
TRADITION, HERITAGE AND SPIRITUALITY

Spiritual Pain and Suffering

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Abstract

Spiritual pain/suffering is commonly experienced by persons with life-limiting illness and their families. Physical pain itself can be exacerbated by non-physical causes such as fear, anxiety, grief, unresolved guilt, depression and unmet spiritual needs. Likewise, the inability to manage physical pain well can be due to emotional and spiritual needs. This is why a holistic, interdisciplinary assessment of pain and suffering is required for each patient and family. The mind, body and spirit are understood in relationship to each other and, in those cases, in relationship to a deity or deities are important to understand. Cultural interpretations of pain and suffering may conflict with the goals of palliative care. Understanding the spiritual framework of the patient and family can help to assure that the physical and spiritual suffering of the patient can be eliminated to provide a peaceful death. Spiritual practices may help in the management of physical pain.

Keywords: Spiritual pain and suffering - physical pain - patients - treatment framework

Asian Pacific J Cancer Prev, **11**, MECC Supplement, 31-36

Introduction

Dame Cicely Saunders, founder of the modern hospice movement, describes the intense suffering by dying patients and their family members as “total pain” – including physical, social, psychological and spiritual pain – all interactive.

“Total pain – all interactive”. So, whose responsibility it is to address it? In traditional medicine, the general practitioner was the one called up as the only doctor to see the patient and treat the total patient. With the compartmentalization of the medical field, it was relatively easy to decide whose role it was.

If the patient has pain, call the medical doctor.

If the pain is psychological in nature, call the psychiatrist.

If social and involves family and friends, call in the social worker

If spiritual in nature, call in the ...

But wait a minute, if total pain is all interactive, does it become the responsibility of only one member of a team to deal with it? Does it require a team approach? How do we go about becoming comfortable with understanding the cause behind spiritual pain, let alone deciding who should be treating it? Spiritual pain is an on-going issue, not something that needs to be addressed only at the last moment by a chaplain.

My first employment in hospice was as the Director of Pastoral and Bereavement Care of the Visiting Nurse Service of New York. As a member of the interdisciplinary team, we cared for patients and their families in three New York City boroughs of Manhattan, Queens and the Bronx. At first, people wondered why they needed a full time

chaplain to serve this wide area. Others asked about my role – would I be responsible for “death bed conversion?” Others indicated that they had worked in hospital where chaplains were available, but never quite knew their role expect to “pray with the patients when asked.” Few, if any, in the beginning, had any concept of what spirituality was all about – or even “total pain” as define by Dame Saunders. It took a little to help them understand.

In my hospice career, I have always very carefully drawn a distinction between spiritual and religious. By definition, spiritual is to rise stand above and/or see beyond the material expression of the universe. It involves a personalized system of beliefs though which an individual understands the meaning and purpose of his/her life.

All people have spiritual dimensions. Taking the religious teaching of the three faiths represented in this room, Islam, Judaism and Christianity, we all share a similar creation story that emphasizes that dimension. The creation story tells how God (“the Transcendent Other” – or what ever name we wish to use) took a lump of clay (or several pieces of different colors of clay) and breathed into it “the breath of life.” That breath – however you chose to understand or name it (soul, spirit, breath of life, energy, or essence) is the core of the individual – his/her spiritual dimension. It is the gift of life granted at birth which continues with the individual until the moment of death when it returned to the Source from which it came. It binds the individual with The Holy Other. While it is the same energy that animates the life of the individual, it is as different as DNA. Common elements might be involved, but there are differences that make it unique to the individual. Each individual builds his/ her own unique personal system of beliefs to answer the basic questions

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of life, such as

Who am I?
Is there purpose to my life?
What do I hope to accomplish with my life?
What do I value in life?
How do I live out my relationships with others?
And the ultimate meaning of life and death itself.

Take a moment to ask yourself – what gives meaning to your life? Friends, career, family, nature, art, animals, music, a higher Power? List five of them. There probably are as many answers to that question as there are people sitting in this room. Is one answer more appropriate than another? Is one answer more important than another? It is, only to the extent that it is YOUR answer and has meaning for you. While you might even have similar items on your list from those sitting around you, how you rank them in order of importance makes your list different and unique to your understanding of the meaning of your life.

While each of us has this spiritual dimension, its expression varies from individual to individual. Spirituality may be expressed in the form of a religion as a relationship with a deity. How one understands the concept of “deity” can vary from a personal relationship with God, Allah, Adonai, to a more general relationship with other concepts, such as nature, energy, force, belief in the good of all, believe in the importance of family and community. Whatever is made the center of one’s understanding of the universe becomes the object around which everything else is given importance and value. Even atheists have a personal belief system that helps them manage, understand and relate to the world around them.

