THE JOHN STANLEY COULTER LECTURE

The Power of Compassion and Caring in Rehabilitation Healing

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Rehabilitation of persons with catastrophic illnesses or injuries is a complex, labor-intensive interaction between patients and caregivers. Experiences of overwhelming loss and suffering evoke strong emotions that shape the behavior of both patients and staff during the rehabilitation process. In response to each patient’s unique experience, compassion, caring, and other humanistic qualities of the effective caregiver help create a healing environment. Although these qualities are universally accepted as important, they have not been widely studied or critiqued, patient hatred of staff, and staff hatred of patients and their families.

First, I want to explain what I mean by compassion and caring. Webster’s dictionary defines compassion as “to feel sorrow for the sufferings of others accompanied by an urge to help.” As for the term caring, it is defined as “being responsible for, looking after, providing for.” It is worth noting that both words convey the twin concepts of feeling and action that I think are essential to promoting a healing environment. However, these definitions do not capture everything conveyed by compassion and caring in settings in which I have worked.

Six years later, a second discussion on this topic appeared by Larry Mullins, a psychologist at the University of Oklahoma, this one entitled, “Hate Revisited: Power, Envy, and Greed in the Rehabilitation Setting.”6” Now there were 2 articles on hate I knew of on more positive emotions to provide some balance. With this in mind, I pulled out a folder and labeled it “Compassion and Caring in the Rehabilitation Setting.” Over the past decade, I have added articles and clippings to the folder with the idea that someday I would write an article or give a talk on this topic—and I believe Stanley Coulter would be pleased to know that the lecture in his honor has made that “someday” finally arrive.

It is not my intention to minimize the importance of hate, anger, and envy in settings where we work with individuals who have sustained major trauma and life-changing losses. Rather, I would like to focus on some of the complementary qualities I believe play a much larger role in the rehabilitation experience—qualities such as caring, compassion, and empathy, which enhance life and create a healing environment.

I am April 1983, Jerome Gans, a physician at Braintree Hospital in Massachusetts, published an article “Hate in the Rehabilitation Setting.”1 Gans’s thesis was that hate is an intrinsic part of the rehabilitation process and has been overlooked as a clinical issue in most rehabilitation hospitals. Common manifestations, he believed, include patient self-hatred, patient hatred of staff, and staff hatred of patients and their families.

These may sound like harsh words, however, I believe Gans was right. In my own experience, hate is not something I have ever heard discussed in the hospitals where I have worked. Anger maybe. Dislike definitely. But hate? No! Yet I knew it was there and Gans’s article struck a responsive chord.

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First, I want to explain what I mean by compassion and caring. Webster’s dictionary defines compassion as “to feel sorrow for the sufferings of others accompanied by an urge to help.” As for the term caring, it is defined as “being responsible for, looking after, providing for.” It is worth noting that both words convey the twin concepts of feeling and action that I think are essential to promoting a healing environment. However, these definitions do not capture everything conveyed by compassion and caring in settings in which I have worked. Rather, these words encompass all the countless, unnamed acts of providing comfort and therapy by nurses and occupational therapists, as well as acts of teaching and nurturing by speech and recreational therapists and by the whole array of service personnel and professionals—either individually or collaboratively as a team, scripted or spontaneous. These acts and words of kindness, empathy, and understanding are part of the person-intensive, complex interaction between patient and caregiver, between someone who feels that his body is broken and invalid and someone whose job is to respond to those feelings and relieve the suffering, to mend and heal, to make whole. This is what all of us try to do, each in our own imperfect way—professional to person, person to human. This and much more is what I mean by compassion and caring.

With this introduction, I now outline a conceptual model that provides a framework to discuss rehabilitation healing. This framework is expressed in terms of scientific and humanistic health care (table 1).

SCIENTIFIC AND HUMANISTIC HEALTH CARE

Scientific health care refers to the rapidly expanding and often dazzling body of objective and reproducible knowledge developed by using the scientific method. It is empirical, rational, and quantitative, and it comprises the enormous repository of information contained in the basic sciences, along with the skills that are required to apply that information in a clinical setting to diagnose, cure, and prevent pathologic conditions. Historically, scientific health care has come into its own during the past century and today is the dominant force in American medicine.

Humanistic health care, by contrast, refers to the broad accumulation of human experience and knowledge that has evolved over the centuries in each culture and in the life events
of each individual. It is subjective, intuitive, and empathetic, and it encompasses all of the skills of personal interaction and caring that have characterized the best tradition of healers in all societies and ages. For most of recorded history, humanistic health care was the dominant force in medicine, that is until the latter part of the 19th century. Since then, it has slowly and steadily given way to scientific medicine until now when most health care is perceived as largely scientific. In a sense, the pendulum has swung from extreme to extreme.

