WHOLISTIC HEALING PUBLICATIONS

THE INTERNATIONAL JOURNAL OF HEALING AND CARING
IJHC

WHOLISTIC HEALING
WHP
PUBLICATIONS

WHOLISTIC HEALING
WHR
RESEARCH

September, 2001 **Volume 1, No. 1**

DOCTORING AS A HUMAN EXPERIENCE: ON DEVELOPING A HEALING PARTNERSHIP - Patients' Experiences

Ronald S. Banner, MD

Introduction

Over the last two years I have taken care of a wonderful man named Stanley. Sadly, Stanley became severely ill and his condition progressively deteriorated despite my best efforts to help in every way I could devise. Stanley jokingly said to me that he could write a book with all he has gone through. We both agreed that using some of his experiences would be helpful to other health carers. Through all his physical, emotional and spiritual pain, what shines through - clearer and larger and more beautiful - are his spirit, his soul and his heart.

Stanley was in his mid fifties when I started treating him. He had worked all his life and was dedicated to his employer and trusted by him. He remarried many years ago, was devoted to his wife and nursed her through brain surgery. He was also involved with his boys from the earlier marriage, helped them with their work and was concerned about their personal lives. He was interested in, worried about and grateful to everyone in his life. Most of all, he depended on himself. His life was in his work, his cooking, his caring.

Then the horror began. An ill-defined joint disease required steroid medication. However, when that improved and the steroids were tapered down, he developed partial blindness in one eye. Fortunately, the vision stabilised with a return to high dose steroids. Every time the steroids were tapered he lost more vision. Then he developed clots in his legs, requiring surgery and blood 'thinners'. Several vertebrae collapsed in his spine, producing excruciating back pain. Despite all these problems, he remained stoical. He had to give up working and sold 'his' van. He bought a car for his wife and depended on her for transportation.

Then he suffered a severe pneumonia, leaving his lungs scarred and requiring continuous oxygen. He went home and began to get stronger and was able to resume cooking. Next came another hospitalisation for a blood stream infection. Although that improved, he noticed his legs were numb. Emergency neurological evaluation confirmed that the crushed vertebrae in his back had compressed his spine, paralysing him from the waist down (paraplegia). Surgery was unlikely to relieve the paralysis and also was fraught with life threatening complications.

How do patients live with such severe and debilitating illnesses? How do their families, friends and doctors both help the patients and also cope themselves? Since practitioners' education revolves around their patients, the growing capabilities of practitioners are dependent on learning from their patients. There is more to good medical practice than what appears in books and journals and what consultants add. Some of the most important teachings come from struggles over issues with patients and with medical practitioners' own personal issues.

If I have been fortunate in being exposed to good teachers, consultants and books (on Internal Medicine and other subjects), I have also been blessed with wonderful patients, whom I have tried hard to help and who have helped to teach me. I dedicate this paper to them, and to Stanley, whose terrible struggles and giant spirit will be referred to throughout this article.

Background

This article is based on a presentation I gave for the 13th Anniversary of the Jewish Medical Ethics Study Group of the Albert Einstein Medical Center in Philadelphia. Over those years the study group explored many topics: care of the terminally ill, allocation of scarce health care resources, and AIDS, to cite three examples. For the last two years we discussed spirituality in health care.

A central problem I faced with the talk was how to organise so much material into a coherent whole, and how to discuss a subject of the heart while presenting a lecture of ideas. Indeed, my own pattern is such that in analysing a problem my intellect precedes my emotions. In modifying the lecture for this article, I have inserted Stanley's story, other clinical examples and personal experiences. This approach was recommended by several people, including the editor of this publication, so please do not view my frequent use of personal references as manifestations of lack of humility. Indeed, I hope that reading both the ideas and experiences awaken in you your own reflections and experiences.

A few more points of introduction. Whenever the term doctor is used, we can substitute Health Carer. This is not a 'how to' talk such as one might find in a recent paper by Bryce Templeton in *Philadelphia Medicine* on 'Improving Communication with Patients. Rather it is a sharing of insights, perspectives, attitudes, approaches and understandings from several papers and books.

Before beginning with the front piece written by Lorin L. Stephens, M. D. in David Reiser and David Rosen' *Medicine as a Human Experience*, let me respond in anticipation to those who would say that much of this presentation is from this book. When critics told Johannes Brahms that the theme from the last movement of his first symphony copied Beethoven's 9th, Brahms said, "Any donkey can see that."Here then is Dr Stephen's front piece.

Theme

There are those who will tell you that being a physician is a curse, a life of endless and ambiguous work, where at best we are consumed in a holding action - and all that, without experiencing appropriate appreciation of our sacrifices.

