

SPECIAL ARTICLE

THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE

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Abstract The question of suffering and its relation to organic illness has rarely been addressed in the medical literature. This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological enti-

THE obligation of physicians to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research, or practice. I will begin by focusing on a modern paradox: Even in the best settings and with the best physicians, it is not uncommon for suffering to occur not only during the course of a disease but also as a result of its treatment. To understand this paradox and its resolution requires an understanding of what suffering is and how it relates to medical care.

Consider this case: A 35-year-old sculptor with metastatic disease of the breast was treated by competent physicians employing advanced knowledge and technology and acting out of kindness and true concern. At every stage, the treatment as well as the disease was a source of suffering to her. She was uncertain and frightened about her future, but she could get little information from her physicians, and what she was told was not always the truth. She had been unaware, for example, that the irradiated breast would be so disfigured. After an oophorectomy and a regimen of medications, she became hirsute, obese, and devoid of libido. With tumor in the supraclavicular fossa, she lost strength in the hand that she had used in sculpturing, and she became profoundly de-

ty. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself. (N. Engl J Med. 1982; 306:639-45.)

pressed. She had a pathologic fracture of the femur, and treatment was delayed while her physicians openly disagreed about pinning her hip.

Each time her disease responded to therapy and her hope was rekindled, a new manifestation would appear. Thus, when a new course of chemotherapy was started, she was torn between a desire to live and the fear that allowing hope to emerge again would merely expose her to misery if the treatment failed. The nausea and vomiting from the chemotherapy were distressing, but no more so than the anticipation of hair loss. She feared the future. Each tomorrow was seen as heralding increased sickness, pain, or disability, never as the beginning of better times. She felt isolated because she was no longer like other people and could not do what other people did. She feared that her friends would stop visiting her. She was sure that she would die.

This young woman had severe pain and other physical symptoms that caused her suffering. But she also suffered from some threats that were social and from others that were personal and private. She suffered from the effects of the disease and its treatment on her appearance and abilities. She also suffered unremittingly from her perception of the future.

What can this case tell us about the ends of medicine and the relief of suffering? Three facts stand out. The first is that this woman's suffering was not confined to her physical symptoms. The second is that she suffered not only from her disease but also from its treatment. The third is that one could not anticipate what she would describe as a source of suffering; like

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other patients, she had to be asked. Some features of her condition she would call painful, upsetting, uncomfortable, and distressing, but not a source of suffering. In these characteristics her case was ordinary.

In discussing the matter of suffering with lay persons, I learned that they were shocked to discover that the problem of suffering was not directly addressed in medical education. My colleagues of a contemplative nature were surprised at how little they knew of the problem and how little thought they had given it, whereas medical students tended to be unsure of the relevance of the issue to their work.

The relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession. As in the care of the dying, patients and their friends and families do not make a distinction between physical and nonphysical sources of suffering in the same way that doctors do.¹

A search of the medical and social-science literature did not help me in understanding what suffering is; the word "suffering" was most often coupled with the word "pain," as in "pain and suffering." (The data bases used were *Psychological Abstracts*, the *Citation Index*, and the *Index Medicus*.)

This phenomenon reflects a historically constrained and currently inadequate view of the ends of medicine. Medicine's traditional concern primarily for the body and for physical disease is well known, as are the widespread effects of the mind-body dichotomy on medical theory and practice. I believe that this dichotomy itself is a source of the paradoxical situation in which doctors cause suffering in their care of the sick. Today, as ideas about the separation of mind and body are called into question, physicians are concerning themselves with new aspects of the human condition. The profession of medicine is being pushed and pulled into new areas, both by its technology and by the demands of its patients. Attempting to understand what suffering is and how physicians might truly be devoted to its relief will require that medicine and its critics overcome the dichotomy between mind and body and the associated dichotomies between subjective and objective and between person and object.

In the remainder of this paper I am going to make three points. The first is that suffering is experienced by persons. In the separation between mind and body, the concept of the person, or personhood, has been associated with that of mind, spirit, and the subjective. However, as I will show, a person is not merely mind, merely spiritual, or only subjectively knowable. Personhood has many facets, and it is ignorance of them that actively contributes to patients' suffering. The understanding of the place of the person in human illness requires a rejection of the historical dualism of mind and body.

The second point derives from my interpretation of clinical observations: Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or

until the integrity of the person can be restored in some other manner. It follows, then, that although suffering often occurs in the presence of acute pain, shortness of breath, or other bodily symptoms, suffering extends beyond the physical. Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person.

The third point is that suffering can occur in relation to any aspect of the person, whether it is in the realm of social roles, group identification, the relation with self, body, or family, or the relation with a transpersonal, transcendent source of meaning. Below is a simplified description or "topology" of the constituents of personhood.

"PERSON" IS NOT "MIND"

The split between mind and body that has so deeply influenced our approach to medical care was proposed by Descartes to resolve certain philosophical issues. Moreover, Cartesian dualism made it possible for science to escape the control of the church by assigning the noncorporeal, spiritual realm to the church, leaving the physical world as the domain of science. In that religious age, "person," synonymous with "mind," was necessarily off limits to science.

Changes in the meaning of concepts like that of personhood occur with changes in society, while the word for the concept remains the same. This fact tends to obscure the depth of the transformations that have occurred between the 17th century and today. People simply *are* "persons" in this time, as in past times, and they have difficulty imagining that the term described something quite different in an earlier period when the concept was more constrained.

