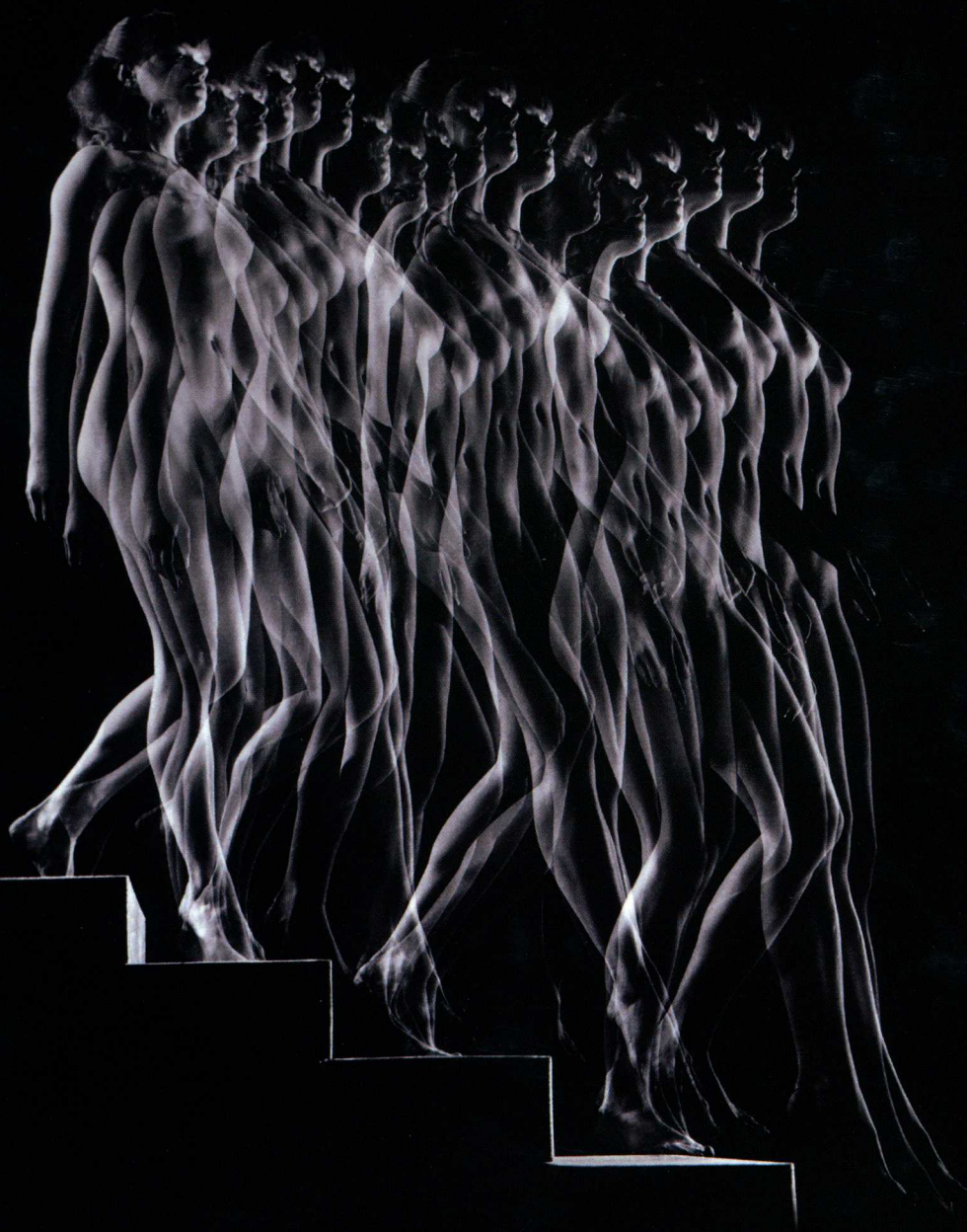


The Patient as Agent of Health and Health Care

MARK D. SULLIVAN



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Perhaps it is necessary that the actuality of the agent and that of the patient should not be the same. The one is “agency” and the other “patiency”; and the outcome and completion of the one is an “action,” that of the other a “passion.” Since then they are both motions, we may ask: in what are they, if they are different? Either (a) both are in what is acted on and moved, or (b) the agency is in the agent and the patiency is in the patient.

