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# Effectively Interacting with the Terminally Ill Patient

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Effectively interacting with the terminally ill patient may be a new challenge for the nuclear medicine technologist. An understanding of chronic pain and the dying process is essential to meet this challenge successfully. The objectives of this paper are to provide the technologist with:

1. An understanding of the physical and emotional reactions associated with the label terminal illness.
2. An understanding of the physical and emotional impact of chronic pain.
3. Strategies to effectively interact with the terminally ill patient.
4. Strategies to successfully counteract the emotional impact associated with working with this patient population.

**Key Words:** chronic pain; terminal illness; grief

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Interacting with the terminally ill patient may be a new challenge for the nuclear medicine technologist. As a technologist, your ultimate goals should be to provide quality patient care, provide the clinician with a diagnostic imaging result, and remain emotionally intact today, tomorrow and in the years to come. An understanding of chronic pain and the dying process is essential to meet this challenge successfully.

## THE LABEL: TERMINAL ILLNESS

The label "terminal illness" can evoke emotions including fear, anger and depression (1,2). The universal emotion shared by all terminally ill patients is fear: fear of the unknown; fear of the dying process; fear of living with a debilitating illness. You will see the patient and family showing signs of fear, especially as the time of death comes closer. You may encounter questions from the patient or family members that are difficult or impossible to answer: "How bad will this get?" "What can we expect?" "Do you believe in life after death?" These questions are difficult. When you consider the diversity of our patient

population, there are no right or wrong answers. In most cases, the patient is not seeking the meaning of life. She is seeking the warmth and understanding of another human being. Being an attentive listener, providing a warm smile or a little hug therapy may be the only support necessary.

In many cases, anger quickly follows the feeling of fear: anger at the unfairness of the situation; anger at those who continue to reinforce the terminal sentence; anger at those enjoying the benefits of good health. If the emotions of anger and fear continue without intervention, the patient may plunge into the depths of despair and depression. Working with a patient that is angry in the morning, sad in the afternoon and fearful the following day can be frustrating as well as challenging. The most important thing to remember and share with your patient is that these feelings of fear, sadness and anger are OK. It's OK to be afraid of dying. It's OK to be sad. It's OK to be frustrated and depressed. Recognizing that erratic emotions are normal is a small step towards acceptance and peace.

Over time, you will see the patient physically deteriorate. This deterioration may be seen as weight loss, jaundice, bloating, loss of motor or cognitive skills and, throughout this process, increased pain. While a technologist may find temporary relief by resorting to humor about a patient's baldness from chemotherapy, it is difficult to find any humor in a situation that finds a previously walking patient in a wheelchair or on a stretcher. Watching this erosion of the body can dramatically affect the emotions of those close to the patient, including the technologist working with that patient over several months or years.

As the patient's condition deteriorates, you may see signs of chronic stress experienced by the patient's family and friends. As the patient and family attempt to cope with the stress associated with the dying process, they may turn to the support of food, drugs, alcohol or the absence of everything, including food, to help them through the day (3). It is not uncommon to have a patient or the patient's family or friends come to the department clearly under the influence of alcohol or other drugs. This dysfunctional behavior confirms that the patient or family is suffering from chronic stress. Working effectively with this patient or family may be extremely difficult. In most cases, a warm, caring attitude will be the only tool necessary to

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provide the patient or family with a quality experience. However, in extreme cases, calling the patient's social worker or attending physician may be necessary to provide competent support.

### **CHRONIC PAIN**

Chronic pain is a common attribute in terminal illness. An understanding of the physical and emotional impact of chronic pain will help you deal more effectively with these patients.

Chronic pain causes many negative emotions including anxiety, anger and depression (4). People who are in pain are generally not on their best behavior (5). They may be gruff and grouchy and difficult to deal with. Their attention spans may be poor and their ability to understand and remember simple instructions may be nonexistent. Remember that the pain is the most intense sensation experienced by the patient. Everything else is secondary. As you attempt to provide the patient with information pertinent to the exam, you may become frustrated when the patient continues to misunderstand information provided or continues to ask questions that have been answered. If your frustration becomes evident, or if the patient becomes frustrated with her own lack of comprehension, you may become the target of displaced anger. Most often, this anger is displayed in the form of verbal abuse. Although you do not deserve this abuse, and should not have to tolerate this behavior, an understanding of its origin can help to make the experience more tolerable.

