Spiritual Care Near Life’s End including Grief and Loss in the African American Community

Abstract

“Dying is a spiritual process with medical implications.”

Original quote: Gwendolyn London, DMin

The recognition that spiritual exploration is an integral part of the dying process is based on an understanding of the universal nature of spirituality and the ways that spirituality affects everyday life. The word spirituality is derived from the Hebrew word “ruach,” which is usually translated as “spirit” but can also mean breath and wind. “Ruach” was understood by the Jewish Kaballah to refer to the emotional self, which was believed to be one of the three parts of the human soul.

For purposes of this discussion, spirituality is defined as “the inner desire to connect with a higher reality and to experience through that connection a sense of completion and wholeness.” At the heart of spirituality is the human desire to find meaning in life and the universal search for that meaning. This search grounded in the awareness that, as humans, we are part of some reality that is greater than ourselves.

Spirituality is elusive and can be difficult to understand but reflects the awareness that the “spirit” of each person is inherently related to some larger reality, which is described as a higher power. Spirituality is the relationship of a person’s inner being to that power, however it is conceived and expressed. Spirituality encompasses one central values in life, especially those values that give life meaning.

It is these values that influence a person’s deepest sense of who one is and what life is about. Spirituality is the inner search for meaning and an understanding of universal questions of human existence such as “Who am I?” “Why am I here?” and “What is my purpose in life?” When a person’s spirituality is denied or not acknowledged, it can be experienced as an insult to that person’s inner being.

Though often viewed as synonymous, spirituality is a much broader concept that may encompass many of the habits, rituals, gestures and symbols of religion but does reside entirely in the domain of organized institutions of religions. Spirituality is an inner search to find meaning and an understanding of the universal questions of human existence. Religion is a set of structured guidelines and beliefs that are practiced within a religious tradition or institution. Religion is structured around doctrines that propose answers to the universal questions of spirituality. All religions are a form of spiritual expression but no one religion encompasses the totality of spirituality.

In recent years, spirituality in religion has come to represent the believer’s faith as being more personal, less dogmatic, more open to new ideas and influences, and more pluralistic than the beliefs expressed by established religions. It is also thought to express the personal nature of a believer’s relationship with God as opposed to the general nature of the relationship that is understood in many religions.

Conversely, some persons speak of spirituality as opposed to religion and generally believe that there are many “spiritual paths” and that there is no objective proof about which is the best path to follow. These persons emphasize the importance of finding one’s own path rather than following the path set out by other persons or religious doctrines.

There is an ongoing debate among some religious groups about the idea that an approach based on “spirituality” rather than the observance of a specific religious doctrine is not a true expression of our relationship to God. In fact, most African Americans practice some form of organized religion and, within those structures, embrace a wide range of religious beliefs. This diversity of beliefs, customs and practices is superimposed over their shared history of slavery, discrimination and oppression, which has
been a factor in the shaping of the spiritual and religious understandings of the African American community.

Research suggests that for most persons, spiritual issues become paramount at the end of life. Faith often plays an important role in the coping responses of persons facing life crises such as a serious or life-threatening illness. Even persons who have not previously ascribed to a specific religious tradition often begin a spiritual search when suppressed or ignored spiritual concerns begin to emerge. Spirituality encompasses one’s central values in life, especially those values that give life meaning.

**SPIRITUAL ISSUES AND SPIRITUAL NEEDS**

The spiritual tasks of dying revolve around identifying, developing or reaffirming sources of spiritual energy that can encourage faith and hope. Spiritual issues are unresolved questions or concerns that deal with one’s ultimate purpose in life, one’s relationship to God and one’s relationship to other people. Spiritual issues can be expressed in a number of ways and are often difficult to identify or decipher.

