

National Hospice and Palliative Care Organization

Palliative Care Resource Series

REFLECTIONS ON CONDUCTING A SPIRITUAL ASSESSMENT: AN INTERDISCIPLINARY APPROACH FOR PALLIATIVE CARE PROFESSIONALS

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WHY A SPIRITUAL ASSESSMENT?

During a recent conversation with a nurse practitioner (NP) at the hospice where I am employed as a chaplain, the NP shared a story about needing to increase pain medication for a patient in her care. This is a fairly common occurrence; however, the nurse practitioner had already increased the patient's pain medication several times. During her visit with him the previous day, the patient was agitated and restless and she perceived that he had some unresolved issues. The NP confided that she sensed they were unresolved *spiritual* issues. She suspected that the pain medication was keeping him comfortable physically but not spiritually and confided that she felt totally unprepared to deal with unresolved spiritual issues. My colleague pointed at me and said, "That's why we have you."

I have had similar conversations with physicians, nurses, aides, and social workers. At times, they have expressed a willingness to deal with spiritual issues, but they have also expressed an inability and sense of discomfort when dealing with them. They simply do not possess the training. When a patient and/or family have declined chaplaincy services, as was the case with the previously mentioned patient, the responsibility of addressing spiritual concerns falls to the rest of the hospice and palliative care team.

The purpose of this resource, therefore, is to enable hospice and palliative care team members to complete—either informally or formally—a spiritual assessment and to increase their comfort level when addressing a patient's spiritual needs.

HITTING THE "SPIRITUAL" BRICK WALL

Spiritual assessments are critical when caring for patients. When conducting an assessment, it is important to understand the difference between spirituality and religion. At one time, these words were used interchangeably (Speck, 1998), yet they are quite different.

Spirituality may be defined as a connection to self, to others, to community, and to God (or a Higher Power). It may also be considered more personal and informal than religion.

Formal religion is an institutionalized, systematic, and organized pattern of values, beliefs, and symbols. It is generally expressed through a community of faith with ordained leaders (Hutchison, 2013).

Spiritual assessments aid when patients hit the "spiritual" brick wall. Before a person has been diagnosed with a life-limiting illness, that person typically has plans. Those plans may revolve around today, tomorrow, next week, next month, and even next year. Some people even plan far in advance having a five-year plan and a plan for retirement. When a person is diagnosed with a life-limiting illness, that person will often hit a "spiritual" brick wall (Rusnak, 2005).

The following example may help to clarify: When a car crashes into a concrete barrier, the laws of physics dictate that certain consequences occur. There will be physical damage to the car, the airbag will be deployed, and emergency personnel will be called to assist the person in the car.

Similar consequences occur when someone hits the "spiritual" brick wall after the diagnosis of a life-limiting illness. The person's plans for the future are altered or even damaged. The process of life review is deployed. During the process of life review, the person will reflect upon what was good and/or bad in his or her life. A favorable review may cushion the impact of the diagnosis. A negative life review may cause a person to experience a crisis of faith or crisis of meaning. During these kinds of crises, a person's previous coping styles may not work as well as they previously did (Sheafor & Horejsi, 2015). It is at this point that the "emergency" personnel of the hospice and palliative care team are frequently called upon to assist.

THE EFFECTS OF HITTING THE "SPIRITUAL" BRICK WALL

Some may have seen the collision coming. They may have prepared and braced for the crash. For these patients, the experience may not be overwhelming and normal coping mechanisms may suffice. We, as hospice and palliative care personnel, are called upon to journey alongside them. It is surely easier for us when the person with the life-limiting illness and his or her family are accepting and are coping well; when they feel that theirs has been a life well-lived.

But, what of the situation/s when a patient and family are not coping well? It typically becomes more difficult for them, and for us, to help them handle the experience of hitting the "spiritual" brick wall. The focus becomes acceptance of the negative elements of a patient's history and the history of the family system. Under these circumstances a life review may involve:

- Confusion about God
- Questions about suffering
- Loss and grief regarding the relationship with God, loved ones, and others
- Loss and a diminished role in community
- Loss of independence
- Questions about death and the afterlife
- An altered sense of the meaning of life
- Loss of previously sustained and held beliefs
- Feelings of being unworthy and damaged
- Anger, guilt, shame, regret

These issues (Rusnak, 2005), and possibly others, can result in great spiritual pain and suffering. No pain medication will adequately relieve them. So, how should we respond?

LISTENING TO THE SPIRITUAL PAIN AND SUFFERING

I have been fortunate to serve as a hospice chaplain for more than ten years. When a hospice patient and/or a family member shares his/her spiritual pain and suffering, I still become anxious. Other hospice and palliative care staff have told me that they too become anxious and uncomfortable when someone who is experiencing spiritual pain and suffering approaches them.

