What I Wish I’d Known: Initial Insights about Oncology Chaplaincy

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For my third unit of clinical pastoral education (CPE), I asked to work in oncology. I quickly found that oncology chaplaincy offered unique challenges for which I was unprepared. Prior to starting my first internship as an oncology chaplain, I looked in vain for the equivalent of “Oncology Chaplaincy for Beginners” to guide me. Although I still have much to learn, after two units as an oncology chaplain, I believe I have enough experience to safely share some of what I’ve learned, specifically how this specialty differs from other types of chaplaincy. I hope my experience will be helpful to chaplains beginning work in this area.

The need for oncology chaplaincy

According to the American Cancer Society, almost one-half of all men and more than one-third of all women will be diagnosed with cancer at some point in their lives. The prevalence of this disease and the current treatment modalities mean that cancer patients likely will represent a significant percentage of patients in the healthcare system for the foreseeable future, particularly when those receiving outpatient treatments such as radiation or chemotherapy are included.

Cancer is a disease with a number of unique characteristics. Some patients do not experience any symptoms in the early stages, a fact which may make the diagnosis seem unreal and thus difficult to absorb emotionally. The outcome of treatment is often uncertain; it may take months to determine whether a particular treatment is efficacious. Treatment may be prolonged and often entails difficult side effects that significantly affect the patient’s quality of life.

This article discusses the unique characteristics of oncology chaplaincy from the perspective of a chaplain who is relatively new to this specialty. It explores the need for spiritual care for this population, the tension between patients’ inner feelings and self-image and the potential for the chaplain’s identification with individual patients. It also addresses specific issues relating to ministry to individuals undergoing outpatient treatment and provides suggestions for praying with cancer patients.

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Cancer is not necessarily a terminal diagnosis; however, even when remission or stabilization is achieved, patients generally remain aware of the possibility that the cancer may recur. As a result, it has been my experience that cancer is a disease that leads patients to ask fundamental questions:

- Why me?
- What meaning has there been to my life?
- How could God do this to me?
- If I only have a short time to live, how do I want to spend the rest of my life?
- Is there a lesson that I need to learn from this?
- Will I be able to face death with courage?
- What will happen to me after death?
- What will become of my family when I die?

Accordingly, I maintain that there is a great need for providing spiritual care to cancer patients at each stage of illness, from initial diagnosis to end of life.

Identification with cancer patients

The first challenge for the oncology chaplain is confronting his/her personal history and feelings associated with cancer. In the summer of 2005, I led a training session on oncology chaplaincy for five clinical pastoral education (CPE) students. Each of the students knew a cancer survivor, and each had experienced the death of a relative from cancer. None had been unaffected by the disease. Subsequent training sessions have replicated this result. In fact, I think it is safe to say that the probability of any adult in this society who has neither experienced cancer personally nor had someone close to him/her do so is almost zero.

While the issue of identification with patients arises all the time, there is a different quality of identification that occurs with cancer patients. This is particularly true in outpatient settings, which is where the majority of patients receive chemotherapy and/or radiation treatment. When we see patients in the hospital, it is generally obvious to us that they are quite sick, and their normal daily routines have been disrupted. In contrast, cancer outpatients often appear to be living reasonably normal lives. Although they may have issues relating to cancer, they are also concerned with their families, their jobs or other ordinary aspects of daily life.

While it is relatively easy to see the difference between oneself and an eighty-eight-year-old inpatient with renal failure, oncology chaplains will encounter outpatients who essentially appear to be just like them. Other than the fact that they have cancer and the chaplain doesn’t, the patient and the chaplain could easily switch seats. This similarity makes it even more important for chaplains to remain aware of their own histories with and feelings about cancer, which may interfere with their ability to offer spiritual care.

When I first volunteered to work in oncology, it did not cross my mind that my mother was a long-term cancer survivor and that both my father and stepfather had died of cancer. However, these facts quickly surfaced! Particularly when working with older male patients, I found myself reliving the emotional turmoil I had experienced during the illnesses and deaths of my father and stepfather. There were times when these patients indirectly signaled that they wished to talk about fears and concerns relating to death, and I missed these signals because I was unwilling to relive my own feelings. It was only after they were pointed out to me in verbatim work with my CPE group and supervisor that I perceived these signals and acknowledged my reaction to them. I also needed to become aware of and to face my own fear of contracting cancer so that it wouldn’t interfere with my working with patients.

