

RE-THINKING THE DOCTOR-PATIENT RELATIONSHIP:
A PHYSICIAN'S PHILOSOPHICAL
PERSPECTIVE

by

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DISSERTATION ABSTRACT

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The principle of respect for autonomy has been the center of gravity for the doctor-patient relationship for forty years, replacing the previous defining concept of physician paternalism. In this work, I seek to displace respect for patient autonomy with narrative and phronesis as the skills that must be mastered by the physician to engender a successful therapeutic clinical relationship.

Chapter I reviews the current state of affairs in the philosophy of medicine and the doctor-patient relationship and explains how and why autonomy has become so central to physicians' understanding of how to conduct a clinical encounter with a patient. Chapter II argues that "respect for autonomy," while remaining a valid rule to be considered in some clinical relationships, cannot be the central concept that defines the relationship both because it fails to describe accurately human selfhood and also because it empirically lacks universal applicability—many humans, and most seriously ill patients, actually lack autonomy. Shared decision making, an autonomy-based model of the doctor-patient relationship, suffers from this critique of autonomy as well as its own shortcomings in that it maintains a strict fact/value distinction that is untenable.

Chapter III introduces narrative philosophy and its extrapolation, narrative medicine, as a possible alternative to an autonomy model of care. I defend a narrative view of selfhood, while recognizing that even if we are in some sense narratively constituted, this still leaves many questions regarding the relationship between story and self, particularly in a clinical encounter. In Chapter IV, I seek to limit the claims of narrative by arguing that story and self can never be fully equated and that narrative must be understood as demonstrating alterity rather than eliminating it. In Chapter V, a new conception of the physician's role in the doctor-patient relationship is presented, combining phronesis, or practical wisdom, with narrative skill in four aspects of the clinical encounter: diagnosis, treatment, assistance in medical decision making, and emotional support of the patient.

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CHAPTER I
AUTONOMY AS THE PRINCIPLE THAT SHAPES THE DOCTOR-PATIENT
RELATIONSHIP

Introduction

Several years ago, I attended a meeting between the obstetricians and home birth midwives in our community, after a bad outcome had occurred in a home birth. A contentious discussion began when an obstetrician in my group announced that the midwife should have “forbidden” the patient from attempting to deliver her baby at home, because of the particular risks of this case. A midwife defended her colleague by taking issue with the idea of “forbidding” patients, or clients, as midwives refer to the women in their care, to make decisions. Only midwives, she said, truly know how to treat their patients as “autonomous.” Doctors, she continued, routinely violate patient autonomy, much to the detriment of their patients’ care.

I found her attack so inconsistent with my own beliefs that I did not know where to begin. Despite my belief that respecting patient autonomy does not necessarily lead to good care, I said that for a doctor to express his or her professional opinion about a patient choice that may be dangerous or ill-advised is not an instance of violating patient autonomy. What I did not say, however, was that I think her statement is wrong at several other levels.

First, I have often thought that midwives tend to have relationships with their clients that are more intimate and therapeutic than typical doctor-patient relationships, precisely because they focus more on attending to and providing for needs (both intuited and articulated), rather than on “respecting the autonomy” of the pregnant woman. I see this as a matter of degree, not as an absolute. It is not that midwives “trample” their patient’s autonomy, but rather that this is not the central concern—it does not *structure* the relationship the way it seems to within physician-led clinical encounters.

Second, I believe that holding autonomy as a primary principle in determining the nature of the clinical relationship has done more harm than good. That is, although autonomy serves as a safeguard against paternalism, it can act as a barrier or pre-fixed limit to the relationship that at times prevents adequate physician guidance and even expressions of empathy. Thus, to engage in a debate about which profession treats its patients/clients with the greatest autonomy is to be arguing on the wrong side of this issue. I should emphasize that I am not arguing in favor of violating autonomy.

Autonomy is an important principle that should only be violated when there are other overriding concerns. However, we must find a different way of envisioning the nature of the doctor-patient relationship. There are values other than autonomy which should *structure* the relationship; autonomy should not be a “structuring value,” if you will, but rather a *limiting* one. Autonomy does not describe what is central to the relationship.

Third, even within the framework of principles described in the theory of medical ethics now known as the *Principlist* method, autonomy is but one of the four principles, and any principle can in a given case be overridden by another principle that is judged to be more important or relevant to the circumstances (Beauchamp and Childress 2009).

