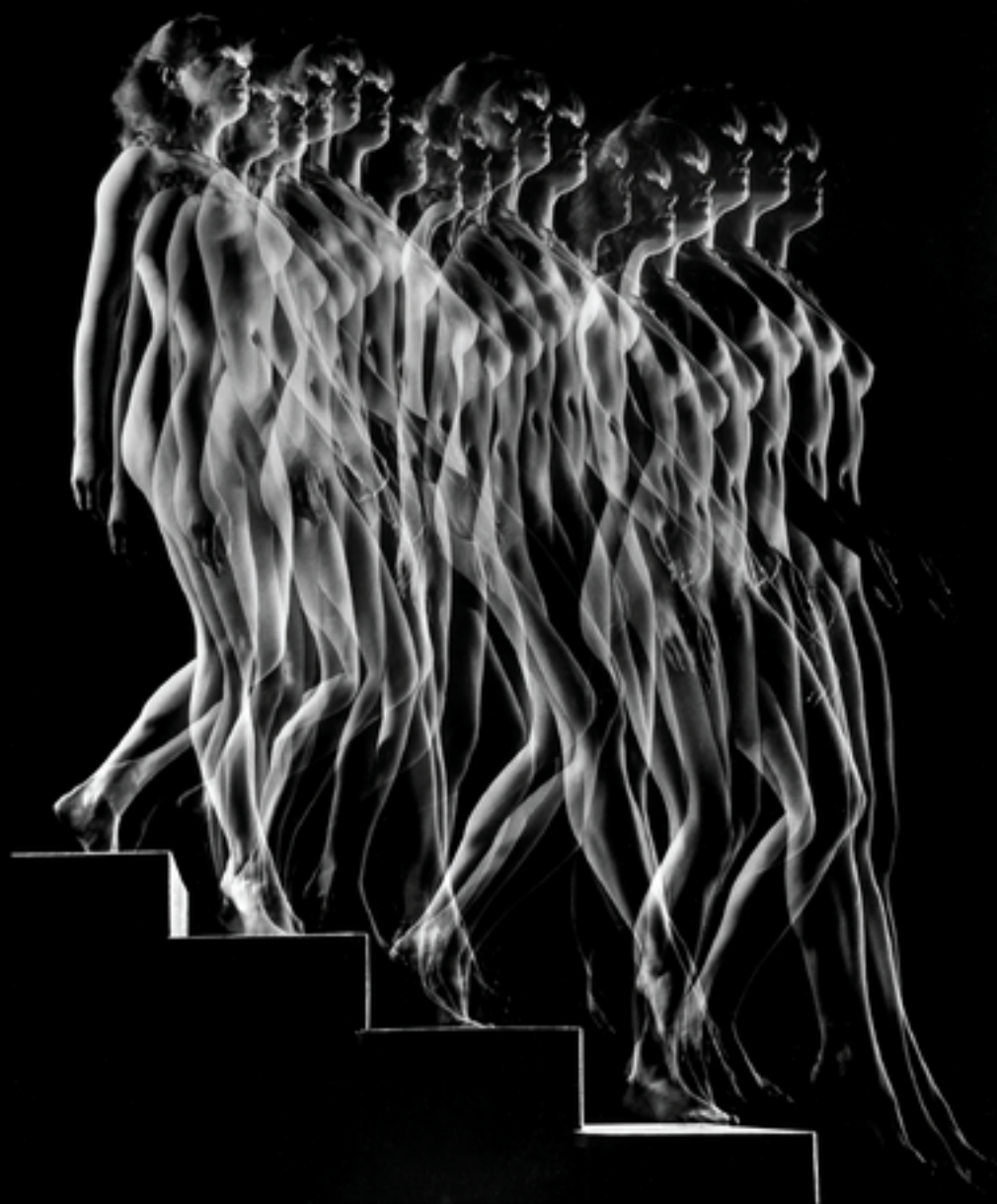


The Patient as Agent of Health and Health Care

MARK D. SULLIVAN



THE PATIENT AS AGENT OF HEALTH
AND HEALTH CARE



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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 consider 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

century as an adjective meaning tolerant. By the 14th century, it also meant enduring hardship without complaint. Later that century, “patient” was also used as a noun meaning a sick person or a person who receives rather than initiates an action. These meanings echoed the classical Latin *patient*, meaning “able or willing to endure or undergo, capable of enduring hardship, long-suffering, tolerant.”²⁰ It is important to note that these qualities will still help you be considered a “good patient” in modern medical centers.

I am intrigued by how tightly our language links “sick person” and “person acted upon.” Sickness and passivity are linked in our minds every time we use the term “patient.” This was generally a productive association as long as the threats to health were primarily from acute and infectious disease. Rest and compliance with doctors’ orders worked together to promote recovery from these time-limited conditions. Because 20th-century medicine has been so successful in treating acute infectious illnesses such as pneumonia and influenza, chronic and degenerative conditions such as diabetes and heart disease, osteoarthritis, depression, and dementia, loom as the unsolved problems for 21st-century medicine. These are conditions for which patient passivity is not helpful. Some way must be found of transforming the patient into the agent of his or her own health.

The “informed and activated patient” plays a central role in Wagner’s Chronic Care Model, but it is not clear whether the patient is initiating or receiving activation in this model of care. On the one hand, the concepts of information and activation imply a capacity for knowing and acting in the patient. On the other hand, the patient receiving care in the Chronic Care Model is on the receiving rather than the initiating end of this informing and activating. What we really want is a patient who has become an agent on her own behalf, an autonomous patient. Yet health care that aims for patient autonomy is engaged in a paradoxical task: it is trying to provide autonomy to another when autonomy is precisely what can’t be given to someone else. This paradox is known to parents of toddlers and teenagers who must allow their children to fall down and crash cars if they are ever to learn how to stand or drive on their own. We need to ask afresh: What kinds of things *do* patients *know*? What *can* they *know*? What kinds of things *can* patients *do*?

I have named this book *The Patient as Agent of Health and Health Care* to highlight the passivity–activity dynamic at the heart of modern patienthood. People become patients because they need assistance with illness. Their health has become a barrier rather than a door into life. The patient role is a receptive role. In serious acute illness, it is a quite passive role. But in chronic illness, the patient cannot be passive. The clinician must help the patient not only become healthy, but resume self-care. This person must contain both “patiency” and “agency,” and thereby become what Aristotle thought was impossible (see Epigraph): a self-moving, self-changing, self-healing entity.

3.2. What Is the Goal of PCC?

Sometimes advocates argue for PCC as the most ethical and humane model of care. Other advocates argue for PCC as the most effective model for the chronic illness era

we now face. It is not clear which is the most basic or important argument. I believe this confusion arises for important and instructive reasons. The leading edge of bioethical debate now appropriately involves questioning what constitutes medical effectiveness. Bioethics is beginning to look at medicine's ends as well as its means. Similarly, the health services literature on effectiveness is incorporating patient-centered outcomes, or results of health care "that really matter to patients." Valuing health outcomes according to the patient's perspective brings the effectiveness literature into dialogue with the ethical literature.

The ultimate point of intersection between these diverse literatures and disciplines concerns the nature of medicine's goals. Specifically, it concerns the definition of health itself. Professional medicine greatly prefers to speak of disease rather than health because it is more objective, easier to define, and more apparent from a professional perspective. But in an era of chronic disease, a negative definition of health as "no disease" is not only inadequate but simply false. In geriatric practice in particular, the patient may be thriving and in vibrant health despite having many diseases.

