Levin, et al., 1994).
Cultural wisdom about health, spirituality, and religion is often the venue of women elders. This information, support, and important health knowledge remains a powerful healing tool for the aging individual. For the Hispanic woman, spirituality is often a blend of Christian beliefs and indigenous influences from the pre- and post-colonial era. The mind, body, and spirit are inseparable and older women are considered wise. They may serve as health practitioners, called *parteras* or *curanderas*, and provide information to their community members about health-related issues (Musgrave, Allen, & Allen, 2002).
The Older Woman

- Today’s older woman is part of a diverse group that varies in income, education level, health, functional abilities, living arrangements, and access to support services. Because women live longer than men, they face unique economic, social, and health challenges.

- Gist and Velkoff (1997) note the following statistics:
  - Women comprise 55% of all persons aged 60 and over.
  - Due to widowhood and the geographic mobility of their children, nearly 80% of older persons who live alone are women.

- Aging can be especially difficult for women. Society says that a man becomes more “mature” as he ages but a woman loses her beauty. As a result, body image and anxiety can be major problems for aging women. Spiritual growth for women as they age means they often have to discard society’s definition of beauty and youth, which can be a difficult task. However, this “letting go” can be a form of “death” that results in new spiritual life (Fischer, 1998).
Spiritual Elders

- Women’s spirituality focuses on the value of lived experiences. This spirituality places women at the center, rather than at the margins, of life experience. It strives for the integration of the mind, body, and spirit into a balanced whole (Lauver, 2000). Menopause, for example, may be seen as a psychological, physical, and spiritual event in women’s lives. It represents a challenge to a woman’s view of herself and the world and, as a result, represents a time when a woman’s spiritual beliefs may challenged. Determining a woman’s spiritual beliefs can provide important information about her level of stress during this period in her life (King & Hunter, 2002).

- For women, spirituality is associated with positive health outcomes. The spiritual woman experiences improved perception of health, increased rates of positive health behaviors (such as use of mammography), and an increased ability to withstand poverty (Musgrave et al., 2002). Yet, the emerging importance of spirituality and religiosity among women, especially those of various ethnic groups, has received little attention (Levin et al., 1994).

- Women experience and express spirituality differently than men (Burkhardt, 1994).
Women are consistently found to be more religious than men and they have a greater likelihood of being church members, praying, attending religious activities, and reading the Bible. Their traditional family-centered roles involve them in behaviors and attitudes that involve nurturing and guidance—behaviors and attitudes that are more consistent with religious practices (Levin et al., 1994). Peace, love, joy, and harmony are not qualities unique to women, but women have often developed these qualities more than men because of their traditional roles and life experiences (Miller, 1995).

Women may value a belief in God or an ultimate being, prayer, meditation, a sense of inner strength, and relationships with others and nature. They often derive more strength from being outdoors and connecting with nature than men do. Women state that spirituality involves the importance of meaning in their lives; influences how they change over time; helps them pay attention to “the quiet inside”; and helps them develop an awareness about the connectedness of events, self, and the process of the life journey (Burkhardt, 1994). This spirituality and religious orientation provide an effective coping method for women during times of stress.
Spirituality is an integral part of the health and well-being of older adults, especially as they face the many challenges of aging. Religion and spirituality provide men and women with effective strategies for dealing with loss, personal difficulties, stress, illness, surgery, and death. Unique approaches to life can also be learned from the wisdom of spiritual elders.
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Key Concepts

1. Spiritual concerns in later life are often driven by the paradoxes of growth and loss, weakness and strength. In the face of these paradoxes, aging individuals can find wisdom, reflection, strength, a sense of purpose, inner peace, and transcendence in their spiritual beliefs.

2. Spirituality in the second half of life involves an ability to think abstractly, tolerate ambiguity and paradox, experience emotional flexibility, and commit to universal values.

3. For many people, sexuality and the expressions of love are also a reflection of spirituality. Most people will maintain their sexual interest and activity well into their advancing age.

4. Many individuals, especially older adults, express their spirituality through their religion and religious practices and behaviors, and most older adults rate religion to be important in their lives.

