Special Section: Terra Incognita:
Uncharted Terrain between Doctors and Patients

The Creation of Partial Patients

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Armstrong describes the rise of a new mode of medical practice that he calls "surveillance medicine," in the following terms: "Despite the obvious triumph of a medical theory and practice grounded in the hospital, a new medicine based on the surveillance of normal populations can be identified as emerging in the twentieth century."[1] Surveillance medicine gives rise to a novel and underexplored aspect of the long-standing tension between the different goals of clinical medicine and public health.

The claim that will be made in this paper is that this new style of medicine has brought into existence a new social category which will be called that of "partial patient." This category relates to people who do not feel themselves to be ill or disabled either most or all of the time but who have been informed medically that because of certain personal characteristics, they have or may have a disease or other medical condition or are at risk of acquiring such a disease or medical condition.

Several types of "partial patient" can be distinguished. These will be described, together with examples of each. Typically, such people are monitored medically on a long-term basis, and may be receiving long-term treatment as well.

Although medical conditions that might be thought to fit the category of partial patient were described in previous centuries (e.g., epilepsy), it will be proposed that a conceptual difference has emerged in the twentieth century which suggests otherwise. Therefore the notion of "partial patient" represents a new configuration of ideas that has not yet been clearly delineated, and those who fit the category enter a new social role that has not been fully described and evaluated. The importance of this new role is not only conceptual but raises ethical issues in relation to clinical care and health policy that are becoming increasingly important as more and more programs are instituted that have the potential to create "partial patients." Hence both the conceptual and ethical aspects will be explored here.

Types of Partial Patient

Seven types of partial patient will be distinguished. The first three listed below are perhaps the most readily apparent because they relate to people who have never felt themselves to be ill or considered that they had a medical problem before the question was raised through medical investigation. All these cases arise from different types of screening and personal prevention of disease and may be differentiated on the grounds of patients who have:

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- precursors of or risk factors for medical conditions, e.g., HIV infection; a genetic family history (such as Huntington's disease); raised serum cholesterol as a risk factor for coronary heart disease
- early symptomless medical conditions, e.g., carcinoma of the cervix in situ
- established symptomless medical conditions, e.g., essential hypertension

The three following types of cases concern patients who have recognized medical conditions that have caused them to be ill in the past, but are currently not making them feel unwell for most or all of the time. Patients falling within this group may be distinguished as having:

- a medical condition that may recur, e.g., cancer, which has been successfully treated, but for which total eradication cannot be certain
- a medical condition in remission or in a latent phase, e.g., tuberculosis and syphilis in certain stages
- a medical condition under control, e.g., diabetes and angina when treated and stable

The final type of case is that involving people who seek medical help for a particular symptom and then become enmeshed in what Sobel has called a cascade of referrals and investigations, potentially unending, because none definitely establishes or excludes the presence of a medical condition.[2]

The Concept of the Partial Patient

Two conceptual changes have occurred without which the emergence of surveillance medicine and hence of the partial patient would not have been possible. The first relates to certain logical consequences of the acceptance of the biomedical model of disease in the second half of the nineteenth century; the second concerns the gradual shift in medical norms, from the beginning of the twentieth century, which encompass a statistical approach. Taken together these changes enabled medicine to extend its scope both to a concern with entire populations and to people who, although diagnosed as having a medical condition, do not feel themselves to be unwell.

Considering these changes in turn, the biomedical model, as originally developed in relation to infectious diseases, contained three elements organized in a hierarchy: the clinical syndrome, the pathological lesion, and the specific causal agent—with the clinical syndrome subordinated to the other two elements.[3] In addition, the clinical syndrome does not consist of a straightforward account of the patient's problems as presented to the doctor, but is the doctor's selection from and interpretation of that account within the framework already established by the other elements of the disease model. So in the clinical encounter the process of searching for a diagnosis will lead inevitably to a separation of the patient's subjective account of illness from the doctor's formulation of disease. There must always have been some difference in perspective between doctors and patients, but biomedical theory not only produced a much greater separation but also one that is qualitatively different. For the first time, the doctor could diagnose disease in the absence of the lowest-ranking element, the clinical syndrome. Now the patient's account was no longer essential. Clinicians have an adage, "treat the patient, not the laboratory," which those who

are wise continue to follow, but the need to state the counsel probably reveals how commonly it is ignored.