Patient-centered medicine should be health-centered medicine. Only if the patient is seen as the primary producer of health do we overcome the tension between the ethical and effectiveness arguments for PCC. The patient produces health not only through health behaviors such as exercise and diet, but through his or her vital capacity to live an independent life. The healthy geriatric patient may not be disease free, but she is active, resilient, and full of vitality. These nonobjective features of her health status cannot be delivered to her but can be fostered and protected.

Theoretical biologists have discussed biological autonomy as the capacity of organisms to shape their environment rather than to be shaped by it.²¹ On a simple level, this means the ability of warm-blooded organisms to maintain a body temperature different from ambient temperature. On a more complex level, it means the ability to select and pursue one animal as a mate and another as prey. I want to draw this scientific notion of biological autonomy into the bioethical discussion of patient autonomy. The root from which patient autonomy grows is the biological capacity of the organism to be an agent shaping its environment. Specifically, I want to propose that patient autonomy is not only a value to guide health care, but is also the goal of health care for chronic disease. *Autonomy is not just an ethical problem in medicine, it is a clinical problem. It is perhaps the core clinical problem for a medicine facing aging and chronic disease.*

In understanding the biological roots and the expanded clinical role of patients' autonomy, we will come to a new understanding of the relationship between health and health care. While health care may help restore health, it is not the origin of health. Health originates as the agency of the person. This agency refers to the general capacity for doing, making, and changing things. In clinical care, this active state of agency exists in dynamic equilibrium with the passive state of "patency." Patients return to being healthy persons as their *agency* is restored. When agency is employed in a free and self-directed way by persons, it becomes *autonomy*. I am thus interested in a broader sense of patient autonomy than is usually addressed in bioethics.

I am interested in autonomy as the general capacity for self-directed activity and not just as the capacity to make independent health care decisions. When discussing how policy may foster health understood in terms of agency and autonomy, I will refer to *capability*. This is the concrete capacity for meaningful action that includes not only freedom but resources for action. Health policy should focus on providing health capability and not just health care.

3.3. *How Does Patient-Centered Care Promote Patient Agency?*

This is the most complicated and abstract of our three questions because it points to the need for a general theory of patient knowing and acting. *We need to know the patient as a subject as well as we know the patient as an object.* We will need to examine the nature of “action” and understand how it differs in conception and implication from the term usually substituted for it, “behavior.” Briefly, action is something you do (where there is real, not just apparent agency), whereas behavior is something that just happens. Action is most apparent from the first-person perspective, whereas behavior is most apparent from the third-person perspective. This distinction is important because I will define health in terms of capacity for action.

Ida Foster

Ida agreed to take venlafaxine for her neuropathic pain and depression for a month as an experiment. She also agreed to try walking in the hall of her retirement home every day. And she was going to visit one friend at the home each day. I wrote a prescription for venlafaxine XR 37.5 mg per day. She took it every day after breakfast. By the end of the second week, when I spoke to her on the phone, she didn't mention her pain, but talked about a conversation she had that week. By the time she came to see me in clinic a month after her first visit, she said her pain was still there, but she felt better. She agreed to take the medication for another month, when she would come to see me again. At that visit, she was enjoying her sitcoms and her friends again. Her pain was still there, but it seemed less important. She agreed to keep taking the venlafaxine and her walks and visits. In fact, she took the venlafaxine until she died following a stroke about a year later.

In this case, Ida was relatively passive in treatment selection. She let me and Robert talk her into taking the venlafaxine. To make the treatment work, she had to take the pill and push herself to resume some of her favorite activities. She did achieve some reduction of her neuropathic pain with the venlafaxine. But the ultimate and most important effect of this treatment was neither the correction of a pathophysiological neuropathic process nor the reduction of her pain. The most important and patient-centered effect of the treatment is that it made Ida feel like her life was worth living again. She was once again capable of making a life for herself. Her agency was restored, at least to the extent possible for someone now 98 years old.

As we explore the agency of patients in the following chapters, it will reveal a new perspective on our problems with health and health care. We will understand the limitations of current visions of PCC. We will discuss patient agency from a bioethical perspective, focusing on patient autonomy as an antidote to physician paternalism that arises from the “modern” juxtaposition of patient subjectivity and physician objectivity. We will discover the pitfalls in current definitions of health-related quality of life. We will learn that patients with chronic disease need to be autonomous rather than activated. In the end, we will understand why the patient should be recognized as the primary agent of health perception and production. This is best served not through a right to health or a right to health care, but a right to health capability.

A patient-centered approach fosters interactions in which clinicians and patients engage in two-way sharing of information; explore patients' values and preferences; help patients and their families make clinical decisions; facilitate access to appropriate care; and enable patients to follow through with often difficult behavioral changes needed to maintain or improve health. R EPSTEIN, K FISCELLA, CS LESSER, KC STANGE, "Why the Nation Needs a Policy Push on Patient-Centered Health Care"¹

2

Patient-Centered Care or Patient-Centered Health?



1. INTRODUCTION

In order to see clearly what an emphasis on patient agency and health capability adds to current proposals for patient-centered care (PCC), we must understand the history of efforts to define and support patient-centeredness. After an auspicious beginning when it contained some revolutionary elements, PCC has recently become the “mom and apple pie” of health care reform: the repository of all humane and reasonable proposals to improve the process of health care. We have reached the point at which no one is opposed to PCC. This is a sign that this policy has been drained of meaningful and significant reform. If a policy is supposed to transform an industry involving nearly a fifth of the US economy and no one is upset about it, this suggests that patient-centeredness has lost its bite. Let us examine how this has occurred.

2. PATIENT-CENTERED MEDICINE: A BRIEF HISTORY

Modern calls for patient-centered medicine are generally thought to have originated with Michael Balint, a psychoanalyst who studied and worked with general practitioners at the Tavistock Institute in London.² Balint opposed patient-centered medicine to “illness-centered medicine”:

Illness-centered medicine means that the doctor has to understand the patient's complaints, as well as the symptoms and signs that he can find, in terms of

illnesses, that is in terms of a pathologically changed part of the body or of a part-function of the body. The danger of this orientation is that it may not give enough consideration to the patient as a unique human being with his own personal conflicts and problems. On the other hand, it must be admitted that this illness-centered orientation, scientific medicine has had spectacular successes, having in fact, almost doubled the average expectancy of life in the Western world during the last hundred years. The other way of thinking, patient-centered medicine, tries to understand the complaints offered by the patient, and the symptoms and signs offered by the doctor, not only in terms of illnesses but also as expressions of the patient's unique individuality, his tensions, conflicts and problems. We call the understanding based on illness-centered thinking "traditional diagnosis," while the understanding based on patient-centered medicine we call the "overall diagnosis."

