

CANCER SURVIVORS

SYMPOSIA SERIES II

Issues & Solutions for Life After Cancer

Healing the Spirit After Cancer

November 29, 2007

Finding Hope & Meaning After Cancer

Introduction: Tim Ford, MA, MS, CT, Chaplain, VCU Massey Cancer Center/VCU Health System

I'd like to go ahead and welcome everybody here tonight. It's nice to have you all here. My name is Tim Ford. I am the [unintelligible] of Care Chaplin at the Virginia Commonwealth Health System, and I have the honor of being your moderator tonight for this lecture tonight from the Cancer Survivors Symposium called, *Healing the Spirit After Cancer*.

As someone who works in the trenches with this, I'm particularly excited to be here. I think that spirituality is something that's very difficult to apply, very difficult to understand. And we are blessed tonight to have two speakers who will be able to put a lot of their expertise and their experience to this topic. I'm very excited about listening to what they have to say to us tonight.

We have Dr. Keith Bellizzi from the Office of Cancer Survivorship at the National Cancer Institute. And we also have Dr. Inez Tuck from VCU School of Nursing.

We're going to go ahead and have their talks, and then afterwards, we're going to have a panel, which I'm going to ask Dr. Diane Baer Wilson to moderate so I can sit in on that. We'll take all of your questions and answers at that time.

Before we get started, I do want to acknowledge our sponsor for this program tonight, the Komen Cure for—the Komen for the Cure Foundation—easy enough for me to say—and our partner, the Massey Cancer Center. I also want to acknowledge the Life Science and Religion Community Forum in appreciation for all the work that they've done in bringing this together tonight.

We have some resources out there—I think you might have seen them as you came in—on the table, which are there for you. There are also the handouts for the slides that are available if you want to go through those with the notes. I'd also ask you to please take time to fill out your evaluations that are on your seats. The feedback from this is very important to us and it helps us to determine not only how well you liked us, but also what we can do for future sessions. It's extremely important.

I'm finally going to ask you to silence your cell phones, your pages, your MP3 players, your Palm Pilots, your laptops, anything else that makes noise—that does not include spouses. I'm also going ask to

please not turn off your hearing aids, if you have any. Leave those on. And since this is a talk on spirituality, I think it would be silly for us to spend time turning off all of our electronic gadgets and not to spend a moment just to silence ourselves as well. So, if you will also please silence your minds and your hearts, and let your spirit come here with us for this talk tonight, I think you will find the experience worth it.

It is my distinct honor to introduce Dr. Keith Bellizzi, who's going to be speaking to us on making meaning from your cancer experience. I'm also going to introduce Dr. Inez Tuck, who's going to be talking to us on how to use spirituality in the healing process and how that can impact wellness.

Dr. Bellizzi is a behavioral scientist and program director in the Office of Cancer Survivorship in the National Cancer Institute. And he himself is a 12-year survivor of cancer. His primary research interests are in survivorship, but also emphasizing aging, resiliency, and quality of life. He is a member of the Bristol-Meyers Squibb 2005 Tour of Hope National Team with Lance Armstrong, and he received a governor's citation in recognition for his commitment to cancer control efforts.

I'm going to go ahead and introduce both speakers so we can go seamlessly from one talk to another.

So, I'm going to be honored right now to talk about Dr. Inez Tuck, who is a professor here at the VCU School of Nursing. She teaches spirituality in nursing and healthcare, and her primary research focus has been spirituality on healing and health. For the last 10 years, she's developed a spiritual intervention for people with chronic disease, and she's right now working on a spiritual intervention for people with breast cancer.

So, afterwards we will have our question and answer. I'm happy to bring it over to Dr. Keith Bellizzi.

Part I

Keith Bellizzi, PhD, MPH

Dr. Bellizzi is a behavioral scientist and program director in the Office of Cancer Survivorship in the National Cancer Institute. He is also a 13-year cancer survivor. His primary research interests in the area of survivorship include the impact of aging, resiliency and quality of life after cancer. He is a member of the Bristol-Meyers Squibb 2005 Tour of Hope National Team with Lance Armstrong and he received a governor's citation in recognition for his commitment to cancer control efforts.

Good evening. First I want to thank Diane, Brian, and Julie for inviting me this evening to speak to all of you about a topic that I'm passionate about from both a personal standpoint, and as a researcher. I'm going to be wearing two different hats tonight as I speak to you about finding meaning. I'm a 13-year, two-time cancer survivor, and finding meaning played a really important part in my own healing process, so I'll share a little bit of my story with all of you. And also I'll be talking as a researcher and presenting some information from the literature on finding meaning after cancer.

I'm going to be covering several topics tonight in the next 20 minutes or so. I'll provide you with some background information related to cancer survivorship in order to put my talk in some sort of context for you. I'll talk about the different ways that individuals integrate the cancer experience into their everyday life. I'll then introduce the concept of meaning-making, highlight some of the research in this

area, and then provide some tips for those of you interested in exploring meaning-making in your own lives.