ARISTOTLE, *Physics III*, 3

In terms of the medieval distinction between “the patient” and “the agent,” this freedom-centered understanding of development is very much an agent-oriented view. With adequate social opportunities, individuals can effectively shape their own destiny and each other. They need not be seen primarily as passive recipients of cunning development programs. There is indeed a strong rationale for recognizing the positive role of free and sustainable agency—even of constructive impatience.

AMARTYA SEN, *Development as Freedom*



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PART ONE

Introduction



We are not speaking of disease and *also* of the patient, but of the patient *first* and the disease and pathophysiology *through* the patient.

ERIC CASSELL, *Doctoring*¹

1

Patient-Centered Medicine: Who, What, and How?



WHERE DOES HEALTH come from? How is health produced? What does being healthy mean? Who defines health and determines when it is present? As we enter a health care era dominated by the challenges of chronic illness, these questions are more relevant and pressing than ever before. The experts leading health care reform assume they know the answers to these questions. But they are doubly wrong about this. Not only are the usual professional answers to these questions wrong, but they are not questions to be decided by professionals. It is the patient as a person who is the primary producer and definer of health. It is the patient as an agent who produces and enjoys health. Neither health nor action are well explained by modern biological science, which struggles to understand self-moving and self-changing beings (as did Aristotle, see Epigraph). Health care may help a patient regain agency in his life. But health care is not the source of this agency and may, in fact, stifle it (see Sen, Epigraph). Health is what allows us to be immersed in our life and in the world. Health should be primarily defined and experienced from within that life. Health observed from outside life as it is lived is useful but secondary. If we get health wrong, we will surely get health care reform wrong.

Consider the following clinical interaction. Bob, an overworked colleague of mine, was perhaps 100 pounds overweight. He had an unfavorable cardiac risk profile and was already on statins and other medications to manage this. When his cardiologist noted that he was becoming glucose intolerant and proposed that Bob begin metformin for this, he told his cardiologist to go f*** himself. A year later, Bob has quit his job, lost 100 pounds, and is running marathons. He sees this confrontation with his cardiologist as one of the most important turning points in his life.

How are we to understand this confrontation? The initial reaction of most clinicians would be to consider Bob a bad patient. He was abusive, noncompliant, and appeared to be acting against his own best interests. (A year later, many clinicians would have a grudging admiration for what Bob accomplished.) This conflict between doctor and patient cannot be resolved by turning to evidence-based medicine. Both diet with exercise and metformin are strategies proven to prevent the development of diabetes. The conflict might be resolved by turning to a patient-centered care strategy that strives to align care with Bob's preferences and values. Perhaps the cardiologist should have asked Bob whether he preferred diet and exercise or metformin to address his growing glucose intolerance. But very few patients can lose 100 pounds through diet and exercise. And few choose this option. So the cardiologist may have assumed that Bob would not be interested in the diet and exercise option. Bob's past behavior suggested as much.

But I think we are missing the most important part of this conflict if we understand it as a matter of treatment choice. Bob did not just make a choice, but transformed himself. He rebelled against the role of the patient as a medical consumer. He reshuffled the priorities in his life and found new energy to pursue them. He was already becoming healthier before he had actually run any marathons or lost any weight. This is because he had found a way to become an agent in his health and his life again. He didn't so much choose a treatment strategy for diabetes as he rejected the diagnosis and the identity of the diabetic patient. Many patients do this unsuccessfully, but, in this case, Bob succeeded. In his success, there is an important lesson to be learned. In refusing the metformin, Bob not only insisted that his care be patient-centered, but that his health be patient-centered. He was going to define it and produce it in his own way. No one could have told Bob to quit his job, start running marathons, and lose 100 pounds. Bob would have probably used the f-word then, too. But something about this clinical encounter awakened Bob's capacity to be an autonomous patient in the broadest sense. He once again saw a way to be the author of his life and his health.

Bob's personal challenge is important because it is a small version of the challenge faced by our health care system. How can we produce health when faced by chronic illness in a way that is effective, efficient, and personally meaningful? My argument in this book will be that our efforts to reform health care to make it more patient-centered and more responsive to the challenges of chronic illness have been too superficial. Experts interested in reform have asked questions about *health care*, when we need to ask questions about health itself. They have focused on health care processes when we need to focus on the patient as the author of her own health. We continue to think that professionals define health and provide it to their patients through health care.