These 2 approaches to health care were described in an earlier publication and are compared in table 1 for 10 variables. These variables are divided into 3 groups using the conceptual framework proposed by Donabedian: structure, process, and outcome. To illustrate what I mean by the terms scientific and humanistic health care, let us consider 2 examples. The first is the process variable “Problem orientation.” The general orientation of scientific health care is toward disease, whereas humanistic health care is toward illness. Disease is defined as the interaction of a pathologic process with individual molecules, cells, and organs. It is essentially a biologic event. Illness, on the other hand, is essentially a human event. It represents the resulting interaction of a person with a disease.

The second example is the outcome variable “Objectives.” Scientific health care is generally concerned with curing disease and enhancing physiologic function, whereas humanistic health care is focused on healing the person and enhancing functional performance. Curing is defined as removing or reversing a disease process, whereas healing is defined as decreasing discomfort and enhancing a sense of physical and psychologic well-being. For both patient and staff, healing is more active, whereas curing is more passive. Healing does not exclude curing but extends beyond it to include caring.

It is important to stress that nothing I have said implies a value judgment. In fact, both the scientific and humanistic components in medicine are essential for good health care and both are necessary in a system that acknowledges the strengths and limitations of each. Although professionals in any specialty can practice a blend of humanistic and scientific medicine, rehabilitation as a field is uniquely suited to achieving this balance. From its inception, the philosophy of rehabilitation has been strongly oriented toward the humanistic approach while developing an ever-expanding scientific and research base.

**HUMANISM IN REHABILITATION MEDICINE**

With this model in mind, I turn to a discussion of the humanistic qualities I believe are an intrinsic part of rehabilitation healing—qualities that emerge from the kind of catastrophic patient problems we often deal with and the range of responses they evoke from caregivers, both emotional and behavioral.

Table 2 outlines 3 aspects of the healing process that can occur in an acute rehabilitation setting: what happens to patients, what patients experience and feel, and what caregivers feel and do. Under the column “What Happens to the Patient,” I list 4 potential responses to a devastating illness or injury. Starting with physical and psychologic loss, there is sometimes a loss of 1 or more limbs, as with a man who is a quadruple amputee. Sometimes there are losses that are not physical but you know are there, as in the young man with tetraplegia who is unable to stand and walk or stop the flow of his urine.

What do these patients experience and feel? To begin with, there is a significant alteration in body image, in one’s sense of self. Our physical body determines so much of who we are, the way it looks and feels and works without our giving it the slightest thought, especially when young. Then all of that is transformed in an instant—say, an auto crash, a fall, a fire occurs and we are changed forever. Self-esteem plummets and for a time we may feel worthless and broken beyond repair.

What do the caregivers feel and do? Fortunately, what we do (ie, what nurses, nurse technicians, aides, and therapists do, for they provide most of the acute rehabilitation care) is fairly well proscribed. We turn the patients, give them food and slake their thirst, exercise their limbs, and wash their feet. All this is at 1 level. At another level, we tend to a wounded human, a person whose feelings of self-worth are shattered. By tending to these wounds, the caregiver comes to know a sense of her own loss, her own grief, her own sorrow.

It is this knowing, this understanding, that empowers and leads to the thousands of undocumented, selfless acts of caring and compassion. From experience, caregivers know where the hurt places are; they can ask questions without prying because they know what the patient’s concerns are. From experience, they know that, in time, healing will occur. By their confidence and acceptance, they validate the person inside the broken body. This is the caregiver as witness who allows the patient to say, “If you can accept me in all the ways that I am wounded, then maybe, just maybe, I can accept myself.”