Chronic pain, and its companion depression, is associated with a diminished quality of life. Depression is a difficult emotion to deal with and one which may emerge when least expected. Over time, the terminally ill patient is forced to accept a diminished quality of life. In the past, that patient probably enjoyed a very active life-style; however, chronic debilitating pain will limit the patient's ability to participate in many activities previously enjoyed. It is important for you to remember that activities and sports that we take for granted and openly discuss with coworkers as we set up patients for imaging procedures may be the same activities or sports that the patient was forced to give up. Patients become very sensitive to their losses and may become irritable, sad or uncooperative when they hear others discussing an activity they no longer can enjoy (6).

Suicidal tendencies, as the result of severe chronic pain or depression, are not something we deal with on a daily basis. You may overhear the patient's discussion with family or friends regarding not wanting to go on . . . can't take the pain any more . . . what's the use of living like this. Statements such as these emphasize that *the needs of the patient are not being met*. Perhaps the pain medication is no longer effective or the patient is no longer able to find quality within the quantity of life remaining. Alerting the attending physician or another appropriate health care professional may help to improve that patient's quality of life and make another day seem worthwhile.

Fortunately, we are not always faced with grouchy patients with poor attention spans that scream at us, cry or are difficult, in general, to work with. But understanding the various reasons

why they may react as they do can help you prepare to work with them more effectively in the future.

### **STRATEGIES FOR EMOTIONAL SURVIVAL**

Building specific strategies can help you cope with the emotional stress associated with working with a patient population that provokes feelings of anxiety, stress, anger, fear or sadness. Remember the goals are quality patient care, diagnostic imaging results and emotional survival for the technologist.

#### **Understanding Grief**

Understanding grief from a patient's perspective, as well as from a personal perspective, is the first essential building block in strategies for success. Grief is a natural response to any important change or loss. It is not necessary to lose someone through death to experience grief. Experiences such as divorce, loss of a job, the last child moving away from home, or a best friend moving out of town can trigger a grief response. Most of us at some point in our lives have experienced grief.

The first reaction to grief is denial, which is to say, "I don't believe this, it's just not possible." This pause in reality allows the mind to record this terrible event without accepting the impact of that loss. Once the shock wears off, feelings of anger may quickly follow. Anger can be directed at anyone or anything. Questions such as "Why me?" are common. An attempt to control the impending loss may follow in the form of bargaining: a trade of something if the tragedy or loss will just go away. For example, if the patient feels that he has failed his family in some way, he may promise God that he will be the best father and husband if only God will cure him of his terminal illness. The bargaining process is an attempt to control the situation. It gives an individual hope that the loss may not be permanent.

As weeks pass and the individual keeps all promises made, but the tragedy or loss is not resolved, depression may be the next emotion encountered. Depression signals a loss of control; a feeling of hopelessness. In some cases, depression may be associated with feelings of guilt for the burden being placed on others. If there is time, and if the individual is able to work through the denial, anger, bargaining and depression, the final stage in the grief process is acceptance. In the case of terminal illness, such acceptance allows the patient to make a gradual separation from life, ties and roles. The patient understands that life will go on without him. The most important aspect of acceptance is the feeling of peace (7).

Unfortunately, the stages of grief are not systematically experienced from denial to acceptance. A patient can be accepting in the morning, angry in the afternoon and depressed at the conclusion of his exam. Working with this patient can be a roller coaster ride that is emotionally damaging for you if you do not understand the emotions associated with the grief process.

#### **Anticipatory Grief**

Another aspect of the grief process that is seldom understood is anticipatory grief. When family and friends see their loved one no longer able to fulfill her role in life, they will

grieve *before* that person dies. Part of anticipatory grief may be a distancing of family members so that they are prepared for the patient's death. If the patient's treatment is successful, and the patient lives longer than expected, this can actually be a problem. The family members are ready. They have pulled back. They have accommodated their lives to continue without the patient. But the patient hasn't died. What you will see in this situation is a family that had been loving and attentive in the beginning but, over the course of months, has become more distant and matter-of-fact. The patient feels abandoned at a time when she most needs the love, care and closeness of her family. Death is anticipated. Both patient and family will prepare to accept its inevitability. Unfortunately, their rate of acceptance is not uniform, one will get there a little early and the other will get there a little later.