If the mind-body dichotomy results in assigning the body to medicine, and the person is not in that category, then the only remaining place for the person is in the category of mind. Where the mind is problematic (not identifiable in objective terms), its very reality diminishes for science, and so, too, does that of the person. Therefore, so long as the mind-body dichotomy is accepted, suffering is either subjective and thus not truly "real" — not within medicine's domain — or identified exclusively with bodily pain. Not only is such an identification misleading and distorting, for it depersonalizes the sick patient, but it is itself a source of suffering. It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person. An anachronistic division of the human condition into what is medical (having to do with the body) and what is nonmedical (the remainder) has given medicine too narrow a notion of its calling. Because of this division, physicians may, in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer.

AN IMPENDING DESTRUCTION OF PERSON

Suffering is ultimately a personal matter. Patients sometimes report suffering when one does not expect it, or do not report suffering when one does expect it.

Furthermore, a person can suffer enormously at the distress of another, especially a loved one.

In some theologies, suffering has been seen as bringing one closer to God. This "function" of suffering is at once its glorification and its relief. If, through great pain or deprivation, someone is brought closer to a cherished goal, that person may have no sense of having suffered but may instead feel enormous triumph. To an observer, however, only the deprivation may be apparent. This cautionary note is important because people are often said to have suffered greatly, in a religious context, when they are known only to have been injured, tortured, or in pain, not to have suffered.

Although pain and suffering are closely identified in the medical literature, they are phenomenologically distinct.² The difficulty of understanding pain and the problems of physicians in providing adequate relief of physical pain are well known.^{3,4}

The greater the pain, the more it is believed to cause suffering. However, some pain, like that of childbirth, can be extremely severe and yet considered rewarding. The perceived meaning of pain influences the amount of medication that will be required to control it. For example, a patient reported that when she believed the pain in her leg was sciatica, she could control it with small doses of codeine, but when she discovered that it was due to the spread of malignant disease, much greater amounts of medication were required for relief. Patients can writhe in pain from kidney stones and by their own admission not be suffering, because they "know what it is"; they may also report considerable suffering from apparently minor discomfort when they do not know its source. Suffering in close relation to the intensity of pain is reported when the pain is virtually overwhelming, such as that associated with a dissecting aortic aneurysm. Suffering is also reported when the patient does not believe that the pain can be controlled. The suffering of patients with terminal cancer can often be relieved by demonstrating that their pain truly can be controlled; they will then often tolerate the same pain without any medication, preferring the pain to the side effects of their analgesics. Another type of pain that can be a source of suffering is pain that is not overwhelming but continues for a very long time.

In summary, people in pain frequently report suffering from the pain when they feel out of control; when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic.

In all these situations, persons perceive pain as a threat to their continued existence — not merely to their lives, but to their integrity as persons. That this is the relation of pain to suffering is strongly suggested by the fact that suffering can be relieved, in the presence of continued pain, by making the source of the pain known, changing its meaning, and demonstrating that it can be controlled and that an end is in sight.

It follows, then, that suffering has a temporal element. In order for a situation to be a source of suffering, it must influence the person's perception of future events. ("If the pain continues like this, I *will* be overwhelmed"; "If the pain comes from cancer, I *will* die"; "If the pain cannot be controlled, I *will not* be able to take it.") At the moment when the patient is saying, "If the pain continues like this, I will be overwhelmed," he or she is not overwhelmed. Fear itself always involves the future. In the case with which I opened this paper, the patient could not give up her fears of her sense of future, despite the agony they caused her. As suffering is discussed in the other dimensions of personhood, note how it would not exist if the future were not a major concern.

Two other aspects of the relation between pain and suffering should be mentioned. Suffering can occur when physicians do not validate the patient's pain. In the absence of disease, physicians may suggest that the pain is "psychological" (in the sense of not being real) or that the patient is "faking." Similarly, patients with chronic pain may believe after a time that they can no longer talk to others about their distress. In the former case the person is caused to distrust his or her perceptions of reality, and in both instances social isolation adds to the person's suffering.

Another aspect essential to an understanding of the suffering of sick persons is the relation of meaning to the way in which illness is experienced. The word "meaning" is used here in two senses. In the first, to mean is to signify, to imply. Pain in the chest may imply heart disease. We also say that we know what something means when we know how important it is. The importance of things is always personal and individual, even though meaning in this sense may be shared by others or by society as a whole. What something signifies and how important it is relative to the whole array of a person's concerns contribute to its personal meaning. "Belief" is another word for that aspect of meaning concerned with implications, and "value" concerns the degree of importance to a particular person.

The personal meaning of things does not consist exclusively of values and beliefs that are held intellectually; it includes other dimensions. For the same word, a person may simultaneously have a cognitive meaning, an affective or emotional meaning, a bodily meaning, and a transcendent or spiritual meaning. And there may be contradictions in the different levels of meaning. The nuances of personal meaning are complex, and when I speak of personal meanings I am implying this complexity in all its depth — known and unknown. Personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking it into account.

A SIMPLIFIED DESCRIPTION OF THE PERSON

A simple topology of a person may be useful in understanding the relation between suffering and the goals of medicine. The features discussed below point

the way to further study and to the possibility of specific action by individual physicians.

Persons have personality and character. Personality traits appear within the first few weeks of life and are remarkably durable over time. Some personalities handle some illnesses better than others. Individual persons vary in character as well. During the heyday of psychoanalysis in the 1950s, all behavior was attributed to unconscious determinants: No one was bad or good; they were merely sick or well. Fortunately, that simplistic view of human character is now out of favor. Some people do in fact have stronger characters and bear adversity better. Some are good and kind under the stress of terminal illness, whereas others become mean and offensive when even mildly ill.