However, it would be wrong to conclude from Bob's case that the best path to patient-centered health for most patients consists of a wholesale rejection of medical advice and medical treatments. Consider the case of a patient I treated (names changed to protect confidentiality):

Ida Foster

Robert brought his 97-year-old mother, Ida, to the pain center because she was in pain and was no longer looking forward to her 98th birthday, due in a couple of months. Indeed, Ida looked downcast and worn out. She said she just hurt too much and didn't want to do anything. She had an aching back, with pain that shot down her leg, and burning feet. These pains had started 5 years previously, but had gotten much worse since a lumbar laminectomy 4 years earlier. These were not Ida's first problems with musculoskeletal pain. Her left knee had been successfully replaced 8 years previously.

Physical examination revealed an elderly white female with bluish swollen feet bilaterally, characteristic of venous insufficiency. She flexed her lumbar spine well but had almost no extension or lateral bending. She had an area of painful numbness on her right lateral thigh, but intact sensation to pin prick below her knees. She had no focal weakness in her lower extremities including full strength on upward and downward flexion of the feet. Straight leg raising to detect a compressed spinal nerve root was negative. Brief cognitive testing revealed no evidence of dementia, and Robert reported no history of cognitive decline.

Ida verified that she just didn't enjoy much of anything anymore. She remained barely independent in her basic activities of daily living. But she didn't want to see her friends at the retirement home to which she had recently moved. She wanted to go home and lie down. She had been sleeping poorly for months despite taking Tylenol PM and lorazepam every night. The phenytoin given to her by her primary care physician over the past 3 years for her leg pain wasn't doing much. She was too tired all the time and thought maybe she had lived long enough. "Everyone has their time," was her sensible explanation. She couldn't get comfortable sitting because of her burning thigh, so she didn't enjoy TV or reading or chatting anymore. Ida had no idea how to get on with her life.

Ida's problems concerning her body, her health, and her life present new types of challenges to health care that I believe will be typical of what is to come in the current century. The focus on preventing death and treating disease that has been so successful in 20th-century health care is no longer adequate. The prevention and management of chronic illness stands as the unsolved health problem for the 21st century. To address these problems of chronic illness in the most effective and ethical manner, many have called for a more patient-centered model of care. This patient-centered model has been defined in various ways, which we will explore in the next chapter. For now, I will state the lessons to be derived for health care from patients like Ida as briefly and bluntly as possible.

1. We cannot assume that death and disease are the most important targets for health care.
2. We must draw on the patient's perspective to define the nature of the clinical problem and the criteria of success for our clinical interventions.
3. We must always aim toward increasing the patient's capacity for self-care.

We will now turn to each of these in turn.

1. We cannot assume that death and disease are the most important targets of health care.

Saving lives and postponing death remain sacred tasks for medicine, but not all the deaths in our aging population are unwelcome or premature. We are not sure whether Ida wants her life prolonged. The vast majority of deaths in the United States now involve some decision to withdraw or withhold medical care.² We can no longer measure our clinical success simply in terms of deaths prevented or lives saved. Indeed, the population of older adults now fears inappropriately prolonged lives and states of life worse than death as much as premature death.³ We seek to prevent premature deaths and to save lives of adequate quality. We turn to patients and families to help us decide which deaths are premature and which lives are of adequate quality. We can no longer talk heroically about saving lives without talking about the quality of the lives being saved. Ida is not sure she wants any more health care. Our decision about whether and how to prolong her life must now be made in terms of the quality of the life that can be provided for her.

Mortality and morbidity are the “hardest” and most objective measures by which modern medicine gauges its success. But these traditional measures are now inadequate to give an accurate account of the burden of chronic disease at the population or individual level. The classic objective metrics of cure, saved life, repaired injury, healed wound, or eradicated infection are no longer adequate to guide us in addressing these chronic diseases. These conditions cannot be cured; they must be either prevented or managed according to some other nonobjective standard of success. I will propose that this standard should be the patient’s health capability or capacity for action.

Medical science and technology now allow us to do so much to detect and control disease that we risk doing too much. Our capacity to identify objective pathology in patients’ bodies through sophisticated imaging is better than ever, but we may be seduced into allowing this imaging to dominate our clinical judgment. The most common pain complaints are musculoskeletal, with back pain the most common and disabling.⁴ The many objective tissue defects that Ida has on physical examination and imaging (e.g., venous insufficiency, osteoarthritis) offer targets for treatment. But these objective defects may also distract us from the real needs of the patient. Deyo and colleagues have documented rapid growth in the use of lumbar magnetic resonance imaging (MRI),⁵ epidural injections,⁶ and lumbar fusion procedures⁷ in the Medicare population of older adults with low back pain. This has resulted in greatly increased costs but no improvement in patient’s lives.