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**Table 1: Comparison of Scientific and Humanistic Medicine for Selected Health Care Elements**

<table>
<thead>
<tr>
<th>Health Care Elements</th>
<th>Scientific Medicine</th>
<th>Humanistic Medicine</th>
</tr>
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<tbody>
<tr>
<td><strong>Structure</strong></td>
<td></td>
<td></td>
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<tr>
<td>1. Physical setting</td>
<td>Impersonal</td>
<td>Personal</td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Problem orientation</td>
<td>Disease</td>
<td>Illness</td>
</tr>
<tr>
<td>3. Physician’s role</td>
<td>Doer, Knower</td>
<td>Teacher, Learner</td>
</tr>
<tr>
<td>4. Patient’s role</td>
<td>Passive</td>
<td>Active</td>
</tr>
<tr>
<td>5. Care orientation</td>
<td>Physician (staff)-oriented</td>
<td>Patient-oriented</td>
</tr>
<tr>
<td>6. Physician’s relation to patient</td>
<td>Reserved</td>
<td>Empathetic</td>
</tr>
<tr>
<td>7. Physician’s relation to health team</td>
<td>Dominant</td>
<td>Facilitative</td>
</tr>
<tr>
<td>8. Physician’s relation to colleagues</td>
<td>Competitive</td>
<td>Collaborative</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Therapeutic approach</td>
<td>Treatment of disease</td>
<td>Management of illness</td>
</tr>
<tr>
<td>10. Objectives</td>
<td>Curing</td>
<td>Healing</td>
</tr>
<tr>
<td></td>
<td>Enhancing physiological function</td>
<td>Enhancing functional performance</td>
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* Adapted from Halstead and Halstead.3
What else happens to the patient? As outlined in table 2, there is pain—both physical and psychologic—that is almost palpable in a little girl who has lost both arms because she shocked a high-tension wire. For most of us, comprehending her sense of physical loss and devastating change in body image is impossible. If that comprehension is beyond our reach, how can we understand her emotional pain, her feelings of isolation and despair, which one imagines is without measure? Although this girl’s loss is not typical of what we deal with in most acute rehabilitation settings, it would still be difficult to say whose grief is greater, whose suffering runs deeper. Consider a 26-year-old tetraplegic father of 3 who has been hit by a drunk driver. He has his arms but cannot tie the bow in his daughter’s hair. He has his legs but cannot move his toes. There is no convenient scale of grief, no way, in Reynolds Price’s phrase, to measure “the bottomless mystery of suffering.” All of us feel that we have suffered in 1 way or another. And have there not been times when you felt your suffering was the worst of all?

How does the caregiver respond to this kind of pain? It is hard to answer such a question. There are no studies that address this issue, only anecdotes and personal experience. Surely there are moments, however fleeting, when we are overwhelmed by powerful emotions such as hate, frustration, and bitterness—emotions that are often viewed as negative but are part of a defense that allows us to cope with our own fears, our own black nights, our own mortality. For an instant, we are in that bed, reclined in that wheelchair with Tilt-in-Space technology. I would contend that the best caregivers among us experience at some level, even if only subconsciously, the other person’s grief. And when this happens, there is the potential for our compassion to rise to the level of the other person’s suffering.

By the nature of what takes place in an acute rehabilitation environment, day in and day out, from morning to night, it is inevitable that the physical isolation is diminished. Patients have a schedule to follow. They have to get up and get dressed. They have to move from their hospital rooms to the therapy areas. Rehabilitation is a physical process. There is a lot of touching and body contact. As a society, we do not indulge in hugs very often, but there is power in the hug from a parent, a spouse, or a friend. When a nurse helps someone sit up in a wheelchair or a therapist massages someone’s back, all that touching is a kind of hug. There is a tactile warmth, a feeling of the caregiver’s energy as her hands work the patient’s body. There is a person-to-person contact that momentarily, at least, breaks through the isolation and transfers energy from one to the other.

I know I felt this when I was recovering from polio years ago, and a nurse would wash my face or a therapist massage and stretch my legs. This kind of touching does not happen just once, but countless times throughout the day. When you think of the professionals on the rehabilitation team—many of whom are young and healthy and vibrant with energy, with a can-do, optimistic attitude and no shortage of smiles—is it any wonder that patients often come back from therapy with a smile and say they feel better?

In addition to the touching and body contact, caregivers do a lot of listening. They listen to the grief and anguish and confusion, listen to all the voices that cry out from the dark night of the soul. Sometimes caregivers listen withoutresponding, knowing that just talking can be therapeutic, and just listening is a way of affirming that what a patient is feeling is understandable, normal, natural. The patient can ask the same questions, have the same doubts, tell her story a hundred times, and spread out her grief in a thousand ways. She will talk to everyone on her team and others as well, professionals with social work and doctoral degrees, or the people who bring the food and clean the toilets, or other patients and their families. They are all part of the healing community and each contact has the potential for a therapeutic lift: old people, young people, and people of the same or different ethnic group or socioeconomic class. It is an extraordinary mix and all part of the power and magic of rehabilitation healing. Is it any wonder that it is hard to study and prove how it works or that it works at all?