5. All cultures use some form of communication with a God-force or higher being and may incorporate meditation, prayer, contemplation, or rituals in their spirituality.

6. Women experience and express spirituality differently than men, and women are consistently found to be more religious than men.
Questions for Reflection

1. The words you use to describe people may indicate your underlying thoughts and feelings about them. Take a few minutes to think about the adjectives you use to describe older and aging individuals. What words come to mind? Are they words that indicate respect, appreciation, or admiration (such as experienced, insightful, and wise)? Or are they words that may indicate a lower or condescending opinion (such as crotchety, shrunken, or cute)?

2. Think about some of the older people you know personally, such as close friends or family members. What are some of the spiritual challenges they face or have faced? What resources could their care providers use to help them deal with these challenges more effectively?
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Spiritual Care of the Dying

Section Description

- The dying experience is unique for each individual. For many individuals, death is not an end to life. It is simply a passage to another dimension, sometimes called heaven, the spiritual world, another plane of existence, or nirvana.

- As knowledge of issues involved in death and dying increases and positive attitudes are promoted, the spiritual care and support for people who are dying will improve. The goal of this course is to provide healing strategies that can assist health care providers in the spiritual care of the dying. Spiritual, psychological, social, and cultural aspects of dying will be explored.
Learning Objectives

Upon completing this course, you will be able to do the following:

1. Describe the spiritual, psychological, and social dimensions of dying.
2. Examine cultural considerations at the end of life.
3. List some interactions, caregiving strategies, and healing strategies that can assist health care providers in the spiritual care of the dying.
4. Discuss ways to help individuals at the moment of death.
5. Describe the use of the senses in rituals for the dying.
6. Identify and describe aspects of hospice and palliative care.
7. List advantages and disadvantages of dying at home.
What happens during death, that final life transition? With the knowledge of impending death, spiritual and religious beliefs play an essential role for individuals in making sense out of life. However, most people have done little to prepare psychologically, spiritually, or socially for death. Spiritual issues may not surface until individuals are faced with mortality. At that point, they often search for meaning in their own death or in the death of a loved one. Bereaved people may ponder the existential issues of life, not only with regard to the loss of a loved one, but for themselves as well as the life they once had. During this life transition, a person’s most deeply held beliefs are challenged and opportunities for growth are experienced. To die peacefully and to die with the knowledge that life has had meaning is important to the dying person (Dossey, Keegan, & Guzzetta, 2000; Kuebler, Berry, & Heidrich, 2002; Lueckenotte, 2000).

In the past, health care has typically avoided the topic of spiritual care at the end of life and left clients to their own private beliefs and practices. However, as the interest in spirituality grows, care at the end of life is emerging as an essential dimension of holistic health care. Spiritual care is the work of all individuals involved in caring for the dying person. Spiritual care at the end of life means acknowledging and supporting the beliefs of the dying so that during the dying process their needs are met (Flarey, 1999; O’Gorman, 2002).
Introduction

- Spiritual care of the dying considers and acknowledges the relationships of a person’s life—relationships with the Ultimate, the self, and others. Spiritual care at the end of life provides an opportunity for the dying person to reflect on his or her successes, failures, hopes, fears, and sorrows. A framework for treatment decisions can be based on an understanding of the person’s goals, values, and wishes, taking into account spiritual and religious as well as cultural beliefs (O’Gorman, 2002).

- At the end of life, people usually go through a process of integration, an attempt to put the pieces of their life together in a pattern consistent with the whole of their life. This can include honoring significant relationships and commitments, exploring questions of meaning and purpose in life, engaging in relevant rituals, and making plans consistent with their values. Integration also involves the grieving and mourning of multiple losses associated with the ending of life. Spiritual integration is a healing process that provides closure and a sense of dignity as well as addressing unfinished business and mending broken relationships (O’Gorman, 2002).

