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## Cultural Beliefs and Understanding Cancer

JUDITH BLACK FEATHER

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I would like to begin by sharing with you an excerpt from a poem called "Knots" by R. D. Laing that will express how some feel about our lack of understanding:

There is something I don't know  
that I am supposed to know.  
I don't know what it is I don't know,  
and yet I am supposed to know,  
and feel I look stupid  
if I seem both not to know it  
and not to know what it is I don't know. . .

I feel you know what I am supposed to know  
but you can't tell me what it is  
because you don't know that I don't know what it is.

We must share with each other, which I hope to do this afternoon, in order to enable us to have a better understanding of Native American culture as it relates to the care of cancer patients.

The attitudes and beliefs of Native Americans are as diverse as are the tribes throughout the United States. I have often addressed descriptions of Native Americans based upon modified sociologi-

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cal definitions: traditional, transitional, assimilated, and dualistic. The traditional folks follow their traditional ways and customs. The transitional folks are in the process of accepting the ways of the mainstream culture in which they have relocated. The assimilated folks have become alike or similar to the environment and culture which they have adopted as their new lifestyle. The dualistic folks, which I believe many successful people of ethnicity have found to be most satisfying, live in and adapt to both cultures and consciously adjust to each with flexibility.

Ever since the American Indian Movement and publication of the book *Roots* by Alex Haley, another description has appeared—"Returning"—which describes those who have returned to find their heritage and, for some, a new chosen lifestyle. Cultural adaptation occurs for all who have originally come from different ethnic backgrounds.

There are several ways to compare the European worldview with the Native American worldview, i. e., to compare the psycho-behavioral modalities, the values and customs, and the ethos, or philosophy, of these two populations. Indeed, there are some unique differences between "mainstream" and Native American views. The European or mainstream culture pictures humankind as unique, different, and individual, while Indians view themselves as a part of a group with common stock that encourages sameness, that emphasizes *we*, not *I*. Even today, Indians seldom, if ever, talk about a given individual's success, but they may say that the tribal group has enjoyed success. For example, they will discuss the tourist and industrial development that has occurred on several reservations in Arizona in terms of the tribe rather than in terms of individuals.

The values and customs from the European perspective emphasize competition and independence, while the Indian community strives for interdependence, collective responsibility, and cooperation through a definitive hierarchy. Traditionally, there are, among many tribes, clan systems and class systems, none of which rank one person higher than another, but each has responsibilities or a place in the community structure. In addition, their beliefs are tied to the earth, and they are one with nature, brothers and sisters with all living things, plants and animals, living harmoniously with one another. Interestingly, the ethos of mainstream society has been changing as it reevaluates this concept of ecological balance from an environmental as well as a philosophical perspective.

Now let us look at how these differences in values and beliefs

affect the patient and the family response to a diagnosis of cancer. The diagnosis of terminal cancer continues to challenge persons, because to know that life has become limited is difficult for most. For those who live with long-range plans, this type of diagnosis can really be devastating. Coping becomes essential, and people must redefine what is important in their lives. Some, however, may not be able to accept the seriousness of the situation. They deny the fact that they are dying until their final moments. The process of acceptance is as varied as the grieving process is after the death of a loved one. Others, instead of accepting the diagnosis, lose their ability to cope and their will to live. This does not have to happen. We can choose the way we wish to face each day. Even if very ill, people still have physical and emotional reserves. The problem is deciding whether or not to call upon those reserves to revive the spirit and the will to live.

We are all born with the will to live. Exactly what influence the will has in curing disease—especially cancer—continues to be debated, but there is little argument that a strong desire to live can enhance the patient's quality of life. Those who are determined to live fight harder and sometimes seem to do better.

Many Native American cultures do not stress long-range planning, because, until recently, their life span was considerably shorter than that of non-Indians in mainstream society. As recently as the 1950s, the average life span of Native Americans was less than fifty years; today the average life span has been extended to sixty-plus years. Nevertheless, Native Americans today are still a very young population, with over 50 percent of them under the age of twenty.