When I see patients who are younger than I and who are not going to survive to reach my age, I have to deal with my own feelings of relief, guilt, grief and/or anger. I have found that while I am able to accept as fact that there are a certain number of people who are going to die of cancer at a young age, this acceptance is much more difficult to achieve when the statistic has a human face. These patients not only make me aware of my own mortality but also of the randomness of the length of my life. I need to acknowledge these fears in order to be present with an open and accessible heart to the patients that I am called to serve.

Tension between inner feelings and self-image

There is a particular circumstance which seems especially prevalent in patients undergoing outpatient treatments...
such as radiation or chemotherapy—the conflict between their deep feelings about having cancer and their coping mechanisms for dealing with the disease. The results of another exercise that I led with the CPE students illustrate this.

I asked them to imagine how they would feel on being given a diagnosis of a type of cancer that was generally terminal, but for which experimental chemotherapy studies showed promise. Their reactions included the following: afraid, uncertain, stubborn, sad, angry, uncomfortable about choice, depressed, anxious, grief-filled (feelings of loss), disbelieving and guilty. As we discussed this exercise, it was clear that receiving such news would be overwhelming and that they would have a number of strong and difficult feelings with which they would have to cope. These feelings are typical of the cancer patients whom I have encountered.

I then asked the chaplain interns these follow-up questions:

- How would you want to respond to this news?
- How would you want to handle this situation?
- How would you want to be perceived by your family and friends?

Their answers included the following. Those marked with an asterisk (*) are coping strategies that I frequently observe in cancer patients, whose most common response to the question of how they cope is “to stay positive.”

- Be strong for my family.*
- Be calm.*
- Be able to cry.
- Be as independent as possible for as long as possible.*
- Allow caregiving (knowing that this would be difficult).
- Try not to whine or express anger.*
- Be honest about my feelings.
- Resolve issues in my life.
- Express love.*
- Not be a burden.*
- Be alone.

The differences in the interns’ answers illustrate the wide gap between one’s actual inner feelings and how one would like to deal with those feelings as well as how one wants to present oneself to the world and how one wants to be perceived. As chaplains, it is very important to be sensitive to this dynamic.

This tension between inner feelings and desired mode of presentation is prevalent in patients undergoing chemotherapy or radiation, especially if they are not feeling particularly ill. It also holds true for patients dealing with chronic diseases with long-term negative prognoses, e.g., congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD).

There are certainly many occasions when patients may wish to share some of their inner feelings. However, there are other times when it is very important for them to present themselves as they want to be and not the cancer patient on chair 26 in the chemotherapy room. They may want to talk about their professional lives, their gardens or their grandchildren and we need to honor this.

Although this may seem basic, I discovered that initially I viewed the latter as evidence of the patients being in denial. I thought that it was my job to break through that denial and to get them to talk about the deep feelings that I knew must be inside them. I would imagine how I would feel, project those imagined feelings onto the patients and then feel the need to elicit them. I had to learn that it was not my job to elicit these feelings, nor could I measure the “success” of a chaplaincy visit by the depth of feeling revealed. Paradoxically, it was when I allowed the patients to set the emotional and conversational agenda that they were most likely to trust me and to express their deeper feelings.

**Ministry to chemotherapy outpatients**

There are other dynamics that are unique to ministry with outpatients undergoing chemotherapy. If a relationship of trust is established during the first encounter, patients often will share their feelings about the illness and how they are dealing with it, including where they are spiritually or theologically. These feelings may be quite deep.

However, the next visit, which typically occurs two or three weeks later, frequently will be quite different. As the patients already have described where they are in the illness process, have expressed their deep emotions and nothing significant has changed, the second visit may be quite casual.

Over time, individual patterns develop. Some patients just like to touch base. Once they tell the
chaplain what has been going on in their lives, the visit is complete as far as they are concerned. Others obviously relish receiving a blessing and will want one during each visit. Most often, the nature of the visit depends on the patient’s treatment status.

It is important for the chaplain to understand where patients are in the monitoring of the success of a particular treatment. At some point, usually weeks or even months after a course of treatment has begun, a CAT scan or MRI will be ordered, and it is only then that the patients and their doctors will be able to evaluate the success of the treatment. This is not the only benchmark as frequent blood tests are ordered for a variety of factors, including whether the patient is healthy enough to withstand the rigors of a chemo treatment. However, it is generally the CAT scan or MRI that determines whether a particular course of treatment will be continued. Where patients are in this cycle and how they are dealing with it will often determine what comes up in the visit. Dealing with the tremendous uncertainty inherent in cancer treatment opens up the possibility of addressing theological questions, such as where they find God in this process.