- Health care professionals can assist dying individuals and their families by incorporating the physiological, psychosocial, spiritual, and cultural aspects of dying into the care they provide, and by acting as guides to help the dying person and family members through this final life transition.
In addition to alleviating physical symptoms, care of the dying person should also meet spiritual, psychological, and social needs. The dying person is usually the best guide for what is best for him or her in this process. While choices may be made about the place of death (such as home, hospital, or hospice, for example), the place of death is not as important as the care, trust, compassion, acceptance, and love that are provided and shared at this time (Dossey et al., 2000).

**Spiritual Dimensions**

- Through transitions such as dying and death, an individual’s most deeply held beliefs are challenged and opportunities for growth (or regression and despair) are presented. As Chandler (1999) writes, “Perhaps more than any other human experience, the hope of life after life, or even the fear of its absence, launches a spiritual journey” (p. 63).
- Dying is a profound process of spiritual transformation. It is a spiritual event of enormous importance. Often, attention is turned away from the outer distractions in the world and turned inward, toward a greater peace and comfort in spiritual fulfillment.
To support individuals during this time of transition, the health care provider can help clients incorporate spiritual care into the plan of care. For example, if the hospitalized client is a practicing Buddhist with a fear of dying, providing quiet time and space for meditation could be a helpful intervention. If the person is a practicing Roman Catholic, experiencing the Sacraments might be essential to maintaining strength in the face of loss. If the person is a fundamental Christian, prayer and Bible quotations might speak to his or her soul. If the person is Jewish, providing foods that are appropriate to his or her traditions could perhaps give as much support as a half-hour of counseling (Collins, 2002).

If an individual is nonreligious, agnostic, or even atheist, discovering the central guiding principle for his or her life can be essential when providing quality care. Health care and spiritual care providers can use that knowledge to provide support and guidance. It is not important to agree with the beliefs or values, but it is important to recognize that a specific principle, reading, practice, or perspective is important and meaningful to that client. Since all persons are spiritual beings, it is only a matter of discovering what spirituality, what life-perspective, what self-transcendent resources make sense to the person receiving the care, and creatively and humbly using that perspective to bring healing and hope to the individual.
• When family members struggle to assimilate and understand the dying process, they may find it helpful to seek as much information about the illness or condition of the dying person as possible. If they see the illness or condition as part of the person’s life, they may find meaning in the person’s life and in the illness or condition, be successful in maintaining family roles and relationships, address unfinished business, and advocate for appropriate treatment. The result of these tasks is a sense of peace and closure for the family (Burkhardt & Nagai-Jacobson, 2002; O’Gorman, 2002).

• As part of the holistic process, health care and spiritual care providers should also come to terms with death as they assist families and clients in the dying process. The ability to respond to the many aspects of suffering creates a variety of situations for those providing spiritual care. For example, a provider’s own experiences of death and dying, questions of meaning, and feelings of vulnerability may cause suffering as well. To further complicate the situation, the repeated attachment, detachment, and reattachment to new clients may be very distressing. Closure is a vital component of spiritual care for the provider as well as the client (O’Gorman, 2002).
Psychological Dimensions

• In addition to spiritual considerations, a number of other factors are important in determining an individual’s attitude and approach to impending death. One such factor is the psychological dimension. Psychological responses may be influenced by the client’s age, sociocultural factors, religious background, physical status, level of social isolation or loneliness, and feelings about the meaningfulness of everyday life.

• A variety of psychological symptoms such as anxiety, depression, sadness, and grief may be experienced at the end of life. Concentration may be difficult for the dying person due to physical symptoms or feelings of anxiety or depression. Sadness can result from thinking about missing future events. The terminally ill may have worries about their family, loss of independence, pain, concerns about physical problems other than pain, and fears that they are a burden to their family.

