Diagnosing Suffering: A Perspective

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The alleviation of suffering is crucial in all of medicine, especially in the care of the dying. Suffering cannot be treated unless it is recognized and diagnosed. Suffering involves some symptom or process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future. The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different. The complex techniques and methods that physicians usually use to make a diagnosis, however, are aimed at the body rather than the person. The diagnosis of suffering is therefore often missed, even in severe illness and even when it stares physicians in the face. A high index of suspicion must be maintained in the presence of serious disease, and patients must be directly questioned. Concerns over the discomfort of listening to patients' severe distress are usually more than offset by the gratification that follows the intervention. Often, questioning and attentive listening, which take little time, are in themselves ameliorative.

The information on which the assessment of suffering is based is subjective; this may pose difficulties for physicians, who tend to value objective findings more highly and see a conflict between the two kinds of information. Recent advances in understanding how physicians increase the utility of information and make inferences allow one to reliably use the subjective information on which the diagnosis and treatment of suffering depend. Knowing patients as individual persons well enough to understand the origin of their suffering and ultimately its best treatment requires methods of empathic attentiveness and nondiscursive thinking that can be learned and taught. The relief of suffering depends on physicians acquiring these skills.

Ann Intern Med. 1999;131:531-534.

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> One must not always think so much about what one should do, but rather what one should be. Our works do not ennoble us, but we must ennoble our works.
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> Meister Eckhart, *Work and Being*

Physicians who care for the dying agree that the relief of suffering is a central issue. Too much pain is inadequately treated, and too much suffering is undiagnosed and unrelieved. Such circumstances may be more common now than a generation ago because current treatments keep people alive long enough to enter the chronic, terminal phase of their illness; the duration and severity of their suffering are thereby increased. Some who strongly oppose assisted suicide believe that if suffering were relieved, most of the demand for assistance with dying would disappear (1).

If you do not make the diagnosis, you cannot relieve the suffering. Making a diagnosis of suffering, however, differs from the usual diagnostic process that internists are familiar with because suffering is an affliction of the person, not the body. That fact helps resolve some of the puzzles of suffering. We know, for example, that some patients suffer with pain and other symptoms whereas others do not suffer from symptoms of the same degree. We know that suffering seems related to the meaning of the symptom—when, for example, terminal cancer is the cause, or death threatens, suffering is more common. In addition, fear of the future contributes to suffering, as when patients who formerly had cancer suffer at the thought of the recurrence of their condition. Suffering can start with anguish over the possibility that if the symptom continues, the patient will be overwhelmed or lose control—"I won't be able to take it."

Suffering as a Threat to the Integrity of Persons

The aforementioned examples, and others that clinicians can call to mind, suggest that suffering involves at least some symptom or process (physical or otherwise) that poses a threat, the meaning of that threat, fear, and concerns about the future. Suffering has been defined as a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts

until the threat is gone or integrity is restored (2, 3). Suffering is related to the severity of the affliction, but that severity is measured in the patient's terms and is expressed in the distress they are experiencing, their assessment of the seriousness or threat of their problem, and how impaired they feel themselves to be (4). The language that describes and defines the patient's suffering is different from the language of medicine—there is too often an actual disconnect between our case history and the patient's narrative (5). Herein lies one of the reasons for the inadequate relief of suffering. Physicians are trained primarily to find out what is wrong with the body—our complex personal and technological methods are aimed at bodies—in terms of diseases or pathophysiology; they do not examine what is wrong with persons. It would seem, from looking at training programs and physicians' actions, that people, with all their ideas, conceptions and misconceptions, fears and fancies, and misleading behaviors, are too often seen as something a physician has to get out of the way in order to diagnose and treat diseases and their manifestations. When physicians attend to the body rather than to the person, they fail to diagnose suffering.

The problem is made worse because what causes suffering in one person may not do so in another. Suffering is not only personal—that is, involving the person—it is also individual. Physicians not only have to be aware of the personal characteristics of a patient to know that suffering is present or to relieve it; they must understand the nature of this particular person. Suffering can vary in its intensity and duration; the differences depend on the particular person. For example, the neurologic deficits of early multiple sclerosis may be a source of intense suffering for a cellist but only moderately distressing for a scholar. A 47-year-old single woman, in whom the sudden appearance of widespread metastatic breast cancer caused her to be hospitalized and near death, suffers. But it is not primarily the weakness, profound anorexia, and generalized edema, as distressing as they are, that are the source of her suffering, but the loss of control and inability to prevent the evaporation of her career whose brilliant promise had finally been realized a few months earlier. The facts and physical consequences of metastatic disease are something that physicians know but that the patient does not easily comprehend, even if she knows them intellectually. She struggles to understand and suffers most from what has happened to her personal life. It is the increasing awareness of the impact of the physical state on the person, not the physical impairments per se, that causes the suffering. Does this mean that suffering is psychological in the sense of affecting or pertaining only to the mental and emotional as opposed to the physical state of a person? No, because just as reading, riding a bicycle, or working as a physician may involve any aspect of a person—physical, emotional, and social—so too does suffering, although a psychological insult such as grief may be a precipitating cause.