I do not feel that way. Being a physician I consider the highest privilege I can imagine. Along with the joys from my family, my life as a physician has provided me with moments of epiphany, transcendental moments of lucidity. . . To be a physician - to be permitted, to be invited by another human being into his life in the circumstances of that crucible which is illness - to be a trusted participant in the highest of dramas - for these privileges I am grateful beyond my ability to express...

Where to Start

Much of my growth as a physician has come from experiences and material outside the domain of reductionistic internal medicine. As human beings, we try to find meaning in, and be at peace with, life - both as we live our experiences and later as we assimilate and use those experiences as 'teachers'. As physicians, we do this hopefully both for ourselves and also for our patients.

One of these 'teachers' for me have been the films of Akira Kurosawa. For many years I have had in my office a picture which is a single frame from his movie, *Red Beard*. In the picture there is a young girl patient, afraid. An experienced doctor, with kindness and confidence on his face, is giving the patient a spoon of medicine. A young doctor in the

background, watches with interest and amazement, because when he had earlier tried to give the patient the medicine, she had knocked the spoon away. Under the picture are the words, "To look into their hearts as well as their bodies."

In my preparation for the talk, I re-read the book, *The Soul of a Tree,* by the late, world-renowned woodmaker, George Nakashima. This recounts his life and the paths he travelled that eventually led him to his woodworking craft. I became excited with the idea of beginning the talk with the learning-as-we-journey-through-life concept, since I had met Nakashima and especially since he made the desk in my consultation room - a wonderful bridge between my patients and me, rather than a barrier.

So what can we learn from the journeys of an artist of the soul (of a tree)? As a boy, Nakashima enjoyed roaming the mountains of the Pacific Northwest. They had a profound meaning for him, "a sense of viewing creativity at its source. . . struck by nature's many moods" (Nakashima).

His education is also illuminating. In addition to his formal studies as an architect at the University of Washington and M. I. T. , he was deeply shaped by his travels. In talking about Paris of the 1930's and reading of Nietzsche's 'wonderful sense of freedom' Nakashima says, "I no longer felt any particular attachment to technology or the rootless concepts of art popular at the time. . . It was perhaps inevitable that I should become disenchanted with the strictures and limitations of architecture, the profession I had prepared for."He then travelled to Japan, appreciating Japanese houses and trees and looking upon nature with reverence."What seemed necessary to me was to synthesize these traditions with the demands of the contemporary world". He then travelled on to India where, in addition to his architectural duties, he explored and experienced spirituality.

Returning to the United States after the outbreak of World War II, he lived through America's paranoid reaction of placing West Coast Japanese Americans in concentration camps. He moved to the less threatening East Coast, initially to work for someone else, but eventually set up his own workshop in Bucks County, Pennsylvania. It is still there today."Our approach is to realize a synthesis between the hand and the machine. . . Meanwhile, we have created a congenial atmosphere for a combined family and business life. . ."

Nakashima's goals were to make "the wood he had rescued live again in new ways" and to "create an object of utility to man, and, if nature smiles, an object of lasting beauty."[3]

Let us turn from Nakashima's education to medical education.

Medical school teaches mainly about diseases and their treatments, with the implication that the patient is the storehouse of diseases. Thus, the patient as a person - affected by and capable also of influencing his or her disease - is often ignored, or worse. And the doctor is viewed as a disease detective, a storehouse of facts and techniques, a computer to be programmed to be a 'provider' of cost effective treatment. From my own experience, I can recall early in practice my excitement when it seemed that the patient's symptoms might represent an unusual disease. With time, I have identified more with the patients than with their diseases and my hope has changed - to find benign or treatable diseases.

In seeking to understand the doctor and the patient, let us first look at the patient.

How can we better understand the experience of becoming and being a patient?
Stages:When serious symptoms arise, a person goes through a disruptive crisis which forces him or her to deal with becoming a patient. A person goes through three stages in becoming a patient. [2]

1. *Awareness and ambivalence* - This is a dynamic struggle between denying that there may have been a change vs acknowledging the change and craving to know the truth. It is a period of great anxiety but is often mercifully brief.

2. *Disorganisation* - With the diagnosis confirmed, no longer able to deny the change, the patients' sense of omnipotence is shattered. The universal, magical belief that 'it could never happen to me' is destroyed. They ask, 'Why me? 'They may feel overwhelmed and helpless, confused, anxious, and despairing. Patients feel, and often are, isolated from daily connections. Usually this period is also surprisingly brief.

Our treatment here should address the helplessness and isolation.