Spirituality is always searching for the answers to the questions of life. These answers are never constant, but are fluid as we grow and experience the world around us and the world around us changes. Who I understand myself to be today will change because of a new experience or relationship I form tomorrow and now needs to be incorporated into my world view. How I understand my purpose in life has grown from that of a young man to a man now in his 60’s. But these answers become one’s faith system which is unique to the individual, is based on the unseen and unknown, and gives meaning and order to life.

“Religion”, on the other hand, is a more structured belief system that addresses the same universal questions. Coming from the Latin word *religare* it means “to bind together”. It, too, provides a framework for making sense of the meaning of existence. In addition, it provides rules and ritual that can provide a concrete way of expressing spirituality. Corporate and group based by nature, it often requires general adherence to a particular body of beliefs (doctrines) regarding one’s relationship with the Deity in order to participate and remain a member of the group.

Is being spiritual the same as being religious? Both spirituality and religion involve the search for meaning and attempt to answer the question of the purpose of life. They, however, do not always overlap. I have illustrated this by drawing to separate circles – each one complete and separate to it. For some people, those we consider

holy people, these two circles almost always overlap. Their spirituality is a driving force in their lives and how they chose to express who they are as their live out their faith. For others, rules and rituals can be always obeyed and followed to the letter of the law. There is however, no spirit behind what is being done – just that it is being done because one has to do it. For the vast majority of people, the overlapping of these areas occurs in varies degree from large to very small.

Let me give you an example. I recently finished showering at the local health club and was proceeding to get dressed. My routine for doing so is “religiously” followed each day. Certain articles of clothes are put on first, then others, and the system never varies. A gentleman next to me commented about his ritual in putting on his socks and shoes. One sock first, followed by the shoe on that same foot, and then the other sock and shoe. He would never vary it from procedure, he said, putting both socks on first and then the shoes. While he did this he commented about a TV episode he had seen many years ago about a similar situation being the butt of a joke. If asked why he did it that way, probably he could not give an answer, just that it had always been so. So religiously he followed his tradition, without understanding or sensing why.

It is important to remember that even when there is a corporate identity of an individual to a religion, each individual still develops his/her own unique relationship with the Transcendent Other. One cannot simply conclude because the chart indicates Orthodox, Jewish, or Muslim that you will be able to know exactly what the individual believes or what is important to him/her. These things can be influenced not simply by his own spiritual growth or the religious teachings of the accepted religion, but by such factors as family traditions, community and culture. One’s relationship to his/her Higher Power or God may be religious or philosophical, expressed or unexpressed. So we need to begin by asking the patient – what gives meaning to YOUR life?

Illness, especially life threatening illness, will always raise spiritual questions about forgiveness, afterlife, the value of life, etc. not normally asked in the course of daily living. “Why is God punishing me?” “What did I do to deserve this?” “Life isn’t fair!” are all questions that indicate the presence of spiritual pain and suffering. Confronted with their own mortality, the individual faith system is tested.

For some, it is a source of strength and hope as they rely upon their understanding of the Transcendent Other to comfort and be with them this crisis into new life after death. For others, their religion can contribute to their spiritual pain and act against the very purpose of palliative medicine. Pain may be seen as a “payback” for a particular lifestyle they have led (i.e., disobedience to God’s law, willful separation from God’s command, sin, and alienation from the will of God.) If they see pain as “redemptive” they will welcome it and encourage more as a way of earning more points for “getting into heaven.” For some, philosophically speaking, the request that nothing be done to take away the pain comes from a sense that “it tells me I am still alive.” We need to always begin

by asking the patient – “what gives meaning to your life?”

Loss of Identity

Spiritual anguish can be considered in terms of the past (painful memories, guilt), the present (isolation and anger) and the future (fear, hopelessness). As the basic assumptions of their personal belief system are being tested, the patient can experience the sense and reality of loss. The first and major loss is their sense of identity – who am I?

For many years in training hospice staff and volunteers, I used a simple tool that I referred to as “Ten Questions”. Giving them each a sheet of paper and a pencil, I would ask a series of ten questions. “Who are you?” They would quickly write their answer and look up for the second question. “Who ARE you?” I would ask. “You already asked that question” some would respond, while others wrote. The same question a third time, a fourth time and so through question number 10. “Listen carefully, I would say: “why are you?” Inevitably, the answers were given in terms of nouns – telling me about their relationships with other people, or their professional life, but rarely would someone use a verb or adjective to describe themselves. When I lose a relationship, I lose my identity and need to go exploring to find out who I am.

