

# CANCER SURVIVORS

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## SYMPOSIA SERIES II

*Issues & Solutions for Life After Cancer*

### ***Healing the Spirit After Cancer***

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Part II

#### Healing the Spirit After Cancer

Inez Tuck, RN, PhD, MBA

*Dr. Tuck is a professor at the VCU School of Nursing, teaching spirituality in nursing and healthcare. Her research focuses on the role of spirituality on healing and health. For the last ten years, she has developed a spiritual intervention for people with chronic disease, and is currently working on a spiritual intervention for women with breast cancer.*

Good evening. I, too, want to thank the Komen Foundation and Massey Cancer for being the sponsors of this event this evening. And I want to commend you for taking time out of your busy schedule to come to such an event. I know you have many choices of how you could spend an evening, so we certainly appreciate your being here with us this evening. Hopefully, it will be a meaningful experience for you.

It was good to hear Keith's story. Part of the reason that I've gotten in the work that I'm now engaged in is because I have listened to those stories over time as a nurse. And as a faculty member in nursing for a number of years, I've heard those stories and have heard those stories as from family members and friends. I commend him for sharing that with us. I think that was a very powerful way of getting us started this evening.

Spirituality is an area in nursing and in the helping disciplines that in the last 10, 15 years have just exploded. Prior to 1985, early '90's, there was very little in the literature related to spirituality and religion. It was this whole idea of separation of church and state, so we weren't looking at these kinds of things. In the last few years, the literature has just expanded tremendously. So, I thought I start this evening with some definitions from the literature. I'm going to present four for you. These four are definitions that I think capture some of the ideals that I use in my work, so hopefully they'll be helpful to you.

First of all, spirituality is a basic human phenomenon, and that creates meaning in the world very much as Keith just shared with us, the whole idea of meaning-making. It is the combination of sense of well

being in relation to God, and a sense of life purpose and life satisfaction. It includes transcendence, purpose, hardiness, serenity, peace, connection, and hope.

I offer two other definitions. It is holistic, multidimensional, meaning body, spirit. It also has to do with meaning, purpose, and mission.

And finally, spirituality is a relationship or connectedness with self, others, nature, and an ultimate other.

In 1998 when I was beginning this work, I also coined a definition. Part of the difference in this definition and the preceding four, is that I insert the idea that how we manifest our spirit is outwardly. So, I have included this definition, the outward manifestations of thoughts, feelings, and behaviors that allows meaning-making, peace, hope, and connectedness with self, others, nature, and God or a higher power.

One of the challenges of doing research in the area of spirituality is indicted on this slide, that for a number of people, particularly in the South and in this culture, spirituality equals religion. There are no distinctions. When we talk about spirituality, there are individuals who will say, "My spirituality is very much related with my spirit with God." But there is also more of a secular view, much more of a New Age view of spirituality where there are persons who say that my spirituality has nothing to do with my religion, I actually don't have a faith system. Then there are others who say that, "My spirituality is greater than, it's more than my religion." So, the question is, which of these is the one that fits you, and your lifestyle, and your worldview. Part of the challenge of doing research in this area is that I work with persons in all three of these places, and have to be able to accommodate those different viewpoints.

When we talk about spirituality, we recognize that it comes from the English word *spirit*, and the Anglo-French version is *esprit*; Latin is *spiritus*; Greek, *pneuma*; and Hebrew is *ruah*. It has to do with "breath." So, a lot of the interventions that I have done, and work with clients, have involved "breath." So, a spirit develops and grows as an integral aspect of the living being.

So, how important is spirituality? Well, according to this most recent Gallop poll, spirituality is very important, particularly in this culture. Ninety-five percent of Americans believe in God or a higher power. Eight-two percent of Americans feel like they want to experience spiritual growth. And 85% of Americans pray daily as a spiritual intervention.

Why is it significant for cancer research and for cancer survivorship? And I've just alluded to three points here that I think show or demonstrate that relevance. The first is a study that included participants, and 85% of those women use a complimentary or alternative method of treatment. And 88% of that sample found spiritual or religious practices helped them cope with their cancer. Another study that actually looked at physicians, looked at 772 physicians, found that 16% of that group recommended guided imagery; 48%, meditation; and 27%, some movement therapy—yoga, tai chi—as adjuvant treatment in addition to chemotherapy and other kinds of cancer treatments. So, studies have documented that physical health and psychological outcomes are increased when there is prayer, medication, guided imagery, or some kind of movement therapy used along with the cancer treatment. Both of those slides show that as Americans and as a society, we do value spirituality, and that there is a growing body of evidence to say that spirituality does really matter in the outcome of cancer treatment.