It is a challenge to deal with our personal angst and still meet the needs of the person or family in front of us. During my chaplaincy training, one of my coping mechanisms when dealing with stressful situations was to talk, and talk. My training supervisor noticed this. He wisely shared that we have two ears and one mouth and should use them proportionately. Thus, I learned to listen.

We may not know what to say when someone shares his or her pain and suffering but, we can listen. By listening intently to the patient and the family, we take the attention away from ourselves and our shortcomings. We place our full attention on them. We practice deep listening to uncover the connections the person with the life-limiting diagnosis has (Savage, 1996) to life and spirituality.

Spirituality may be defined as connection to self, to others, to community, and to God (or a Higher Power) (Hutchison, 2013). Therefore, we listen for the meaningful connections. We may also see the meaningful connections by noticing the personal items that a person has within his/her hospital room and/or nursing home room. A person is limited to what he or she can bring into that small, confined space. Therefore, most people will bring only what is necessary and meaningful. In a similar way, the clinician may view the personal belongings in a person's home or bedroom to understand what is meaningful.

Deep listening needs to occur without judgment and without placing our professional values above our own personal values. We may not agree with a patient's belief system, but it is our obligation to meet patients where "they are" not where we would like them to be. (Kirst-Ashman, 2013). When I am a patient, I would like staff to honor my belief system. It is that belief system that helps me cope, and makes me a better patient.

ASSESSING THE SPIRITUAL PAIN AND SUFFERING

By listening, we hear what the patient will voluntarily tell us. At times, however, we need to ask questions. We need to delve more deeply in order to understand a patient's religious and spiritual connections.

Key Assessment Areas	Sample Question
Concept of God or deity	Is religion or God significant to you? Can you describe how/why?
Sources of hope and strength	Who do you turn to when you need help? Are they always available?
Important religious practices	Are any religious practices important to you?
Relationship between spiritual beliefs and health (Highfields, 2000)	Has being sick made any difference in your feelings about God or the practice of your faith?

Based on the answers to these questions, we will be able to understand something about a patient's religiosity and/or spirituality. As we know, religion is an institutionalized, systematic, and organized pattern of values, beliefs, and symbols. Religion is generally expressed through a community of faith with ordained leaders (Hutchison, 2013). A reconnection to a patient's community of faith may be helpful to him or her. It is where trusting relationships have been built (Speck, 1998).

In comparison, spirituality involves a series of connections, which may or may not include an organized religious institution. In addition there are those who are spiritual but not religious. They may be called the nonreligious (Thiel, 2015).

The nonreligious may be a confusing term. When one mentions a person being nonreligious, one may think this person is an atheist, unchurched, or a heathen. On the contrary, nonreligious persons may ascribe to a sincere philosophy of life that is not attributed to a particular set of organized religious beliefs and practices. Their philosophy of life anchors their being—but just not with organized religion (Thiel, 2015). In addition, the nonreligious may attempt to find meaning within the current context of illness. Yet, they do not want the imposition of a religious framework upon their inner explorations (Speck, 1998). The nonreligious also have several characteristics in common.

- skeptical of dogma
- distrustful of institutions
- willing to listen to many sides
- may mix traditions
- want to experience what is true, not be told what is true
- are sensitive to hypocrisy

In addition, their definition of spirituality may be a personal quest to find meaning and purpose in life by trusting and related to Something Greater Than Oneself (SGTO). Some spiritual and religious SGTOs include:

- God
- Higher Power
- Scripture
- religious texts
- religious items
- and the congregation

Some secular SGTOs may include:

- science
- medicine
- friends
- ancestors
- community of fellow sufferers
- vocation
- philosophical belief
- humanism
- and humankind

Additional secular SGTOs may be extended family, country of origin, legacies, sports teams, music and dance, the military, patriotism, heroes, values, beauty, pets, environment, and justice (Thiel, 2015).

CASE STUDY IN SPIRITUAL ASSESSMENT

How does one aid a person who does not belong to a religious community and is a self-proclaimed atheist? I traveled to a small rural town to complete an intake on a male patient who had amyotrophic lateral sclerosis (ALS). In an attempt to build rapport with him, I noticed a book on a nearby table. It was John Dominic Crossman's *The Historical Jesus*. I was familiar with this book. It is not about the Jesus of faith but is a review of who Jesus was in secular, historical records. I asked my patient what he thought of it and we had a nice discussion. Near the end of the intake, I asked a few questions to learn about the patient's and family's religious practices (Koenig, 2002). Without hesitation, the patient said he was an atheist.

When I served as a chaplain resident at a Veteran's Administration Medical Center in a large metropolitan area, I had many patients who were not Christian. Nevertheless, they still had spiritual needs. I think the patient and family were surprised by my non-reaction. They reside in a small town where such non-belief was not common or readily accepted. When I asked if they wanted a chaplain, they agreed. I think, in part, because I would be assigned to the patient and I was accepting of their belief system.

During the next few months, I visited "Samuel" on a weekly basis per his request. The visits would take place in his bedroom where the hospital bed was located. I learned during some life review that "Samuel" had been employed, first, as a teacher, then as an administrator in the small community where he now lived.