Thus, in the aforementioned midwife case, telling the young woman that giving birth at home would put her baby at serious risk and strongly urging her to transport to the hospital might be seen by some to violate her autonomy, but to fail to do so violates the principles of beneficence and non-maleficence. Beauchamp and Childress did not envision autonomy to be the ascendant principle, and those who do distort the intent of the Principlist Theory (Gillon 2003). When Gillon writes that autonomy is “first among equals,” he acknowledges the power that the principle has gained both in medical ethics and in physicians’ minds as they approach a patient encounter. Doctors are reluctant to admit that they ever choose to make a decision that overrides patient autonomy, even though Beauchamp and Childress never intended autonomy to be a “first principle.”

Some may argue that the debate about who respects autonomy more, midwives or physicians, amounts to nothing more than a “pissing contest” and reduces the principle of autonomy, so carefully explained and delimited by Beauchamp and Childress, to a mere caricature of its true meaning and value. In this light, others have sought to reform the principle of autonomy in medicine, while simultaneously critiquing and acknowledging the flaws in its current conception (Tauber, 2003; Tauber, 2005; Keller, 1997).

While there have been some excellent efforts to critique and reformulate the principle of autonomy, this endeavor is doomed to failure, because no matter how flexible and nuanced the reformulated principle of autonomy becomes, it nonetheless should not positively define, but only limit, the doctor-patient relationship. It is not simply that physicians misunderstand the principle of autonomy, although many most assuredly do; it is also that autonomy has been given the wrong role or place in determining the doctor-patient relationship. To paraphrase Paul Ricoeur’s description of the clinical relationship,

at the center of the relationship resides the *phronetic* act of finding the *just distance*—the proper therapeutic relationship appropriate for that singular encounter, arrived at through experience, medical knowledge, and an appreciation of the patient and her illness obtained by attention to the patient narrative_(Ricoeur 2007; Qualtere-Burcher 2009). Deontological principles, such as autonomy, that generate rules of the relationship are not central to the relationship, because in most cases these limits serve merely as boundaries not to be transgressed. They are “the protections necessary in a profession where money and power always place the patient at risk” (Morris 2002). The limits of the relationship no more describe the relationship than the injunction against adultery describes the nature of marriage.

Medicine needs to look anew at the doctor-patient relationship, and seek again to describe or structure it, in ways that do not ignore the boundaries or rules necessary to prevent transgressions that destroy the clinical encounter, but that focus instead on what is central to the encounter. The aim of this work is to articulate a positive conception of the doctor-patient relationship. I will engage the current understanding of the ends of medicine and the doctor-patient relationship, and then discuss the alternatives currently in play to reform the existing structures. None of these is adequate to replace the autonomy model of the clinical encounter, but narrative medicine comes closest. While narrative medicine has its shortcomings, too, it is a better starting place than autonomy, because it accommodates a multiplicity of principles rather than confining the relationship to one. As Mark Johnson describes in *Moral Imagination*, principles arise from narrative structures; beginning with one principle, then precludes, or at least reduces the role of, narrative, as well other important principles (Johnson 1993).

A Philosophy of Medicine

Medicine is in crisis on multiple fronts. Continuing issues of health care economics and the pace of technological advance have challenged medicine for decades, with no resolution in sight. There is an internal crisis, variously characterized, about the “soul” of medicine as well. Kathryn Montgomery argues that some of medicine’s problems are internal to its own lack of understanding of itself (Montgomery 2002). She describes this failure in terms of an art/science divide that is both misrepresented and poorly negotiated by both practitioners and philosophers of medicine. Physicians overrepresent themselves as scientists at the risk of neglecting the judgment required in clinical medicine. Montgomery writes that the science/art dichotomy is actually a false one, because medicine is actually neither. At its root, medicine is a moral practice that uses both art (as practical judgment or *phronesis*) and science to accomplish the end of caring for the patient. The point here is that medicine lacks the tools to understand itself, and that physicians fail to grasp their own profession because they do not appreciate that at the center of their field, the founding moment of medicine, is neither art nor science, but the care rendered to a suffering other as patient.

