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## The Relief of Suffering

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The relief of suffering is considered one of the primary aims of medicine. However, what suffering actually is and what physicians must do specifically to prevent or relieve it is poorly understood. Because of this, the most well-intentioned and best-trained physicians may cause suffering inadvertently in the course of treating disease and may fail to relieve suffering when that might otherwise be possible.

Suffering must be distinguished from pain or other symptoms with which it may be associated. Although physicians, patients, and the medical literature generally link pain and suffering, they are distinct phenomena. For example, patients may tolerate severe pain without considering themselves to be suffering, if they know the source of the pain, that it can be controlled, and that it will come to an end. However, even apparently minor pain or other symptoms may cause suffering if they are believed to have a dire cause (eg, a malignant neoplasm), if they are viewed as never-ending, or if patients consider the symptom (and themselves) to be beyond help, or if their condition is considered hopeless. Suffering may occur in the absence of any symptoms whatsoever, eg, when one is forced to witness helplessly the pain of a loved one. Indeed, helplessness itself may be a source of suffering.

Suffering may occur in relation to any aspect of a person.<sup>1</sup> The word "person," as used herein, refers to all the possible dimensions of an individual. As such, it is larger than and includes the self or personality. A simple topography of person would include personality and character; the lived past; the family's past; associations and relationships with family and others, culture, and society; the person's work and social roles; body image; the unconscious mind; political affiliations; the secret life (which everyone has, whether in reality or in dreams); the perceived future; and the transcendent or spiritual dimension, lending to each person the sense of being greater and more lasting than an individual life.

Sickness, with its pain, dyspnea, weakness, nausea, and the whole panoply of symptoms and disabilities, is important because of what it does to the person, not merely because of its effect on the person's body. Suffering occurs (clinical observation suggests) when the illness or its symptoms threaten not only interference with some aspect of person—virtually any illness does that—but when it destroys or is perceived to destroy the integrity of the person through its effects. Most generally, suffering can be defined

as the state of severe distress associated with events that threaten the intactness or wholeness of the person. Suffering continues until the threat is gone or the integrity of the person can be restored in some other fashion. Thus, although pain or other symptoms may, as examples, disrupt a person's relationships with others, interfere with someone's ability to work, or make the patient's usual presentation to the world impossible, the sickness usually does not cause suffering until the patient believes that the changes will continue into the future. Silently or otherwise, patients will continue to suffer until they no longer believe the disruptions to be enduring, come to see the possibility of being whole again, or believe themselves to be total, intact persons, despite the loss of some aspect of themselves or their function. As all physicians know, the capacity of persons and of the human spirit to overcome sickness and loss is wonderful beyond words.

It has always been important for physicians to relieve suffering, but understanding what suffering is and what to do about it has a special urgency in this era. A new category of patients exists for whom the potential for suffering is enormous—the chronically severely sick patient whose life medical technology can now prolong. The most obvious cases involve patients with metastatic disease whose malignant neoplasm and complications are partially controlled. For example, a woman with surgical stage II endometrial cancer with notable myometrial invasion, who had radiation after her hysterectomy, was given cisplatin and doxorubicin hydrochloride therapy, when intestinal obstruction and an abdominal mass heralded recurrence. She had a good response to chemotherapy.

After one year, "second look" laparotomy disclosed a return of the tumor. Postoperatively a small bowel fistula and sepsis developed. Because of total parenteral nutrition and antimicrobial agents, she was discharged from the hospital five weeks after undergoing an operation and she looked well and vigorous. Soon the original fistula reopened, followed by several others, and she died at home six weeks later. With such a patient, the number and severity of symptoms, the quantity and cost of medical care, the toll on the patient, family, and friends, are well known to physicians. These cases are common and are the results of current therapeutic gains. A similar situation pertains to some patients who have end-stage congestive heart disease, chronic obstructive pulmonary disease, neurologic diseases, or multiple coexisting diseases. The essential point is not merely the chronicity, which is not new, but the long duration of severe and demanding sickness previously associated only with acute, short-lived illness.

It is also true that the survivors of such illness, either the

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families or the patients (if they live) do not have good memories of the medical care given. This is especially unfortunate because the care of seriously ill patients frequently demands enormous dedication as well as skill. However, the survivors recall inadequate pain relief, long waits for simple services, an endless parade of seemingly (to the patient) unnecessary procedures, impersonal attention, changing house staff and tangled lines of command, and inadequate information and explanation ranging from what Willard Galen, MD, calls "truth-dumping" to half-truths and lies.