A person has a past. The experiences gathered during one's life are a part of today as well as yesterday. Memory exists in the nostrils and the hands, not only in the mind. A fragrance drifts by, and a memory is evoked. My feet have not forgotten how to roller-skate, and my hands remember skills that I was hardly aware I had learned. When these past experiences involve sickness and medical care, they can influence present illness and medical care. They stimulate fear, confidence, physical symptoms, and anguish. It damages people to rob them of their past and deny their memories, or to mock their fears and worries. A person without a past is incomplete.

Life experiences — previous illness, experiences with doctors, hospitals, and medications, deformities and disabilities, pleasures and successes, miseries and failures — all form the nexus for illness. The personal meaning of the disease and its treatment arises from the past as well as the present. If cancer occurs in a patient with self-confidence from past achievements, it may give rise to optimism and a resurgence of strength. Even if it is fatal, the disease may not produce the destruction of the person but, rather, reaffirm his or her indomitability. The outcome would be different in a person for whom life had been a series of failures.

The intensity of ties to the family cannot be over-emphasized; people frequently behave as though they were physical extensions of their parents. Events that might cause suffering in others may be borne without complaint by someone who believes that the disease is part of his or her family identity and hence inevitable. Even diseases for which no heritable basis is known may be borne easily by a person because others in the family have been similarly afflicted. Just as the person's past experiences give meaning to present events, so do the past experiences of his or her family. Those meanings are part of the person.

A person has a cultural background. Just as a person is part of a culture and a society, these elements are part of the person. Culture defines what is meant by masculinity or femininity, what attire is acceptable, attitudes toward the dying and sick, mating behavior, the height of chairs and steps, degrees of tol-

erance for odors and excreta, and how the aged and the disabled are treated. Cultural definitions have an enormous impact on the sick and can be a source of untold suffering. They influence the behavior of others toward the sick person and that of the sick toward themselves. Cultural norms and social rules regulate whether someone can be among others or will be isolated, whether the sick will be considered foul or acceptable, and whether they are to be pitied or censured.

Returning to the sculptor described earlier, we know why that young woman suffered. She was housebound and bedbound, her face was changed by steroids, she was masculinized by her treatment, one breast was scarred, and she had almost no hair. The degree of importance attached to these losses — that aspect of their personal meaning — is determined to a great degree by cultural priorities.

With this in mind, we can also realize how much someone devoid of physical pain, even devoid of "symptoms," may suffer. People suffer from what they have lost of themselves in relation to the world of objects, events, and relationships. We realize, too, that although medical care can reduce the impact of sickness, inattentive care can increase the disruption caused by illness.

A person has roles. I am a husband, a father, a physician, a teacher, a brother, an orphaned son, and an uncle. People are their roles, and each role has rules. Together, the rules that guide the performance of roles make up a complex set of entitlements and limitations of responsibility and privilege. By middle age, the roles may be so firmly set that disease can lead to the virtual destruction of a person by making the performance of his or her roles impossible. Whether the patient is a doctor who cannot doctor or a mother who cannot mother, he or she is diminished by the loss of function.

No person exists without others; there is no consciousness without a consciousness of others, no speaker without a hearer, and no act, object, or thought that does not somehow encompass others.⁶ All behavior is or will be involved with others, even if only in memory or reverie. Take away others, remove sight or hearing, and the person is diminished. Everyone dreads becoming blind or deaf, but these are only the most obvious injuries to human interaction. There are many ways in which human beings can be cut off from others and then suffer the loss.

It is in relationships with others that the full range of human emotions finds expression. It is this dimension of the person that may be injured when illness disrupts the ability to express emotion. Furthermore, the extent and nature of a sick person's relationships influence the degree of suffering from a disease. There is a vast difference between going home to an empty apartment and going home to a network of friends and family after hospitalization. Illness may occur in one partner of a long and strongly bound marriage or in a union that is falling apart. Suffering from the loss of

sexual function associated with some diseases will depend not only on the importance of sexual performance itself but also on its importance in the sick person's relationships.

A person is a political being. A person is in this sense equal to other persons, with rights and obligations and the ability to redress injury by others and the state. Sickness can interfere, producing the feeling of political powerlessness and lack of representation. Persons who are permanently handicapped may suffer from a feeling of exclusion from participation in the political realm.

Persons do things. They act, create, make, take apart, put together, wind, unwind, cause to be, and cause to vanish. They know themselves, and are known, by these acts. When illness restricts the range of activity of persons, they are not themselves.

Persons are often unaware of much that happens within them and why. Thus, there are things in the mind that cannot be brought to awareness by ordinary reflection. The structure of the unconscious is pictured quite differently by different scholars, but most students of human behavior accept the assertion that such an interior world exists. People can behave in ways that seem inexplicable and strange even to themselves, and the sense of powerlessness that the person may feel in the presence of such behavior can be a source of great distress.

Persons have regular behaviors. In health, we take for granted the details of our day-to-day behavior. Persons know themselves to be well as much by whether they behave as usual as by any other set of facts. Patients decide that they are ill because they cannot perform as usual, and they may suffer the loss of their routine. If they cannot do the things that they identify with the fact of their being, they are not whole.

