

Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center, and Dr. Miller is a Medical Oncologist specializing in pain and palliative care and he also serves as the Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion, you can contact the doctors directly, the address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening we look at the growing field of Psychooncology with Dr. Jimmie Holland. Dr. Holland is the Wayne E. Chapman Chair of Psychiatric Oncology at Memorial Sloan-Kettering Cancer Center and begins with the description of the field.

Holland This area is the part of cancer care that deals with the psychological; the emotional reaction to this illness at all stages of disease for the patient, family, and the staff who have their own burden in taking care of this. The flip side to it is the psychological, social, and behavioral issues that have an impact on cancer incidence and survival, for example, smoking. We would like to look at both sides of it; what cancer does to people and what people may do to influence getting cancer or surviving.

Miller Along those lines, there was the feeling 10 to 20 years ago that stress caused cancer. If someone said, "My family is a pain in the neck," then that person would end up with head and neck cancer. Can you talk a little bit about that?

Holland That was a very unfortunate part of our cultural adaptation to cancer and our reactions to cancer. There is always a tendency, when you do not know the cause of a disease, to blame somebody for getting it. Tuberculosis, for example, we used to think had a psychological cause until we found the bacteria. Cancer has been much the same way, and it was such a shameful disease to have so people kept it as a secret and did not talk about it. It was the feeling that they must have done something awful to bring this on themselves, and that added to the burden of not only having the disease, but having to keep it a secret. Society supported that idea that they had done something awful to get it, so they blamed the victim very often.

Miller From your perspective, have we moved beyond that?

Holland We have moved a long way beyond it, in part because we know the causes of cancer and we know cures for several cancers. As the knowledge about the disease improves, the mystique of it disappears. We have a microcosm of this with AIDS. If you remember, starting in the early 80s, we were all frightened to death. We had no idea how you caught it or how to treat it. Now AIDS is very much confined to certain kinds of behaviors and people do not worry about getting it anymore.

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- Miller Looking at the flip side of that, the things that people can do to manage stress, participating in support groups, positive thinking, and positive imagery and guided imagery, what role do they have in the process of getting better?
- Holland Let me speak first on positive thinking. I have called this the tyranny of positive thinking because there is this sense in society that if you do not think positively, you are letting your tumor grow faster. Who can be positive when they are nauseated and vomiting and going through arduous treatments? Of course you are going to feel depressed and sad and nervous. We would like to get away from the idea that positive thinking is good for all people, for those who are more cynical, quiet and reserved, putting that on them that they have to be positive is another burden. In terms of guided imagery, all kinds of relaxation and meditation are helpful techniques to some people. There is no one size fits all for coping with cancer. Some people like counseling, they like to talk about it either with a counselor or with other people who have the same disease, but not everybody does. We get into trouble when we say this is the one way to cope with cancer, so I try to say to families to respect how the person in the family is coping with it. That is the best for them. We cannot change people in the middle of the road when they have a disease, you look for the strengths the person has and you enhance those strengths. You do not say that they are coping in a wrong way.
- Miller As you are talking I am thinking that people have their own path and their own trajectory in terms of the illness so what may work for one person may not be helpful for someone else.
- Holland Very true. The challenge is changed over time. The diagnosis is one set of problems, what is the best treatment, who is the best doctor, how do I get started with treatment? As time goes on it becomes, how do you cope with the side effects of treatment, and then, how do you cope with having it be all over? Interestingly enough, when the treatments are over people get a kind of paradoxical new level distress. They are not being treated any longer and they think, what if it comes back? These kinds of things are adaptation to survival that we are beginning to know much more about and realize there is a baggage that goes along with being cured of cancer.
- Miller Let me ask you a little bit more about that because you are actually here this week at Yale as our keynote speaker for a survivorship conference. That baggage that people carry after cancer, can you give us some examples that tell more about it?
- Holland The first thing is, anyone who has ever had cancer has a nagging fear that

it could come back. It gets less over the years, but it is always there. This disease is one that you can never be quite sure about, so the fear of recurrence is always there. Some people will have posttraumatic symptoms from the treatments, particularly something very arduous like a bone marrow transplant where they may have been isolated for a month or six weeks in the hospital with multiple infections and difficult treatment. They may think back on that and have nightmares, become anxious or be startled by loud noises. These are typical symptoms that were first seen with Vietnam Veterans, and that was when the term posttraumatic stress was coined. Some of those symptoms can surface years later. It is not so prominent now, but some patients, if they get a reminder of the chemotherapy that they had, like a smell of alcohol or even looking at a room that looks like the treatment room, they can feel anxiety and a sense of nausea. We see it less because the drugs we have to control nausea and vomiting are so powerful and effective today.