Patients who are approaching the end of life often articulate their spiritual issues in the form of questions or statements that may have various interpretations. Some examples of spiritual issues that may be raised by patients include the following:

- Who am I?
- What do I really believe?
- What are the things that I value in life?
- Is this all there is to life? Is there any more?
- What are the things that give my life meaning?
- What have I contributed by this life that I have lived?
- What are the things that I have left behind that are good?
- What are the mistakes that I have made?
- What are the things that I have left undone?
- What is the state of my relationships?
- What are the things that I have left unsaid?

Because spirituality is personal and unique, it can manifest in a variety of expressions, including prayer, meditation and other spiritual practices that are utilized to address spiritual needs. It is important that persons who are providing spiritual care at the end of life be able to identify spiritual needs that need to be addressed. Spiritual needs generally fall within the following areas:

- **Need for Belonging and Need for Relationship:**
  - To be cared for, not abandoned or isolated
  - To give and receive love
  - For comfort and peace
  - Relationship needs: family, significant others, higher power

- **Need to Explore Meaning in Life, Suffering and Death:**
  - To experience affirmation or self-worth
  - For acceptance of self, of others, of human events
  - To recognize sources of strength to face death
  - To contemplate what gives a sense of purpose and fulfillment
  - To discover personal meaning of pain and death
  - To refine hopes and goals
  - To move on to detachment and solitude
  - To die appropriately
  - To find hope that extends beyond the grave
  - To acknowledge unfinished/unresolved conflicts
  - To recognize nagging resentment and bitterness
  - To recognize feelings of guilt and blame
  - To be able to forgive and accept forgiveness

Just as some patients may experience or report serious physical pain, some patients will experience spiritual pain. Spiritual pain is pain in their inner being and can be a greater deterrent to comfort than physical pain.

Spiritual pain is a distinct factor in total suffering. It is important to remember that spirituality involves the moral consciousness and includes thinking, motivation and feeling. If an individual is dissatisfied with his or her inner being, there will be spiritual distress. Inner anguish is often expressed by physical symptoms because it may be easier than articulating difficult spiritual concepts.

Patients search for answers to the meaning of their illness, why they have to suffer and what is going to happen next. Even when medical interventions may be deemed
At key junctures along the journey toward death, patients and their families face choice points: well as friends. Certainly, these concerns can be issues for patients and/or their loved ones, which can include the biological family as care providers connect on the level of the spirit and convey the loving, accepting and inviting attitude of God. This work requires an attitude that is directly opposite. Some refer to the work of the spiritual caregiver as a ministry of presence. The spiritual care provider is consistently present for the patient and loved ones regardless of their beliefs and issues. In so doing the care provider connects on the level of the spirit and conveys the loving, accepting and inviting attitude of God.

The most important skill that spiritual care providers must possess is the ability to listen without judgment. The most important skill that spiritual care providers must possess is the ability to listen without judgment. Spiritual care providers for those at the end of life are often asked if they find the work depressing. The answer is almost always “no.” Most will say that they feel called to this work and are renewed and refreshed by this particular opportunity for service.

Patients and families greatly appreciate someone who is understanding and not judgmental. All too often, patients have spiritual concerns but reject spiritual care for fear that the care provider will be preachy and want them to assert specific beliefs. This work requires an attitude that is directly opposite. Some refer to the work of the spiritual caregiver as a ministry of presence. The spiritual care provider is consistently present for the patient and loved ones regardless of their beliefs and issues. In so doing the care provider connects on the level of the spirit and conveys the loving, accepting and inviting attitude of God.

Focusing on spiritual rather than religious concerns, the emphasis of spiritual care at the end of life is on addressing the spiritual needs of the dying patient and family. Religion can be defined as an organized set of practices that surround a traditionally prescribed belief in the existence of God or a divine ruling power. Religion can also be seen as a set of tools used to express or practice one’s beliefs, so religious issues are usually related to a specific faith tradition or community and are attached to an agreed-upon set of doctrines. Spirituality is one’s relationship with the divine and the way that relationship is lived out with one’s fellow men and women. It is the God in each person; that part that communes with the divine. Spirituality is what is sought when persons reach for meaning in their lives. If spirit is what gives life animation, then spirituality is about the of faith—what drives and motivates it and what people find helpful in developing and sustaining it.