• In caring for the dying client, it is important for health care providers to anticipate these feelings, discuss them with clients and their families, and allay the client’s fears and concerns. It is also important to anticipate the individual’s need to grieve over the losses as death approaches (Kuebler et al., 2002; Lueckenotte, 2000).
Cultural Considerations at End of Life

Customs pertaining to language, food habits, religious practices, kinship structures, music and movement, manner of dress, standards for modesty, reactions to fear, responses to pain, and so forth, are learned, shared and transmitted from one generation to another. (Ross, 1981, p. 4)

• The cultural, ethnic, religious, spiritual, and social aspects of a society usually shape an individual’s view of death and dying. Unlike ethnicity, which refers to an individual’s membership in a group bound by common racial, religious, national, or linguistic backgrounds, culture refers to the learned behaviors, beliefs, and values that define an individual’s experience. It affects the individual’s views of health, illness, dying, and life after death. Because different cultures prescribe different ways of caring for the dying and rituals surrounding the time of death, culture may influence end-of-life care (Kuebler et al., 2002; Matzo et al., 2002).

• Culture plays a prominent role and influences the decisions and behaviors of the individuals involved in the dying process. According to Ross (1981), culture
  – affects the assessment of comfort care needed for the dying and the kind of care provided;
  – influences the selection, perception, and evaluation of health care providers and their methods;
  – shapes beliefs about causes of death and dying; and
  – determines preparation of the body, and funeral and burial rituals and practices.
Cultural Competence

- While the current cultural knowledge about death and dying needs further research, any effort to improve the quality of end-of-life care should be sensitive to cultural considerations, as one’s culture provides a meaningful context for dying (Corr, Nabe, & Corr, 2003; Hallenbeck, 2001). Cultural competence and sensitivity on the part of health care providers helps individuals achieve a peaceful death within the context of their belief systems. Cultural competence addresses the many dimensions of culture, including ethnic identity, race, gender, age, differing abilities, sexual orientation, religion and spirituality, socioeconomic factors, and place of residency (Matzo et al., 2002).

- Providing compassionate spiritual care means displaying sensitivity to all cultures and acknowledging the uniqueness of each individual. Because the information presented about the various cultures cannot be generalized to all people of a specific culture, it is imperative to ask the dying person and his or her family about specific beliefs, practices, and customs that may be important to their care while receiving treatment (Cobb & Robshaw, 1998).
Miscommunication among individuals of different cultures as they interact is caused by a lack of awareness of the various beliefs, communication styles, and decision-making approaches of the culture. However, an attitude of acceptance for all worldviews and belief systems helps health care and spiritual care providers avoid generalizations about any ethnic or cultural group and recognize that there are variances in all groups (Ekblad, Marttila, & Emilsson, 2000).
General Beliefs and Practices

• It is essential to avoid stereotyping because no cultural group is a single, homogenous entity. For example, among Asian Americans, there are people who trace their ancestry to Cambodia, China, Japan, Korea, Vietnam, and other Pacific countries. A study that draws conclusions about blacks/African Americans living in New York City might not be equally valid for blacks/African Americans living in rural Alabama. Older Japanese Americans who were born in Japan may have very different views from the second generation born in the United States (Corr et al., 2003). However, the following section illustrates some general beliefs, practices, or customs related to several cultural groups.

  – Many Mexican Americans believe that particular omens (such as the appearance of an owl or messages in dreams) are signs of an approaching death. Mexican American practices may include elaborate concern with death and the traditional religious celebration of the Day of the Dead (Lueckenotte, 2000; Ross, 1981). They may also include a unique form of grave art that is practiced during the Day of the Dead festival. Altars of food, flowers, pictures, candles, and artwork are placed on graves as a healing ritual for the living to come to terms with their loss, and therefore, make death less threatening (Luckmann, 1999; Wing, 1999).
Some Native Americans believe in the concept of a “good” death or a “bad” death. A good death comes at the end of a full life and means that the person has prepared for death. A bad death is defined as a death that occurs unexpectedly and violently, leaving the deceased without a chance to say good-bye. Native Americans see the universe as a harmonious whole in which human beings are one with nature. Death is a normal part of life, to be accepted like the changing seasons. For Navajos, care must be taken in handling the dead person’s body or the spirit of that person may continue to threaten the members of the community in this world (Corr et al., 2003; Ross, 1981).