Every person has a body. The relation with one's body may vary from identification with it to admiration, loathing, or constant fear. The body may even be perceived as a representation of a parent, so that when something happens to the person's body it is as though a parent were injured. Disease can so alter the relation that the body is no longer seen as a friend but, rather, as an untrustworthy enemy. This is intensified if the illness comes on without warning, and as illness persists, the person may feel increasingly vulnerable. Just as many people have an expanded sense of self as a result of changes in their bodies from exercise, the potential exists for a contraction of this sense through injury to the body.

Everyone has a secret life. Sometimes it takes the form of fantasies and dreams of glory; sometimes it has a real existence known to only a few. Within the secret life are fears, desires, love affairs of the past and present, hopes, and fantasies. Disease may destroy not only the public or the private person but the secret person as well. A secret beloved friend may be lost to a sick person because he or she has no legitimate place by the sickbed. When that happens, the patient may

have lost the part of life that made tolerable an otherwise embittered existence. Or the loss may be only of a dream, but one that might have come true. Such loss can be a source of great distress and intensely private pain.

Everyone has a perceived future. Events that one expects to come to pass vary from expectations for one's children to a belief in one's creative ability. Intense unhappiness results from a loss of the future — the future of the individual person, of children, and of other loved ones. Hope dwells in this dimension of existence, and great suffering attends the loss of hope.

Everyone has a transcendent dimension, a life of the spirit. This is most directly expressed in religion and the mystic traditions, but the frequency with which people have intense feelings of bonding with groups, ideals, or anything larger and more enduring than the person is evidence of the universality of the transcendent dimension. The quality of being greater and more lasting than an individual life gives this aspect of the person its timeless dimension. The profession of medicine appears to ignore the human spirit. When I see patients in nursing homes who have become only bodies, I wonder whether it is not their transcendent dimension that they have lost.

THE NATURE OF SUFFERING

For purposes of explanation, I have outlined various parts that make up a person. However, persons cannot be reduced to their parts in order to be better understood. Reductionist scientific methods, so successful in human biology, do not help us to comprehend whole persons. My intent was rather to suggest the complexity of the person and the potential for injury and suffering that exists in everyone. With this in mind, any suggestion of mechanical simplicity should disappear from my definition of suffering. All the aspects of personhood — the lived past, the family's lived past, culture and society, roles, the instrumental dimension, associations and relationships, the body, the unconscious mind, the political being, the secret life, the perceived future, and the transcendent dimension — are susceptible to damage and loss.

Injuries to the integrity of the person may be expressed by sadness, anger, loneliness, depression, grief, unhappiness, melancholy, rage, withdrawal, or yearning. We acknowledge the person's right to have and express such feelings. But we often forget that the affect is merely the outward expression of the injury, not the injury itself. We know little about the nature of the injuries themselves, and what we know has been learned largely from literature, not medicine.

If the injury is sufficient, the person suffers. The only way to learn what damage is sufficient to cause suffering, or whether suffering is present, is to ask the sufferer. We all recognize certain injuries that almost invariably cause suffering: the death or distress of loved ones, powerlessness, helplessness, hopelessness, torture, the loss of a life's work, betrayal, physical agony, isolation, homelessness, memory failure, and

fear. Each is both universal and individual. Each touches features common to all of us, yet each contains features that must be defined in terms of a specific person at a specific time. With the relief of suffering in mind, however, we should reflect on how remarkably little is known of these injuries.

THE AMELIORATION OF SUFFERING

One might inquire why everyone is not suffering all the time. In a busy life, almost no day passes in which one's intactness goes unchallenged. Obviously, not every challenge is a threat. Yet I suspect that there is more suffering than is known. Just as people with chronic pain learn to keep it to themselves because others lose interest, so may those with chronic suffering.

There is another reason why every injury may not cause suffering. Persons are able to enlarge themselves in response to damage, so that instead of being reduced, they may indeed grow. This response to suffering has encouraged the belief that suffering is good for people. To some degree, and in some persons, this may be so. If a leg is injured so that an athlete cannot run again, the athlete may compensate for the loss by learning another sport or mode of expression. So it is with the loss of relationships, loves, roles, physical strength, dreams, and power. The human body may lack the capacity to gain a new part when one is lost, but the person has it.

The ability to recover from loss without succumbing to suffering is sometimes called resilience, as though nothing but elastic rebound were involved, but it is more as though an inner force were withdrawn from one manifestation of a person and redirected to another. If a child dies and the parent makes a successful recovery, the person is said to have "rebuilt" his or her life. The term suggests that the parts of the person are structured in a new manner, allowing expression in different dimensions. If a previously active person is confined to a wheelchair, intellectual pursuits may occupy more time.

Recovery from suffering often involves help, as though people who have lost parts of themselves can be sustained by the personhood of others until their own recovers. This is one of the latent functions of physicians: to lend strength. A group, too, may lend strength. Consider the success of groups of the similarly afflicted in easing the burden of illness (e.g., women with mastectomies, people with ostomies, and even the parents or family members of the diseased).

Meaning and transcendence offer two additional ways by which the suffering associated with destruction of a part of personhood is ameliorated. Assigning a meaning to the injurious condition often reduces or even resolves the suffering associated with it. Most often, a cause for the condition is sought within past behaviors or beliefs. Thus, the pain or threat that causes suffering is seen as not destroying a part of the person, because it is part of the person by virtue of its origin within the self. In our culture, taking the blame

for harm that comes to oneself because of the unconscious mind serves the same purpose as the concept of karma in Eastern theologies; suffering is reduced when it can be located within a coherent set of meanings. Physicians are familiar with the question from the sick, "Did I do something that made this happen?" It is more tolerable for a terrible thing to happen because of something that one has done than it is to be at the mercy of chance.

Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares those meanings. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension, it is deeply spiritual. For example, patriotism can be a secular expression of transcendence.

WHEN SUFFERING CONTINUES

But what happens when suffering is not relieved? If suffering occurs when there is a threat to one's integrity or a loss of a part of a person, then suffering will continue if the person cannot be made whole again. Little is known about this aspect of suffering. Is much of what we call depression merely unrelieved suffering? Considering that depression commonly follows the loss of loved ones, business reversals, prolonged illness, profound injuries to self-esteem, and other damages to personhood, the possibility is real. In many chronic or serious diseases, persons who "recover" or who seem to be successfully treated do not return to normal function. They may never again be employed, recover sexual function, pursue career goals, reestablish family relationships, or reenter the social world, despite a physical cure. Such patients may not have recovered from the nonphysical changes occurring with serious illness. Consider the dimensions of personhood described above, and note that each is threatened or damaged in profound illness. It should come as no surprise, then, that chronic suffering frequently follows in the wake of disease.

The paradox with which this paper began — that suffering is often caused by the treatment of the sick — no longer seems so puzzling. How could it be otherwise, when medicine has concerned itself so little with the nature and causes of suffering? This lack is not a failure of good intentions. None are more concerned about pain or loss of function than physicians. Instead, it is a failure of knowledge and understanding. We lack knowledge, because in working from a dichotomy contrived within a historical context far from our own, we have artificially circumscribed our task in caring for the sick.

Attempts to understand all the known dimensions of personhood and their relations to illness and suffering present problems of staggering complexity. The problems are no greater, however, than those initially posed by the question of how the body works — a

question that we have managed to answer in extraordinary detail. If the ends of medicine are to be directed toward the relief of human suffering, the need is clear.

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LOVE

Is a Medical Miracle

"There are no incurable diseases, only incurable people," says Dr. Siegel, who believes that love, hope and a positive attitude are responsible for the amazing cures he has witnessed

By Bernie S. Siegel, M.D.

Martha, a mother of three young girls, had been diagnosed as having leukemia. She came home and told her daughters, "Girls, I have leukemia and the doctor says I'll be dead in a year. But don't worry—I won't die until you're all married and out of the house." Eight years later Martha was at her youngest daughter's wedding, alive and well.

Many doctors would assume that Martha's case was an error in diagnosis. Other physicians might say her unexpected recovery was a matter of luck. After more than 20 years of practicing surgery, I would come to a different conclusion. Scientific research and my own patients have taught me that there's more to medicine than lab reports, pills and incisions. The unexplained cures and survivals I have witnessed have convinced me that the state of mind changes the state of the body and that there are no incurable diseases, only incurable people. Those who are able to love and hope, have peace of mind and faith send their bodies a "live" message, while those who are constantly depressed, fearful, despairing and in conflict and do nothing about it give their bodies a "die" message.

I decided I must try to teach people to utilize the power within themselves to fight disease. In 1978 I started a therapy group called Exceptional Cancer Patients (ECaP). My work with this group has further reinforced my belief that there are certain psychological and spiritual qualities that survivors—or "exceptional patients," as we call them in our group—possess. None of this is to say that traditional medical therapies aren't valuable; rather, that there are factors far beyond the physical that also play a vital role in healing.

The healing power within

The extent to which we love ourselves determines whether we eat right, get enough sleep, smoke, wear seat belts, exercise, and so on. Each of these choices is a statement of how much we care about living. These decisions control about 90 percent of the factors that determine our state of health. The trouble is that most people's motivation to attend to these basics is deflected by attitudes hidden from everyday awareness. As a result, many of us have mixed feelings about living.

Unreserved self-adoration, stemming not from vanity and narcissism but from self-esteem and a determination to care for our own needs, remains the essence of health. It is the most important asset a patient must gain to become exceptional. Yet a fundamental problem of many of my patients is an inability to love themselves, having felt unloved by others during childhood or some other crucial part

of their lives. If we weren't hugged enough as children or loved unconditionally, that is, just for ourselves, rather than for being neat, smart, polite, obedient—a "good" girl or boy—we might not feel worthwhile as adults either, making ourselves vulnerable to illness.

So I tell my patients, *You are not that unloved child anymore.* You can be reborn, rejecting the old messages and their associated diseases. When you choose to love yourself, you will have those days when you're not all you'd like to be, but you can learn to forgive yourself. You can't change your shortcomings until you accept yourself despite them. I emphasize this because many people, especially those at high risk of cancer, are prone to forgive others and crucify themselves.

When I can get people to accept themselves as authentic individuals, lovable as they are, they then become able to give unconditional love to others—another important element in self-healing. They find that loving others does not subtract from some limited emotional storehouse. Instead it multiplies itself. It feels good to give, it makes the recipient feel good; sooner or later it returns. One of my patients who understood this was Fran, a blind diabetic amputee who had cancer and who had lived far longer than statistics would have predicted. She always spent a lot of time on the phone, cheering up other patients. She and other exceptional patients have taught me that love can dramatically affect the body and that the ability to love is not limited by bodily illness.

An immediate reward of love is a "live" message to the body. I am convinced that unconditional love is the most powerful known stimulant to the immune system. And even though love is hard to study scientifically, medical research is beginning to confirm its effects. For example, at the Menninger Foundation in Topeka, Kansas, it's been found that people who are in love, in the romantic sense, have reduced levels of lactic acid in their blood, making them less tired. And they have higher levels of certain "feel good" brain chemicals called endorphins, making them euphoric and less subject to pain. Also, their white blood cells responded better when faced with infections, and thus they developed fewer colds.