Ida had evidence of osteoarthritis of the spine and spinal stenosis on computed tomography (CT) scan that prompted her orthopedic surgeon to perform a decompressive lumbar laminectomy. Although this procedure was competently executed with a result that looked great on imaging, it unfortunately did not help Ida. All the objective defects apparent on Ida’s imaging and other tests should not be corrected. This

point hardly needs to be made for a 97-year-old patient. The amount of spinal pathology apparent on imaging reflects the age of the patient more than her back pain. But even in the broader population of adult patients, many “abnormal” findings on lumbar imaging, including herniated discs, are found in patients with no back pain.^{8,9} We cannot decide whether abnormalities on imaging are pathological without understanding whether and how they impair that patient’s ability to live her life.

These concerns about overreliance on imaging are not limited to back pain. Recent trials have also suggested that physicians may be too ready to provide angioplasty or stenting to correct narrowed coronary arteries seen on angiography in patients with stable coronary disease. In patients with significant coronary stenosis and myocardial ischemia but stable coronary artery disease, angioplasty or stenting does not reduce the risk of death, myocardial infarction, or other major cardiovascular events when added to optimal medical therapy.¹⁰ Some clinicians have even advocated whole-body screening with CT or MRI scanners for early detection of disease.¹¹ But these whole-body scans find many lesions, such as small lung nodules, of which 98% identified by CT scan are benign. Once these lesions are found, it is difficult not to do further invasive testing to clarify the meaning of these findings.

Medical critiques of these screening scans draw on principles of clinical epidemiology and have invoked concepts such as “false positives” and “pre-test probability of disease.” Rarely mentioned in these critiques, however, are basic problems with the idea that objective tissue pathology *alone* qualifies as disease. At the boundaries of chronic disease are now multiple asymptomatic proto-diseases such as prehypertension and prediabetes. It is unclear whether identifying these proto-diseases helps patients or harms them. In the face of modern medical therapeutic success and impressive imaging technology, we can forget that imaging is appropriately used to help clarify and address patient distress and dysfunction. The first sentence in the most popular pathology textbook reminds us, “Pathology is literally the study (*logos*) of suffering (*pathos*).”¹²

2. *We must draw on the patient’s perspective to define the nature of the clinical problem and the criteria of success for our clinical interventions.*

We often reduce the patient’s perspective on health to preferences for treatment. We have learned to turn to patient preferences to help make treatment choices. In the most stark and stereotypical formulation, the doctor supplies the facts about the objective disease diagnosis and the therapeutic options. The patient then expresses a preference about treatments and makes a free and informed choice among them. Stated baldly, the doctor discovers the facts of the disease, and the patient provides the values concerning its treatment. This model of medical interaction neglects the important facts about symptoms, function, and quality of life that can only be provided by the patient. It is clear that patients bring to physicians not only defects in their bodies, but also problems with their health and impediments to their lives. These patients supply important facts about these problems as well as values about treatments for

them. Our health care system and our medical science need to make a place for these “subjective” facts. Our clinical goals need to be subordinated to patients’ life goals.

We turn to the patient to provide values to help us make difficult choices among conflicting clinical priorities. But patients often don’t want to make the hardest choices themselves. And their choices can be distorted by the very medical condition that is presented for treatment, such as Ida’s pain and depression. We understand that the patient’s quality of life is an important goal, but we don’t understand how to fully integrate this with the diagnosis and treatment of disease. We really want to find a way to recover Ida’s vitality, but something so personally real cannot be directly observed and is perhaps not fully real in a disease-focused medicine.

Patient permission for treatment is not an adequate model for patient participation in health care. Informed consent is an important protection for vulnerable patients, especially in the hospital. But often this consists only of a right to veto treatments proposed by clinicians. Furthermore, many patient refusals of treatment (e.g., refusal of smoking cessation) need to be discussed rather than simply honored. And, more importantly, ambulatory patients can and need to do much more to define and produce health than submit to or resist the treatment suggestions of clinicians. Almost all chronic illness care occurs in the patient’s home, not in the clinic. As we shall see, patients, not professionals, are the primary producers of health.