Miller Let me ask you more about posttraumatic stress. Does that get labelled with other terms of someone with cancer, six months later, 12 months later, who is having a lot of these reactions? Does that get misdiagnosed?

Holland It probably is not called posttraumatic stress. The patient themselves are saying, "I do not know why I am more worried now and more nervous now that the treatment is all over. I should be opening the Champagne bottle and I do not feel like that, I feel like I am more worried than ever." That comes across as reactive anxiety, maybe due to some depressive symptoms, but I think there is an aspect of that that is clearly posttraumatic.

Miller On the flip side of depression, are people diagnosed with an anxiety or mood disorder when in essence it is a reaction to distress?

Holland Absolutely it can be.

Miller I know that you refer to stress as the sixth vital sign, what does that mean?

Holland One of the things that happened is that pain management has improved enormously in this country, and it improved essentially because the doctors began to ask their patients how their pain was on a scale of 0 to 10. Patients began to get the idea although they did not like it to start. They can tell you, my pain is an 8 right now, it was only 2 yesterday and there is an algorithm if it is over 5, you have to look at pain management medications. So that became the fifth vital sign, doctors have to look at

blood pressure, temperature and respirations, but in addition, they must ask about pain at every visit and pay attention to it. We feel that the most neglected area of care is what we have called distress, this whole psychological side. Because it is so neglected it is often not asked about in patients visits. What we have proposed is for patients to just use the word distress. How is your distress level today, 0 to 10? What we found is if the patient says more than 5, that is a sign to ask more questions. Is it something at home, whatever it is, we need to know. The oncology nurse or the oncologist should ask those questions, or the social worker. We have proposed that a sixth vital sign should be distress, after pain, how is your distress level, 0 to 10? This has been initiated in Canada and they have, across their cancer care guidelines, the sixth vital sign as distress. The US could learn something from Canada.

Miller From what you have heard about and seen in the Canadian system, when the patients are asked, what numbers are they giving, 7, 8, 9, and 10, or is it different across the board?

Holland It is highly variable. The numbers that are very high, that is a red flag because this is someone who needs to be further explored quickly. We tried to use a very short question just to find out if a person is distressed, and obviously they want to know why, and that is a second level, but this first level is very helpful and many people say, "I am a 1 or 2, or it's not worth talking about." But you may find somebody who says, "Yes, I am scoring high, but I know why today and I will be fine tomorrow." You have to go beyond the number, but the reason why it is helpful is that patients do not want to sound like they are wimps, they do not want the doctor to think they are not coping well. They are embarrassed to say that they are not sleeping well or that they are not having sex. And the doctors are busy and they are not knocking themselves out to ask more questions because they have 25 people sitting out in the clinic. The opportunity to talk about this is so limited, and the word psychological is so frightening to people, that we hit upon the word distress. Obviously you have stress if you have cancer, it is normal to be stressed, but you can be a lot distressed, and that is what we need to know.

Miller Are you depressed, are you anxious, would those be terms that would have stigma?

Holland I think they do. Unfortunately, they should not, but they do. Distress is a very neutral word and so that is how we came to use it as a vital sign rather than nervous or anxious.

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Miller Pain is certainly well understood and something people can certainly rate, but if the patient asks what it means, how would you define it for them?

Holland I do not care what the feeling is, just give me what it feels like, 0 to 10. If yesterday you were calm and okay, how are you today? And they can give you a number and this has been validated. It is being used in a lot of countries around the world. Anything that is above a 5 should be followed up on. The patients are pretty good. They are more reliable than we used to think.

Miller We would like to remind you that you can e-mail questions to us, myself and Dr. Jimmie Holland, at canceranswers@yale.edu. We are going to take a short break for medical minute. Please stay tuned to learn more information about the emotional side of cancer with Dr. Jimmie Holland from the Memorial Sloan-Kettering Cancer Center.

