The Cancer Journey

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Cancer is the second leading cause of death in America. Because the majority of cancer patients today survive at least 5 years, cancer can be reconceptualized as a chronic illness. A diagnosis of cancer and subsequent treatment brings physical, emotional, and cognitive changes and challenges. Psycho-oncology is a relatively recent discipline that assists patients in coping with these changes. This article examines the experience of the human being facing cancer, and the potential role for behavioral professionals and biofeedback practitioners in assisting the cancer patient. There are certain periods during the cancer journey that appear to be more challenging. Biofeedback can assist patients in coping with these challenges.

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Cancer is the second leading cause of death in the United States—exceeded only by heart disease. According to the American Cancer Society (2009), the chances of developing cancer over a lifetime are 1 in 3 for women and 1 in 2 for men; therefore, we will all be touched by this disease. About 1.5 million new cases of cancer are expected to be diagnosed in 2009. Approximately 11.1 million Americans were living with cancer in 2005 (latest figures) (American Cancer Society, 2009). The 5-year relative survival rate for all cancers diagnosed between 1996 and 2004 is 66%, up from 50% in 1975–1977 (American Cancer Society, 2009). Cancer has truly become a chronic illness.

For far too long, only the physical aspects of cancer were acknowledged; only the body was treated and the person inside that body was ignored. Cancer was considered a death sentence. It was not uncommon for the patient not to even be told of the diagnosis—family knew, but it was felt that the patient would not be able to handle it. It was referred to as the “C word,” and the word cancer was seldom uttered outside the medical community. There was a stigma to having cancer—people did not talk about it. It was not until Jimmie Holland, a psychiatrist, began to speak about the human side of cancer in the late ’70s and early ’80s that the psychological aspects were even acknowledged. She started the first full-time psychiatric service in a cancer research hospital in 1977 at Memorial Sloan Kettering in New York—and thus began the field of psycho-oncology. Even then, she would get comments from other providers such as “What are you, a psychiatrist, doing here? These people are really sick” (Holland, 2000).

Still today, there is misunderstanding about the need for psycho-oncology services in some sectors of the medical community and sometimes even resistance from patients. Comments from patients such as “I’m not crazy” and “Why should I see a psychologist?” are not uncommon. I often have to stress to patients that I am a health psychologist and I only work with people who have medical illnesses. I am just as much a part of their treatment team as their other providers. Cancer and its treatment is a difficult experience, and distress is to be expected. It is important to normalize these feelings. If patients are not feeling a little anxious and sad at the time of diagnosis, I wonder if they are in touch with reality.

The Diagnostic Phase

Getting a diagnosis of cancer is ego smashing. The world as one knew it no longer exists. That safe, predictable place where one felt in control is no more. It affects every aspect of life: body, mind, and spirit; family (extended and nuclear); friends; job; and future. It may even affect one’s relationship with God.

A diagnosis of cancer can give one a feeling of being totally out of control—physically, mentally, and emotionally. On a physical level, treatment can cause fatigue, pain, irritability. Worrying about one’s present and future can interfere with sleeping. On an emotional level, feelings come and come quickly and intensely at times. Cognitive changes can occur. Difficulty with memory and concentration are fairly common side effects of treatment. For someone who has always felt in control, these changes can be very challenging. Understanding the psychodynamics involved in a cancer diagnosis will aid in treatment planning.

Most likely, the patient will experience many emotions in response to these changes. And these emotions may
continue long after treatment ends. There are no standard, “correct” emotional reactions to these changes. Some of the emotions may be positive, as in a greater appreciation for life and loved ones. Others may be uncomfortable or confusing. There are no right or wrong emotions. It is important, however, to be authentic in regard to emotions—to acknowledge the emotions, experience them, and then either accept them or change them.

Although these emotions may crop up at any time, there are certain times in which one is more vulnerable. The period from first symptoms through diagnosis is one of those times. When symptoms first appear, there may be a tendency to dismiss them as nothing important and assume the symptoms will disappear. One might even delay seeking a medical opinion, hoping the symptoms will go away. When the symptoms do not go away, thoughts can run wild. “Don’t remember feeling this lump before, it’s probably nothing, but it then again could be…oh, my goodness you don’t suppose it is…?!” And then one begins to scan the body for any other symptoms—aches, pains, warts. Things that have been there forever now take on new meaning. Waiting for an appointment with the physician can seem excruciatingly long. One’s perception of time changes depending on circumstances. Time speeds up subjectively when one is enjoying something and slows down when one is doing something tedious, or, in this case, waiting for something threatening. Now, the few days or so one must wait for an appointment seems to take forever.

Anxiety and Fear
It has been said that the greatest fear of all is the fear of the unknown. While waiting for the diagnosis, one is in limbo. There is a saying in oncology: “It ain’t cancer until the pathologist says it is.” The patient is at a fork in the road and does not know which path will need to be taken. Nothing can be planned until the pathologist speaks. This waiting and wondering and imagining all sorts of things can be very anxiety provoking.

When the diagnosis is finally made, there may be shock and numbness or there may be relief at finally knowing for sure. Again, there is no right or wrong way to respond. With the diagnosis come decisions about treatment. It is not uncommon for patients to be expected to make these decisions while they are still in the shock-and-disbelief state. Patients need to be encouraged to take their time in making these decisions. Seldom does another day or two make a difference, and the decisions they make will affect them for the rest of their lives. In this state of shock and disbelief, it is hard to process all the information that is being given. Patients should be encouraged to bring a friend or family member with them and/or a tape recorder, and they may need to ask the doctor to write down pertinent information in lay language.