Some of the most telling work has been done in Israel by Jack Medalie and Uri Goldbourt. The two researchers studied 10,000 men with the risk factors for angina pectoris—abnormal heart rhythms and high anxiety levels. Medalie and Goldbourt used psychological tests and questionnaires to find out what factors determined which men would actually develop the chest pains. The most accurate predictor turned out to be a "No" answer to the question, "Does your wife show you her love?" Furthermore, as Leo

Buscaglia has pointed out, insurance companies have found that if a wife kisses her husband good-bye in the morning, he has fewer auto accidents and lives five years longer.

Unfortunately, there isn't always a direct relationship between spiritual change or white-cell count and the cure of an illness. The idea is to love because it feels good, not because it will help us live forever. Love is the end itself, not the means. Love makes life worth living, no matter how long life lasts. It also increases the likelihood of physical healing, but that is the bonus, the icing on the cake. The process is the product.

The key to survival

Because exceptional patients love themselves, they refuse to be victims. They educate themselves and become specialists in their own care. They question the doctor because they want to understand their treatment and participate in it. They demand dignity, personhood and control, no matter what the course of the disease.

It takes courage to be exceptional. I remember one woman who, when told she had to go to the X-ray department, replied, "No. This test hasn't been explained to me." When the attendants told her, "You could die tonight if you don't have this test," she said, "Then I'll die tonight, but I'm not leaving my room." Immediately someone appeared to explain what the test was all about.

Exceptional patients want to know every detail of their X-ray reports. They want to know what every number in their lab test printouts means. A doctor who harnesses that intense self-concern, instead of rejecting it and being "too busy," dramatically improves the patient's chances.

Physicians must realize that the patients they consider difficult or uncooperative are those who are most likely to get well. Leonard Derogatis, Ph.D., professor of psychology at the Johns Hopkins School of Medicine in Baltimore, studied 35 women with metastatic breast cancer

and found that the long-term survivors had poor relationships with their physicians—as judged by the physicians. They asked a lot of questions and expressed their emotions freely. Sandra Levy, Ph.D., associate professor of psychiatry and medicine at the University of Pittsburgh School of Medicine, has shown that passive breast cancer patients were in worse shape biologically than those who readily expressed their feelings, including the negative ones. Levy and others have also found that aggressive "bad" patients tend to have more killer T cells than docile "good" patients. A group of London researchers recently reported a

10-year survival rate of 75 percent among cancer patients who reacted to the diagnosis with a "fighting spirit," compared with a 22 percent survival rate among those who responded with "stoic acceptance" of feelings of helplessness or hopelessness.

Those who become exceptional patients know that life comes with no warranties. They willingly accept all the risks and challenges. As long as they're alive, they feel in control of their destiny, content to receive some happiness for themselves and to give some to others. They have what psychologists call an *inner locus of control*. They do not fear the future or external events. They know that happiness is an inside job.

Yet, unfortunately, doctors don't always encourage patients' desires to maintain control. I learned from my own patients what many doctors are like in their offices. They shout. They keep people waiting for two hours but refuse them five minutes of discussion. A patient told me of walking into a doctor's office and finding a sign on the desk that said, "Compromise means doing it my way." My advice is, if you see a sign like that, turn around and walk out.

Exceptional patients, however, also are loving, and thus understand the difficulties a physician faces. In most cases, my advice to a dissatisfied patient is to give the doctor a hug. Usually this makes the doctor more willing to respond to the patient's needs, because you become an individual, not a disease. You become what I affectionately term "crazy." If the hug doesn't work, however, then it's time to get another doctor, because I

Insurance companies have found that if a wife kisses her husband good-bye in the morning, he has fewer auto accidents and lives five years longer.

know patients who are literally being killed by their relationships with their doctors.

Hope is a potent healer

For most physicians, giving "false hope" simply means telling a patient that he or she doesn't have to behave like a statistic. If nine out of ten people with a certain disease are expected to die of it, supposedly you're spreading "false hope" unless you tell *all ten* they'll probably die. Instead, I say each person could be the one who survives, because all hope is real in a patient's mind.

Even if what you most hope for—a complete cure—doesn't (continued on page 181)

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come to pass, the hope itself can sustain you to accomplish many things in the meantime. *Refusal to hope is nothing more than a decision to die.* I know there are people alive today because I gave them hope and told them they didn't have to die.

The exceptional patient often ignores a doctor's heavy-handed pronouncement of doom. I have a copy of a letter from a young woman named Louise. As a teenager Louise developed cancer of the ovary with metastases to the lungs and abdomen. With chemotherapy, her oncologist "gave" her six to twelve months to live. She told him only God could decide when her number was up, and began to take her life into her own hands. She left home because of stressful living conditions there, got her own apartment and spent her last \$10 to place a newspaper ad looking for other cancer patients who needed her help. At one point her oncologist had refused her any further treatment because she was "too far gone," but six months after she had taken the path of her own choosing, all her tumors had disappeared. Her doctor couldn't even tell her this good news out loud. Instead, with tears in his eyes, he handed her a prescription form on which he'd written the statement, "Your cancer has disappeared." On the day she was supposed to be dead, Louise sent him a joking note asking, "Where should I send the casket?"