What else does the patient experience? For many persons with severe neurotrauma, there is a loss of autonomy and a dramatic, unimaginined increase in physical dependence on others. Suddenly, one is unable to bring food to the mouth, cleanse the loins, avoid soiling the sheets. The patient often feels infantilized. During the period of acute recovery, many social roles in the family, at work, and in the community are lost or changed. The past takes on a disproportionately large part of one’s life, as if to say, “That’s who I once was. That was what I could do. That was the real me.” Then a patient shows you pictures of when he was in a football uniform or a wedding tuxedo or on graduation day: all smiles when health was a never-ending sunny day. Now that future, those dreams are uncertain—possibly gone forever.
IS THERE A SCIENTIFIC BASIS FOR REHABILITATION HEALING?

I began with a discussion of the scientific-humanistic model of health care and how in the rehabilitation setting the humanistic interactions between patients and caregivers help create a healing environment. Now I return to the scientific-humanistic paradigm and address a question that is especially relevant to rehabilitation professionals: Is there a scientific basis for some of the humanistic elements of rehabilitation healing? A review of the literature over the past 25 years reveals many anecdotes and philosophic discussions. Only in recent years has there been a serious attempt to use scientific methods to explore humanistic elements or what is now being called complementary and alternative medicine. It is outside my scope to review this new field, but I have summarized 7 articles (table 3) that illustrate research-based interventions with potential for enhancing outcomes in traditional rehabilitation populations. These studies cover a broad spectrum of diagnoses and therapies, but provide only a glimpse into what might be applied to our clients. The studies range from fairly traditional research interventions to the “outer edge of the envelope” of alternative medicine.

The first article describes a study conducted by Halstead et al.13 that was in the mid-1980s. Our goal was to look at the behavioral impact on individuals with spinal cord injury (SCI) and team members of a team conference format that deliberately made the conference client-centered. Rather than the traditional medical model, with the subject lying passively and team members standing at the bedside talking primarily to each other, we had the participant dressed, sitting at the table, and actively engaged as a member of the team.

One team and 2 control teams experienced this intervention for 18 months. Baseline recordings were made before the study and then during and after the intervention. Blinded evaluators scored verbatim transcripts of all conferences and a Group Environmental Scale (GES) was used to assess clients’ and team members’ subjective feelings about different aspects of the team conference experience. There was increased participation by individuals with SCI and decreased participation and domination of the agenda by the staff during team conferences. There was significant improvement in GES ratings and increased satisfaction by the clients and staff with team conferences compared with the control groups.

In response to the question, “What does this have to do with compassion and caring?” I would answer that team conferences are at the heart of an inpatient rehabilitation program. It is the only time each week when the team gets together with the client to review progress, problems, and goals. By making the conference deliberately client-centered and client-focused, this group of 6, 8, or 10 professionals communicates collectively and individually its concerns for how that individual is doing. For the duration of that conference, the group’s time, energy, and expertise is focused on nothing else but that person—his
concerns, her complaints, her progress. It is an example of team caring and can be a powerful experience that reinforces other caring activities throughout the week.

The second study was conducted by Ozer et al., who implemented a health promotion program for stroke victims during comprehensive rehabilitation. The intervention consisted of education regarding risk factors and risk-factor modification among persons with stroke and their families to help prevent a second stroke. The results for a group of 105 individuals at the time of follow-up showed that between 78% and 90% knew what their blood pressure, cholesterol, and medication goals were. The unspoken message was that of staff caring and personal empowerment: we care enough about you and your health that we want you to know how to change your behaviors so you can reduce the risk of more disability or even death.

The third article by Kjendahl et al. reviews the effects of acupuncture in a group of individuals with subacute stroke in a traditional rehabilitation setting. Patients were randomized into treatment and control groups, and acupuncture was performed according to the schedule described in table 3. Follow-up of the treatment group at 1 year revealed a significant improvement in activities of daily living (ADLs) and motor and quality of life (QOL) scores compared with the control group.