For the past 10 years, I have been focusing on healing and spirituality. I have done that with three different interventions. One is a spiritual growth group—and there is a 6-, 8-, or 10-week version;

storytelling very much like Keith was describing earlier, talking about that experience; and a weekend healing retreat.

I know this is kind of a complex model, but this is the model that guides my work. As you will notice, the spiral figure here in the center has the individual as a dynamic individual, and that it's an interaction of mind, body, and spirit. I do believe that we are holistic in that way, and for me, spirit is an essential part, and I actually put that more in the central part of the individual. So, we come to an experience with previous life experiences, and I've listed those as the pre-existing conditional factors. So, we come with a life when we come to an experience of illness and that illness—and in this instance, that illness is cancer—does impact me as an individual. It impacts me in a physical level, psychological, emotional, and also on the spiritual level.

This diagram also depicts the next stage, which I think is some level of struggle. And we're going to talk about struggle in a moment. Through this process, you're exposed to have the opportunity to have cancer treatment of some type. What I proposed in my work is that we add a spiritual intervention to those treatments, help the individuals deal with that struggle, and move to the phase of healing. If you will notice in the diagram, there are two sets of arrows there. One's leading to well-being and one's leading to distress. I do think there is pivotal point in personal healing where you could go either way. You could go towards a higher level of well-being, or you could experience more distress. My studies have been to offer an intervention that would make an impact on that struggle with the potential of altering the human response, and hopefully in the positive direction toward greater well-being. Because I believe that an individual is holistic, then that well-being needs to happen on the physical, mental, and spiritual levels.

I will just interject that I differentiate healing from curing. I think that a person that is experiencing a terminal illness can be healed. So, we're not talking about the disease and symptom management here, we're talking about healing of the individual.

So, you saw the word "suffering," inserted in that model, and I thought I would just give you a couple of responses. I also like Victor Frankl, so he's here as well. A different quote from him: "We can discover this meaning in life in three different ways: by doing a deed; by experiencing a value; and by suffering." "Such is hope, heaven's own gift to struggling mortals, pervading like some subtle essence from the skies, all things both good and bad." Charles Dickens.

And Helen Keller offers two quotes that I like: "Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved." "We would never learn to be brave and patient if there were only joy in the world."

I know this is a fairly busy slide, and I'm not going to go through each of these. The ones that I'm going to spend a little more time with are the ones that are in bold. I wanted to list these. I have 11 assumptions for the work that I do, and I've already alluded to a number of these. I believe that the individual is holistic, the interaction of mind, body, and spirit, that we have all those dimensions and that we are not in balance unless those dimensions are in balance. There is also a secular and a non-secular view of spirituality and we express our spirituality in various ways. I used the word "religiousness," and I think spirituality can be associated with religion, and that it can be expressed through a specific faith community, but it doesn't have to be that for everyone. And an individual defines the nature of their own spirituality. I can define it for me; I can't define it for you. The apprehension of the spirit is personal and may not be reflected in words. That will give you some

direction in terms of some parts of my intervention. It's more than words, it's an integrative energy. It is intentional, and it's intentional to make meaning and connections with one's experience. And you increase your awareness of spirituality by sharing your experiences with others.

So, assumption #4. Spirituality comes into conscious awareness through reflecting, sensing, sharing, meditating, being open and exploring, attending, apprehending or some type of introspective activity. So, I'll talk with you and just share—and maybe when we get in the question and answer period, we can talk in more detail—about some of the activities that I have included in my interventions that get people to reflect, or to meditate, or to explore, or to apprehend. I think that conscious awareness of it—we all have a spirit, but the meaning-making I think happens when we bring that to a conscious awareness. One of the ways that we can do that is by reading inspirational materials. This is a book that I've written on forgiveness that is a part of one of my interventions. It is another way of getting people to bring things to consciousness and to become fully aware.

We also get that by communing with nature. Whether you love to walk along the beach, which is one of my favorite kinds of things to do, or you like to take that pet jogging, or you spend time with your kids, there are ways that we commune with others and with nature that also help us to be much more reflective and much more aware. I do think there are sacred spaces and we can get grounded in those sacred spaces and enhance our spirituality.

One of the studies that I've done was a qualitative study, meaning that we interviewed and had a number of participants tell us their definition of spirituality. One of the things that you struggle with in the literature is that scientists can coin all of these definitions and they may not be relevant to patients. So, this particular study required 75 persons who were living with HIV disease to define their definition of spirituality. These two statements here—one from persons with HIV disease and one from healthy adults—is the composite, the essence of those statements. For the HIV participants, spirituality is relating and believing in God who is always present. It's perceived as being guided, or helped, or inspired, or given unto. Spirituality includes the processes of journeying, discovering, and centering, and is outwardly expressed.