Spirituality is the outworking in real life of a person’s faith—what the person does with what he or she believes. A life-threatening illness often causes patients to re-examine their spiritual beliefs as they search for ways to understand the meaning of their lives in light of their life-threatening illness. Even persons who do not have traditional religious beliefs or who have not followed any particular religious tradition can be drawn to spiritual exploration as a way to make sense of not only their illness but their entire lives.

An important concept that undergirds spiritual care at the end of life is the idea that each patient has the right to chart his or her own spiritual course. At this stage in a patient’s life, every belief is subject to reexamination as he or she tries to prepare for an experience unlike any they have had before.

The primary role of the spiritual caregiver is as partner in and facilitator of that spiritual exploration. The goal is to help the patient examine and explore his or her own spiritual concerns, issues, beliefs, values and spiritual resources to assist in life’s closure, whatever the religion or lack of religion may be.

CHARACTERISTICS OF SPIRITUAL CARE PROVIDERS

Each end-of-life care patient has the right to chart his or her own spiritual course, so anyone offering spiritual care to the dying must be sensitive to their right to do so. The most important skill that spiritual care providers must possess is the ability to listen without judgment.

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Most African Americans, in fact, most people, travel the journey from initial diagnosis to death with the support of a community of like-minded believers. Within these communities they pray and are prayed for, study sacred texts, share faith stories that are both communal and personal, and sing songs of inspiration.

Many of these activities are provided by members of the faith community for the dying patient when that person is no longer able to communicate nor is conscious. Faith communities, whether or not they are represented by clergy, are often a primary source of support for African American terminally ill patients. This discussion does not focus on the ordinary needs of dying patients but explores those who experience spiritual distress at life’s end and require more than the usual attention from a spiritual care provider.

They can be grouped into three categories: those who struggle with end-of-life decision making; those who are concerned about afterlife; and, those who incessantly search for meaning and/or a way to understand suffering. Certainly, these concerns can be issues for patients and/or their loved ones, which can include the biological family as well as friends.

END-OF-LIFE DECISION MAKING

At key junctures along the journey toward death, patients and their families face choice points: Upon diagnosis, they may have to decide whether to undergo curative treatments that might have distressing side effects. This decision too often calls into question the patient’s will to live, either in his/her own mind or in the minds of those who love the patient. Most families desire to keep their loved one in the home. and most patients desire to die at home. Nevertheless, caregiving can become a challenge that requires outside support. At this time, the family might be forced to consider nursing home placement and/or hiring private caregivers to assist with home care. These decisions often have financial implications and can raise concerns about depleting the family’s resources.

When the patient’s physician determines that curative treatments are no longer effective, the patient must decide whether or not to continue trying despite medical opinion. Sometimes, the patient and family might be offered the opportunity to engage in experimental trials of exploratory medications.

Most people fear pain more than they fear death. Fortunately, in today’s world, rarely is there a need for anyone to endure discomforting pain, yet the issue of what kind of pain medication and how much loom large for a lot of patients and families. Fears of addiction and the wish to remain alert and communicative compete with the desire for comfort.
Two vexing issues for a number of patients and families involve feeding and resuscitation. The inability to eat is especially troubling to a number of patients and families for whom feeding is a sign of loving. Even when medical burdens outweigh benefits, the patient and family might have trouble foregoing artificial feeding approaches and agreeing to a Do Not Resuscitate Order that can be viewed as choosing to die.

These are difficult issues, especially for families that have not engaged in Advance Care Planning. The difficulty can be exacerbated if the patient and/or loved one believes that there is a response desired by God. Too often, deeply held religious views are invoked to compel a particular decision by someone who is well-meaning. The spiritual caregiver can play a pivotal role by diffusing the tension that exists within the patient or between the patient and loved ones or among loved ones.