The Difficulty of Recognizing Suffering

In the care of the suffering patient, attending to the person means more than caring about the patient or being compassionate. Often, as one hears physicians talk about dying patients' personal characteristics, details of life and work, and relationships with family, their care and compassion are evident, but suffering is not suspected unless the patient makes its presence clear. Lack of recognition and treatment of suffering does not come about only because of absence of compassion or concern, whatever our public may believe; it is also the result of physicians' poor diagnostic and therapeutic knowledge and skills about persons—that is, an inability to focus on the person rather than the disease, the pathophysiology, or the immediate physiologic crisis. This blindness to persons may seem strange, since we all know about persons; each of us is one, we live among them all the time, and we care about others and ourselves as persons. But familiarity is not enough; after all, we lived among bodies all the time (including our own), but we did not know about them as physicians until we were trained in how they function and how to examine them, gather evidence, and think about them as part of our work.

Making a diagnosis of suffering means first of all maintaining a high index of suspicion in the presence of serious disease and obviously distressing symptoms. As a start, it means asking whether the patient is suffering and why. Even though patients often do not know that they are suffering, they must be questioned directly: "Are you suffering?" "I know you have pain, but are there things that are even worse than just the pain?" "Are you frightened by all this?" "What exactly are you frightened of?" "What do you worry (are afraid) is going to happen to you?" "What is the worst thing about all this?" Once asked, patients have to be given the time to answer. The questions are purposely somewhat vague: they tell patients that they have permission to talk about things that usually no one wanted to hear before, and they do not specify what answers are expected. In the beginning, physicians may find these to be very uncomfortable conversations because no one enjoys hearing about unrelieved pain, misery, and suffering. Physicians are also frequently concerned that they will be helpless in the face of the patients' answers. It is often surprising how little

is actually required of the physician—asking the questions and attentively listening to the answers are usually helpful in themselves—and how little time the process takes. The gratification that commonly follows these interactions more than repays physicians for their discomfort, and with time they become easier.

The subjective assessments one discovers by these questions may, however, be a problem for physicians. Medicine has tried throughout the past two centuries (most successfully in the last generation) to see diseases and the body as part of directly observable, objectively existing, and purely material states of affairs, in the way that biological science generally sees nature. Physicians seek as much objective evidence as possible for the physical aspects of disease. It isn't surprising, therefore, that in medicine a conflict has arisen between objective and subjective information. Objective knowledge is considered scientific and valuable, whereas subjective information is thought to be "soft" and second-rate. For the relief of suffering, that conflict is not only false but an impediment. The work of clinicians is made more difficult by the continuing worship of objective fact and discrediting of subjective information: these tendencies encourage treatment of disease as an object of science rather than treatment of persons who do (or do not) have a disease.

For persons, once one gets past demographic characteristics, the evidence is mostly subjective. Singer and colleagues (6) suggest that five domains are of concern to dying persons: adequately relieving pain and symptoms, avoiding inappropriate prolongation of dying, achieving control, relieving others of the burden of their dying, and strengthening personal relationships. They quote other sources with similar concerns (7–9).

From Evidence to Inference about Suffering

The first problem in actually diagnosing suffering is that much of the information about a suffering patient is subjective and therefore devalued. Go back a step, however, and see how we deal with even objective findings. We look at a chest radiograph and see a big, white, fluffy, irregularly shaped shadow in the left upper lung field—as objective as anything can be. Do we say "big, white, fluffy, irregularly shaped shadow?" No, we say, "6-centimeter mass, probably cancer." The objective finding has been converted into the statement of an interpretation, and that leap to what it means for both the physician's actions and the patient's future (even if it is correct) is subjective. The finding is objective, but the knowledge derived from the radiograph has been changed by the subjectivity of the physician—his or her judgments, trains of thought, worries, concerns, beliefs. Good clinicians are disciplined and try to stay as close as possible to the finding itself, postponing final interpretation until all the evidence is available. This same subjectivity in inexperienced physicians may cause them to jump to an interpretation without examining the radiograph to its fullest or considering other possibilities. Jaundice is also an objective sign, but a subjective visual estimate of its intensity reflects the state of the liver less accurately than a correctly performed serum bilirubin measurement. This example highlights a confusion that has arisen in medicine so that something measured is believed to be more objective than the thing seen, palpated, heard, or smelled. The mountain that you see does not become more objective because you know how tall it is. Measurement means, however, more reliable (that is, more reproducible) information.