In *Doctor’s Stories: The Narrative Structure of Medical Knowledge*, Kathryn Montgomery Hunter argues that medical practice requires both phronesis and narrative skill, but she means this in a different way than Rita Charon, who has written much to popularize narrative medicine (Montgomery Hunter 1991; Charon 2006). Montgomery Hunter is referring to the way the physician must discover, and then tell, the story of the

illness. This begins in the patient's story, which is the focus of narrative medicine as Charon describes it, but Montgomery Hunter emphasizes how each illness is a story separate and unique from the disease that causes it. She describes the hermeneutics of medical diagnosis, the recursive path from the unique to the general and back, as that which distinguishes clinical practice from science:

Medicine is an interpretive activity, a learned inquiry that begins with the understanding of the patient and ends in therapeutic action on the patient's behalf. Far from being objective, a matter of hard facts, medicine is grounded in subjective knowledge—not of the generalized body in textbooks, which is scientific enough—but the physician's understanding of the particular patient... The interpretation of the individual patient's physical signs in order to construct a coherent and parsimonious retrospective chronological account of the malady is a methodology that, while thoroughly rational, is distinct from that characteristic of the physical sciences. That physicians are scientifically educated and technologically trained alters not one bit the narrative structure of their *practical knowledge* (Italics added) (Montgomery Hunter 1991).

Montgomery Hunter claims further that the failure to understand medical practice as phronetic and narrative has done harm to the doctor-patient relationship. Making medicine appear to be a science gives physicians and patients unrealistic expectations (Montgomery Hunter 1991). It also distorts the clinical encounter in that it fails to recognize the uniqueness of each patient and each illness. The equation of illness with disease produces a reification and a metonymy—the woman with heavy periods becomes the uterus with fibroids. Diseases become ontological entities rather than a classification system, and people with ailments are reduced to their ailments, or even failing body parts, as the scientist focuses only on the general phenomenon represented by the specific instance, rather than the tension and relation among person, illness, and disease. Obviously, this scientific model of medicine places little importance on the niceties of

patient interaction, care, or empathy. Furthermore, it is thoroughly compatible with an autonomy-based model of the relationship in that just as the fact-gathering of science is supposed to leave its subject untouched and unchanged by the scientific process, the physician as scientist gathers information from the patient, reaches conclusions, and offers this back to the patient in the least intrusive manner. That is, the patient is left untouched by what the doctor comes to know about her.

If Montgomery Hunter is correct that medicine fails to understand itself, mistaking an interpretive enterprise for a physical science, and that this in turn leads to distortions and misconceptions about the nature of the doctor-patient relationship, then certainly part of the work that needs to be done in any philosophy of medicine would concern the doctor-patient relationship. But simultaneous with this is the need to reopen the discussion of the nature of the clinical encounter and what its philosophical underpinnings actually are, since the practice of medicine is not, as Montgomery Hunter concludes, a scientific enterprise. I believe that the work of developing the philosophy of medicine, a work which Arthur Caplan believes is still to be done, includes this project (Caplan 1992).

Arthur Caplan describes the crisis within medicine as arising from the incoherence surrounding a philosophy of medicine (Caplan 1992). He argues that the unsuccessful efforts to date in finding a unifying principle or foundation for a philosophy of medicine have hampered progress both in medical ethics and in medicine's struggles with economic, political, and technological issues. Furthermore, he decries a lack of "problems" within the body of work that inadequately constitutes the field of philosophy of medicine. By this, Caplan means that a philosophy of medicine has yet to identify what

its central issues are. Although Caplan believes that a philosophy of medicine must be metaphysical and epistemological, ultimately it grounds the normative concerns of bioethics. One concern that has been prematurely settled within the philosophy of medicine is the nature and implications of the doctor-patient relation, and Caplan is correct that this is foundational to developing an ethics of the clinical encounter.

The Doctor-Patient Relationship before an Autonomy Model

Although I will soon describe the historical reasons for the ascendancy of an autonomy model in the clinical encounter, it is of some value to review the conceptions of the doctor-patient relation prior to autonomy's domination. It is largely assumed that autonomy models vanquished a paternalistic approach to medicine. While this is true to some extent, it overlooks that prior to an autonomy or rights-based version of the clinical encounter, there were those who viewed the relation through a lens that was neither paternalistic nor founded in autonomy. Thomas Szasz and Marc Hollender, both practicing psychiatrists, published an often-cited paper in the *Archives of Internal Medicine* in 1956 (Szasz and Hollender 1956). They described three models for the doctor-patient relationship, arguing that no model is superior to another, but rather that the patient, the disease, and multiple other factors needed to be considered to ascertain which model is appropriate in any given circumstance.