In a training video on end-of-life care, Reverend James Forbes of Riverside Church in New York told two sisters that “God does not have the answer,” as they argued about taking their father off a ventilator following a stroke that left him in a persistent vegetative state. How true!

People should be encouraged to pray and talk to God about the decisions they are facing, but it is misleading and potentially destructive to allow anyone to be oppressive. The belief that there is only one good decision and that God wants them to choose it.

People need to understand that it is their decision and that God will continue to support and love them regardless of what they choose. We have been given minds to use to think and weigh options prior to deciding. We do so by gathering all the available information and perspectives, i.e., by being well-informed. (If the patient is not capable or is unwilling to digest data, then a chosen loved one can do it for him/her.) Intelligent decision making reflects our human nature—products of God’s self.

God also wants the patients and loved ones to engage in harmonizing processes. In other words, God wants the participants to engage in a process of decision making resulting in closer relationships with one another and with God. How does that happen? It occurs when the participants enter a process of discernment and engagement that has integrity and involves listening and hearing intently. Each person should know that his/her point of view has not only been heard but is valued. We know that we have been heard when the other participants are able to accurately reflect our point of view—both in content and in meaning.

God’s investment is in thoughtful, loving processes, not particular outcomes. To be sure, it is not always possible to engage in such processes. Sometimes people refuse to value the opinions of others. When that occurs, the spiritual care provider must support the patient in her/his discernment process and help the patient articulate his/her perspective to those who might disagree.

The spiritual care provider does so even when he or she disagrees with the patient’s decision. The spiritual care provider can assure others that the patient’s decision making was thoughtful and prayerful, if it has been. Clerical support for an unpopular decision can prove invaluable.

Sometimes patients and/or loved ones pray for a cure despite medical predictions to the contrary. Aware of their fervent prayer request, the spiritual caregiver should pray for a cure with and for the patient and/or family member. Doing so will not induce false hope. The patient and/or family have been told that the patient is dying. They need the spiritual caregiver to hear and respond to the hope they have in God’s ability to perform a miracle. They will appreciate someone who understands them and be thankful even if the patient dies. God, not the spiritual caregiver, will be held responsible for the death and, more than likely, the prayerful person will now say that the death was God’s will.

CONCERNS ABOUT THE AFTERLIFE

Spiritual caregivers who work with people who are nearing life’s end are fortunate to encounter many different belief systems including some who profess no belief. At some point, the spiritual caregiver will learn what the patient and loved ones believe happens at the end of life. Afterlife beliefs can be a source of comfort to patients and/or loved ones. Even those who do not believe that there is an afterlife can be comforted by the recognition that pain and other forms of suffering will end. Some people are unsure about getting to heaven on philosophical grounds.

Those who believe in reincarnation often look forward to the chance to live an improved life the next time around. Others assert that their concept of afterlife is vague—they believe that the energy that is life does not dissipate but are unsure what form afterlife will take.

Most African Americans are either Christian or Muslim and believe in heaven; many also believe in hell. Conflicts about qualifying for heaven can occur within the patient or a loved one or between the patient and a loved one or between loved ones. Some people are unsure about getting to heaven on philosophical grounds.

They assert that they cannot know the will of God because no one can, and they are comfortable being ignorant. Others have doubts or feel that they are not heaven bound. They believe that their past behavior(s) are preventing them from entering heaven. Sometimes it is not the patient but a loved one that has the concern.

The spiritual caregiver must put him/herself in that loved one’s shoes and think about how bad it feels to believe that the person you love is going to hell, especially if you concept of hell is everlasting excruciating pain. Although the spiritual caregiver’s ultimate concern must be the patient, there is an enormous responsibility to minister to the entire network of loved ones. That task becomes complicated when there is disagreement.

Whether it is the patient or a member of the love relationship, concerns about afterlife imply one of the following beliefs: that the Divine is punitive, that the patient does not deserve forgiveness or has not asked for it or that the patient is unworthy.