Grief and Loss
There may be anticipatory grief during this time for the loss of a body part or body function. The more a person’s self-concept is wrapped up in physical appearance, the harder this may be. It is important for patients to remember that their identity is not irrevocably tied to a specific body part. That body part is part of the person and that person may grieve the loss of that part, but the person still exists. There may be anger. It is not unusual to hear responses such as “Why is this happening to me? I did everything right.” Guilt may be expressed over some perceived lapse in caring for self. There may be anxiety if the person is searching for a second opinion or other treatment options.

The Treatment Phase
The next vulnerable period is that of treatment. A lot of energy is invested in fighting the disease and coping with treatment effects. There may be considerable anxiety at the beginning of treatment. Common questions or concerns at this time include “What will this be like?” “Will I be able to handle the side effects?” and “How will I care for my family?” During treatment, one may need to depend on others to help out. Most of us are very good at helping others but have more difficulty accepting help. There may be grief with loss of well-being—loss of that old, healthy self.

There are also the physical side effects of treatment. There may be nausea/vomiting (although we are doing a much better job at controlling that with medication). This may be anticipatory—just seeing the clinic and experiencing the smells and sounds associated with the clinic are sometimes enough to initiate nausea and vomiting.

During this time of treatment, patients count the weeks left, the number of treatments left—they can’t wait for life to get back to normal. And then treatment ends. There’s a feeling of accomplishment: “I did it! I made it through.” But this may quickly turn to anxiety. All of a sudden, patients are not seeing their treatment team every day or every 2–3 weeks. An appointment is given for 3–4 months later. The patient’s life has been wrapped up in the treatment for several months, and now he or she wakes up in the morning and has no place to go. Then just when life
finally approaches normal, it is time for a follow-up. “Has it recurred? What will they find this time?”

**Anniversary Effects**

Anniversaries are another vulnerable time. The anniversary of the diagnosis may bring back all the emotions experienced at the time of diagnosis and can be a particularly difficult time.

If treatment fails and the disease recurs or begins to progress, the process repeats. Decisions regarding the next approach have to be made. Feelings of anger, guilt, and hopelessness may flood the patient. “Why me and why me again? What did I do wrong? Does it even matter what I do now? How do I balance treatment effects against quality of life?” The cancer may have been picked up at an advanced state or may advance due to treatment failure. Either way, there may be considerable psychological distress at this time.

**End of Life and Palliative Care**

The last vulnerable period is that of palliative care and involves end-of-life issues. Coping with loss of independence, without the hope of regaining it, is a difficult issue that people may face at that time. Pain control is very important at this stage for physical and psychological reasons. Pain is an added stressor on the body and interferes with functioning. Pain also can prevent a person from engaging with family and friends and thereby prevent closure of unresolved issues. There may be guilt over things done, or not done, and considerable time and energy may be involved in resolving those issues. There may be other family issues that need to be settled. Supportive therapy is so important at this time.

**Assessment**

One way to assess the level of distress a patient is experiencing is to use the Distress Thermometer developed by the National Comprehensive Cancer Network (2009). This is a screening tool in which patients are asked to rate their level of distress and check the problem areas they are experiencing. The problem areas that are assessed include practical problems such as child care, financial issues, family problems, emotional problems, spiritual/religious concerns, and physical problems. Scores of 4 or above need further evaluation. Therefore, patient’s responses not only indicate the level of distress but also indicate the areas that are contributing to the distress (Bultz & Holland, 2006).

Anxiety, anger, muscle tension, immune functioning, pain, insomnia, and anticipatory nausea/vomiting are all areas that may respond to biofeedback. Some patients like technology. They like gadgets. They like to see their response to treatment, and for them, biofeedback is perfect. Others just want to process what is going on with them, and they may feel that “technology” gets in the way. This can change as treatment progresses. The key is having many tools in your toolbox and being in tune with the patient—sensing what is right at each visit.

**Biofeedback Interventions for Cancer Patients**

Biofeedback can be helpful throughout the cancer journey by reducing a wide range of symptoms associated with stress such as anxiety, depression, and pain. Rollin McCraty (2008) defined stress as “the emotions—feelings such as anxiety, irritation, frustration, lack of control, or hopelessness—that are truly what we are experiencing when we describe ourselves as stressed” (p. 30).

Uncertainty also adds to the feeling of being stress. Not knowing what will happen next or how it will turn out can be very stressful. The numerous physiological, cognitive, and emotional changes leave the patient feeling uncertain about everything and in control of nothing. Although biofeedback can not change the uncertainty, it can help the patient gain a sense of control in coping with the uncertainty.

A direct link between stress and cancer is elusive; however, Cohen, Janicki-Deverts, and Miller (2007) stated there is an increased risk due to stress for various diseases including cancer. Negative emotions deplete the physiological systems leading to depressed immune function and increased susceptibility to disease. Biofeedback promotes self-regulation, which results in reduced stress. Stress is insidious. Many times people are unaware of the degree of stress they are under until the stress is removed or they have some way of recognizing it. Although any biofeedback modality could be used to assist patients in coping with cancer, I prefer to use heart rate variability (HRV) for many of my patients.

HRV is a form of biofeedback that can help patients to identify when they are stressed and to change their physiology to promote optimal functioning. By exercising the baroreflex, HRV allows the body’s endogenous modulatory reflexes to function with greater ease. As patients learn to optimize the variations in their interbeat intervals, respiration falls in line, muscle tension decreases, and the cognitive system is informed that the body is no longer in danger.

Perhaps the greatest benefit from biofeedback for cancer patients involves giving them a sense of control in their lives. There seems to be little doubt that biofeedback can
enhance the quality of life for those who are successful, allowing them to take an active role in their treatment.

We all hold the keys to healing within ourselves. Our job as providers is to help patients find those keys. Biofeedback is one tool that can aid in this process.

References


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