Whereas in the first half of the nineteenth century medicine had been characterized by the link between the clinical syndrome and localized pathology (often referred to as "hospital medicine"), in the second half of the century a third element, the specific causal agent, was added. In combination with localized pathology, the causal agent became so powerful as to eclipse all previous assumptions concerning the indispensability of the patient's complaint on which the clinical syndrome is based. The linkage of a causal agent and pathology proved irresistibly attractive because that link seemed to place medical science on an entirely objective basis for the first time. The practical implementation of this theoretical possibility was crucial in the development of screening for disease and personal prevention. The separation of illness dependent on the patient's subjective account from disease dependent on the doctor's apparently objective account, and the legitimacy of no longer requiring the presence of illness, enabled the scope of medicine to enlarge and to seek out disease in apparently healthy populations as well as in those who present themselves to the doctor.

The second conceptual change involved a further phase that entailed a reconfiguration of medical norms and developed in two distinct but related ways. One depended on the first conceptual change, and further extended medicine's remit to include not only those apparently healthy people with disease but also those at risk of developing a disease. This accomplishment came about early in the twentieth century, in parallel with the "epidemiological transition" that marked the decline of infectious disease and the rise of noncommunicable, degenerative disease as the principal cause of morbidity and mortality and occurred at about the same time in all the developed countries of the West.[4] With this new epidemiological pattern the traditional unifactorial model of disease gave way to the multifactorial model. This change entailed the substitution of the specific causal agent by a number of causal risk factors, understanding of whose relative importance and relationships depended on the use of techniques of statistical probability.

The importance of this development in relation to screening and personal prevention was twofold. It dispensed with the "all or nothing" qualitative notion of cause and replaced it with a quantitative gradation, in which a risk score for particular diseases could be applied to whole populations. Now there was the potential for every citizen to become the subject of medical attention, there being a gradient of concern from patients with identifiable disease, through patients at high risk, medium risk, and low risk of developing certain diseases in the future. In addition, because risk factors were less directly linked with pathology than the specific causal agent, the relationship between cause and pathology was partially uncoupled. This loosening then enabled a further reinforcement of the priority given to the causal element, so that within the multifactorial model it became possible to envisage dispensing with the need to observe not only the clinical syndrome but also the pathological lesion to define an individual as a "patient." Thus individuals at high risk came to be interpreted as having a latent medical condition, even though there was only a probability that they would ever develop symptoms or pathological change.[5] Risk factors alone may then be used to suggest that an otherwise healthy person is medically abnormal and that monitoring and intervention are appropriate.

The other element that had an important role in bringing about this second conceptual change began to gain acceptance slightly earlier than the emergence of the multifactorial model and concerned the new perspective of growth and development in child health that became increasingly important from about 1900. The focus here was not on disease but rather on the physical and psychological development of the child, and relied on the assessment of all children in terms of statistical norms. As Armstrong points out (in relation to height and weight growth charts whose use became universal in all schools in Britain after the setting up of the school health service in 1907), within this new frame of reference "[a]bnormality was a relative phenomenon. A child was abnormal with reference to other children, and even then only by degrees."[6] The notion of what constituted a normal child was therefore extended to include ideas that had no relationship with disease but applied to children who were at one end of a statistical range in relation to certain variables that were disvalued.

The common element in these related developments was the introduction of statistical methods to produce a quantitative approach that requires the measurement and assessment of whole groups of the population as the basis on which to make judgments about normality and abnormality.