Louise chose to hope, love and give, making the kind of spiritual and psychological changes that people who experience self-induced healing always make. It takes enormous strength to do this when the voice of authority is telling you you're supposed to die. Far better for a physician to admit that a situation is grave, yet to remind the patient in truth that there is no "incurable" disease from which someone has not recovered, even at the threshold of death.

When a doctor can instill some measure of hope, the healing process sometimes starts even before treatment begins. I recall one of my patients who had been preoccupied with death when she entered my group, but not long afterward began thinking more positively. When she visited her radiologist one day, he told her that the drugs were working, because her bone scan had improved dramatically. She replied, "If you'll look at my schedule, you'll see I haven't started chemo-

therapy yet. It must be Bernie Siegel's groups—they told me I didn't have to die."

POSITIVE THINKING CURES

Essential to a feeling of hope is positive thinking. To become exceptional in caring for the body, one must take stock of the beliefs one has about it, especially those so ingrained that they're normally unconscious. If a person can turn from predicting illness to anticipating recovery, the foundation for cure is laid.

I have a patient, a frail woman named Edith, who weighs all of 85 pounds. She told me, "I don't need you and your group. My mother always told me when I was a youngster, 'You're scrawny, but whatever happens, you'll always get over it. You'll live to be ninety-three, and then they'll have to run you over with a steamroller.'" Edith has survived a heart attack, a bleeding duodenal ulcer, breast cancer invading the chest wall, and the death of her husband. She is now alive more than half a dozen years after her cancer surgery. Every time something happens, she hears her mother's words.

If we were all programmed this way, we'd all be survivors. Instead, negative conditioning, which results in a fatalistic attitude, is all too common. Over the years, I've found that my patients tend to get the same diseases as their parents and to die at the same age. I think conditioning is at least as much a factor as genetic predisposition (I call it "psychological genetics"), because I've seen people change the scenario once they become aware of it. When a patient says resignedly, "I first learned about my cancer in March, I had a recurrence in March, and here it is March again," then has a second recurrence and dies within a month, you begin to see that there's more involved than genetics. *Fatalism can be fatal.* Too many people think they're doomed to reenact their parents' scripts. As a nurse told me after one of my lectures, "I think you may have saved my life. I've been waiting to die of cancer, because my mother has it and my father had it. It never occurred to me that I didn't have to have it as well."

THE BEST MEDICINE

Show me a patient who is able to laugh and play, who enjoys living, and I'll show you someone who is going to live longer. Laugh-

ter makes the unbearable bearable, and a patient with a well-developed sense of humor has a better chance of recovery than a stolid individual who seldom laughs.

Many times when I'm in a hospital room with a "dying" patient, we are laughing. Out in the hallway, the other staff members often think we are denying reality. We're simply still alive and thus able to laugh. We must realize that people aren't "living" or "dying," they are either alive or dead. As long as they are alive, we must treat them that way. For this reason, I find the word "terminal" very upsetting. It means we've begun to treat that person as though he or she were already dead, incapable of laughter and joy.

I remember Joselle, an ECaP member with an exceptional sense of humor. Though quite a hefty woman, she would come to meetings wearing a tight shirt, shorts, high socks and an outlandish hat—all as sort of a performance to give the others a laugh. One day she said that her chest X-ray showed the cancer was going away. I said, "I know why." Everyone leaned forward, waiting for some erudite explanation. "It's because no self-respecting cancer would appear in an outfit like that." People continue to see humor if they retain a childlike spirit—that is, a sense of innocence and play—and I know Joselle's sense of humor contributed to her progress in getting well. As long as people are alive, things can still be funny, and we can help them laugh.

There are sound scientific reasons why we call robust, unrestrained laughter "hearty." It exercises the lungs, increasing the blood's oxygen level and gently toning the entire cardiovascular system. All the muscles of the chest, abdomen and face get a little workout. After the laughter, all the muscles are relaxed, including the heart—the pulse rate and blood pressure temporarily decline. This relaxation response has been measured as lasting as long as 45 minutes.

According to some scientific studies, laughter also increases the production of a class of brain chemicals called catecholamines. Increased amounts of some of these compounds in the blood can reduce inflammation by activating a part of the immune system. In addition, they increase the production of endorphins, the body's natural opiates. Thus humor may relieve pain directly, by physiological means, as well as by diverting our attention and helping us relax.

Humor's most important psychological function is to jolt us out of our habitual frame of mind and promote new perspectives. Psychologists have long noted that one of the best measures of mental health is the ability to laugh at oneself in a gently mocking way.

Julie, a young lady who came to ECaP because of blindness resulting from diabetes, showed us all how laughter makes life better. Once, when out to dinner at a restaurant, her family and friends sat her down in a chair, and she, presuming the table was in front of her, inched her chair forward. (continued)

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She kept inching and inching, and ended up across the room. Everyone was silent, not knowing how to respond. Finally, she bumped into another table, where the people asked, "Would you like to join us?" As soon as she realized what had happened, she started laughing, and the whole restaurant also exploded in laughter.

One day Julie was walking with her boyfriend, who kept telling her, "Be careful. Step down. Step up." He was so concerned about her that he fell off the curb. So she handed him her cane and said, "Here, you need this more than I do." Julie has since regained her sight—truly a healing miracle—and no longer fears blindness. Her statement to me was, "Blindness taught me to see, and death taught me to live." She is now one of our co-therapists.