Another important dynamic of outpatient treatment is its duration. When one ministers to the same patients long term, a level of familiarity and intimacy often results. They know when you’ve gone on vacation and ask you about it. They show you pictures from their vacations. This raises important issues about emotional boundaries. Because so many of an oncology chaplain’s patients will die, it is crucial that the chaplain learn to protect him/herself emotionally. Obviously, one can’t be a chaplain and be aloof and distant. It is important for the chaplain to learn how to be emotionally available without becoming overly vulnerable.

In order to disconnect emotionally from my patients when I leave the hospital, I maintain a core area of self that is reserved for family and friends. I think doing this actually helps me stay open and accessible when I am at work. Of course, there are patients with whom I establish close relationships, but even with them, I try to keep a certain measure of internal distance. It is a very delicate process to stay open and self-protected at the same time, and each of us must find our own place of comfort.

The nature of healing and prayer

For many patients, the possibility of cure is real. Most first-time cancer patients hope for remission, and, in some cases, this is a realistic aspiration. However, many are forced to abandon this hope when the cancer either spreads or recurs, and their goals change accordingly, e.g., stabilizing the condition, maintaining a particular quality of life, living as fully as possible in whatever time is left.

When there is no possibility of complete remission, the concept of healing changes. Long-term cancer survivors have told me that cancer is their partner. One patient referred to it as keeping the tiger in its cage and finding a way to live with it. Healing becomes reconciliation with the reality of having cancer and finding peace with that reality.

One aspect of the healing process manifests itself in changing priorities—not “sweating the small stuff.” A woman in her thirties told me about another mother who complained that chaperoning a school field trip interfered with her tennis game. We laughed together about the possibility of her asking this woman if she wanted to switch problems and what the woman’s reaction might have been. But after we laughed, she told me that she understood the woman.

Even though it made her a little crazy to hear the complaint, she understood that the other mother spoke from her reality and she had compassion for the woman’s frustration. To me, this is an example of someone who has experienced healing: she demonstrated being whole in a profoundly compassionate and human way. Many patients comment about the gifts that having cancer has brought them, and usually add—often accompanied by a laugh—that they would be happy to forgo such gifts and not have the cancer.

There are other aspects of healing as well. Learning how to accept help is often one important lesson. Frequently, a diagnosis of cancer allows family and friends to express feelings of love to the patient that would otherwise be too embarrassing or demonstrative to express in ordinary conversation. Patients, in turn, need to let these feelings in. This is frequently painful, particularly when patients feel that they will never be able to return what is being given, but it is profoundly moving as well.

I keep these perspectives on healing in mind with respect to prayer. I usually offer prayer during my visits. I tend to pray spontaneously rather than liturgically—partly because I am Jewish and most of my patients are Christian—but
mostly because I feel that this type of prayer is best tailored to the needs of the individual. However, my “spontaneous” prayers are built around certain phrases.

I generally pray for God’s healing energy to manifest within the patient. I think healing is a legitimate thing to pray for; all of us are capable of healing, regardless of what may be happening to our physical bodies. I have found profound instances of healing in cancer patients that don’t have anything to do with physical cure. Many patients hope for a cure, however, and some will request that I pray for this specific outcome.

I am uncomfortable with this request as I don’t know what the progress of a patient’s disease will be, and further, I find it theologically difficult. I don’t like to encourage the perspective of the “Janis Joplin” God. (Readers of my generation may remember this line from one of her songs: “Oh Lord, won’t you buy me a Mercedes Benz”). I believe God’s love and healing energy are available at all times, regardless of our particular circumstances. To pray for a cure from a particular disease and then have it not happen may lead people to distance themselves from these divine gifts. If necessary, I will pray that it be God’s will that the patient be cured. There are of course many reasonable approaches to this situation, but it is helpful to have thought through one’s own theology ahead of time.

Often I ask that God help patients to be the people that they want to be and to give them the ability to meet whatever circumstances they encounter with dignity and grace. This is a prayer that many cancer patients have found meaningful and helpful.

**Conclusion**

Rabbi Simcha Bunam of Prysucha taught that we should keep two pieces of paper, each with its own message, in our pockets. When we are filled with pride, we read the paper with the words, “I am nothing but dirt and ashes.” When we feel crushed and our sense of self has been decimated, we reach into the other pocket and read, “For my sake, the world was created.” *(Striving Toward Virtue: A Contemporary Guide for Jewish Ethical Behavior* Olitzky and Sabath, 35)

Perhaps we oncology chaplains also should carry two pieces of paper in our pockets: one which says, “You can always do this better,” and the other, “You cannot do this wrong.” May we be blessed with open hearts and may God give us strength, wisdom and compassion—both for our patients and ourselves—as we pursue this holy work.