Apart from their own subjectivity, which can be trained and disciplined but not avoided, clinicians have no choice but to work with subjective information from patients—symptoms, emotions, beliefs, fears, and concerns—the stuff of which patient reports and histories are made and that influence behavior. For knowing whether a patient is suffering, there is no substitute. The relationship between patient and physician, through which medical care flows and which is itself indispensable for the discovery and relief of suffering, arises and flourishes in the land of subjectivity. One might think, in reading the literature, listening to tutors, and hearing colleagues, that we must choose between objective information and subjective. If objectivity wins, however, the relief of suffering as a goal of medicine is a long way off.

This stark dichotomy between objective and subjective is mitigated by the developing awareness in recent decades of three characteristics of the information, objective or subjective, that doctors use in clinical thinking. First, the act of consciously thinking about information, whatever its origins—numbers on a printout, a report of pain, your feelings about a patient—makes it objective, an object of consciousness. Second, information is not merely true or false, black or white, but probabilistic—more or less probable, existing within confidence limits. Third, there is increased appreciation of the nature of predicting the future, particularly its inherent uncertainties: that what is going to happen to the patient or what the patient is going to do (remember, the future starts a second from now) is inherently probabilistic. All of this means that the physician's task with inference, whether from a radiograph or the thought that the patient is suffering, is to objectify it in thought, increase the probability of its truth, narrow its confidence limits, and in-

crease its predictive value. Or, to put it another way, the task with subjective or objective information is to increase its precision, accuracy (reliability), and predictive value. Examining again, looking again, reflecting, listening again, enlarging the scope of inquiry, asking more questions, and thinking about what one has learned does this.

Knowing a particular patient requires something more after the questions have been asked and the history taken. Premature interpretation of findings of any sort distorts information within the subjectivity of the physician but is a special problem in knowing patients as persons. Almost anything one says about people in everyday life—she's beautiful, he's smart, bossy, fun, paranoid, charming, anxious, aggravating, sexy—whether correct or not, shuts off the observation with a premature interpretation. This is why the various classifications of personality that have been proposed get in the way of clinicians' knowledge of persons. Bias or preconceptions, judgments made about a patient that are not based on what you know about this patient, can be especially misleading (10). One needs to listen to what is said and unsaid, watch face and body for expression and actions, smell (fear, hygiene, or perfume), learn to let it all come in without interpreting or judging, and stay silent inside and out (beyond small talk). In doing this, one begins to know something about the patient, still unspoken but enough for the care of many sick patients. This "passive" knowledge is not sufficient, however, for the care of the dying or the suffering patient, just as the knowledge of pathophysiology is also not enough. Here, it is the nature of the person and the specific threats to their personhood that determine the nature of suffering.

Now comes the hard part: learning to be simply open in the presence of the patient, as though there were a door to the inside of you—to your heart or soul, call it what you will—and you consciously opened it so the patient would flow into you. If this idea has a touchy-feely "New Age" sound, do not be put off; good clinicians are strange instruments. This has sometimes been labeled sympathetic listening, empathic communication, or empathic attentiveness, and it can be taught and learned (11). This stance is not something you do as much as something you are. Properly done, no one but you will know exactly what is happening, not even the patients. They will simply experience you as being trustworthy, caring, and understanding. It may seem threatening to you at first, as though your defenses were down. Remember that you are working. It is you, the doctor, doing and being this way, not the personal you. What will you learn? For one, what the patient is feeling—ultimately, you can get to the point that you can feel their feelings even over the telephone. It is important at times to identify those feelings specifically, to name them. Mostly, however, you will not put words to what you learn in order not to foreclose the experience. You will, over time, come to trust the intuitive thinking that takes place below awareness as your mind continually processes the experience. This is intuition not as something magical but as a kind of nondiscursive thought common to experts in many fields (12–14).

Learning these skills makes it possible to diagnose and treat suffering even when the cause of the suffering cannot be removed. It is not final expertise that is required; the crucial step is starting on the path to knowledge about patients as persons. The relief of suffering depends on it.

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