I'm going to guess if I were to ask those of you in the audience to raise your hand if you ever had any sort of inclination that you would be sitting here in this auditorium listening to a talk on healing the spirit after cancer, I'm going to guess very few of you, if any of you, would raise their hand. Well, I have to admit, I never thought that I would be standing in front of an audience talking about this topic.

I graduated from college with a degree in business. I landed a really great job as a management consultant. I was on the fast track, I guess, to being a successful businessman. To me, money was my #1 priority. Well, that all changed in 1994. Four days prior to my 25th birthday, I was diagnosed with stage three testicular cancer, which spread to my lymph nodes, to both of my lungs, and it was on its way to my brain. The doctors said to me that my chance of survival was around 50%, and if I did survive, the likelihood of me being able to father a child without expensive in vitro fertilization techniques is slim to none, which was as devastating to me as the diagnosis itself.

Now, at around the same time, a good friend of mine went into the hospital for what the doctors originally thought was spinal meningitis. Two weeks later, he died of aggressive brain cancer. This occurred during the time when I was diagnosed. And, of course, I wondered if that was going to be my fate as well. To make matters worse, three months after my original diagnosis, the doctors called me into the office and said that, "The CAT scan that we just did revealed a golf-ball size mass in your left kidney, and we want to do a biopsy." And they did. And it turned out to be kidney cancer, unrelated to the testicular cancer. So, within three months, I was diagnosed with two different cancers.

I had several operations including removing my left kidney, several rounds of aggressive chemotherapy. I had to be hospitalized for my treatments since I was without a kidney and they needed to keep me hydrated during my chemotherapy treatments. I had a lot of time to think. I was forced to face my mortality at a very young age. I thought that cancer was something that happened to other people. I thought a great deal about where I was in life, what was important to me, how I wanted to spend the remainder of my life.

I remember one afternoon I was lying in the hospital bed. I'd just finished a treatment. I looked over at my wife—who I was dating at the time—the nurses that were in the room, and my parents, and I made a promise. I told them if I survive this, I'll quit my job and I'll dedicate my life to the cancer cause. After I recovered from treatment, I did just that. I quit my job and business and went back to school. I spent 10 years in graduate school. My wife almost killed me. But I earned a master's degree in Psychology, a masters in Public Health, and then a PhD in Human Development and Family Studies. I now work at the Office of Cancer Survivorship at the National Cancer Institute. I'm not sure how many of you are familiar with the Office of Cancer Survivorship, but if you're not, you should be, because your tax dollar supports our office and my salary.

Our office was established in July of 1996 by Congress in recognition of the large number of individuals now surviving cancer for long periods of time, and their unique and poorly understood needs. The creation of our office was actually the direct result of a very strong, articulate, and compelling advocacy community lobbying Congress. Here is a picture of President Clinton at a Rose Garden ceremony which formally announced the launch of our office. So, the mission of our office is to enhance not only the length of life but the quality of life of cancer survivors. We do this by championing research that focuses

on understanding, preventing, or reducing the burden of cancer on individuals. And lastly, we educate health professionals, cancer survivors, and their families.

I just wanted to point out to you a growing number of cancer survivors in the United States. You may have seen this before or heard of these numbers. Back in 1971 when President Richard Nixon declared war on cancer and passed the National Cancer Act, there were approximately three million cancer survivors in the United States. In 30 years, that number has more than tripled. Today it's estimated that there are 10.8 million cancer survivors in the United States, which represents 3.6% of the U. S. population. So, the main point I want to show here is that there a lot of folks trying to figure out how to move forward after their diagnosis. We're not alone.

This quote is from a woman who participated in a study by Dr. Betty Ferrell. She works at the City of Hope in California. She says, "The cancer journey is like parachuting into a jungle with no survival skills." This quote really resonates for me. We were never taught how to deal with a life-threatening illness. At least it was never part of my education. We're kind of just forced to figure things out on the fly or, as I like to say, baptism by fire. I think many of us here could probably relate to that.

I think one of the most remarkable medical achievements in the latter part of the last century is our ability, or was our ability to turn cancer, once a uniformly fatal disease, into a cure for some—particularly our young survivors—but for the majority a disease that many people will live with. A couple of things that have contributed to that success have been advances in early detection and screening, and new and innovative treatments.

That forced the medical community to start thinking about the implications of living with cancer. Some of the medical community are now looking at cancer as a chronic disease, some cancers as a chronic disease. Their focus has shifted somewhat from not only just treating the disease, but also to managing some of the late and long-term side effects of disease. But the medical management is only part of the picture. There are the psychosocial needs of individuals. And by psychosocial needs, I mean things such as managing fears of recurrence, or anxiety, distress, depression, relationship issues, employment issues, counseling in terms of lifestyle behaviors. Those sorts of things are now becoming more important to cancer survivors

Hopefully, I have provided you with some background information to kind of set the stage for the remainder of my talk.

There are various ways, there are different ways that individuals integrate the cancer experience into their everyday life. I really want to stress and point out that cancer is a very unique and personal experience. So my variability exists as to how people respond to the disease, and there's no one right way to respond to your illness.