If objective diagnosis cannot alone determine appropriate treatment, neither can subjective patient preference alone. If Ida demands that she have “zero pain” as the only acceptable goal of treatment, I must instruct her that this is not possible. Her preference about not living until her 98th birthday, if it is shaped by treatable depression, may not be sufficient to indicate the proper course of treatment. To determine whether a treatment refusal is being driven by depressive hopelessness, I must consider her overall medical situation, including her chances for improvement with treatment, her understanding of her condition and the treatment available, the consistency of her preferences with long-held values, and her son’s understanding and agreement with these wishes, as well as other symptoms of depression that may be distorting her judgment. Many aspects of Ida’s agency, or the ability to conduct her life, may be affected by her illness, including her ability to make decisions. Her wishes may be reasonable and valid or the symptom of an illness that needs treatment. No ready division of clinical elements into objective medical facts and subjective patient values is adequate here.

3. We must always aim health care toward increasing the patient’s capacity for self-care.

By definition, chronic disease cannot be cured. Professional care for chronic disease therefore does not have a clear end, as it does in acute illness such as pneumonia. In back pain, diabetes, and heart disease, professional care supports a more basic and enduring effort at self-care. I am certainly not able to take away Ida’s osteoarthritis or even take away all of her back and leg pain. Successful treatment will be defined not in terms of the cessation of morbidity (osteoarthritis) or of symptoms (back and

leg pain), but of achieving enough relief that Ida can move her life forward again. Ida is healthy when she is once again an agent in her life. The amount of pain that must be relieved before this is possible is not predetermined. It can only be determined through conversation with Ida and Robert.

In chronic disease care, self-care is both a means to care and an end in itself. When a patient with chronic disease presents to her doctor with the demand, "Fix me," the likelihood of a good clinical outcome is low. Patients must be partners in chronic disease care. Once Ida feels capable of managing her pain and getting on with her life without the assistance of health professionals, her treatment has succeeded regardless of what abnormalities persist on her lumbar MRI or what numerical pain level on a 0–10 scale has been achieved. Pain is an impediment to life. Reducing pain and improving self-care of pain are both means toward freeing Ida of this impediment. Once Ida's capacity for meaningful action has been restored, the goal of health care has been achieved—regardless of the pain level she reports.

1. TIDAL SHIFTS IN DEMOGRAPHY AND EPIDEMIOLOGY

I begin with the case of Ida because I think it sketches out the coming landscape of medical practice. Our population is aging, which is changing the ends as well as the means of medical practice. During the 20th century in the United States, life expectancy at birth increased from 48 to 75 years for men and from 51 to 80 years for women. This is due both to a reduction in premature deaths and to an increase in lifespan. While life expectancy at birth increased primarily early in the 20th century, life expectancy at age 65 improved primarily after 1950. Among men, life expectancy at age 65 rose from 12 to 17 years and among women from 12 to 20 years. Improved access to health care, advances in medicine, healthier lifestyles, and better health before age 65 are factors underlying decreased death rates among older Americans.¹³ While overall US population growth is slowing, the percent of the population that is older keeps growing. The population over age 65 will increase from 12% to 19% of the total population between 2005 and 2030.¹⁴

This older population carries a heavier burden of chronic conditions. There are now more than 100 million Americans with chronic conditions, and nearly half of these have their daily activities limited in some way. Two-thirds of Medicare beneficiaries older than 65 have multiple chronic conditions. The 15% of these with six or more chronic conditions account for more than 41% of the \$324 billion spent on traditional Medicare.¹⁵ The rest of the world is following close behind in this "epidemiologic transition." Chronic diseases are already the most common cause of death in the world.¹⁶ *These chronic diseases are not cured by physicians, but managed by patients with help from physicians.* These chronic diseases share similar behavioral risk factors: tobacco use, unhealthful diets, lack of physical activity, and alcohol use. This means that the locus of successful treatment must also be in the patient's home. On average, a diabetic patient spends 3 hours per year with a health professional, while the remaining 8,757 hours are spent in self-management of his or her diabetes.¹⁷

2. THE CALL FOR PATIENT-CENTERED CARE

There is the widespread sense that the priorities of our health care system need to be changed so that it is more responsive to the needs of patients with chronic conditions. These calls for a more patient-centered medicine have been made with increasing frequency over the past 50 years by primary care physicians, foundations, professional groups, and governmental bodies. There is increasing research into “patient-centered care” (PCC) as well. From 1994 to 1999, there were 1,891 “patient-centered” citations in PubMed, whereas from 2000 to 2006 there were 3,137 citations, and from 2007 to 2014 there were 10,233 citations. The “patient-centered” idea has obviously captured something of broad interest in health care. There is widespread recognition that we must make health care more responsive to the needs of patients as persons with preferences, values, and lives of their own.