Hospital Medicine and Surveillance Medicine

All of these conceptual changes are clearly interrelated both historically and logically. They represent a major and highly significant development in the twentieth century, that of surveillance medicine, which arose as an addition to, rather than a replacement of, the hospital medicine characteristic of the nineteenth century. A direct consequence of surveillance medicine is that the stage was now set for the entrance of the partial patient, and the extension of publicly funded healthcare in the twentieth century. These developments, when combined with the ever-increasing range and availability of technical tests, have ensured the designation of more and more types and total numbers of partial patients and this trend seems set to continue.

The overall effect of this process, which has brought with it the new social role and status of partial patients, can now be seen to have implications not only for surveillance medicine but also for hospital medicine, as can be demonstrated in the following table (which relates to competent adults):

		Personal Perspective (relating to patient)	
		Ill	Well
Medical Perspective (relating to doctor)	Abnormal	A	B
	Normal	C	D

The most obvious change between hospital medicine and surveillance medicine relates to those represented by B. In hospital medicine, patients who have

not complained of illness do not become subjects of medical attention and so cannot be found to have a medical condition. Now those represented by D, though not directly affected by surveillance medicine, must also come under medical scrutiny in order that B and D can be distinguished.

The status of those represented by A and C might be thought to remain unchanged because they continue to be subjects of hospital medicine. However, they are also affected in a subtler way because the multifactorial disease model is more complex and more open to interpretation than the unifactorial model. This model allows medicine to make a more sophisticated discrimination between A and C, thus rendering the patient's subjective account even less relevant than previously. Just as surveillance medicine ensures that a person's claim to be well no longer determines medicine's response, so the patient's claim to be ill becomes further disregarded in the new hospital medicine of the twentieth century. The medical norms determining the lines of separation between A and C have then been partially redrawn through a reconfiguration of the biomedical model that has simultaneously reinforced the authority of a technical perception of medicine.

An important consequence of this redefinition of medical norms is that patients in category C come to be viewed as "medically problematic" and the physical symptoms of which they complain come to be labeled "psychosomatic." In this instance patients who define themselves as ill are being denied the status of being "real" patients and so occupy an ambiguous position in which they are often held in contempt by doctors. These patients are in fact the mirror image of the partial patient in category B. While those represented by B feel themselves to be well but are designated as medically abnormal, those represented by C feel themselves to be ill but are designated as medically normal. B and C are linked by the conceptual changes that in each case have been interpreted in such a way as to prioritize the medical at the expense of the personal. This result demonstrates that surveillance medicine was not just added to hospital medicine, but that hospital medicine was substantially changed too. Hence the conceptual innovations introduced in the twentieth century have affected the norms of medicine as a whole.

Introduction to Ethical and Social Issues

The concerns to be raised in this section are not intended to advocate that the screening and personal prevention procedures now in routine use should be abandoned wholesale, for to do so would seem to imply the possibility that simply setting the clock back would resolve the difficulties—clearly not an option. What will be attempted is to examine more carefully the underlying assumptions and consequences of the long-term and continuing trend that is creating more and more partial patients. Re-evaluation and modification of some current procedures will be entailed, as well as a more critical appraisal of future proposals.

Illich is the most trenchant critic of the whole process of the medicalization of life. He describes what he calls "cultural iatrogenesis" as representing the third level of medical nemesis (superimposed on clinical and social iatrogenesis):

> This cultural iatrogenesis is the ultimate backlash of hygienic progress and consists in the paralysis of healthy responses to suffering, impair-

> ment, and death. It occurs when people accept health management designed on the engineering model, when they conspire in an attempt to produce, as if it were a commodity, something called "better health."[7]

His concern is with what he sees as tacit collusion between doctors and laymen that leads to the creation of patients who, by becoming dependent on medicine, relinquish responsibility for their lives. He proposes that this process involves agreement between doctors and potential patients about the designation of disease, in contrast to the present concern with partial patients, where the doctor perceives there to be a medical problem though the layperson has no medical complaint—a situation likely to lead to ambiguity and tension between them. If the patient accepts the doctor's opinion, he will be half way to being regarded as a patient; equally, if he rejects the opinion he will still be implicated, simply by having been involved. So both cases involve the creation of partial patients, patients who are neither ill nor well but who occupy an uncomfortable and ill-defined status somewhere in between.