You will see that it's fairly similar to the definition that's coming from healthy adults. I do believe that we all have to nurture our spirits, so it's not limited to those persons who are having devastating life events, or chronic or terminal illnesses. We all have to nurture our spirits. So, their definition was it's a strongly-held belief, a personal relationship with God. It's integral to them as an individual. A connection with nature, others, and a higher power, and it's also a process, a journey, a guide, and a struggle.

My assumption #7 is that sharing in a communal way deepens one's understanding of spirituality.

I believe that healing can happen through storytelling, telling your story to others. Storytelling promotes spiritual well-being—and it's defined by Taylor in 1997 in some work—and it allows the translation of distress into language that ultimately allows us to forget or to move beyond the experience.

One of the studies that I've had the opportunity to do—actually on the Palliative Care Unit here at VCU Health System—was to interview persons who had cancer. On the Palliative Care Unit, it was terminal cancer where there were no further treatments. Through that experience, asking them to tell their story with the idea that, if you go back to my previous slide, storytelling can be therapeutic. These are two quotes from two of those participants: "Devastating. Well, it was hard. I mean, if anybody tells you, you got breast cancer, it's awful! Something you have to just deal with. You know, it takes a toll on you,

wears you out, wears you thin, comes at you like a bolt of lightning.” Some of you may be able to identify with that. “I basically take my faith at home, and pray, and hope that it gives me enough strength to get me where I need to go.”

Core assumption #10. Spirituality allows one to transcend pain and suffering. I believe you can transcend that pain and suffering through creative expression of spirituality. I want to show you some drawings. In my spiritual growth group, one of the sessions is allowing people to draw a spiritual scene, something that’s meaningful for them. So, I’m just going to show a few of those drawings. Right now, we have about 150 drawings that we’re doing some analysis on.

This is an example of a person who is living with HIV disease. This is another person who’s living with HIV. A person who’s living with breast cancer. That didn’t come out as clear. There is a sunset there, if you don’t see it, if you can’t see it. It kind of fades away. Another individual living with breast cancer. A healthy adult. Another healthy adult.

We are looking at patterns in drawings. You probably have noticed that there was water, some form of water, some form of nature in each of those scenes that were depicted. These were areas that represented spirituality. So, if you could ground yourself in your spirituality, where would you go? That’s what these drawings are about. I hope you also noticed there’s not a great variability between those person who were experiencing the chronic or terminal illness of HIV and those persons who were experiencing breast cancer, or sometimes even the struggles that healthy adults go through.

So, I’m proposing in a part of my interventions that I think there are some strategies to promote healing. I am very much an advocate for quiet reflection and meditation. We know that physiologically some things happen when we meditate. You know, our blood pressure changes, our pulse rate, our minds stop racing. A lot of physiological things happen normally and that particularly in stressful situations, it is even more beneficial. Also prayers, whether these are prayers of petitions; or intercessory prayers where you pray for the well-being of others; or centering prayer, a technique that’s a combination of praying and meditating. Reading spiritual or religious materials, appreciating the spirit through using your senses. And that’s a lot about the nature piece, but also just experiencing what food is like, or wonderful sex, or whatever it is that allows you to experience and get a sense of joy. Also, worship. We do know that persons that attend church regularly, for instance, have more positive outcomes than non-attendees. So worship. But there are also opportunities for communal sharing. Journaling. Keith talked about that as well. Very therapeutic and there are numerous studies out here that validate the value of journaling. Movement and physical activity. So, whether you are doing aerobics, or riding your bike, or walking, or t’ai chi, or some of the more complimentary kinds of interventions, we do know they have a positive affect. Use of daily affirmations that, looking in the mirror every morning and saying this is going to be a great day, or whatever you need to do to kind of keep you going. Experience of nature. Experience of outdoors. There are data out there that indicate that people who own pets have more beneficial outcomes as well. I’m also an advocate for creative expression of spirituality. And whether that’s through drawings, or poetry, or stories, or dance, or music, I think that outward manifestation of spirituality is very healthy.

I want to end with a few quotes. This one is from Ralph Waldo Emerson: “The foundations of a person are not in matter but in spirit.”

“There are some people who have the quality of richness and joy in them and they communicate it to everything they touch. It is first of all a physical quality; then it is a quality of the spirit.”

“There are thoughts which are prayers. There are moments when, whatever the posture of the body, the soul is on its knees.” That’s a quote by Victor Hugo.

My message to you is to continue to heal your spirit. Thank you.