It is important to note how radical this original formulation of patient-centered medicine was. We might be most struck by its psychodynamic tone, but its most important feature is its "repersonalization" of the diagnostic process. Pathologically based diagnosis of impersonal diseases is here subordinated to the patient's "complaint" and the place it has in his overall life. One might summarize by saying that "traditional diagnosis" concerns the patient's body, whereas "overall diagnosis" concerns the patient's life. Perhaps the contemporary formulation closest to that of Balint is that of Eric Cassell, cited as the epigraph to the previous chapter, "We are not speaking of disease and *also* of the patient, but of the patient *first* and the disease and pathophysiology *through* the patient."³ I will argue that if we are to fully engage the patient in the production of health, we must repersonalize diagnosis, treatment, and the very pathophysiological processes of disease.

A patient-centered concept similar to that of Balint was developed at the Family Medicine Department at the University of Western Ontario by Ian McWhinney and Moira Stewart. McWhinney began his research into the "real reason" (physical, social, or psychological) that the patient presented to the doctor in 1972, close in time and spirit to Balint's work. He had a grand agenda for this work, as is apparent from the following quote:

It is not simply a matter of learning some new techniques, though that is part of it. Nor is it a question of adding courses in interviewing and behavioral sciences to the curriculum. The change goes much deeper than that. It requires nothing less than a change to what it means to be a physician, a different way of thinking about health and disease, and a redefinition of medical knowledge. . . . Does the patient-centered method improve patient's health? There is good evidence that it does. But I believe that we are mistaken if we make this its justification. Some things are good in themselves. The justification of the patient-centered method is its moral basis.⁴

There are a number of radical elements in this manifesto. First, McWhinney proposes that the patient-centered model does not simply add new domains to medical knowledge, but redefines this knowledge. Second, although the patient-centered model may improve the effectiveness of health practices (we'll examine the evidence for this later), the principal reason for its adoption is a moral one. What is proposed, therefore, is a basic redirection of medical theory and practice from a focus on disease to a focus on the patient. The central justification for this is that this patient focus is a more morally appropriate mission for medicine.

Extending the work of McWhinney, Moira Stewart explains that patient-centered medicine “may be most commonly understood for what it is not—technology centred, doctor centred, hospital centred, disease centred.”⁵ McWhinney and Stewart remain close to Balint in their claim that “the conventional biomedical model ignores the person with the disease.” They propose a “patient-centered model” “that includes the conventional biomedical approach but that also goes beyond it to include consideration of the patient as a person.”⁶

Tanisha Bates

Tanisha was 54 years old and had a busy life. The last of her three kids would finish high school next year. The event-planning business she started after her divorce was doing pretty well. She could handle a lot on her plate, but her blood pressure would not go down no matter what her doctor prescribed. At one point, she was on chlorthalidone, lisinopril, and amlodipine, but her pressure was still about 150/100. When her primary care doctor suggested adding another medication, she decided to find another doctor.

Her new doctor, Dr. Prutkin, started in like all her doctors had, telling her she needed to lose weight, exercise more, and eat less salt. Tanisha explained that she tried to do all those things, but that she was busy raising her kids and running her business. She was driving around most of the time, so she needed to eat on the run. She got to bed late after doing the books for her business and then needed to get up early to get her son to swim practice before school. She didn't have the luxury of a relaxed life. Just when she expected Dr. Prutkin to pick up the prescription pad, he sat down next to Tanisha and said, “Walk me through one of your typical days, step by step.”

In recent years, the emphasis has shifted from an ambitious effort to define patient-centered *medicine* to the more modest agenda of defining patient-centered *care*. This has side-stepped the original tension between a disease-centered clinical model and a patient-centered clinical model based on understanding the patient's complaints in the wider context of the patient's life. I have summarized the components of PCC proposed by various organizations and individual scholars in Appendix Table 2.1. It is clear that PCC is a multifaceted concept that has been loosely defined and variably applied.⁷ As currently advocated by organizations such as the World Health Organization and the Institute of Medicine, PCC excludes the most disruptive components of Balint's

original idea and includes other, less disruptive components. This is because we have largely ceased to talk of patient-centered *medicine* and now talk of patient-centered *care*. Whereas Balint and McWhinney initially sought to repersonalize diagnosis and the nature of the clinical problem, we now focus on the more limited agenda of making care more humane. We have turned away from Eric Cassell's challenge to personalize pathophysiology.

Among these various formulations of PCC, the core seems contained in this principle: "align care with patient need and preference." The traditional means by which this has been accomplished is through informed consent by the patient to treatments or procedures proposed by the physician. The more modern form of this practice is "shared decision-making," to which we will return in Chapter 8. For now, it is important to note that true patient-centeredness requires that the amount and type of patient involvement needs itself to be determined by the patient. The most recent studies indicate that patients differ in the extent and manner to which they want to be involved in medical decisions.¹⁰ Furthermore, patients cannot be simply classified as "active" or "passive" because patients have different preferences for different components of the decision-making process, with both demographic and illness-related factors shaping these preferences.¹¹

However, aligning care with patient need and preference may be more difficult than is often assumed. Patients are understood in modern medicine to have valid and important preferences concerning care. This is codified in rules concerning informed consent. Although patients are recognized as having legitimate needs for health care, they are not the ones who currently determine which of those needs are legitimate. Since the right to health care was first proposed in France after the Revolution, physicians have reserved for themselves the right to determine who needs medical care and who does not. Insurers enforce this prerogative, distinguishing services that are "medically necessary" from those that are not. Patients can present themselves to their primary care provider's office, and, in some health plans, to a specialist's office, looking for care.¹² They can and do demand medications they have seen on TV,¹³ but they are not considered to be the legitimate authority to determine true health care need for diagnostic tests, surgical procedures, hospitalizations. To give patients more authority to define health care need would be to take a significant, even radical, step toward patient-centered medicine. This goes beyond Berwick's argument to honor patient preferences for care. We will return to examine how this might be done in the final chapter.

3. PATIENT-CENTEREDNESS: PERSPECTIVE VERSUS ACTIVATION

More than a decade ago, Judith Hibbard described three ways in which consumers/patients can participate in and improve the health care they receive.¹⁴ The first role is the *informed choice role*, which is similar to consumer choice concerning other goods. Consumer/patients function in this role when they select providers, plans, and hospitals

on the basis of quality. This selection is hampered by lack of patient understanding, by the overwhelming complexity of health care quality reports, and by a tendency to focus on the more easily understood cost differences among health plans. The other forms of patient participation Hibbard described are more specific to health care. In the second role, patients can function as *co-producers* of health through decisions about when to seek care, engagement in self-care, and adherence to agreed-upon treatment regimens. Peer-led programs for self-management of chronic illness as well as collaborative care for chronic disease draw upon the patient as a co-producer of health. In the third role, patients can function as *evaluators* of care, when the patient's perspective is included in the assessment of care quality. These assessments can include reports of patients' experiences of care, reports of how care improved symptoms and functioning, and reports of how supported patients feel as partners in care. Although the informed choice role follows tradition in both its classical consumer form and its clinical informed consent form, the co-producer and evaluator roles are new and form the core of what is now called PCC.