Medicine's response, however, tends to deny any special problem, apart from the need to ensure compliance with the medical perspective. For doctors, partial patients are essentially the same as other patients, who if they disagree with the medical view need to be persuaded to conform. The assumption underlying this position is that medicine is unequivocally beneficial if the profession can screen for and treat or prevent medical conditions or prevent recurrence, even if only on a statistical basis. Any problems screened patients have are then seen as unfortunate side effects to be managed in the best possible way, but are not regarded as a challenge to the medical view. The main focus of what follows will therefore be on a range of issues that confront this medical assumption.

Medical Labeling

The commonest way to create partial patients is through screening individuals, either undertaken by special programs or "opportunistically," i.e., when patients are already consulting a doctor for another purpose. A cardinal principle in determining whether to screen for disease is the assessment of costs and benefits but, as already indicated, the general tendency for medicine is to focus on the benefits and ignore the costs. (I refer here to personal rather than financial considerations.) Two aspects will be considered. First, attention is usually paid mainly to patients who have a positive result, discounting the possibility that patients found to be negative may be detrimentally affected by the program. Second, any adverse effects on those found to be positive tend to be overlooked or downplayed. Only the second of these considerations involves the creation of partial patients and so, although the first is of great importance, it will not be considered further.

Patients found to be positive at screening become socially transformed in the process of making a diagnosis. These patients have been medically labeled, and the seriousness of this labeling has long been recognized in relation to mental illness, especially when treatment involves patients who are subjected to long-term regimens of total institutionalization, as Goffman describes in his classic work *Asylums*.[8] In these cases patients may adapt so completely to the labels assigned them that the whole of their behavior and demeanor is visibly altered

in a stereotyped way. With physical illness such dramatic changes are not usually apparent, but the consequences may nevertheless be very serious, because once labeled, people are viewed differently by others and they come to perceive themselves as different.

False Positives

The concern with labeling applies not only to those with disease but also to patients falsely diagnosed as having disease. These patients may either be advised to have treatment or to undergo a series of further investigations before they are finally found to be free of disease. Assuming that in both cases such people feel well, both must be regarded as types of partial patient. They are affected slightly differently but are of no less concern than those who actually have a disease. The comparative lack of studies of patients with false positive results is itself an indication of the medical bias in attention given to personal benefits rather than to costs, although an editorial in the *British Medical Journal* reviewed such evidence as exists and drew attention to the need to remedy the situation:

> People receiving false positive results have been shown in three different screening programmes (for congenital hypothyroidism, breast cancer, and Down's syndrome) to suffer high levels of anxiety which do not resolve immediately when subsequent testing shows no signs of disease.[9]

Statistical Probabilities

The conditions referred to so far all concern "qualitative" disease processes, which are present or absent unequivocally. Further problems arise where "quantitative" disease processes or risk factors are being considered on the basis of statistical probabilities. The reason is that in most programs if left to their own devices, the majority of those identified as positive will never become ill from the condition being considered. Also, the number of people implicated as diseased or as having risk factors for disease and so warranting intervention is likely to be both very large and highly variable according to the level at which cut-off points are defined. Screening for coronary heart disease and hypertension is perhaps the most notable example both in terms of the scale of screening programs and the seriousness of the condition. The tendency here has been to diagnose and treat hypertension more rather than less frequently on the basis of technological optimism.[10] The editorial referred to above indicates the sorts of issues that may arise:

> People found in workplace screening programmes to be hypertensive have increased sickness absence, increased anxiety, and reduced self-perceived health status, regardless of whether their hypertension warranted treatment. Several studies on the effectiveness of cholesterol testing have shown a paradoxical effect: a reduction in deaths from heart disease but a small increase in total mortality. It has been suggested that men who know that they are at increased risk of dying of heart disease may be more inclined to take other risks. Some of these