The antidote for acute afterlife concern is acceptance of God’s forgiveness and love. Too often, patients with this level of suffering have a punitive concept of God. Helping them to feel forgiven even when there is no apparent wrongdoing is the role of the spiritual caregiver.

Whether or not the spiritual caregiver believes that the patient has erred is unimportant if the patient or loved one believes it. The spiritual caregiver offers the patient a opportunity to be forgiven and emphasizes God’s desire to reward (have a close relationship with) all of God’s people.
Those who seek/need forgiveness can point to a historical act or acts that give rise to the need for forgiveness. If they can believe that their error is the most grievous event enacted, it can be helpful for the spiritual caregiver to provide assurance that s/he is aware of a range of injurious actions for which others have sought and felt forgiven.

It can also help to emphasize that God forgives those who sincerely ask for it, and that God looks at the current state of one’s heart, not past injustices. Finally, it can help to insist upon the loving nature of God that continues to call us into a closer relationship with God. The loving forgiveness of God is manifested in the consistent and understanding presence of the spiritual caregiver who is not daunted by knowledge of the person’s past.

There are times when forgiveness is sought from another person who cannot or will not give it. The person seeking forgiveness is helped to understand that God’s forgiveness trumps all.

The most challenging people to work with in relation to afterlife issues are those who feel inherently unworthy. Instead of pointing to an act or acts for which they feel responsible, those who feel unworthy point to themselves as undeserving of forgiveness and/or God’s love.

Those who feel this way more than likely have histories of serious childhood abuse and/or neglect. Early in life, others responded to them in ways that made them feel unlovable. They usually require a professional in mental health to help them overcome their beliefs. The spiritual caregiver consistently continues to manifest God’s love and forgiveness and finds consolation in knowing that one day the person will know his/her inherent worth in God’s eyes.

THE SEARCH FOR MEANING

Some patients and loved ones strive to make sense of their experience or to find meaning in it. They are suffering and ask the questions “Why me?” or “Why my loved one?” Pain and suffering are personally determined and cannot be compared to another’s. What one experiences as painful, another might not.

It is never appropriate to trivialize the person’s suffering by suggesting that s/he should not feel that way. It is the person’s experience and should be honored as real for that person. Sometimes the person’s suffering is complicated by well-meaning religious people who aver that “if you know God or know where you are going (heaven), you should not be suffering as you do.”

Try as one might, oftentimes, people never come to terms with the circumstances they have faced. For example, it is especially difficult for mothers to make sense of, or find meaning in, the suffering and death of a child.

In fact, it doesn’t make sense. Yes, there are those who console themselves by saying that tragedy and the suffering consequent to it are God’s will, but there are others who rail against that same God for causing such agonizing pain. Still others are confused and question their faith. Each of these reactions is normal and to be expected.

Some dying patients who have lost mobility will ask God to take their lives.

They feel useless, have no unfinished business and are ready to die. They cannot understand why the God for whom they have been faithful now allows them to suffer unbearably. The spiritual care provider is unable to respond in a satisfactory way because immediate death is the only resolution desired. The role of the spiritual caregiver is to bear witness to the suffering and in so doing “burden share” with the sufferer. The spiritual caregiver consoles him/herself with the knowledge that the sufferer will have a different perspective in death.

There is research evidence that the longer a person searches for meaning in the tragedies of his or her life, the more likely he or she is to experience mental health difficulties. In other words, this relentless irresolvable search eventually gives rise to illness.

Although it is impossible for some people to find meaning or make sense of their circumstances, there can be long-term benefit in surviving tragedy and suffering. Surviving the unthinkable often demonstrates that the person has greater capacity than anticipated—more emotional strength and/or greater resilience and/or stronger relationships and/or more faith. God may be credited with giving the survivor the ability to pull through. The survivor is heard to say “I never thought I could get over that.” Sometimes the survivor develops a new understanding of his or her faith and relationship with God. This new faith can accommodate tragedy that had never been contemplated before the suffering. His or her understanding of the nature of God has broadened.