Michie¹⁵ has organized PCC into two categories that parallel those of Hibbard: (1) taking the patient's perspective (as evaluator) and (2) activating the patient (as co-producer). Patient-centered components that would comprise taking the patient's perspective include exploring not only (objectively defined) disease but also (subjectively experienced) illness, understanding the whole person (e.g., taking the biopsychosocial perspective), and finding common ground with the patient (customization of care based on patient preferences and values). Patient-centered components that would comprise activation of the patient include sharing power and responsibility, supporting patient self-management, and involving the patient in the design of care. Some components in the Appendix table appear to include both dimensions (e.g., supporting patient self-management through goal-setting and confidence-building).¹⁶

Michie¹⁵ reviewed 30 studies describing the effects of interventions designed to enhance one or the other aspects of patient-centeredness. They found that 20 studies that focused on eliciting and responding to patients' beliefs generally resulted in improved patient satisfaction (6/10 studies) and improved patient adherence to treatment recommendations (6/9 studies). However, these interventions did not generally improve physical health outcomes (2/9 studies). In contrast, the 10 interventions that sought to activate patients in their own care enhanced physical health outcomes (6/7 studies) as well as adherence (5/7 studies) and satisfaction (2/2 studies) with care. They hypothesize that "It may be that supporting patients' independence to manage their own illness has effects on health outcomes over and above the extent to which patients adhere to specific advice given within each consultation." They suggest that the reason that patient activation appears to have benefits both within and beyond the clinical encounter is that it "may encourage patients to set their own goals and develop their own plans for achieving them." My interpretation of their findings is that the collaborative goal-setting component of patient activation actually requires taking the patient's perspective. So, taking the patient's perspective is a prerequisite for patient activation. This means that the comparison in the Michie paper is then between a

one-step model (patient perspective) and a two-step model of patient-centeredness (patient perspective and patient activation). Taking the patient's perspective is a prerequisite for activating patients on their own behalf.

4. PATIENT PERSPECTIVE

Health care organizations need to take the patient's perspective on care as part of their marketing and service efforts. Businesses entice customers by taking their perspective. My own hospital, the University of Washington Medical Center, has launched a Patients Are First initiative. This initiative focuses on satisfying patient needs for privacy and confidentiality, effective communication, professional conduct, accountability for service, and respect. Satisfaction of these needs is likely to make patients happier but may not make them healthier. This initiative is focused on health care *service* rather than health care *outcome*.

This common understanding of patient satisfaction as a form of customer satisfaction has led many clinicians and policy-makers to have doubts about the validity of patient satisfaction as a measure of health care quality: "Because consumers are not always equipped to evaluate technical competency, they tend to rely on peripheral elements of the encounter such as friendliness and the quality of personal interactions."¹⁷ Even if patients focus on the quality of the care delivered rather than the way it is delivered, they tend to like providers who order more medications and tests, especially if they are not paying for these. In certain clinical situations, such as the prescribing of controlled substances, a simple mandate to maximize patient satisfaction can produce patient harm through overuse of opioids and benzodiazepines.¹⁸

But it may be possible to focus patient satisfaction assessments more on quality of care than on quality of service. Indeed, professional and patient assessments of quality of care tend to track each other. For example, hospitalized patients' satisfaction increases with professional adherence to treatment guidelines.¹⁹ Surveys can capture care-focused communication, which is associated with other important outcomes, rather than more general interpersonal care experiences. Assessments that concentrate on patient-provider interactions at specific visits tend to track professional assessments of quality, especially if they are timely and risk-adjusted.¹⁷

One cardinal feature of patients may be neglected in these debates about the value of patient satisfaction: they are sick. This sickness creates a vulnerability that shapes patients' approach to care. Internist and economist Allen Detsky recently drew on his 30 years of experience to describe what patients want from health care. What they want most is their health restored.²⁰ This means that they want to resume their lives. They also want care that is timely, kind, and hopeful. They want care from well-regarded providers who know them and who talk to each other. Sick patients also like private rooms, no out-of-pocket costs, and treatments that do not demand too much effort on their part. Providers are often a poor judge of patients' health beliefs and preferences, but this can be substantially improved when patients are actively engaged

in the consultation with their provider.²¹ It is clear that patients want to be known as people by their providers because this allows patients to trust and engage their providers during times of illness.²²

Tanisha Bates

Tanisha couldn't really believe that Dr. Prutkin wanted to hear the details of her day, but she decided to play along, at least for a while. Surprisingly, he understood that having a kid on the swim team meant getting up at 5 A.M. every day, since his daughter swam at her high school. This helped her talk about the relentless pressure of the event-planning business, with everything coming at the last minute and needing to be done right now. As Tanisha talked about getting started with her workday, she realized that she liked the intensity of it. It kept her mood up. She felt useful and productive. It kept her from lapsing into depression like her mother had, which had put her in bed for days on end. When Tanisha started talking about her mother, tears started dribbling down her cheeks. She quickly grabbed a tissue and wiped them, and sat up straight in her chair. Dr. Prutkin also sat up and said, "I can see that there is a lot at stake for you in slowing down your lifestyle."

It is also important to remember that taking the patient's perspective includes much more than attending to patient satisfaction. Patients' perspectives on their health and their life are at least as important as their perspectives on their care experience. A recent review of literature on PCC in family medicine recommended starting from the patient's situation to legitimize the patient's illness experience, acknowledge his or her expertise, and offer realistic hope. The provider should develop an ongoing partnership with the patient and provide advocacy for the patient in the health care system.²³ It is most important to remember that patient satisfaction is not the primary goal of health care. Patient satisfaction is a good thing, but it is not the primary goal of health care, which is health. As I shall argue in Chapter 3, this health is neither a purely objective professionally defined state of the body nor a purely subjective personally defined mental state of well-being. When patient satisfaction and health point health care in different directions, we are obligated as health professionals to turn to shared decision-making and other patient-centered communication strategies to resolve the difference.

Eliciting the patient's perspective requires skills at patient-centered communication. Investigators such as Debra Roter and Ronald Epstein have systematically studied the characteristics of patient-centered communication. Roter explains the central role of communication for medical practice as follows:

Just as the molecular and chemistry oriented sciences were adopted as the 20th century medical paradigm, incorporation of the patient's perspective into a relationship-centered medical paradigm has been suggested as appropriate for

the 21st century. It is the medical dialogue that provides the fundamental vehicle through which the paradigmatic battle of perspectives is waged and the therapeutic relationship is defined.²⁴

This growing importance of communication was recognized in 1999, when the Accreditation of Council for Graduate Medical Education added a requirement for the accreditation of residency programs focusing on “interpersonal and communications skills that result in effective information exchange and teaming with patients, their families, and other health professionals.”

Epstein and colleagues have focused on communication as a crucial and concrete component of PCC. Definitions and measures of patient-centered communication in the professional literature vary considerably. However, among nearly 5,000 patients seeing 100 different physicians, Epstein’s group identified four different measures that were useful. These were autonomy support, trust, physician knowledge of the patient, and satisfaction. These four comprised a single factor with high internal consistency.²⁵ Patient-centered communication therefore hangs together as a coherent strategy in clinical practice.

In a 2011 report, the Institute of Medicine listed seven basic principles²⁶ to guide patient–clinician communication. These include mutual respect for patient and clinician as full decision-making partners with respect for the special insights that the patient brings into his or her ideas, values, and living context. Goals for care should be harmonized based on a mutual understanding of the risks and benefits of care options and agreement on the care plan. This is promoted by a supportive environment that accepts the patient’s culture and allows the patient to speak openly about sensitive issues. The patient and her partners need support in decision skills to allow for full participation in shared decision-making. Necessary information must be elicited from the patient about perceptions, symptoms, and personal practices. And the provider needs to be clear about limits to the scientific evidence for care options and to what the health system can do to implement these care options. Finally, good communication depends on continuous learning and feedback between patients and clinicians about clinical progress and emerging options.