> adverse psychological effects probably also have an impact on the family and friends of the individual who has been screened.[11]

Clinical Encounters and Personal Screening

Much of the reason that these problems are neglected lies in the failure by promoters of screening to distinguish between what is properly involved in the clinical encounter when a patient has sought the doctor's help and in a screening procedure in which the doctor approaches people who have no medical complaint, e.g., at a health fair where people off the street are invited to participate. In the former case the implicit contract is that the doctor will do only what is likely to prove of benefit to the patient, having weighed the costs and benefits for each individual. In the latter case it may seem, by analogy, that each person is also being offered something likely to prove of benefit, but in most programs this benefit cannot come to the majority of people screened. However, this result is not usually clear to those involved because the personal costs and benefits may seem to be weighed just as they were in the traditional clinical encounter and because the onus on doctors is to act only when the overall equation is to the benefit of each patient. But screening does not work on this basis because analysis of personal costs and benefits relates to statistical groups, not to individuals, and the situation is made worse in practice because the personal costs are so commonly discounted.

Disclosure of Information

Another problem may arise when the results of screening are considered positive but are judged not to be of serious significance. Should the person to whom they relate be informed? If the doctor is open about this diagnosis, he will in the process of disclosure have created a partial patient, but concealing the results is paternalistic and may lead to other problems in the future. For example, Doyal considered the case of a woman screened for cervical cancer and found to have early pathological changes for which she would normally be required to have a further check-up after six months. He raises the question of what the doctor should say to the patient.[12] To tell her that the smear is not normal is likely to cause her considerable anxiety, but if he tells her that the smear is normal he will have betrayed her trust by lying and will also be in difficulty explaining the need for follow-up.

The Attribution of Responsibility

So far a range of specific issues has been considered in relation to the creation of partial patients. There is also a more pervasive concern about how screening programs are usually designed to identify particular characteristics of individuals and so take for granted the appropriateness of a narrow focus on the traditional medical model of disease. Guttmacher et al. recognize the importance of this issue, which they raise in relation to screening for hypertension:

> . . . favoring a medical approach to prevention reflects a bias that extends beyond hypertension. It channels attention and action away from altering the social factors that generate risks to physical and mental well-

> being and toward socially acceptable techniques of medical control. This sort of diversion has the double disadvantage of leaving the root of the problem untouched and of rendering a greater number of people dependent on the health care system. For all the value that lies in the detection and amelioration of hypertension, the medical model of prevention shows the limitations of our ways of confronting the social dimensions of health problems.[13]

Clarke also considers the dangers in relation to genetic screening, and "geneticization":

> Attention to social and environmental as well as genetic factors is required for a balanced account of human disease, which in turn is needed for the effective and equitable provision of health care. Although developments in genetic technology may lead to benefits in gene therapy or rational drug design, the application of genetic technologies to individualised health screening is quite different. Geneticisation exaggerates personal responsibility for health, denigrates the collective solutions to health problems that may be the only hope for those with few resources, and favours corporate profits over the collective and equitable provision of health care around the world.[14]

Now attention has been drawn to one of the most important issues, i.e., attribution of responsibility. Because a social and environmental approach to prevention does not identify individuals and thereby creates partial patients, the individual is not made to feel responsible for complying with treatment or altering behavior. Rather, the social group must find ways to deal with the situation collectively.

Other Issues

Attention will now be briefly turned to patients who already have an identified medical condition that is under clinical control or in remission but may recur. These people are already partial patients by definition. Hence the question whether they should have been brought into being does not arise. However, many of the problems already considered in relation to the creation of partial patients apply equally here; given their existence, the main question is how to mitigate these problems. The most important first step is for healthcare professionals to accept that patients under long-term surveillance and/or on treatment for medical conditions who nevertheless feel well all or most of the time are different from traditional patients and thus should be treated accordingly. Appropriate treatment involves adopting an attitude quite dissimilar from that applicable to sick patients, and also requires recognition that many medical routines, such as being treated alongside sick patients in hospital clinics, may be inappropriate.