In many Asian cultures, the loss of an older adult who is perceived as having accumulated years of wisdom and knowledge may be mourned more than the loss of an infant or a child. The child is viewed as having made a lesser contribution to society because of fewer years of life experiences. In the Chinese culture, the life-threatening aspects of an illness may not be told to the client. Instead, the client’s family is given this information. When the client dies, the family often stays at the bedside. Clothing may be left at the hospital for a time to allow the “evil spirits” to leave. Many Chinese Americans tend to be stoic in the face of death, and death is a taboo subject among some Chinese Americans (Corr et al., 2003; Kuebler et al., 2002).
In the Jewish culture it is important to clarify who should be called as the client nears death. Any drains, catheters, or items that have the client’s blood in them should be left attached to the body. The family may not want the hospital staff to touch the body because they may wish to perform a ritual washing after death. Some families may call a “burial committee” to make sure the body is prepared for burial according to Jewish law. Jewish religion dictates that burial should take place within 24 hours of death. Rather than taking the body directly to the morgue, special arrangements are often made for the body to be wrapped and taken directly to a funeral home. Traditional Judaism is opposed to embalming and cremation (Collins, 2002; Kuebler et al., 2002; Ross, 1981).

For Muslims, death is considered a transition from one state of existence to the next state of existence, and they will reap the benefits of their endeavors on Earth in the life to come. Death is not considered a taboo subject for Muslims but rather an issue to be reflected on frequently. Muslims ideally wish to die at home. Many family and friends will come to be with the dying person, to pray for the person’s welfare in this life and the life to come. If they practice Islam, members of the family will often remain at the person’s bedside reciting from the Koran. When the person dies, the body should face in the direction of Mecca, the eyes and mouth should be closed, and the limbs should be straightened. The body is usually washed and shrouded in simple unsewn pieces of white cloth, a funeral prayer may be held in the local mosque, and a graveside funeral prayer may be said. Muslims prefer that the body be buried intact and as soon as possible (Ross, 1981; Sheikh, 1998).
Providing holistic, compassionate, spiritual care means that health care professionals understand the cultural differences that influence death and dying practices. Culturally competent care includes a commitment to respecting clients’ and families’ cultural values, beliefs, and practices.
Spiritual Caregiving Strategies

Health care providers can provide spiritual care of the dying by dealing with spiritual issues from the individuals’ and the families’ perspectives. One way to do this is to help the dying person achieve dignity in death. Another way is to listen to individuals who have a desire and a need to discuss their experience. Additional strategies, such as the following, can assist health care professionals to provide appropriate spiritual care of the dying (Flarey, 1999).

- Conduct a comprehensive assessment of the needs of the dying person and his or her family.
- Develop educational programs related to spiritual care and the growing trend of spiritual importance in the lives of individuals.
- Utilize a team approach to care, integrating clergy, social workers, and health care chaplains into the plans of care for the dying person.
- Obtain more education on strategies that adequately acknowledge spiritual experiences of the dying, regardless of your personal beliefs.
- Develop forums so health care providers can work through their own feelings regarding death and dying.
Interactions with a Dying Person

Dying is more than a medical event; it is a spiritual event. For all involved, it is a time for exchanging love, for reconciliation, and for transformation. The dying person’s loved ones can become compassionate companions who help the dying person along this journey. Each person’s death is as unique as his or her birth. People sometimes appear to “choose” their time of death, which is often influenced by the presence or absence of a family member or the passing of a significant date or time (Kuebler, Berry, & Heidrich, 2002).

No one guide fits every situation, but the following suggestions may help family members and the dying person achieve a sense of peace during the final days of life (Corr et al., 2003).
**Spiritual Caregiving Strategies**

- **Relate to the person.** Individuals and family members should relate to the person, not the illness. People who are dying need intimate, natural, and honest relationships. Hearing is the last sense to be lost, so be aware that dying individuals may hear all that is being said around them. This is often a good time to say good-bye and reassure them that the surviving friends and family will be “okay” and that it is “okay for them to let go.” Saying these words may be helpful in assisting the person to have a peaceful death.