These communication principles are justified on the basis of both ethics and health care effectiveness. I believe these principles summarize some of the best current patient-centered communication practices used to elicit the patient’s perspective on his or her clinical problem.

Ronald Epstein has gone beyond these consensus principles to offer the creative and disruptive concept of “shared mind” as a goal for patient-centered communication. Our usual understanding of patient-centered communication sees treatment decisions as arising from within the informed patient, as resulting from a primarily cognitive process, and ideally as an expression of individual autonomy. But, he reminds us, “important health decisions are usually not made in isolation.”²⁷ Patients engage trusted friends, family, and health professionals in these important decisions. This is not done to abdicate or offload the decision, but to come to a clearer sense of one’s

goals and preferences through dialogue. In unfamiliar or threatening illness, “patients’ preferences may be vague, unstable, and uninformed.” Honoring these preferences may not be as helpful to patients as helping them clarify and define these preferences. When unassisted, these “patients’ decisions might be neither truly informed nor autonomous, and patients may have limited insight into their own cognitive biases and limitations.” Epstein and Street illustrate this principle with the case of a retired epidemiologist who is bewildered by the options for treatment of his pancreatic cancer despite being far more familiar with medical evidence about treatment options than most patients.

Hospital ethics consultants know that it is best to strive for consensus among patient, family, and clinicians when facing difficult and complex decisions about life-saving care. But the concept of shared mind goes beyond the familiar goal of consensus among decision-makers to offer a new understanding of decision-making itself as an interpersonal process. Many of our most deeply held preferences, values, and goals are formed in relationship with trusted others. Our parents help shape our inner lives. Our best friends help us learn things about ourselves that we did not previously know. My best friend can even help me decide if I am really in love.

Clinicians who have seen us through other illnesses can also help us consider new information, adopt new perspectives, and consider new options. This “collaborative cognition” works best in relationships characterized by trust and “affective attunement.” In these safe relationships, “shared deliberation” can occur. This is not a negotiated compromise between well-articulated but disparate views. It is a “sense-making” process by which the situation is jointly understood and options for action articulated. It can result in the phenomenon of “shared mind” where “new ideas and perspectives emerge through the sharing of thoughts, feelings, perceptions, meanings and intentions among two or more people.” Shared mind is not necessary for all clinical decisions, and it is not the only means by which shared decision-making can be achieved. But it is a valuable strategy for the most difficult and distressing health care decisions. And it is an important reminder that non-interference with patients is not always the best way to respect our patients or foster PCC.

This vision of communication and decision-making might be chilling to advocates of patient autonomy who fear indulging physician paternalism. Isn’t this just license for physicians to resume the control of clinical decisions that was slowly wrested from them using legal and ethical arguments during the 20th century? (I review this process in the next chapter.) We must remember that patient autonomy can emerge through relationships (sometimes called “relational autonomy”) as well as be threatened by relationships. The dirty secret concerning physician paternalism is that healing is often more like parenting patients than like repairing patients, especially when healing chronic illness. Both healing and parenting can be focused on obedience, or they can be focused on fostering responsibility and independence. Patient autonomy has been considered by bioethics as something brought by the patient to the clinical encounter, which thus needs only respect from the clinician to function and flourish. An alternate view, compatible with Epstein’s notion of shared mind and my argument

in this book, is that patient autonomy is the goal of the clinical encounter. Serious and chronic illness threatens all aspects of patient autonomy including walking, talking, and decision-making. The central challenge of PCC is restoration of this autonomy. Epstein makes an important contribution to our understanding of the process of restoring autonomy because he helps us see that sometimes taking the patient's perspective also sometimes includes shaping that patient's perspective.

Tanisha Bates

Tanisha told Dr. Prutkin that there was indeed a lot at stake in slowing her day down: getting her son through high school and into college on a swimming scholarship, keeping her business going so she could pay for that college, and having some money to help her older children who were launching their lives. So she didn't really want to slow down her life. Dr. Prutkin suggested that maybe they did not need to slow all of it, or even most of it down. If they could find just a few minutes a few times a day for "mini mental vacations" perhaps her blood pressure medications would work better. He explained that these would involve producing the "relaxation response" by watching her breathing and letting her thoughts pass by with nonjudgmental awareness using a technique called "mindfulness." This sounded strange and unlikely to work to Tanisha, but Dr. Prutkin seemed to understand her pretty well for someone she just met, so she said OK.

5. PATIENT ACTIVATION

Activating patients on behalf of their own health seems very patient-centered, but the most prominent and well-developed programs to activate patients in self-management of their own chronic illnesses have been developed separately from the PCC tradition. Kate Lorig and Hal Holman at Stanford have developed and tested a program of self-management education over the course of the past 25 years for osteoarthritis and other chronic illness patients. Lorig and Holman describe self-management of chronic disease as unavoidable. Lifestyle includes health behavior relevant to chronic disease whether this is acknowledged and addressed or not.²⁸ They present three self-management tasks as central: medical management, role management, and emotional management. Only the first of these tasks would be included in a classical biomedical model of care, with the second and third more about the person managing his or her life than managing his or her disease.

Edward Wagner and colleagues at Group Health Cooperative in Seattle have developed and tested the Chronic Care Model, focused originally on improving the structure and process of care for patients with diabetes. Their initial model for the collaborative management of chronic illness had four main components: (1) collaborative definition of problems, with patient-defined problems identified along with medical problems

diagnosed by physicians; (2) targeting, goal-setting, and planning incorporating patient preferences; (3) creating a continuum of self-management training and support services; and (4) active and sustained follow-up in which patients are contacted at specified intervals to check on health status.²⁹ This clearly incorporates both aspects of patient centeredness, including both taking the patient's perspective and activating the patient.

Major efforts are now being made to disseminate both of these models of care. The Expert Patient Initiative in the United Kingdom is disseminating the Lorig-Holman model, while in the United States the Affordable Care Act has provided incentives to disseminate the Patient-Centered Medical Home (PCMH) model that is based on the Chronic Care Model. Let us turn to consider these now.

6. UK EXPERT PATIENT INITIATIVE

In 1999, the National Health Service in the United Kingdom set up an Expert Patients Task Force to synthesize work done on chronic disease self-management initiatives. The concept of the Expert Patient is based on the insight from doctors and nurses that patients with chronic disease "often understand their disease better than we do." The hope is that developing this "untapped resource" could benefit patients' quality of care and their quality of life. By developing patients' knowledge of their condition, they can become "key decision-makers," become "empowered to take some responsibility for their disease management," and gain "greater control of their lives."³⁰

The Expert Patients Program (EPP) has been implemented since 2001 as a lay-led self-management course specifically for people living with long-term conditions. The EPP course is open to anyone with a long-term condition, without referral from a clinician. The initial EPP course covers topics such as dealing with pain, fatigue, and depression; learning relaxation techniques and healthy eating; communicating with family, friends, and health care professionals; and planning for the future. The course is free and consists of six weekly 2.5-hour sessions. The sessions are run by two lay tutors who both have a chronic condition.

The EPP currently offers courses for approximately 12,000 patients per year through primary care trusts and partner organizations.