As I worked with the dying, I saw again and again that such situations are not unique; they form a common part of the search for meaning. There are three basic questions that people ask when confronted with their mortality. They are the questions that are associated with the struggle to come to terms with the past as it was or could have been, the present as it is, and the future that stretches as yet unknown before them. I hear the dying ask the questions when they are told we have run out of treatment options. I hear the grieving ask them after their loved ones have died and they are left alone. The three questions are:

Who have I been?
Who am I now?
Who am I becoming?

“Who have I been?” is the question of the struggle associated with the past, as the dying person faces the loss and goes through the process called life review. It is usually the first question that appears after the shock and denial phase of being told the nature of the illness begins to wear off. It is also expressed in the angry “why me?” as people begin to review their lives and find nothing that they have done that could merit the state in which they find themselves.

This is especially true with the younger patient. They have not yet had the opportunity to live their lives and accomplish all the dreams that they saw for their future. For others, it is the lives filled with regrets and “if only” as individuals wish they could go back and either undo that they had done, or do so much more. The opportunity presents itself to forgive and/or be forgiven as walls are taken down and bridges are built or rebuilt. It becomes the time to tend to unfinished business, to tie off all the

loose ends that they have put off to some more convenient time in the future. For the living, who fail to do so, it often can produce fear at the time of their own death.

During several sessions with a 92 year old woman, she went back to do this life review. Like an onion, she unpeeled the layers of her life. Each layer was a little more risqué than the one before. Finally she turned to me, having tied off many loose strings into a nicely finished bow, she shared with me an incident she had carried as a burden for over 65 years and never told another human being. When he finished sharing her story, she said “Now, if you are Roman Catholic, you can give me absolution.” She herself was Episcopalian, and I am a Lutheran. I was still able to tell her God had forgiven her a long time ago and now was the time for her to forgive herself.

“Who am I now?” is the second question that people ask. It grows out of the struggle to find completion at this stage when life as they experience it might no longer continue to be. As they are deprived of the roles that they once played, and the responsibilities they once fulfilled, each loss further strips the patient of a sense of meaning and worth. The question becomes, not only “whom am I now, now that I am no longer who I was?” by equally as important “am I still loved now that I can no longer be or do what I once did?” and “am I still needed?”

Sometimes these roles and sources of meaning are taken from the patient by the progression of the disease. If the patient has always been an independent person and cherished a sense of independence and the ability to do for himself/herself, the value that that gave is taken away as he/she is confined to a wheelchair or bed. Now everything must be brought to them and done for them, and anger is the response to this sense of helplessness.

I recently had a mother and daughter come to see me. The parents had been married for over 60 years, and the husband had died. He had been the caregiver for his wife who had macular degeneration and was legally blind and unable to live alone and care for herself. The daughter lived in neighboring community and had moved in to care for her mother. Her mother was angry, not only about the death of her life long partner and love, but at the loss of her independence. She resented this loss of independence, and blamed her daughter for her condition and desired greatly to find a way to live alone at home. She expressed that anger towards her daughter, who could not understand why this was happening since she had put her own life on hold to care for her mother. We talked about the mother’s feelings about the double loss she had suffered – the death of her lifelong partner and her independence, helped clarify the mother’s feelings, and looked for ways for the mother to gain a new sense of control over her life teaching her how to talk to her healthcare providers about living options she could consider for herself.

Sometimes the roles and sources of meaning are taken away by well meaning family members and health care professionals who only wish to ease the final moments of the patient and to protect them. This also increases the sense of loss, causing the patient to feel a deeper sense of isolation and loneliness.

“Who am I becoming?” grows out of the struggle to come to terms with a yet unknown future. It is the question

that revolves around how well the patient has been able to deal with the first two questions. It is the question that brings with it either a great deal of hope and assurance, or fear and helplessness.

Fear/Dread

In Shakespeare's play "Hamlet" the author has the hero contemplate death and what occurs afterwards and concludes: "To sleep, perchance to dream; ay, there's the rub; for in that sleep of death what dreams may come when we have shuffled of this mortal coil, must give us pause: there's the respect that makes calamity of so long life."

Fear almost always relates to the imagined future rather than to the reality of the present. What is it like to actually die? If I have lived my whole life holding on, what will I experience when I finally let go? Will it hurt? Will I feel anything? What will actually happen to me? What will I experience when the spiritual aspect of my being separates from the material body?