- **Be attentive.** Our undivided attention is one of the greatest gifts we can offer to the dying person. Family members and health care providers can offer support by listening without judgment to the feelings and concerns of the dying person. By paying attention to nonverbal cues, they can discover specific needs, desires, and personal truths the dying person may be discovering. Laughing, listening in an interested way, and just silently being present are often appreciated.

- **Demonstrate compassion.** Placing a cool cloth on a perspiring brow; giving a backrub or gentle massage; holding the hand of a frightened, dying person; and listening to a lifetime of stories convey caring and acceptance of that individual.

- **Create a calm environment.** The human presence can be very healing, particularly in the final days of a dying person’s life. Leaving room for silence and reducing distractions can create a calm and receptive environment for the dying person and his or her compassionate, healing care.
Spiritual Caregiving Strategies

Healing Strategies
It is important to spend the final months, weeks, or days in a way that best suits the needs of the family, friends, and dying loved one. Music, art, dance, or poetry can give expression to the urge toward spiritual yearning and promote a peaceful environment. Some individuals may want to spend time talking or simply being together. Others might find it helpful and rewarding to engage in some of the following activities (Chandler, 1999; Corr et al.; 2003; Dossey et al., 2000; Kuebler et al., 2002; Roach & Nieto, 1997).

- **Journal writing:** Journal writing can be an extremely effective healing technique to use during the dying process. It can be done as a family or individual activity. As a family activity, family stories, recollections, and thoughts about the family’s time together can be written down. Adding pressed flowers, photos, small mementos, and other items to a special book will help memorialize the life that is passing. For individual journal writing, the healing effect comes from the process of writing one’s innermost thoughts and feelings.
Organizing family photos or a collection of favorite things: Selecting photos to put in a special album and writing captions next to each photo can help younger family members enjoy family memories and appreciate their family’s history. Organizing a collection of the dying person’s special recipes, books, or other collectibles commemorates that individual’s unique tastes and personality. Adding notes to any books also helps record memories about the person.

Planting a memory garden: Planting a tree or memory garden is a living memorial to the dying person. As the plants grow, they will be a meaningful reminder of the loved one.

Enjoying pet companionship: Depending on individual preference, animal-assisted therapy may bring comfort to the person who is dying. The dying person may also enjoy the company of a beloved pet and may even prefer this to visits from people who are not close friends or family.

Taking short trips: If the person has the strength, going to a favorite place such as a park or favorite restaurant to enjoy some favorite foods may be therapeutic and can take the focus away from the illness. The person may be more interested in one last taste of a favorite dish than eating a carefully planned “prescribed” meal.
Spiritual Caregiving Strategies

• **Using music to soothe the soul:** Music helps promote a client’s physical, mental, and spiritual well-being. Music can be very beneficial at the end of life, when communications often break down and a sense of isolation sets in. Music may help the dying person achieve a deep state of relaxation, reduce pain and anxiety, improve mood, and uplift the individual’s spirit. The key is to find music that will help the dying person feel a sense of relaxation and a sense of peace. Recordings of gentle environmental sounds such as ocean waves, wind, rain, birds, and music from harps, flutes, or stringed instruments may provide a sense of peace. However, not everyone likes music so it is important to pay attention to the dying person’s likes and dislikes.

• **Using art for expression of the spirit:** Art provides individuals with the ability to project their internal world into visual forms. Drawing, painting, or making a collage can be a way for the dying person to express his or her feelings about the end of life. For example, the dying person might draw his or her vision of the afterlife. The possibilities of using some form of art are numerous.

• **Engaging in spiritual reflection:** Many terminally ill people find it helpful to reflect on the spiritual aspects of life as they move closer to dying. Spiritual reflection involves asking some of the questions listed below.
Questions for Spiritual Reflection

- What have I learned about courage, strength, power, and faith?
- How am I handling my suffering?
- What will give me strength as I die?
- What am I grateful for?
- Am I involved in any spiritual or religious groups?
- Do I find meditation or prayer helpful?
- What do I need to do, or let go of, in order to be more peaceful?
- What provides meaning and purpose in my life?
- Do I have someone to turn to for communicating my thoughts and feelings?
- Do I have any unfulfilled goals?