Many Native Americans believe that this life with Mother Earth is only a part of the continuum. Thus we are here only as long as there is purpose determined by a greater being or spirit. There is insight or introspection, which enables them to accept life simply for what it is and in terms of their sense of responsibility regarding their roles as men and women. The traditional Native American view of life is one of living each day completely in the present, with industry, solitude, enjoyment of work, rest, and play. In fact, many still live in the present, not in the past or future. This often becomes a concern as physicians and professional health care providers attempt to guide their cancer patients to finalize their wills and make financial plans for families and children. For the parents of youngsters with cancer, the helplessness and frustration are the same that exist for parents in

mainstream society under similar circumstances.

The traditional elders view materialism differently as well. You will recall I mentioned that the concept of living in harmony is as important as being an integrated part of the whole society. The traditional person utilizes whatever is needed while here on earth but gives away to others the “fruits” or materialistic things that he acquires, thus sharing the success that he, his clan, or his community has enjoyed. The ceremonies offered by many tribes which demonstrate this sharing have different names, including *potlatch*, *give away*, and *summer dances*. Many are generous to a fault.

Some of the twenty-five Native American cancer patients and families with whom I spoke during the past year shared with me their experiences of having terminal cancer: A middle-aged man who has grown children and a wife said that when first told he had terminal cancer, he felt right then and there, as the physician was telling him of his diagnosis, that he had died. Another sixty-year-old male felt that he was not given enough assurance that indeed he would die. So he went and obtained literature and books to learn as much as he could about the disease process and how he could aid in his recovery. A twenty-year-old female given the diagnosis felt that she had just had the rug pulled out from under her. She felt cheated, because she had not yet begun to live and to be independent. A forty-one-year-old male with three children and a dependent wife felt that it was a challenge and that he would give it everything he had—he would fight—to survive.

So you can see each reacted differently to the initial diagnosis that they had terminal cancer. A sixty-one-year-old female indicated that she suddenly felt alone and frightened when she learned about the possibility of dying. She returned from the hospital and now has one of her grown siblings staying with her. She never wants to be left alone. As a public health nurse, I have seen a number of terminally ill patients utilize extended and immediate family to enable them to sustain themselves at home. There are, of course, some tribal cultures that do not offer the solace or belief that dying at home is appropriate. For them, death at home brings evil to the environment. However, offering support to those who desire to die at home is the trend today in mainstream society and is for some tribes the traditional way. When I asked those I interviewed about how the grown siblings supported themselves, the patients responded with phrases such as “the rest of the family” and “we do,” meaning the other providers or extended family within the household. The priority of the entire family was

focused upon the needs of the sick, no matter how long the process took. This family support is based upon the cues from the cancer patient. How the cancer patients were treated often appeared to be the result of how they felt about themselves.

Earlier, I mentioned that each person has the option of choosing how they accept or deny their disease. Of those with whom I spoke, none denied their disease; however, it is interesting that in caring for chronically ill diabetics, my nurse colleagues and I have found that many of them do indeed see the disease (diabetes and its serious complications) as not theirs but as an Anglo disease, and thus their compliance to curative maintenance is poor, as they never take ownership of the disease. I remember a time when tuberculosis was also a disease that was not accepted, but, as cures became a norm, Native Americans accepted it and sought treatment.

If the word *cancer* is so final, perhaps the medical world should indeed reassess its classification system in order to enable the lay public and Native Americans to understand what forms of cancer are terminal, the life span possible with each type of cancer, and which cancers may be curable. Of course, the basic preventive screens available must be made clear, realistically accomplishable, and vigorously marketed to achieve improved compliance.

In closing, I would like to share a thought by Octavia Hill entitled "Remember." It expresses what I hope we can do as health professionals as we develop appropriate and useful research in the future.

It is essential to remember that each man has his own view of his life, and must be free to fulfill it; that in many ways he is a far better judge of it than we, as he has lived through and felt what we have only seen.

Our work is rather to bring him to the point of considering, and to the spirit of judging rightly, than to consider or judge for him.

Thank you.