Within his bedroom were literally hundreds of books. I perused his collection after getting his permission and noticed that many of them were books on atheism. Because I knew he was a former teacher who had earned his doctorate in education, I asked if I could borrow a book. I intended on reading it so that when I came back to visit, we would discuss the book. "Samuel" was enthralled with the idea.

Our subsequent visits consisted of discussions regarding the tenets of atheism, the historical Jesus, and the historical Christian church. I must have earned his trust for he began to share with me why he chose to become an atheist. I came to understand why he did. As his physical condition grew worse, we discussed what he thought the meaning of "death" was for him. Initially, he thought that once one died, there was nothing more. No heaven. No hell. No afterlife. Nothing.

As he reflected on his life, he also reflected on those connections which had meaning for him. One of the major connections was his family. He requested that during his funeral service, a letter be read to his two teenage children. Lee Ann Womack's song, *I Hope You Dance*, was played and then, "Samuel" reflected on the song's lyrics and gave advice to his children:

I hope you never fear the mountains in the distance,
Never settle for the path of least resistance
Livin' might mean takin' chances but they're worth takin',
Lovin' might be a mistake but it's worth makin',
Don't let some hell-bent heart leave you bitter,
When you come close to sellin' out reconsider,
Give heavens above more than just a passing glance,
And why (When??) you get the choice to sit out or dance.

I hope you dance...I hope you dance.

His wife shared with me that "Samuel" reconciled that "death" for him was rejoining the universe. As a result, he died very peacefully.

CONCLUSION

Most of us would say that we want to help our patients die peacefully. However, it is our patients who know best how to do that. We are called to walk alongside them on their journey. "Samuel" died peacefully without any physical or spiritual pain. How this happened isn't really a mystery. Samuel's process may be experienced by persons of all faiths whether they be Christian, Jewish, Muslim, Hindu, Buddhist, etc. Like "Samuel," it may even be the experience of someone who does not ascribe to a particular religious tradition.

After a lot of reflection, this is what I believe happened:

- "Samuel" and his family were accepted with unconditional regard.
- Neither Samuel nor his family was judged about their beliefs.
- Every attempt was made by the author to be fully present.
- Meaningful connections to "Samuel's" life were made.
- There was no attempt to proselytize.
- Samuel's intellectual and spiritual curiosity were explored through books and discussion.
- The author maintained a spirit of humility and learning.
- "Samuel's" and his family's belief system and experiences were affirmed and validated.
- Actively listening was a priority.
- Empathetic listening was intentional.
- Listening occurred with the mind as well as the heart.
- The goal was always to understand and never assume (ELNEC, 2016; Hill, 2009; Rogers, 1989; Wolfelt, 2006)

This process is not always easy. It is frequently challenging. It is challenging to listen to spiritual pain. We may not always feel equipped to do so. Nevertheless, as members of a helping profession we are called upon to assist with both physical and spiritual pain. The first step is to start. Instead of sitting out because of fear or indecision, we can make a choice to dance with the patient and with the family. I hope you choose to dance.

ADDITIONAL EXAMPLES OF SPIRITUAL ASSESSMENTS

Author	Mneumonic	Illustrative Questions
Maugens	S (spiritual belief system)	What is your formal religious affiliation?
	P (personal spirituality)	Describe the beliefs and practices of your religion or spiritual system that you personally accept. What is the importance of your spirituality /religion in daily life?
	I (integration with a community)	Do you belong to any spiritual or religious group or community? What importance does this group have to you? Does or could this group provide help in dealing with health issues?
	R (ritualized practices	Are there specific elements of medical care that you forbid on the basis of religious/spiritual grounds?
	I (implications for medical care)	What aspects of your religion/spirituality would you like me to keep in mind as I care for you? Are there any barriers to our relationship based on religious or spiritual issues?
	T (terminal events planning)	As we plan for your care near the end of life, how does your faith impact your decisions? (Taylor, 2015)
Anandarajah & Hight	H (sources of hope)	What or who is it that gives you hope?
	O (organized religion)	Are you a part of an organized faith group? What does this group do for you as a person?
	P (personal spirituality or spiritual practices)	What personal spiritual practices, like prayer or meditation, help you?
	E (effects on medical care and/or end-of-life issues)	Do you have any beliefs that may affect how the healthcare team cares for you? (Taylor, 2015)
Puchalski	F (faith)	Do you have a faith belief? What is it that gives your life meaning?
	I (importance or influence)	What importance does your faith have in your life? How does your faith belief influence your life?
	C (community)	Are you a member of a faith community? How does this support you?
	A (address)	How would you like for me to integrate or address these issues in your care? (Taylor, 2015)

A secular spiritual resource through which one can share his or her life story is <u>www.legacyletter.org</u>. Another site for secular spirituality is <u>www.spiritualityandpractice.com</u>.

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