3. *Reorganisation* has two essential features: first, recognising that one cannot turn back the clock but must go on; and second, accepting the reality of the condition rather than fighting or denying it. The reorganisational phase often does not begin until after hospital discharge, after the cessation of frequent contact between patients and health carers. It is during the reorganisational phase that the patient may regress or grow, depending on many factors. These may include the patient's personality; previous experience with illness and doctors; the meaning of the illness; the support system; the environment; the severity and nature of the disease; and the effectiveness of medical care. [2]

> *In Stanley's case, the severity of his symptoms (loss of vision, extreme shortness of breath and paralysis) decreased the awareness/ambivalence stage but accentuated the disorganisation and reorganisation stages. However, there were times when he returned to the use of denial, even when facing severe symptoms. In contrast, patients with much milder symptoms and with slower onset of illness may spend a longer time in the awareness/ambivalence stage.*

What is the nature of suffering? Eric Cassel studied the relationship of pain and suffering (Cassel). Suffering can include physical pain but it is not limited to it. For instance, patients may writhe in pain from kidney stones yet tell us they are not suffering because they know its cause and that the pain will soon be over. Pain causes suffering if its intensity is overwhelming, its duration is very prolonged or is chronic, if the source of the pain is unknown, if the meaning is dire, or if patients believe it cannot be controlled.

The common threads in all these situations are fear of what pain will do to one's future and fear of an impending destruction to the intactness of one's personhood - as a complex social and psychological entity. Will I still be a *mensch* (person)? Recall how you felt with a bad cold, how you could not think clearly or enjoy reading, friendships, music or food - and that was just a cold.

The term 'mensch' denotes the complex topography of a person. Persons have personality and character, past experiences (medical and non-medical), family connections (ties and genetic predispositions), cultural backgrounds, roles to play, relationships with others, activities they do, regular behaviours, bodies, secret lives, perceived futures, and spiritual/transcendental aspects - all threatened by the perception of illness.[6]

> *In Stanley's case, his back pain was the least bothersome symptom, as severe as this pain was. The fear of not being able to be self-reliant, work and do for others caused much greater suffering.*

How do patients make decisions? Donald Redelmeier, Paul Rozin and Daniel Kahneman describe how intuitive thought processes and feelings often cause patients to make less than optimal medical decisions. Here are two examples. The first demonstrates a common bias in peoples' perception of risk and the second the role emotion plays in decision making.

People perceive risk differently, based on how the information is presented and framed. For example, in talking to people about a study of 100 patients operated on for lung cancer, a person may decide differently based on whether statistics are presented using survival or mortality numbers. Consider how you might respond to hearing survival statistics: "Of the 100 operated, 90 *survived* and 34 were *alive* five years later." Contrast this with your

response to mortality statistics: "Of the 100 people operated, 10 *died* of the operation and 66 died by 5 years."

People are often poor at predicting future feelings. In one experience, students were given one serving of ice cream and asked to predict how they would enjoy the experience after eating it daily for about one week. There was no correlation between their prediction at the outset and the actual change in liking.

Patients fail to anticipate how their feelings will change over time. In another study, one year after one group of people won a large lottery and another group became paraplegic, the quality of life ratings of both groups were fairly similar.[5]

> *Stanley found it difficult to make decisions and relied on me to help him and to do everything possible for his medical problems. As complications continued to develop, he expressed his confidence in my abilities and my conscientiousness, and in the help of all the other doctors (including world experts to whom we referred him). When we came to make the decision to undergo surgery with little chance of helping the paralysis and with great risks, Stanley found it impossible to decide. He asked his family and me to decide for him. We felt we could not do this. However, when he asked me what I would do if I had his problems, I told him I would not risk surgery and cited the long held precept of medical practice: 'First of all, do no harm. '*

Ronald Banner's will continue his discussion on the healing partnership in the next three issues of the *International Journal of Healing and Caring*, with articles on:

The Doctor-Patient Partnership

Caring for the Human Spirit, the Patient's Soul

The Doctor's Soul

References

Cassel, E.J. The nature of suffering and the goals of medicine, *New England J. Medicine* 1982, 306, 639-645.

Nakashima, G. *The Soul of a Tree: A Woodworker's Reflections*, Tokyo: Kodansha Int. Ltd. 1981.

Redelmeier, D.A., Rozin, P. and Kahneman, D. Understanding patients' decisions, *J. American Medical Association* 1993, 270, 72-76.

Reiser, D. E. and Rosen, D. H. *Medicine as a Human Experience*, Rockville, MD: Aspen Systems Corp 1985.

Reiser, S. J. The era of the patient. Using the experience of illness in shaping the missions of health care, *J. American Medical Association* 1993, 269, 1012-1018.

Templeton, B. Improving communication with patients, Philadelphia Medicine 1993, 89, 347-351.

Ronald S. Banner, MD practices Internal Medicine in Northeast Philadelphia and is Chairman Emeritus of the Medical Ethics Committee at the Albert Einstein Medical Center.
Contact:
2050 Welsh Road
Philadelphia, PA 19115