There are no easy answers to these probing questions, but, nevertheless, the fear is real and needs to be expressed and explored with the patient. When this fear is especially strong, I have often encouraged a person to consider if there is a strong love attachment with some who is already dead, if that person could come and help them make the transition so that they will not have to do it alone. Strange things happen in hospice that I cannot fully understand myself. A social worker I hired early in my career worked for our program for 18 months before her husband died. At the funeral, she shared with me that her experience in hospice had prepared her for his death, but especially one event which occurred three days before he actually died. She looked out the living room window, she told me, and saw her father-in-law (who had died many years before) standing in the garden looking toward the house. She finally realized at that moment that Joe was going to die soon, and he did three days later.

"Where am I going?" is what they wonder. Our concepts of what happen to us after death are strongly influenced by our religious training. Has my life been worthy enough to be with The Transcendent Other, or do I wind up in the other place? And what if I don't like it there? Can I come back?

The nurse told me that a non-practicing Jewish patient wished to talk with me. I suggested I could find a rabbi to visit, but the nurse said she insisted on seeing me. When I arrived at the home, I sent an hour visiting with her. She had but one request – "tell me what heaven is like." I tried to draw out her own understanding of heaven, but she insisted on simply listening to me. I recited from the books of the Old Testament and my understanding of Jewish theology. After an hour she thanked me and I left. Three days later she continued her quest for knowledge by inviting a rabbi in and presented the same request. She either didn't like my response and she decided to gather more information before dying, but a week later, having gathered additional information she died with some idea of where she was going.

There is a third fear of dying that I have begun to

discover among patients. This fear deals neither with what will I experience as I die nor where am I going, but deals with unresolved issues with those who have already died. How will they treat me, and/or what I will say to them once I see them introduces another dimension of fear. An elderly black woman living in the south Bronx, dying of advanced lung cancer, sent word she would like me to visit. I did on a number of occasions. Each time she revealed a little more about her personal history, and the recurrent dream she was experiencing. She was one of seven children. Her father had his favorite three and her mother her favorite three – which quickly told me someone was left out. Her dream consisted of being in beautiful places, dressed in beautiful clothes which she knew did not belong to her. Other people were present in the same place, dressed in the same fancy clothes. She indicated she wanted to ask them if they owned their clothes, but never did. All she wanted to do was to find the exit to get out of there as quickly as she could before "anyone found her out I was there".

The "anyone" finally was acknowledged to be her mother. She had long ago reconciled with her father's lack of love, but being a mother herself, she could not understand her mother's behavior. She was afraid of what she would say to her mother, and rather than face situation, would run away and say nothing. We talked about writing her mother a letter which could be placed in the casket with her and her handing her the mother the letter when she arrived. This eased her fear, allowed her to express her feelings to her mother, and she died peacefully one week later, without a recurrence of the dream.

Anger

Anger is another indicator of spiritual pain, and something that is normally experienced in some form during the dying process. It is a common reaction in advance disease, both for the patient and their families. It occurs when they are threatened, frustrated, helpless or feeling rejected. Anger is also a common response to grief; many people are more comfortable with anger than with sadness.

That pain can be, and usually is directed both inward and outward. While the patient might not be fully aware of the true source of the anger, it commonly is projected or displaced on to situations, doctors, nurses, family members. We probably have all experienced such anger in the past. It is also directed toward God. There is a sense of betrayal and abandonment by God. "I have kept my side of the agreement to worship you, why are you letting this happen to me? Why have you forsaken me?" This for many is the "unforgivable anger", and one that terrifies both patients and their families. They are often unwilling or unable to acknowledge this anger for fear of punishment from the One who they feel can truly help them the most. So anger is shared with and distributed with those who are present.

I have to often help family and friends understand this anger on the part of the patient. As death approaches, it is easier for the patient to separate from someone who is angry with them, than from those they love and still cling

to keep them here. So they push away in anger to make it easier to separate and leave when their time comes.

When I visited with patients, I sometimes would imagine myself as a huge wastepaper basket. I would hold my arms out in front of me and allow the patient to discard all the feelings that they need to be rid of as they performed the process of life review. As they dealt with feelings they had carried with them for years, I would be willing to carry them away and discard those things they had dealt with and no longer need to spend energy on. I would never allow them to become part of me, but would empty the basket as soon as I left the patient's room.