Two kinds of arguments are made for PCC. The first is that PCC is *ethically preferred* because it is a humane model of care that attends to the patient as a person as well as someone with a disease. This argument has its roots in the bioethical literature and focuses on the inherent value of care congruent with patients’ “needs and preferences.” The second is that PCC is the *most effective* model given the challenges of an aging population with chronic conditions outlined earlier. This argument has its roots in the evidence-based medicine literature and focuses on the clinical effectiveness of PCC. Whether the Patient-Centered Medical Home (PCMH) and other models of patient-centered care should be justified primarily in terms of ethics or effectiveness is unsettled. However, this confusion about the principal justification for PCC may hold important lessons, as we will see later.

One of the most important documents arguing for the importance of PCC is the report on improving quality in health care issued by the Institute of Medicine (IOM) in 2001, *Crossing the Quality Chasm: A New Health System for the 21st Century*.¹⁸ In this report, “patient-centeredness is a dimension of health care quality in its own right, not just safety or effectiveness or professionally defined quality.” PCC is defined as “care respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” In a 2009 *Health Affairs* article, Donald Berwick, who chaired the *Chasm* report, offered this updated definition of PCC: “The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”¹⁹ PCC was devised by the IOM Committee as a middle ground between radical consumerism (as in, “The customer is always right”) and classic professionalism (as in, “Patients make decisions that are not in their best interests”). Any experienced clinician reading this definition of PCC will ask Berwick and other advocates of PCC to clarify how far we are to go in honoring patient requests for care: “Does that mean that anyone who asks for a CT scan gets one?” This question highlights the conflict between patient-determined and expert-determined needs for health care.

I don't think this problem can be resolved as long as the patient is not the true customer for health care who determines his own health care needs and spends his own money. I will return to this issue more thoroughly in Chapter 11. At this point, it is important that we should not get lost in debates about which patient preferences for care should be honored versus which should not be honored because this traps us in a narrow conception of the patient as someone who is active only insofar as she has preferences for tests and treatments. Patients have many capabilities, beyond the expression of preferences for tests and treatments, that are necessary elements of health and health care. To understand what these capabilities are and what role they should play, requires that we step back to take a broader view of PCC. Indeed, we must take a broader view of the patient as an agent in health and health care if we are to find truly innovative and effective answers to the clinical, ethical, and economic challenges concerning health and health care.

3. EMBRACING THE PATIENT AS AGENT

PCC has foundered because we have not thought deeply enough about what it is and how it might contribute to patient and population health. A few reasons might be offered for the "theoretical timidity" that characterizes PCC advocacy. First, much of the work on PCC has been done in the context of quality improvement initiatives. These initiatives are designed to be incremental reforms aimed at more effective attainment of goals already agreed upon, such as patient safety. Even the most ambitious PCC initiatives, such as the PCMH, are assessed with standard measures of cost and effectiveness. Second, the bioethical community, which has been one of the strongest advocates of PCC, is dominated by nonclinicians and has typically concerned itself with the means employed by medicine and not its goals. Third, as we shall see in the remainder of this book, a vigorous theory of PCC that encompasses patient-centered health challenges the central tenets of the current biomedical model of medicine with far-reaching and disconcerting implications.

My thesis for the book that follows is that PCC of chronic disease requires that we *recognize the patient as the primary perceiver and producer of health*. By "primary," I mean both original and most important. By "primary perceiver," I mean that health from the perspective of the patient should become the principal goal for health care. By "primary producer," I mean that the patient is seen principally as an origin rather than a recipient of therapeutic action. It will take some time to lay out this argument fully, but let me introduce it briefly.

3.1. *Who Is the "Patient" in Patient-Centered Medicine?*

In all the literature concerning PCC, little serious attention is given to defining a "patient." What happens when a person becomes a patient? According to the Oxford English Dictionary, "patient" was first used in Anglo-Norman languages in the 12th