The next 3 studies (articles 4–6) offer 3 preliminary reports of outpatients using interventions that, depending on your perspective, nudge the envelope farther. For example, massage therapy was provided in a research project to individuals with juvenile rheumatoid arthritis. Twenty children were randomly assigned to receive either massage or relaxation therapies for 30 days. The results showed a significant decrease in pain, anxiety, and cortisol levels in the massage group compared with the control subjects. The other 2 investigations assessed the effect of group therapy in 86 women with metastatic breast cancer and transcendental meditation in 21 individuals with coronary artery disease. Despite limitations of sample size, duration of treatment, and other factors, the research designs in all 3 studies used traditional scientific methodologies to assess the effectiveness of each intervention. As summarized in table 3, the results showed positive outcomes for all treatment groups. Although each study is provocative in its own way, the serendipitous finding in the breast cancer report (discovered retrospectively) is simultaneously breathtaking and humbling. Women randomly assigned to weekly support groups for 1 year survived, on average, twice as long as members of the control group 10 years postintervention. Although none of the 3 studies was in a rehabilitation setting, I do not believe it requires undue optimism to foresee researchers using any or all of these modalities in groups of traditional rehabilitation patients, or for that matter, even among staff members to help them cope with stress and the daily challenges of providing compassionate rehabilitation care.

If you believe massage therapy, support groups, and transcendental meditation are esoteric, the seventh article in table 3 may give pause. This topic concerns what is known as distant healing, which in effect is prayer. In this study, ministers and other religious persons offered up prayer without the individual’s knowledge in a double-blind, randomized group of 40 patients with acquired immune deficiency syndrome (AIDS) over 6 months. The results showed that the treatment group had fewer AIDS complications, that complications were less severe, that there was less fever, and that there were fewer doctor visits and hospitalizations.

In addition to this study, there have been numerous other studies that have looked at the effects of distant healing. A critical review of this literature published in 2000 in the Annals of Internal Medicine evaluated 23 studies that met strict scientific criteria. Of these, 57% showed a positive treatment effect.

Whatever one may think about these studies and distant healing, my own view is that we all have a spiritual self and a spiritual life, regardless of our affiliation with organized religion, and that we do not pay enough attention to this aspect of our patients when they are going through the worst crisis of their lives.
RESEARCH CHALLENGES

I have already discussed several research challenges for the future. I would like to add a few more along with some general observations and recommendations.

First, we need to find ways to increase our involvement with each patient in terms of the life of the spirit. One concrete way would be to include a chaplain or spiritual adviser on a regular basis in team conferences. Although it does not always happen, this is now a requirement of the Joint Commission on Accreditation of Healthcare Organizations.

Second, recently Schwam21 described the phenomenon of compassion fatigue among the nursing staff of an intensive care unit. I have not addressed this problem, but my guess is that “compassion fatigue” is a common phenomenon in rehabilitation settings, too, particularly among nurses and nurses’ aides. We should pay more attention to this phenomenon, learn how to recognize it, and how to develop strategies to prevent and treat it.

Many hospitals have chapels for patients and staff. A recent informal survey at National Rehabilitation Hospital found that 8 of 10 personnel did not know whether there was a chapel on the premises or where it was located. Few had used it. Most also believed that the chapel was reserved exclusively for patients and their families. I doubt these are unique findings. With this in mind, I believe we should develop programs to encourage the staff to use this resource more frequently for meditation, prayer, or just quiet time. In addition to coffee breaks, hospital administrations could promote “meditation breaks.” Another recommendation is to set aside space as a staff “recovery” room. This would be a place where personnel could lie down for a few minutes, listen to quiet music, and perhaps get a massage from other staff on a volunteer basis.

Third, we need to increase research efforts into the application of complementary and alternative health care in various rehabilitation settings. Specifically, we need to identify what types of alternative therapies are effective and for what kind of problems.22-26 It is encouraging that there are currently a number of institutes or centers of complimentary and alternative medicine connected with traditional departments of physical medicine and rehabilitation. This new area appears already to be evolving as a subspecialty within our field and perhaps could be the topic of workshops, instructional courses, or even the theme of an entire conference. In October 1999, a 2-day conference on complementary and alternative medicine in rehabilitation was sponsored by Spaulding Hospital and Harvard Medical School in Boston.

CONCLUSIONS

In our urgent desire to prove to ourselves and to third-party payers that rehabilitation works and is a good investment, I have no concern that the scientific side of rehabilitation will not continue to prosper and grow. But I am worried about the humanistic side. No health maintenance organization I know of has ever called to complain that its patients were not getting enough humanistic care. One way to ensure that they do is to place a higher priority on research studies that use some of the treatments discussed here. It is a curious irony that in this age of scientific medicine there is now a movement, however small, to use scientific methods to show that humanistic treatments may improve outcomes. Perhaps this will be the next frontier for rehabilitation medicine. In closing, I would like to respond to Gans and his 1983 article by saying that yes, there is hate in rehabilitation settings, but there is also an abundance of compassion, caring, and—dare I say it—even love.

References


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