GRIEF AND LOSS

Understanding grief and loss is important for persons who are providing spiritual care to dying patients and their families. The terms “grief” and “loss” are often used interchangeably but have different meanings and implications. The dictionary definition of grief is “a poignant distress caused by a loss.” The word “loss” is defined as “the act of losing possession of someone or something” and as “a feeling of being deprived as a result of a loss or separation from someone or something.”

Grief is the name we give to the various feelings and thoughts we experience when we face, or think that we might face, a loss. In fact, grieving is the process by which we heal following a loss. Grief is a natural reaction to the experience of many kinds of loss, not necessarily a loss through death. The pain, suffering and search for meaning one experiences all help the griever to come to grips with loss and go on with life. To be sure there are some who remain stuck—unable to get beyond a certain point in their grieving process. We refer to their grief as complicated.

Although some people experience grief exclusively as a cognitive process, most talk about the feelings associated with grief—anger, sadness, relief, joy, bitterness. It is fair to say that losing makes us feel. Human beings are marvelously made and, as such, are capable of experiencing more than one emotion at the same time.

The griever may be sad because the loved one will not be seen again, relieved that his/her suffering has come to an end and envious that the griever will see predeceased loved ones in heaven. The complexity of feelings can be great, and the griever may not be able to tease out a particular emotion.
Grief is not confined to the person who is losing or has lost a loved one. Grieving begins for the patient and family at the moment of diagnosis of a life-limiting illness. Sometimes patients and/or loved ones act as though they never heard the diagnosis. Some well-intentioned or misguided individuals will say that that is an indication of denial. Denial is a pejorative term that does not respect the time needed to adjust to this new and devastating news. When diagnosed with lung cancer, the man who has smoked four packs a day wants nothing more than a cigarette. He is not in denial; instead, he is resorting to familiar and dependable anxiety-reducing behavior. After all, it takes time and experience to adjust to news that one’s life is likely to end much sooner than expected. There are so many things that this person can be thinking of—dealing with family reactions, financial implications, whom to tell and why, possibilities of pain. The mind has difficulty dealing with all of these issues at once, so this first grief reaction affords time to decide where to focus and when—that is not denial.

During the process of grieving, the person learns to accept that the loss is real and permanent—the dead loved one is not coming back; the body will not be whole again. While accepting that the loss is real, the griever is also beginning to adjust to living without that which has been lost.

The experiences that come with time force the griever into a new way of being. The widow learns to write checks, and the ill person learns to accept assistance with tasks of daily living. There are feelings associated with each mini-loss and each requires an adjustment. Each loss is, therefore, grieved.

Although the time varies from person to person, the griever eventually begins to reinvest energy into creating a future. The widower might consider dating and seek companionship; the person who is terminally ill begins to set goals for him/herself. At each stage in the illness process, abilities wane, and new goals are set that are realistic for the time being and give meaning and purpose to life. The serious pain of loss gives way to an ever-present reminder that something has been lost.

CONCLUSION

Grieving, like spirituality, is personally determined. It is, therefore, very inappropriate to suggest that grief should be resolved within a specific time frame. In fact, resolution is an inappropriate term for people learning to live with loss, and, for some, the pain of it never completely goes away. The griever (including those who are dying) requires someone who is willing to be a witness to, and bear, some of the pain.

The loving acceptance of the spiritual care provider provides the secure backdrop against which the person works through issues to a more peaceful acceptance. At least that is the goal. That does not always happen, and some people die grieving, kicking and screaming.

Nevertheless, the consistent presence of the spiritual caregiver continues to convey the message that Spirit is present remains present and supportive and continues to invite a closer relationship with the person in pain. Supporting people who are at this stage in life is an honor and a privilege and should be valued as such. The spiritual caregiver will find that he or she reaps the greater reward.

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