Lorig's Chronic Disease Self-Management Program has also been disseminated in the United States. The American Recovery and Reinvestment Act of 2009 provided \$32.5 million to disseminate the program. By 2012, 100,000 middle-aged and older adults had enrolled and 75,000 had completed at least four sessions. Participants had an average of 2.2 chronic conditions, most commonly hypertension, arthritis, diabetes, and depression. Two-thirds of participants were white, with 17% Hispanic and 21% African-American.³¹

The strategic direction of the EPP is based on three themes derived from surveys and interviews with more than 100,000 patients. The first is putting people more in control of their own health and care. The hope is that giving patients control will

increase the effectiveness of care and patients' responsibility for their own health. The second is enabling and supporting health, independence, and well-being. These are the outcomes that the surveys revealed people want for themselves. The third is rapid and convenient access to high-quality, cost-effective care.³² This involves better information about where to locate the most appropriate services and a decentralization of services out of hospitals and into communities. This program is thus intended to represent a "third way" between a "victim blaming" strategy that places all responsibility for health outcomes on the patient with chronic disease and a "paternalistic" strategy that places all authority and responsibility for health outcomes with health professionals.³³

The Chronic Disease Self-Management Program on which the EPP is based has been shown in randomized trials to improve symptoms (pain, dyspnea, fatigue), daily functioning, and depression.³⁴ Its ability to improve objective disease outcomes is limited to modest improvements in diabetes and asthma. Its ability to reduce health care utilization and lower costs appears to be limited to a reduction in emergency department visits in some studies.³⁵ It thus appears to be an inexpensive lay-led program with important benefits for symptom management and daily functioning in older adults, but it does not replace other chronic disease care.

An ethical critique of the Expert Patient (EP) program has also been made, largely in the British nursing and social science literature. This critique argues that EP confuses patient experience with patient expertise. It is doubtful that the patient is an expert in the same sense that the professional is an expert. Since the Enlightenment, Western societies have distinguished between publicly sanctioned expertise and private experience. Health care professionals gain the former through official training, whereas patients acquire the latter through their experience with illness.³⁶ It is different to know *that* you are ill and *what it means* for you to be ill (patient expertise) than it is to know *why* you are ill or to know *how* to make yourself well (professional expertise). Expertise in illness management is not the same as expertise in disease diagnosis.³⁷ Delineating the nature and limits of patient expertise is an important and incomplete task in the definition of PCC.

The critique also argues that EP may result in patient empowerment or in patient domination. This is because EP-supported self-management can appear to convert health into a duty. It certainly seems to shift the management of chronic disease from a public to a private responsibility, and it appears to impose contradictory roles and responsibilities on patients. The ideal EP patient would show an odd combination of compliance with professional recommendations and independent self-reliance.³⁸ EP would place the patient in a role of increased responsibility without increased authority. Health professionals would remain in control of access to prescription drugs. They would decide who could be excused from work or receive disability payments. Overall, it is not clear whether EP emphasis on self-management will enhance or diminish patient autonomy.³⁷ The EP is also not clear on the relation between the expert patient (having special knowledge and skills), the autonomous patient (free to decide), the

emancipated patient (free from legal or social constraint), and the empowered patient (free to act).³⁹ We will disentangle these in the following chapters.

Critics also argue that the EP may not adequately question the biomedical model of disease. Although some authors believe that the goals of EP can be realized by moving health behavior concepts beyond compliance and adherence to “concordance” (i.e., an informed collaborative alliance between patient and practitioner³⁹), others do not believe this adequate. They cite evidence of widespread disbelief in patient expertise by health professionals.³⁸ These EP critics have argued that any effective recasting of expertise between doctors and patients must also entail a basic redrawing of the relation between disease and illness. Within the EP, disease remains the objective and professional characterization of sickness from the third-person point of view, whereas illness is the subjective and patient characterization of sickness from the first-person point of view. EP is focused on self-management groups, so it operates outside the clinical setting, without clear roles for clinicians. It does not require clinicians to think or act differently.

Finally, the EP focuses on individual coping strategies for chronic disease. It does not provide any additional resources or external support for patients to manage their chronic diseases. Successful chronic disease management requires not only skills and confidence, but resources. For example, in Australia, chronic disease self-management training includes training in the development of social networks and social capital.⁴⁰

Although the EP initiative is very ambitious in its goals, some feel it is not ambitious enough. Those who chide the EP for not going far enough are largely nurses and social scientists, not physicians or natural scientists. I believe this is because EP advances no new theory of health or disease, the province of physicians and natural scientists. It appears to be about health behavior, which has traditionally been the province of nurses and social scientists. The EP appears effective at activating patients, but separately from clinical care. To effectively promote a patient-centered medicine, the program would need to engage both patients and clinicians at the level of medical theory as well as at the level of clinical practice.

7. PATIENT-CENTERED MEDICAL HOME

The Affordable Care Act has prioritized the strengthening of the US primary care system in the belief that this is the only way to produce cost-effective care for chronically ill patients. The major primary care specialty societies have proposed a new model for primary care called the Patient-Centered Medical Home (PCMH). The PCMH combines elements of the Pediatric Medical Home model for the care of chronically ill children and the Chronic Care Model for the care of chronically ill adults. The Pediatric Home model advocates a generalist physician team to provide continuous, comprehensive, coordinated, and accessible patient and family-centered care.⁴¹ The Chronic Care Model introduces structural modifications to primary care practice that support

planned proactive care and patient activation. The PCMH is based on the belief that the “best quality care is not provided in episodic, illness-oriented, complaint-based care,” but instead through care based on “continuous team-based healing relationships.” The PCMH model strays from the classic reliance on a “personal physician” to provide continuous primary care because it is not feasible for one professional to provide all the necessary elements of chronic illness care. In fact, just when primary care is most essential, there are looming serious shortages of primary care physicians. Every year, fewer medical students choose to train in primary care specialties due to the high work load and low salaries found in primary care.

The PCMH strategy to address this crisis is to “empanel” patients to a team including registered nurses and pharmacists as well as physicians, to engage medical assistants and other staff to function as panel managers and health coaches to address many preventive and chronic care needs, and to increase support for patient self-care.⁴² It is not clear whether patients experience this as a more personal or satisfying form of care. Some studies in organized care systems suggest that they do. Clinics in the Veterans Administration (VA) health system that more successfully implemented the PCMH model had higher patient satisfaction, higher performance on measures of clinical quality, and lower staff burnout, as well as lower hospitalization rates for ambulatory care-sensitive conditions and lower emergency department use.⁴³ PCMH implementations in less integrated systems have been less successful.⁴⁴ Indeed, the most recent summary of evidence by the Agency for Healthcare Research and Quality (AHRQ) in 2012 concluded that “The PCMH holds promise for improving the experiences of patients and staff, and potentially for improving care processes. However, current evidence is insufficient to determine effects on clinical and most economic outcomes.”⁴⁵

8. PATIENT EMPOWERMENT: A PATIENT-CENTERED CHRONIC CARE MODEL?

I have tried to argue that PCC consists of both taking the patient’s perspective on illness and activating the patient for self-care. Or, more precisely, it consists of taking the patient’s perspective *in order to* activate him for self-care. This is consistent with the argument by Wagner and colleagues that the “informed and activated patient” is one of the two essential foundations of the Chronic Care Model. (The other is the “prepared proactive treatment team.”)