We must learn to give fun a high priority in life. Like all other positive change, this also develops from the essential first step—learning to love ourselves. Each of us must take the time to find humorous books or movies, play the games we enjoy, tell jokes to friends, doodle or have fun with coloring books, whatever the choice is of the child inside you. Not only does play make you feel good, it is also a disinhibitor that opens the door to creativity, an essential element in all self-healing.

LET GO OF ANGER AND ILLNESS

Those who can give vent to their feelings yet continue with their lives generally stay well. The husband of a patient once called me up and asked, "What did you tell my wife?" He said she came home and yelled at him for hours about their 20 years of marriage—and he thought they had been pretty good. I told him, "I didn't say anything to your wife, but she has learned that she has cancer, and she's sharing the resentment that she has built up over the years."

Anger is a normal emotion if it is expressed when it is felt. If it isn't, it develops into resentment or even hatred, and also into depression, all of which can be very destructive. A woman who says, "I'll make this marriage work if it kills me," may find it will. Yet if a person deals with anger or despair when it first appears, illness need not occur.

Depression as defined by psychologists generally involves quitting or giving up. Feeling that present conditions and future possibilities are intolerable, the depressed person "goes on strike" from life, doing less and less, and losing interest in people, work, hobbies, and so on. Such depression is strongly linked with cancer.

There is a specific form of depression even more closely related to malignancy, however. It is the type found in people who continue with their routines and

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display an outward show of happiness, when on the inside their lives have come to lack all meaning. These are the smiling ones who don't acknowledge their rage and frustration but who say "I'm fine," even though you know they have cancer, their spouses have run off, their children are drug addicts and the house just burned down. Working with breast cancer patients, Mogens Jensen, Ph.D., a research associate in the department of psychology at Yale University in New Haven, Connecticut, showed that such "defensive-repressors" die faster than patients with a more realistic outlook. He feels this behavior "disregulates" and exhausts the immune system by giving it mixed messages.

I remember Sandy, a cancer patient who wrote me a long letter explaining how she'd become conditioned to be a "doormat" most of her life. Her mother belittled her efforts to become an actress when she was younger; she later married a man who beat her during drunken rages. When she asked him for a divorce, he put the whole family in the car, took them to the edge of a cliff and threatened to drive off unless she promised never again to talk of leaving him. She made the promise and kept it.

Although she tried to keep up appearances, Sandy decided, on an unconscious level, to be sick. She developed phlebitis and stayed in bed all the time, having no relationship with her husband. After he was killed in an auto accident, her phlebitis cleared up within days. Later, during a second marriage in which she again took a subordinate role, Sandy developed breast cancer. At that time she redirected her life by learning to express her feelings and is well today.

FAITH CAN FIGHT DISEASE

Spirituality means the ability to find peace and happiness in an imperfect world, and to believe that even though one's own personality is imperfect, it is acceptable. Acceptance, faith, forgiveness, peace and love are the traits that define spirituality for me. These characteristics *always* appear in those who achieve unexpected healing of serious illness.

Most physicians won't "try God" until the patient is near death. I remember that one of our patients was told by her doctor the date she was going to die. She said, "What can I do?" He said, "All you've got is a hope and a prayer." She said, "How do I hope and pray?" He said, "I don't know. It's not my line." She has learned how and is alive, far beyond his prediction. She told me, "Little did he know he was prescribing the one thing that was going to make me well."

I believe it is far better to make a connection with the patient's spiritual beliefs earlier, when the job is easier. And, because the meaning of religion varies from person to person, I prefer to avoid doctrinal limita-

tions. In ECaP we seek instead to use what is positive in each patient's beliefs.

But the bottom line is, it's hard to find peace in life if you believe death is a meaningless end or that earthly existence is futile. On the other hand, anyone who believes that the world is basically a beautiful place has a reason to remain in it. A person who believes in a benevolent higher power has a potent reason for hope—and, as we've seen, hope heals.

I want to emphasize, however, that the hope borne of spiritual faith is not at all passive, but very active. It means seeing that the outcome you want is possible, and then working for it. It doesn't mean just sitting there, waiting for a miracle to happen out of the blue. I encourage patients to have faith in God but not expect Him to do all the work.

Let me illustrate what I mean with an old story I've adapted. A man with cancer is told by his primary physician he'll be dead in an hour. He runs to the window, looks up at the sky, and says, "God, save me." Out of the blue, God's wonderful melodious voice says, "Don't worry, my son. I will save you." The man then climbs back into bed, feeling reassured.

His physician calls me and I walk in, and say, "If I operate in an hour, I can save you." "No, thanks," says the man, "God will save me." Then an oncologist, a radiation therapist and a nutritional therapist all tell him,

"We can save you." "I don't need you. God will save me," is his reply.

In an hour the man dies. When he gets to heaven, he walks up to God and says, "What happened? You said you'd save me, and here I am, dead."

God says, "You dumbbell. I sent you a surgeon, an oncologist, a radiation therapist and a nutritional therapist."

Rather than someone who is going to do all the work for you, I think of God as an intelligent, loving energy or guiding light in each person's life. This God is a resource who gives us the tools we need to achieve our own happiness and well-being—the ability to love and forgive ourselves and others, to have control over our lives, to have faith enough to see the beauty in living and also in dying. We all must die someday, but the spiritual way is always open to everyone and can make our lives and deaths beautiful whenever we choose it. Death becomes a healing transition for a tired mind and body. Nothing is taken. It is not a failure and the love shared makes us immortal. As German dramatist Christian Friedrich Hebbel once wrote, "Life is not anything: It is only the opportunity for something." ●

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