It is a sad fact that such serious illnesses are often characterized by sorrow and pain. However, it is an even greater misfortune when medical care fails to relieve such misery, and it is still worse when it adds to it. I believe that three interlocking principles of treatment will permit physicians to take better care of these sick patients while greatly reducing the suffering of the patients and their families. The first principle is that diagnostic and therapeutic goals should be set in terms of the patient not the disease. The second principle is to maximize the patient's function not the length of life. The third is to actively minimize the patient's and the family's suffering. These three principles cannot really be separated from one another because they derive from the more basic understanding that physicians take care of sick persons not diseases. Since patients generally know best what their goals are, which functions matter most to them, and when they are suffering, following these principles inevitably means working with patients and their families.

While space does not permit great detail, I shall attempt to illustrate what these principles might mean practically.

1. Diagnostic and therapeutic goals should be set in terms of patients not diseases. For example, when the patient is seen with tissue-proved, widespread metastatic cancer, the search for the primary tumor site does not contribute to therapeutic planning, but it does increase the patient's discomfort, fears, length of hospital stay, and costs. However, even in cases of advanced malignant neoplasms, radiation to the spine may avert paraplegia and permit death from a more tolerable complication, eg, hypercalcemia. When gangrene of a foot occurs as part of the terminal illness of a patient with diabetes, benign mummification is often preferable to amputation. Thus, choosing a more comfortable mode, time, or place of death should be considered an appropriate goal. When the aims of treatment are primarily patient oriented, then the support mechanisms of the family, group, or community are enhanced rather than interfered with by medicine and its technology. Such planning is not lesser medicine; it is medical care that is appropriate to the particular patient with a particular disease in a particular life situation. As such, it requires considerable knowledge of the patient, the disease, and the situation.

2. Maximize function not the length of life. Patients with illnesses of the kind that I am discussing do not often return to normal work or recreation. However, with skillful treatment, help, and encouragement, they may return to their homes and a useful place in the family structure. For this to be possible, the usual intrusiveness of medical care must be greatly reduced. This means reducing hospital stays to a minimum, reducing the frequency of office visits by using the telephone and house calls as a substitute, employing home care units, and teaching the family to provide care. This strategy involves risk to the patient. Infection may not be detected as early, bowel obstruction may occur, the patient may fall, the wrong medication might be taken, congestive heart failure may go undetected, diabetic con-

trol may be inadequate, and so on. However, if one works with the patient and family as partners, these worrisome possibilities usually do not occur with greater frequency than in the hospitalized patient, and the patients are vastly more comfortable and content. One is, after all, avoiding the alternative risks of greater suffering.<sup>2</sup> The patient is in this way given the opportunity to live as well as is possible, despite a terminal illness. While risks can be discussed with the patient or a family member, the physician should not unduly alarm the patient with fears of complications. Such fear can be as crippling to the patient as the event itself. For example, a patient with metastatic disease to the bone had a pathologic fracture of the femur pinned. But the patient was kept bed bound and chair bound because of her physician's fears of another fracture. If such a patient is to return to any degree of function, that kind of risk must be taken. When making these decisions, one must consider the actual probabilities, not merely unusual possibilities. In general, care of this sort develops one's prognostic sense to a high degree. Sometimes, as with high-dose steroids in late-stage cancer, therapeutic maneuvers should be planned that have only the patient's sense of well-being in mind. However, it is important not to start therapies employed in these situations for symptomatic relief that one cannot easily discontinue, eg, use of a respirator or total parenteral nutrition.

3. Actively minimize suffering. Suffering is an individual matter that must be seen as distinct from physical symptoms, even though they may be its source. One can only know the source of suffering by asking the patient; what the physician or even the family believes is causing suffering may not be a reliable guide. However, adequate pain relief is a hallmark of good care in the sick patient. The proper dose of analgesic is that which relieves pain, something to which only the patient can testify. By proper manipulation of analgesics, eg, phenothiazines, hydroxyzine hydrochloride, methylphenidate hydrochloride, or dextroamphetamine sulfate, pain can usually be relieved without too much sedation or other side effects. Constipation must be attended to. Giving oral analgesics is almost always satisfactory in adequate dosage (eg, 300 mg of meperidine hydrochloride by mouth is the equivalent of 75 mg by injection), but the family or the patient can be instructed in the use of subcutaneous morphine sulfate. As pain can usually be controlled, so too can many other symptoms; however, minimizing suffering does not stop here. The goal is to maintain the intactness and integrity of the person in the face of severe or increasing sickness and a deteriorating body. Any aspect of personhood—emotional, social, physical, familial, or private—may provide the locus of intervention. As in all medical care, the relationship with the patient provides the vehicle for minimizing suffering. That our skills are not equal to the task and our knowledge is inadequate is unfortunate, but this is no different a situation than that pertaining in other areas of medical care throughout the history of medicine. The crucial first step is an understanding that the relief of suffering is a proper goal of medicine.

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