But this description of the role of the patient in the Chronic Care Model is ambiguous in a crucial way. Is the “informed and activated patient” active or passive? It sounds as if an informed and activated patient is an active being, but who is doing the informing and activating, and for what purpose? What are the goals of this activation? Is the patient directing this activation according to his own goals, or is the patient being herded into pursuit of the goals of his providers and health system (e.g., lower Hb A1c)? These questions have led some to question how patient-centered the Chronic Care Model really is.⁴⁶

Consider the effort to get patients with diabetes to become active partners in their health care. Based on their long experience in working as educators of patients with diabetes, Anderson and Funnell explain how difficult it is for clinicians to move beyond what is generally seen as the “problem of patient non-compliance or non-adherence.”⁴⁷ This conceptualization of patient health behavior is borrowed from the acute-care setting and blames patients for not adhering to professional advice about medications and health behaviors like diet and exercise. Patients can resent this blaming and see it as an attempt to control their lives. Health behavior that appears irrational from the clinician’s disease-management perspective may be quite rational from the patient’s life-management perspective. Anderson and Funnell argue that clinicians must realize that patients’ “noncompliance” can be an attempt to maintain or reaffirm control over their own lives. “Ironically, patients can harm themselves physically to protect themselves psychologically.”⁴⁷

Tanisha Bates

Tanisha got the DVD on mindfulness that Dr. Prutkin recommended and she tried to follow the instructions, but it just felt so fake to her. It felt like she was pretending to be a skinny white lady sitting on a yoga cushion. So she quit. She really did not want to tell Dr. Prutkin she had quit because she liked him and wanted him to like her. But it came out anyway. Surprisingly, he was not angry or upset when she explained that she quit the mindfulness because it felt so not like her. He said that maybe that was not the right way for her. He asked whether she was interested in trying any other relaxation techniques. She said yes, but what? He asked what made her feel really calm. She mentioned some hymns that she knew as a kid. He asked how she might be able to enjoy those during her busy day. She thought for a bit, then said she could listen to them in her car since she drove around all day. Dr. Prutkin thought that was a great idea, but suggested that she park in a quiet place and allow herself five full minutes to really let the hymns seep into her bones. She thought that might work.

Clinicians who strive to activate patients often do so with the good intention of promoting healthy behaviors. But if true patient empowerment is to be achieved, then Anderson and Funnell argue, *compliance must be abandoned as the goal of the encounter*. Hence, patient empowerment is not just a counseling technique, but also a new set of goals for the clinical encounter. Patient empowerment results in the adoption of self-determined, but not necessarily healthy, behaviors. “The empowerment approach requires a change from feeling responsible *for* patient to feeling responsible *to* patients.”⁴⁷ This is a very important shift in the nature of clinical responsibility. We are responsible *for* babies and puppies and acutely ill patients who cannot survive on their own. We are responsible *to* spouses and friends and siblings who have their own agenda in life. “The empowerment approach simply recognizes that patients are already in control of the most important diabetes (chronic disease) management decisions.”

Patient-centeredness can be ambiguous in important ways. It can be part of a “patient-centered medicine” that questions biomedical diagnostic practices and disease theory, or it can be part of a more modest “patient-centered care” that questions health care processes but does not question these diagnostic practices and theories. There are also important ambiguities in the concept of patient empowerment. Anderson and Funnell spoke earlier of the “empowerment approach,” which construes empowerment as a specific form of health care. Others have argued that patient empowerment should be understood as a measurable patient-reported outcome for those with chronic conditions.⁴⁸ However, patient empowerment has not been well-defined as a patient-reported outcome and tends to be operationalized using other more familiar concepts. Most studies assessing patient empowerment actually assess patients’ success at illness self-management and at relating to health care providers.⁴⁹ Thus, empowerment is often subsumed under more familiar outcomes like self-efficacy regarding health behavior change or effective self-management behaviors.

A 2015 review of 67 articles defining patient empowerment identified key components of the patient empowerment conceptual map.⁵⁰ The underpinning ethos of patient empowerment concerns patient autonomy, self-determination, and power within the health care relationship. Health care interventions to increase patient empowerment have included training in patient-centered communication, shared decision-making, and motivational interviewing. The effect of these interventions is moderated by personal and contextual characteristics of the patient and provider. This effect is monitored through indicators of patient empowerment such as characteristics of the patient’s mental state (e.g., self-efficacy, coherence) or behavior (e.g., self-care). Finally, patient empowerment may lead to better patient outcomes like quality of life and well-being. Some related concepts may function in multiple roles. For example, health literacy can be a cause or an effect of patient empowerment.

Patient empowerment has most often been understood as a process of activating patients on their own behalf. This patient empowerment is conceived as an antidote to patient powerlessness. “Patient empowerment is therefore most often defined as a process of behaviour change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment.” This process of activating patients seeks to give patients control over medical decisions and treatment. Aujoulat and colleagues argue that this is based “on the assumption that patients most value being in control of medical decisions and management of treatment.”⁵¹

But patients are more complicated and more vulnerable than this. They are sick persons. And because of this sickness, they are dealing not just with health behavior change, but with threats to their bodily integrity and personal identity. They need to be empowered, not just with respect to paternalistic or controlling health care providers, but with respect to their illness.

Empowerment is not just informing and activating patients, as might be implied by the Chronic Care Model, but informing and activating patients on their own behalf. This raises questions concerning the identity of the patient: *Who* is this patient that we are empowering? What are his goals for his health and his life? Are they the same

or different from the goals for his health held by his provider and his health care system? The answers to these questions often change over the course of adaptation to chronic illness. Indeed, the need to reconstruct one's identity in the process of adjusting to chronic illness has been documented in diverse illnesses such as asthma, cancer, chronic fatigue syndrome, diabetes, and traumatic brain injury.^{52,53}

Aujoulat and colleagues argue that patient empowerment and control are not the same thing. Rather, patient empowerment is a process of personal transformation that includes both "holding on" to one's previous identity and roles so as to preserve the self in the face of illness and "letting go" of earlier identities and behaviors so as to integrate the chronic illness into a new self. While the former is a process of gaining control, the latter is a process of relinquishing control. Successful "empowerment occurs when patients come to terms with their threatened security and identity, not only with their treatment."⁵¹ Patient empowerment concerns the threats posed by illness as well as the challenges of health behavior change. Skillful health care providers can facilitate this process through the use of narratives.

9. PATIENT CAPABILITY: THE GOAL FOR A PATIENT-CENTERED CHRONIC CARE MODEL

The patient empowerment movement aims for a quite radical and fundamental change to the clinician–patient relationship. But it does not strive to reform the goals of health care or the structure of the health care system. To truly pursue a patient-centered agenda for health, we need to integrate patient-centered process and patient-centered outcomes, encompassing both the path of PCC and the destination of patient-centered health. This would reconfigure the ethical mandate for PCC (recognize full personhood of patient) and the effectiveness mandate (engage personhood in service of health) to make them compatible with each other. The goal for patient-centered health care would be to improve patients' health by improving their capabilities to pursue health and other vital goods. It will take me the rest of this book to explain exactly what this means.