The final type identified as a partial patient concerns people who are the subject of a cascade of referrals and investigations, without conclusive evidence of disease ever being established. The typing arises largely from the medical ideology expressed in Scheff's decision rule that "judging a sick person well is more to be avoided than judging a well person sick,"[15] combined with a fundamental belief in the efficacy of technical intervention.[16] The number of

these cases will therefore be significantly reduced only through a change in medical values and orientation, which challenges the imperative in favor of diagnosis and technical intervention.

Conclusion

The emergence and growth of surveillance medicine in the twentieth century has led not only to screening for and personal prevention of disease but has also influenced medicine as a whole, giving rise to a new social category and role for which the term "partial patient" seems most apt. Individuals designated as partial patients may react in different ways, accepting, partly accepting, or rejecting the medical label they have been given. In practice, most are likely to accept the label because few people believe they have any choice in the matter. However they respond, they cannot escape the moral and social consequences because they have entered a social role that is medically sanctioned. Once designated as partial patients their lives will never again be quite the same.

An important feature of this new social role is ambiguity, tension, and distress. Patients who are implicated inhabit a twilight world, neither clearly ill nor clearly well but somewhere in between. On the one hand medicine marks them out as abnormal, yet for all or most of the time they feel well and essentially normal. Medicine's claim is to be merely helping prevent and control medical disorder; any personal costs are unfortunate side effects no different in kind from those encountered in the more traditional modes of medical practice. What this position fails to acknowledge, though, is that the ubiquitous influence of surveillance medicine has introduced new norms to medical practice, such that the role of partial patient raises altogether different considerations. Most importantly, the new role is inherently stressful. Hence in the name of alleviating one type of suffering, medicine is simultaneously creating other forms of suffering. One is the inevitable corollary of the other.

This acknowledgment does not mean that the whole series of situations in which partial patients are presently being created should necessarily be reversed, even assuming this were possible. The point is that more serious consideration needs to be given to the general direction being taken. Study will require a wholly different approach in evaluating whether to introduce further new programs of screening and personal prevention as well as a more critical reflection on the wider implications for medicine as a whole.

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Commentary

Henry S. Perkins

As every physician knows, "do no harm" is a basic tenet of medical ethics. Ironically, however, the increasingly powerful science used in patient care may undermine adherence to this tenet. In particular, science now enables the physician to identify "partial patients"—as Greaves defines them[1]—by diagnosing disease or risk factors for disease before physical symptoms occur. But simply by identifying such partial patients, the physician may unwittingly inflict emotional harm on them. "Do no harm" requires the physician to anticipate and minimize such harms.

Minimizing Harm

Greaves's concept of partial patients helps the physician minimize harm in two ways. First, by labeling people as "patients," the concept reminds the physician that partial patients have medical needs that deserve attention despite the lack of physical symptoms. Even if these patients have difficulty saying so,[2] their greatest need may be for the physician to address their fears about disease.[3] Greaves's concept encourages the physician to maintain a high "index of suspicion" for such fears.

Second, Greaves's concept includes a clinically useful typing of partial patients, with which I generally agree:

> Type 1: Patients with only risk factors for disease.
> Type 2: Patients with early asymptomatic predictors of future disease.
> Type 3: Patients with established asymptomatic disease.
> Type 4: Patients with inactive, past disease which may recur.
> Type 5: Patients with active but latent disease.
> Type 6: Patients with active, overt disease under some control.
> Type 7: Patients with symptoms but no diagnosis.

For clinical purposes I suggest several modifications. I differentiate the otherwise similar Types 1 and 2 by defining "risk factors" as inherited, behavioral, or environmental predispositions to disease,[4] and "predictors" as physiologic abnormalities that precede symptomatic disease. I consider Types 3 and 5 to be the same. And I disregard Type 7 because symptoms disqualify these people as partial patients.