Medical Minute

Here in Connecticut the American Cancer Society estimates that almost 1000 people will be diagnosed with colorectal cancer every month. The good news is that when detected early colorectal cancer is easily treated and highly curable. That means that if you are over the age of 50, you should have regular colonoscopies to screen for this disease. In the case of patients that develop colorectal cancer, there are more options than ever before. Thanks to increased access to advanced therapies and specialized care. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for colorectal cancer. The patients enrolled in these trials are given access to medicines not yet approved by the Food and Drug Administration. This has been a medical minute and you will find more information at www.yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller and I am here with Dr. Jimmie Holland who is a Professor of Psychiatry and Director of the Psychiatric Oncology at the Memorial Sloan-Kettering Cancer Hospital. Jimmie lets talk about the mind and body connection. It is a very popular thing to think and talk about, but what does that mean?

Holland We live in a “can-do” culture, so we would like to think that our mind can control what is going on in our body. It is a very appealing idea and there is certainly that appeal about cancer. We went through an era in which there was the idea that if you could visualize your immune cells killing off the cancer cells you were enhancing your immune function. I think that is more fantasy than reality. Clearly, the mind and the body are all in one mechanism and they interact all the time, however, I do not think that there are psychological mechanisms that are going to alter cancer growth. Now, it is quite possible that psychological activities alter behavior like

smoking, and that in itself alters cancer risk. It is also true that our psyches have to do with whether we adhere to the treatment the oncologist recommends. If you are there everyday to get your radiotherapy, you are certainly going to have a better outcome than the person who says it is not for them. So, yes, the psyche affects the cancer treatment but by way of behavior not by any kind of mystique or mysterious mechanism within the body that we can identify.

Miller It is helpful hearing it from you as an expert in this field. You have written a wonderful book called *The Human Side of Cancer, Living with Hope, and Coping with Uncertainty*. How do people cope with uncertainty in this setting?

Holland That is the cornerstone of the illness for most people with cancer who get the diagnosis, and it is very hard for the doctor to say, you are 100% cured, or you are 100% not cured and you are not going to make it. People live in a limbo between being hopeful and that uncertainty that they may not have gotten it all. Finding a way to deal with that uncertainty and putting it into a context that lets you go on with your everyday life is really the essence of the coping. I had a wonderful young man who had a graphic way of telling me about it. He said, "I have these three little gremlins in my head. One of whom says, 'You are not going to make it buddy you are sick', and the other one on the other side says 'Come on miracles happen, you are going to be fine.' And I have this third little gremlin in the middle who has to keep the other two quiet so I can put one foot in front of the other and manage my daily life." Graphically that is what I think happens as people cope with uncertainty.

Miller It is wonderful. Related to that, one word that I think we never use in the clinic is the word cure. It is almost like a dirty word. Have you noticed that?

Holland I think that has changed, people used to talk about cure. Surgeons would say, "Okay your breast is cured, good bye." And there was a kind of certainty about that which was very appealing. Today, a woman gets all these statistics, well you are 85% safe, but there is that 15% so we are going to see you every 4 months forever. You do not walk away with the certainty that you used to in the older days. That certainty was not quite so certain, but it gave you a sense of being alright for now. Given today's very careful follow-up with people, it keeps the cancer in the forefront of their mind. I see people who tell me they get psychotic the week before all their scans, once every 4 months, and I call it their pre-scan psychosis. After the scans are over and they are negative, they are fine until the next

scan. Yes we need to be following people, but I am not sure sometimes if they are too excessive with the scans.

Miller That makes me wonder as well. One of the biggest concerns of patients when diagnosed with cancer is their children and their loved ones in general. What is your advice in terms of how people can share this information with their child?

Holland It is a very important question. Sometimes little ones are sort of neglected when one of the parents becomes ill. Our experience is that children do well as long as they feel they are on the team and they are being told what is happening. They do most poorly when it is a secretive thing, like something is happening and the child feels excluded. Children will imagine the very worst rather than the best, so parents are not really protecting the child when they keep the information at a distance. The child will do much better if he or she feels like they are trusted enough to be told what is going on. "I am going to the hospital, I am going to have this little operation, I am going to lose my hair and yeah, it is not going to be fun, but we will get through it." Then the children feel they are part of what is going on and they handle it.