The intention of PCC is to correct care that has become too disease-centered or too profession- and system-centered. In essence, it strives to counter a pervasive depersonalization of health care. This aim can be lost in many of the recent formulations of PCC because these formulations remain focused on traditional health outcomes. Entwistle and Watt explain in a recent paper that "a tendency to think of PCC primarily in terms of *processes* encourages a tendency to focus on its value as instrumental." We often lapse into comparing PCC with usual primary care in terms of their ability to produce traditional health outcomes. This makes patients the means to achieving population or institutional health metrics "regardless of patients' life projects and priorities." Or we compare PCC with usual care in terms of their ability to produce patient satisfaction. Patient satisfaction can seem like a shallow and easily dismissed goal for health care reform. But the common and slightly broader focus on satisfaction

of patient preferences (e.g., by Berwick) is problematic for the same reason as the focus on patient satisfaction. Are all patient preferences to be honored, even if they are poorly informed, distorted, or counterproductive? If not all preferences, which are not to be honored? What are the limits? By what standard are these limits set? In fact, many patients and families do not want their preferences to dominate those of professionals. They prefer guidance from professionals for difficult, complex, and emotion-laden decisions. They don't want difficult health care decisions "dumped" on them by professionals who are respecting their autonomy. Patients and families have varying preferences about the role that their preferences should play in care decisions.

If we are to succeed at treating patients as persons, we need to look beyond preferences to the defining characteristics of persons. In contrast to the Institute of Medicine report and other institutions calling for PCC, I do not believe patient-centeredness can function primarily as a measure of the *quality of care* received, because it is ultimately concerned with the *quality of patients' lives*. In our modern, liberal society, we try to avoid specifying the nature of a quality life. But this may be a mistake. If we don't know what a quality life is, we can't aim health care toward that goal.

Throughout this book, I will draw on the capability approach to quality of life first developed by the Nobel Prize-winning economist Amartya Sen.⁵⁴ I will provide a brief sketch here. Drawing on an Aristotelean sense of the good life as human flourishing, Sen centers his account of the good life on the ability to do and to be things of value. Rather than focus on income as the primary measure of development for a society, he concentrates on *functionings*, which are actual doings or ways of being, and *capabilities*, which are genuine opportunities that individuals have to achieve particular functionings. Many different capabilities can be valued. The valuing and achievement of these capabilities is shaped through social and political processes, so Sen avoids specifying a core set of capabilities. In their application of the capability approach to health care, Entwistle and Watt focus on a subset of what they call "personal capabilities" that can guide the effort to treat the patient as a person. These include "capabilities to reason, to feel and respond to emotion, to intend and initiate action, to be self-aware and self-directing, to experience particular kinds of suffering, and capabilities to participate socially in a group or community of beings that recognizes each other as having significant ethical privileges."⁵⁵ Sen originally developed the capability approach to lead international development policy away from a focus on income, but it has been fruitfully applied to justice policy within countries, and now, to health policy.

In contrast to most conceptualizations of PCC that are not based on any clear conception of what a person is, "The capability approach employs a fairly specific conception of what persons are, namely, that they are *agents* of their own capability development."⁵⁶ *Without a rich sense of patient agency, we lapse into respecting patient autonomy through noninterference. This is because we don't know how to foster autonomy other than not interfering with it.* The capability approach argues that the most important thing to people is their ability to function as persons. If this is so, health care needs to understand what this is and aim for it. But the most crucial functionings and capabilities

vary from person to person, so no one set of goals will suffice. “A capabilities-based metric is not a simple set of rules but rather guidelines for investigating and identifying people’s values regarding their sense of themselves as persons.”⁵⁶ This investigation of capabilities must occur through patients’ narratives about who they are and how they relate to their illness.

Tanisha Bates

It took some getting used to, but Tanisha found she looked forward to her “hymn breaks” as she called them. She found some quiet spots after she dropped off her son, after lunch, and when she stopped by her office at the end of the day. It worked even better after she bought herself a nice pair of headphones to wear. And Dr. Prutkin was happy. Her blood pressure was down to 142/95 on just one medication. He suggested adding a second medication at her last appointment, but she asked if they could wait another month or so for the hymns to work their magic. He said fine.

10. SUMMARY AND CONCLUSION

Patient-centered medicine started as a fundamental challenge to the dominance of impersonal diagnosis of illness in the care of patients. In more recent years, it has been reshaped into an approach to PCC that seeks to honor patients’ values and preferences but that does not change our understanding of the nature of the clinical problem. Two core components of PCC—taking the patient’s perspective and activating the patient for self-care—have been incorporated into large efforts to promote PCC: the Expert Patient Program in the UK and the Patient-Centered Medical Home in the US. But these efforts to improve the process of health care have not adequately questioned the goals of health care. We must think beyond PCC to consider patient-centered health. This will include efforts to foster the empowerment of patients or, more specifically, to increase their health capability. To understand what is new and important about these efforts, we need to understand previous efforts to “treat the patient as a person,” such as the call by bioethicists to respect patients by respecting their autonomy.

APPENDIX

TABLE 2.1

The Components of Patient-Centered Care								
<u>Clinicians</u>		<u>Foundations</u>		<u>Organizations</u>		<u>Reviews</u>		
Michie 2003 ¹⁵	Stewart 2001 ⁵	Picker 2005	Commonwealth 2005	IOM 2001	WHO 2005	AGS 2015	Bergeson 2006 ⁶	Scholl 2014 ⁸
Patient perspective	Understanding whole person Exploring reason for visit, concerns, need for information		Patient informed and engaged in care	Clinician respectful and responsive	Clinician listening and communicating	Individuals' values and preferences guide all aspects of their health care		Patient as unique person, biopsychosocial perspective
	Respect for preferences, values							
	Physical comfort							
				Customization is based on patient needs and values	Sharing decision-making and management; respecting patients' preferences	Individualized care plan based on the persons preferences		Tailored information, decision collaboration
					relieving pain and suffering	Focus on quality of life as a higher priority that specific health metrics		Support for pain and function

(continued)

TABLE 2.1

Continued								
<u>Clinicians</u>		<u>Foundations</u>		<u>Organizations</u>			<u>Reviews</u>	
Michie 2003 ¹⁵	Stewart 2001 ⁵	Picker 2005	Commonwealth 2005	IOM 2001	WHO 2005	AGS 2015	Bergeson 2006 ⁶	Scholl 2014 ⁸
		Emotional support for patient Involve family and friends	Ongoing patient feedback	Patient acts as the source of control			Increasing patient participation in care	Clinician shows respect, empathy, self-awareness
	Common ground concerning clinical problem	Clinician provides information and education	Publicly avail info on practice	Knowledge is shared, flows freely, be transparent to patients and families	providing education and information	Communication with the team about what the person wants to achieve	Involving patient more in design of care	Trust and caring partnership
Patient activation	Prevention and health promotion			Decision making is evidence based Safety is a system property	Preventing disease, disabilities, and impairments promoting wellness and health lifestyles	Care supported by interprofessional team in which the person is an integral member	Supporting patient self-management through goal-setting/confidence building	

	Coordination of care	Care coordina- tion Clinical info system for QI			More efficient and reliable care coordination	Teamwork, coordination of medical and non-medical care
Enhance continuous doctor– patient relationship	Continuity of care	Integrated comprehen- sive care	Continuous healing relationships System anticipates patient needs		Improving continuity	Continuity of care Patient empowerment
	Access to care	Access to care			Improving access	Access to care

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