The critical point in this discussion is that these reactions are all part of the grief process and are normal in the continuum of dying and death. There is a tendency to feel hostility toward family members that seem to no longer provide emotional support. Understanding the grief process from a family's perspective can help you avoid negative perceptions of family members.

### **Patient's Hostility**

You need to practice avoiding personalizing a patient's hostility on a daily basis. This admonition is easier to verbalize than to practice. On some days it will seem as if every patient is angry, abusive or noncompliant. The key point to remember is that these patients have many reasons to be upset. You are just a convenient target. Diffusing a threatening situation can be as easy as asking another technologist to continue with the patient or, if another technologist is not available, ask for the assistance of a physician, nurse or other health care professional. Above all, avoid responding to anger with anger. The goal is to avert the anger and create a positive experience for everyone involved.

### **Clear Communication**

It is essential to practice clear communication at all times. These patients may be distracted by pain, grief or loss of control. Therefore, clear communication is vital for a successful outcome. Clear communication can be accomplished in a number of ways:

1. Always speak slowly and clearly. Avoid complicated explanations. Use simple words and avoid medical jargon. Be willing to repeat yourself as often as necessary.
2. Enlist the assistance of family and friends when explaining the procedure. The more people listening to your instructions, the better chance you have in achieving some degree of understanding.
3. Whenever possible, put instructions in writing. Keep the instructions short and specific. Use simple words and avoid medical jargon.
4. Take time to explain the exam in detail. This explanation should include any physical requirements such as lying on your back without moving for 50–60 min. This informa-

tion allows the patient to prepare mentally for the exam. If pain is a prohibitive factor, discuss times for the administration of pain medication to ensure optimum pain relief during the procedure. If necessary, obtain orders for additional pain medication from the referring physician. This process may sound time-consuming, but will be time well spent if the patient is physically and mentally prepared for the exam.

5. Practice "WEG" when you talk with the patient. WEG is a social worker's term that stands for warm, empathetic and genuine communication. It is important to understand the difference between sympathetic and empathetic feelings. Empathy says, "I relate to you as another human being; we are equals." Sympathy is hierarchical and implies looking down on something or someone. These patients do not want our sympathy, they want to feel that they are equals. They will respond readily to a warm, genuine individual who treats them as equals (Otis-Green S, *personal communication*, 1993).

### **Stress Relief**

Working with the terminally ill can be extremely stressful. Developing healthy coping mechanisms is an important strategy in relieving stress. Short-term coping mechanisms are activities you do at work to ease a stressful situation. Long-term coping mechanisms are activities that you enjoy away from the work place that help you recharge your emotional batteries.

**Short-Term Coping Mechanisms.** When one patient has been particularly difficult, it may not be possible to provide the next patient with a quality experience unless a break in emotional tension is achieved. This break could involve simply distancing yourself from the situation for a few moments. A quick trip to the soda machine and a long cool drink of a favorite beverage may provide the relief necessary. When a depressed or crying patient has taken a heavy toll on your emotional reserves, it may be necessary to leave the department, walk outside and restore your emotional equilibrium in order to prepare mentally for the next patient.

Another successful coping technique is known as "chocolate therapy." This usually is necessary on a day when nothing is going right. The schedule is off by two hours; the patients are difficult; there's no possibility that anything will get better until late in the evening. One technologist will run to the candy machine to purchase several bags of candy. The staff will take about three minutes to chomp down those incredible chocolate morsels. It's amazing to see how little chocolate candies just seem to make everything better. The schedule is still behind. The patients aren't any better—but the technologists are.

**Long-Term Coping Mechanisms.** Long-term coping mechanisms are those activities you do outside the work place to recharge your emotional batteries. You may enjoy reading, exercising or any other hobby that makes you feel good and allows you to wake up each morning anticipating another great day. These are positive activities that have positive results, as opposed to negative and harmful activities such as overeating, smoking, and alcohol or drug abuse. Building positive coping techniques is essential to recharging your emotional batteries.