Helen P. Hazuda, Ph.D., and Susan Bagby, M.A, made helpful comments on a prior draft of this commentary. Dr. Hazuda also provided some references, and Michael K. Bay, M.D., answered questions about hepatitis C.

Hepatitis C illustrates all five of my types of partial patients. Blood transfusions before 1990 create a risk factor for disease (Type 1). An early positive assay for hepatitis C ribonucleic acid predicts future disease (Type 2). An abnormal liver biopsy identifies the commonly asymptomatic chronic active form of disease (Type 3 or 5). Cure of one genotype of hepatitis C does not protect from infection by other genotypes (Type 4). And antiviral treatments may control active disease without curing it (Type 6).[5–7]

A Case

The experience of a friend of mine who contracted hepatitis C teaches some important lessons about treating partial patients. Jane, a fictitious name, was a divorced schoolteacher in her mid 40s who felt well when she saw her gynecologist for a routine check-up several years ago. Unexpectedly, screening blood tests showed abnormal liver chemistries. The gynecologist referred Jane to a hepatologist who performed further blood tests and diagnosed hepatitis C. The established asymptomatic disease made Jane a Type 3 or 5 partial patient.

Jane was stunned with disbelief. She requested confirmatory tests, but the hepatologist refused, insisting there was no mistake. Jane could remember only one possible source of the infection—blood transfusions during childbirth in the early 1980s. The transfusions had made her a Type 1 partial patient. The hepatologist persuaded Jane to undergo a liver biopsy to assess disease activity.[8] Terrified, she burst into tears just before the procedure. The hepatologist became annoyed, and Jane later complained that she felt like "a slab of meat." The biopsy showed chronic active hepatitis.

Disgusted with the first hepatologist, Jane asked her gynecologist for referral to another. The second hepatologist confirmed her diagnosis and explained that hepatitis C can cause cirrhosis, liver cancer, and death. Now convinced she was dying, Jane agonized over what to tell her teenage sons, her boyfriend, and her school principal; whether she would be permitted to work; and who would support her sons after she died. Despite the small likelihood of it, Jane worried about sexual transmission to her boyfriend. When she told him her diagnosis, he broke off their six-year relationship.

While the second hepatologist conveyed a generally poor prognosis, he also offered Jane some hope. He explained that interferon alpha, natural proteins that help fight viral infections, benefits about 25% of hepatitis C patients. Jane agreed to pay for the expensive injections and eagerly began them. Her liver chemistries normalized, her viral counts miraculously dropped to zero, the specter of a quick death faded, and Jane's spirits rose. She hoped for cure (and hence for becoming a Type 4 partial patient). Suddenly, however, Jane's blood cell counts plummeted near the end of the 12-month course of treatment.[9] Ignoring Jane's pleas to continue, the hepatologist stopped the interferon. Jane felt abandoned to die from her disease and despairingly referred to the hepatologist as her "undertaker."

Desperate, Jane found a third hepatologist, a warm, empathetic, and holistic physician. He reviewed her records, explained he could not improve on her prior treatment, and then asked, What in your life worries you most? The hepatitis, answered Jane. The hepatologist replied gently, "This disease should not control your life." He admitted he could not distinguish cure from mere control (and hence whether Jane was really a Type 4 or 6 partial patient) nor could he dismiss the possibility of a late, life-

threatening complication. But he reminded Jane that she had no detectable virus and no symptoms, and he advised that other than having occasional checkups she should lead her usual life. This caring physician thereby offered what Jane needed most: a healthy perspective on living with a chronic disease.