Miller In terms of spouses and significant others, what have you seen in terms of how people can partner well together?

Holland We say cancer is a family disease. It affects not just the person who has it, but everyone around them. A couple who has a good marriage will probably get closer. If it is a troubled marriage at the time the cancer occurs, it can be very difficult with a lot of conflict. But they need one another and it is a very difficult time when marital situations are not very good. We have a counseling center and we offer family counseling and we offer counseling to children. It is not a sign of weakness to ask for help. There is still this kind of stigma that asking for counseling or some kind of psychological help means they cannot cope with it. This is not true at all. We can help people sort these things out and help them deal with the issues in constructive ways rather than destructive ways.

Miller There is the term posttraumatic stress, and there is also discussion of posttraumatic growth, what does that mean?

Holland That is a good point to bring up. I have certainly talked to people who have said, "As bad as cancer was I am glad it happened to me because it changed my life. I stop to smell roses, I appreciate the little things, and it really was a life-changing event for me." People realize all kinds of things

they are now going to do with their lives. I have had other people who say that is a lot of garbage and they do not think it changed their life at all, except in a bad way. People perceive it very differently, but I do think that many people who survive a crisis, a car accident that brings them to near death, or any kind of near death experience that is very frightening, start thinking about who they are and what the meaning of life is. It is not just with cancer that this happens, but there is a sense of growing from crises. We use adversity often times as a means of personal growth.

Miller Recently, The Institute of Medicine, which is very well respected organization in Washington, showed a very important report on the emotional side and psychological side of cancer. Can you tell us what their findings were?

Holland I am delighted to tell you about that. The Institute of Medicine carried out a 2-year study of what the barriers are for patients getting good psychological/psychosocial care in the course of their cancer treatment. What they found is that people in the US have the best cancer treatment in the whole world, but the psychological side of it is very poor. It is very lagging beside the technical side of care. The Institute of Medicine report says that there is strong evidence that the psychosocial side is important in care, and it has been proven to be important by their interventions. Bottom line, psychosocial needs must be integrated in routine cancer care if it is to meet quality standards today. That is a whole new world because we never had that level of acknowledgement and support before. While it's a top down kind of change, at least there is a standard out there. It has an impact that can be followed up and implemented by recommendations from oncologist's offices. They must include in their workup of a new patient, how much stress they have, if they are having trouble coping with this illness. There are a lot of free resources in this country that are not used adequately, for example, the wellness communities. There are 20 of them around the country that offer totally free counseling and help of all kinds. There is Gilda's Clubs, there is the National Coalition of Cancer Survivorship, and the American Cancer Society, and all of these have free counseling by telephone. We have our American Psychosocial Oncology Society that has a help line, which is APOS-FOR-HELP. We will help you find a counselor in your own community.

Miller So you are saying that whether it be in a community practice or an academic setting, people are entitled to that help and it sounds like it is often available?

Holland It is available and people need to know that this is their right and this is

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part of their care that has to be there to help them get through the illness in the best possible way.

Miller You have been doing this for over 30 years, do you find yourself more optimistic or less optimistic by getting those services out there to people?

Holland I am very optimistic. Things change slowly. We have seen the stigma of cancer diminish over the years so that people are now not so frightened of it. They are still frightened, but they understand it better. I think the psychological side is still a little stigmatized. People do not want to admit that they might need a counselor. That too is improving, and I am an optimist and I figure if we just hang in long enough, we will finally get there.

Miller It is terrific. I want to remind our listening audience that survivorship programs, like the ones we have at Yale, are available at other cancer centers as well. Counseling services are available, and as Dr. Jimmie Holland was saying, that is your right. Jimmie, I want to thank you for joining us on Yale Cancer Center Answers. Until next week, this is Dr. Ken Miller from the Yale Cancer Center wishing you a safe and healthy week.

If you have questions, comments or would like to subscribe to our podcast, go to www.yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, we will discuss the process of helping spouses of cancer patients with Dr. Maria Loscalzo. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.