## **Support Network**

It is important to build a support network that includes your family, friends and professional peers. You need to be able to express your feelings to those who will support you. You need to debrief whenever necessary. A strong, supportive network helps you to nurture yourself, replenish your emotional reserves and be the best that you can be.

If coping techniques fail, and you no longer are able to cope with the stress of each day (burnout), it is important that this support network be broadened to include those individuals who can help you work through your crisis. Never neglect yourself or your emotional well-being. There are plenty of support groups available. Get out and find the one that suits your needs.

## **Professional Competence**

It is important to be the best that you can be professionally. We are all more comfortable being served by a professional who seems knowledgeable. Many people are not comfortable being served by a professional who is clearly "in training." Put that lack of confidence into a patient's perspective when her treatment and life may hinge on the accuracy of the test being performed. You need to provide each patient with a feeling of confidence and well-being through the competence of your actions. You can accomplish this by striving to build your personal competence on a continuing basis.

## **Surround Yourself with Life**

When working with the terminally ill, it is important to surround yourself with life. That may sound like an impossible task when you consider that most nuclear medicine departments are in the basement, without natural light or windows. Little things, however, can be used to brighten up a department including silk plants, bright posters, colorful wallpaper or paint. Anything that says to the patient, "I care about life. I care about the environment that I am providing for you while you're in my department." Patients will respond to this type of environment in a very positive way.

## **Tolerance to Pain**

It may be necessary for you to increase your tolerance to your patient's pain. This is a difficult task for most of us. We strive to provide each patient with a painless procedure whenever possible. For the terminally ill, however, a painless procedure may not be possible. Providing the clinician with a diagnostic procedure mandates that we collect adequate data. Quality images can be used to diagnose new metastatic lesions. Suboptimal images may not identify new sites of disease, thus, delaying treatment.

Enduring a patient's pain to produce diagnostic images requires a great deal of patience and fortitude. Distracting a patient with conversation may mean the difference between suboptimal, nondiagnostic images and a quality diagnostic procedure. The patient will experience physical pain. You will experience emotional pain. Tolerating that emotional pain today may help to reduce or eliminate the patient's pain tomorrow.

## **Head Knowledge/Heart Acceptance**

To understand and apply the information learned, it is important to understand feelings and values from the patient's perspective. This may seem an impossible task since you are not experiencing dying yourself. Intellectually we understand that we will not live forever. However, how many of us accept that fact emotionally and behaviorally? How many of us have written our wills? How many have advanced directives? How many have made funeral arrangements? Yet, how many of us will die? Transferring head knowledge into heart acceptance requires that you walk, at least some distance, in your patients' shoes (Otis-Green S, *personal communication*, 1993). Then, and only then, can you really know how difficult the dying experience is for your patients.

## **Patient Identification**

You need to be aware that you will identify more closely with some patients than with others. A patient may resemble someone you love. When you lose that patient, this can push an emotional button that may trigger some unresolved losses in your own life. In revisiting your own losses, it is important that you look to your childhood teachings and your own beliefs and fears. You need to build a strong emotional platform that you are comfortable with and will serve you on a daily basis. For many of us, there may be old beliefs or values that no longer serve us well, or are unacceptable to our current life-style. Nurturing yourself is imperative. You need to put energy into this process to address your own beliefs and fears before you can deal successfully with the emotional fears associated with death and dying.

## **View Life Differently**

In coping with the concept of terminal illness, it may be necessary for you to view life differently. In the health care environment, too often death is seen as a failure. It is important to realize that death may be a liberator. Death can be an end to pain and suffering. It is important that you be open to this possibility because it can help you to prioritize your own life. It may help you realize that the terminally ill patient can teach each of us a very valuable lesson: *live each day as if it mattered*. As an observer of the dying process in your professional practice, you have a special incentive to reprioritize your personal life. You can be encouraged to live your life so that, in the end, you won't face your own death with regrets.

## **CONCLUSION**

The final lesson to be learned from your terminally ill patients is: *Don't fear death, but fear the incompleteness of life.*

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