Lessons from the Case

Jane's case teaches four important lessons about doctoring. First, by defining the reality of health and disease, physicians wield great power over all patients.[10] The power is called "cultural authority." Ironically, this power is greater over partial patients than over traditional symptomatic patients. Traditional patients can use symptoms to monitor their diseases somewhat independently from the physician.[11] In that way traditional patients judge for themselves when the disease is improving, when it is worsening, when to visit the physician, and even when to change physicians. If Jane had first experienced uncharacteristically severe malaise, fatigue, anorexia, feverishness, or upper abdominal pain,[12,13] the symptoms would have prompted her to visit the physician. After diagnosis they would have provided a way she could monitor the disease. In contrast to traditional patients, partial patients have no symptoms by which they can monitor their diseases. Partial patients depend totally on the physician to define the reality of disease. Thus as a partial patient, Jane depended totally on the hepatologists to define her hepatitis C by interpreting to her the liver chemistries, viral counts, and liver biopsies.

Second, physicians also wield great "social authority," the power to make patients obey medical recommendations.[14] Many patients consider a physician's recommendations to be commands. Some patients even use the term "doctor's orders."[15] The compelling nature of the physician's recommendations stems from patients' complete trust that the physician acts in their best interest. To obey the physician's "commands," patients sometimes act against inclination—as Jane did when she submitted, terrified, to a liver biopsy at the first hepatologist's recommendation. I believe many physicians do not realize the enormous power their cultural and social authority has over patients.

Third, partial patients may change type with time, and the emotional support they need from the physician may change accordingly. The physician must recognize such changes and adjust the approach to the patient as necessary. When the hepatitis C diagnosis first made Jane a Type 3 or 5 partial patient, she needed confirmatory tests to help overcome her disbelief. She also needed a balanced explanation of her prognosis—not only mortality statistics but also a clear statement about the high likelihood of a long, productive life despite the disease. When a positive response to interferon made her a possible Type 4 partial patient, Jane needed cautious reassurance about her improved chances for cure. She also needed emotional preparation for the time the treatments would end. When the second hepatologist stopped the interferon due to low blood counts, Jane feared she would die quickly. She needed to understand the hepatologist's rationale for stopping treatment: that long-term control of hepatitis C does not depend on duration of treatment, that she had already received nearly a full treatment course, and that the low blood counts posed a greater, more immediate danger to her than did the hepatitis C. Jane also needed an honest assessment from the hepatologist that though her viral counts were hopeful, he could not predict her disease course. As a result, she also

needed an expressed commitment that he would see her through whatever lay ahead.

Fourth, technical expertise provides an insufficient basis for treating partial patients. Only by cultivating a vivid "clinical imagination" about patients' illness experiences[16,17] can the physician anticipate the largely emotional needs of asymptomatic patients. Diagnoses, treatments, and prognoses change patients' lives, often dramatically. Fears naturally accompany the changes. When patients cannot express their fears about disease, the physician must not assume such fears do not exist. Instead, a well-honed clinical imagination and a healthy index of suspicion should prompt the physician to anticipate such fears and to take steps to alleviate them. The first two hepatologists treated Jane's disease expertly but ignored her fears. The third hepatologist treated the disease no more expertly but addressed Jane's fears directly. In that way he won her confidence.

Cultivating a clinical imagination requires effort. The physician must work to overcome medical training that too often neglects patients' reactions to disease. The physician needs to perceive patients' helplessness on entering the hospital, the ominousness of any surgery, the devastation of a cancer diagnosis, and the demoralization of chronic pain. Imagining the impact of disease is hard enough with traditional patients who present with symptoms. It is even harder with partial patients who present without symptoms.

Summary

Jane's experience highlights two paradoxes of partial patients. While appearing healthier than traditional symptomatic patients, partial patients may be more vulnerable to the physician's cultural and social authority. The lack of symptoms deprives partial patients of independent judgment about their diseases and gives the physician full authority to define medical reality.[18] The physician must use this authority carefully to avoid inflicting unintentional harm on partial patients. Furthermore, because the needs of partial patients are more emotional than physical, these needs are less obvious (but no less real) than the needs of traditional patients. The physician may have to work the hardest to identify and meet the needs of partial patients. A "clinical imagination," honed by experience, can help. In any case, partial patients deserve conscientious attention and skillful care in full measure. The physician who advocates "do no harm" must do no less.

Notes

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