Depression

Depression is another sign of spiritual pain and suffering. It is a normal part of the dying process, and one should not simply jump at the opportunity to deal with it with medications. At team meetings, the nurse would often announce that she wanted to order an antidepressant because the patient was depressed. I would always ask if she could identify the source of the depression – what the patient was depressed about. If the answer was no, I would ask if the social worker or chaplain had visited to speak with the patient. Again, if the answer was no, I would request such a visit to see if we could identify and deal with the cause of the depression rather than simply masking the symptoms with medications. It might be possible to “cure” the situation with more medication, but that might not always be the case. It might in itself be a cause of the depression – “I am beginning to feel like a medicine cabinet with all the pills that I am taking and no longer an individual.”

People become depressed when they think about their approaching death and all that they are leaving behind and will never have an opportunity to experience – the wedding of a son or daughter, the first graduation of a grandchild from college. One patient I visited simply needed someone to sit with her and let her cry. She had been the steady rock in the family for her whole lifetime, and now needed the family to be strong for her so she could complete the anticipatory grief to prepare for her death. They were unable to allow her to cry, or cry in front of her. They needed her strong, especially her two sons. Needing to complete her own grief work, she was unable to fulfill that role for them and had become depressed. Sitting with her, I listened to her speak through her tears of her needs, her hopes for children and grandchildren's future, and then ways to she could write letter for important events in their lives to still be there for them even though she was dead and not physically present. Two days later the nurse announced she wasn't depressed any more.

Other Characteristics of Spiritual Pain

There are many other characteristics of spiritual pain which need to be considered by the team and acknowledged in the plan of care

Pain, constant and chronic that is not relieved with medication.

Withdrawal or isolation from their spiritual support system

- Guilt/low self esteem
- Feeling of failure in life
- Lack of sense of humor
- Sense of unforgiveness
- Despair

It is important to realize that in dealing with spiritual pain, there may not be concrete answers to the questions that are being posed. It is not as important to try to answer the questions, as it is to allow their expression and for the patient to be allowed and encouraged to work through their own grief process.

Who on the team works meeting the need of the patient and family is not as important as it is that the work be encouraged and allowed. A social worker once came to me to express concern that he had “trampled on my territory.” A woman shared with him a comparison of the dying process with an experience from her youth. She had grown up in the beaches of the state of South Carolina, and as a teenage had ridden dirt bikes on the sand dunes. The only light shone out from the single head light on the bike and there was blackness all around her. Her dying process brought her the same sense of fear and exhilaration. I shared with the social worker that exploring the experience with her was more important than with whom she shared it. We never know which member of the interdisciplinary team the patient and/or family will form bonds with during the process. Therefore, all need to be ready to listen and help in the process of dealing with spiritual pain.

Spiritual Healing

Spiritual healing, as well as psychological and emotional healing can happen even when physical cure is no longer possible. First, it can occur when the patient is helped to find new meaning for the remainder of his/her life. By helping the patient engage in the process of life review, he/she can remember the past and bring a new sense to the present. It can help them interpret the experience of illness in the context of his/her life as a whole. Finding release from the past will increase their confidence and their ability to cope with present difficulties, rather than having a sense of helplessness that may have overcome them.

Second, renewing hope is another avenue for spiritual healing to occur. Hope is a dynamic, fluid experience that flows through the person's life. It changes daily, based on what is happening to the patient. I learned early on to ask a patient “how are you feeling today?” knowing that each day will be different for each patient. The same is true with hope, which changes daily. “What are you hoping for today?” allows the caregiver to be emotionally and spiritual present to the patient in the face of suffering and despair. This will increase the bond of trust between patient, family and caregivers. Nothing is more hopeless than being told, in words and/or deeds, that “there is nothing more that we can do for you.” Remember also, that individuals may take many more emotional and

spiritual risks when facing their own deaths that they might not be willing to take otherwise.

Third, helping patients and their families express the emotions that accompany grief and loss on their way to final acceptance allows healing to occur. As persons are less able to engage in the activities of daily living due to functional limitations, they have time for spiritual reflection and spiritual practices. Because family members will not have another opportunity with their loved ones, helping them heal, reconnect and reconcile may bring peace and comfort to all.

Ira Byock, in his book *The Last Things that Matter Most, A Book about Living*, indicates that when the patient and family do not know what to talk about, we can suggest the following four topics. Each sentence alone can take hours to talk about and open communication that along has been bottled up:

Please forgive me. I forgive you.
Thank you I Love you.

I have included a fifth, which ultimately must be spoken by the patient and their loved ones when the time is right:

Good bye.

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