The research tells us that some people desire to go back to normal following cancer. The experience is not a significant part of their identity. It's something they had, something they want to put behind them. It's not something they want to talk about every day. This sentiment is more common in men than women, and it's more common in diseases with favorable prognoses. There are also some practical reasons for not wanting to talk about your cancer. I don't want to tell everyone I'm a cancer survivor all the time. You do have to think of discrimination in the back of your mind with work, because you don't want to get passed over for a promotion. We also know that some people experience profound changes as a result of their cancer, and these changes can be negative, positive, or a combination of both.

Some people get struck by the fact that cancer can be a positive experience. I'm amazed to see how many people do find a silver lining in a seemingly negative experience. We also know that for many, cancer doesn't end. Your experience doesn't end with treatment. For some folks, for some individuals, some of their hardest challenges or more difficult challenges begin post-treatment. I think that's nicely reflected by this quote. This is a quote from a breast cancer survivor who just finished her last radiation treatment. She says, "I also cried because I would not be coming back to that familiar table where I'd been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me." Fortunately, we have resources now that can help folks transition from treatment to the survivorship phase: Resources provided by the Komen Fund; resources provided by the Massey Cancer Center; resources provided by the National Cancer Institute.

This is a quote from a 79-year old colorectal survivor. He says, "Being a cancer survivor is at the forefront my self awareness. It enters into the conversations that I have with myself about what I want to do, how I want to spend my time, my energy, all of that. Being a cancer survivor has added another dimension to my identity. I am a cancer survivor." And obviously, this quote reflects someone who was profoundly affected by the disease.

So finding meaning can be an important part of the healing process for some. Many individuals seek to understand why they became ill. And I don't mean what caused their illness, because that's a very complicated question with various levels of genetic, environmental, and behavioral factors. I think it's important for all of us to realize that cancer doesn't discriminate; it could happen to anyone regardless of age, regardless of race, regardless of gender. What I'm referring to is the survivor's need to understand what having had cancer means to their lives now, how to integrate their experience and move forward. Many cancer survivors tell us that it can be used as a coping strategy. It helps them deal with some of the uncertainty and fear that surrounds the disease.

So, what's the process of finding meaning? Well, the search for meaning often takes us beyond our everyday boundaries and requires tools that have not been part of our everyday lives. It really requires you to think about areas in your life that perhaps you haven't looked at in a while, or evaluated in a while. And that could be a scary process, but an important process. The timing of this is as variable and unique as the individuals diagnosed with cancer. Some search for meaning within weeks of their diagnosis, but the majority really explore the meaning following their treatment. It allows individuals to be reflective. It allows them to focus on the future, as opposed to daily trials and tribulations of the cancer treatment.

Finding meaning can be positive. We hear survivors—and this, again, is reflected in the literature. We hear survivors all the time talk about how their experience allowed them to grow closer to their family. They spend more time with their family. They make positive changes in their health behaviors, which is really important when you think about some of the late effects of cancer treatment. Many individuals place less focus on career, or change their career, in my case. Some individuals come to the realization that they had this inner strength that they didn't realize they had before. Many report that they now have these skills to cope with future life crises. And then, of course, spirituality and religiosity, which will be the focus of the next talk. Oftentimes, people grow in terms of their spirituality and religiosity as a result of their cancer. It's something that helps them get through some of the more challenging times.

So, for those of you who may be interested in exploring meaning in your life following cancer, here are some tips to consider. Take a new look at old patterns, values, and priorities. Again, focus on areas in your life where perhaps change is needed. And if you desire to move forward and act on that, a great

way to do that is to keep a journal. Write down your thoughts. Expressive writing is really important to this process. You could also create both short-, medium-, and long-term goals, and track your progress towards these goals using the journal. This has been the focus of a number of interventions that have been used to promote meaning-making in cancer survivors. Talking. Talking with a member of the clergy, talking with others, talking with cancer survivors, joining a support group has also been found to be very important to the process. Taking part in a research study or helping others who have had cancer also seems to provide meaning to some individuals with cancer.

I think it's really important to strike the right balance between thinking about your cancer and moving forward in your life. If thinking about your cancer causes a great deal of anxiety or distress, then perhaps you might benefit from talking with a professional. You certainly don't want it to consume your life.

An important reminder to my talk is that finding meaning or positive changes in your life is not a necessary part of the adjustment process, so I don't want you walking out of here thinking if you don't find meaning from this experience that there's something wrong, because there's not. As I mentioned earlier, there are so many different ways individuals respond to a diagnosis and there's no one right way. What I like to tell people is that it's important for cancer survivors, family members, and health professionals to be aware of this possibility in case individuals want to explore their feelings further.

I want to end on two quotes. The first is from an Austrian psychologist, neurologist. He's also a Holocaust survivor and he wrote this terrific book called *Man's Search for Meaning*. He says, "Ultimately, man should not ask what the meaning of his life is, but rather must recognize that it is he who is asked. In a word, each man is questioned by life; and he can only answer to life by answering for his own life." Lastly, "Life is not merely to be alive, but to be well." And I wish you all well on your journey as you move forward. Thank you.