The first model, "activity-passivity," has an entirely passive patient receiving care from the physician, who is also the sole decision maker. Although this is a strong version of the paternalism model, Szasz and Hollender argue that it is a common model of care in

emergency settings and pediatric practice. The second model is “guidance-cooperation,” in which the patient willingly concedes power to the physician and cooperates with the physician’s treatments. This is a weak paternalism, in that the patient chooses to follow the physician based upon the knowledge possessed by the physician. Szasz and Hollender claimed that this was a common model at the time of their writing, particularly for hospitalized patients who were struggling with significant illnesses. The third model of care is “mutual participation,” which Szasz and Hollender likened to a psychoanalytic model:

Philosophically, this model is predicated to the postulate that equality among human beings is desirable. It is fundamental to the social structure of democracy and has played a crucial role in occidental civilization for more than two hundred years. Psychologically, mutuality rests on complex processes of identification—which facilitate conceiving of others in terms of oneself—together with maintaining and tolerating the discrete individuality of the observer and the observed (Szasz and Hollender 1956).

Although the third model sounds preferable to the first two, at least from the patient perspective, Szasz and Hollender make the important claim that all three models are valid and useful in some situations. That is, the third model is one model of care, and the other models should not be judged inferior because patient choice and decision-making ability are more curtailed. The importance of choosing the correct model for the patient and the illness is the insight that Szasz and Hollender first present in this paper. It is important to remember that this insight seems largely to have been forgotten in the literature on the doctor-patient relationship. For example, although Beauchamp and Childress concede that an autonomy model of care is not appropriate for every patient, they do not offer other models for when their model fails.

The other important perception offered by Szasz and Hollender's paper is that the model of care cannot remain static, even with the same patient over time. They give the example of a diabetic patient in a ketoacidosis coma (Szasz and Hollender 1956). The internist first encountering this patient must use the first model of care (activity-passivity). The comatose patient can express no preferences or even cooperate. As the patient recovers, but is still hospitalized and gravely ill, the model changes to the cooperative model. The patient recognizes that he needs to follow the physician's recommendations carefully, if he wishes to recover. For an outpatient, now feeling well, with a chronic disease that requires control, the patient and physician can adopt a mutuality model, in which the patient's decision making and preferences regarding treatment can become the primary aspect of discussion, and "the physician helps the patient help himself"(Szasz and Hollender 1956).

Szasz and Hollender were the first to introduce two aspects of the doctor-patient relationship that I believe are crucial to any model that is truly adequate to describe the full range of possible relations within a medical setting. First, there must be more than one way of understanding the patient-doctor relationship—the model or models must have the flexibility to describe every encounter from a gunshot wound patient in the emergency room, to a laboring woman in a birthing center, to a college student seeking preventative care, to a dying patient with colon cancer who wishes only to be kept comfortable and near his family. Second, it should be recognized that over time, relationships change, people and illnesses change, and any model of care must therefore recognize and be able to describe how such change can be understood and accommodated. Most current models fail utterly on both of these points.

Another important contribution to the dialogue on the doctor-patient relationship, prior to the ascendancy of the autonomy model, is Eric Cassell's book *The Healer's Art: A New Approach to the Doctor-Patient Relationship* (Cassell 1976). Eric Cassell has had a long career as both a bioethicist and practicing internist. James Marcum has described him as a "humanistic practitioner," because the aim of his writing has been to shift the focus of medicine from disease to "the patient's experience of illness" (Marcum 2008). Although Cassell's later work can be seen as responding to an autonomy model of care, in *The Healer's Art*, he addresses his concerns toward the misplaced focus of medical care, i.e., its preoccupation with disease, and its impact on the clinical relationship.

In contrast to the autonomy model, Cassell sees the greatest threat to medicine and the doctor-patient relationship to be not physician power or paternalism, but rather technological training in medical school that renders patients unimportant and places the treatment of disease at the forefront of medicine. In this book, and throughout his long career of writing on medicine, Cassell makes two claims, both of which I support and incorporate into my own sense of what medicine and the clinical encounter must encompass.

- 1) Medicine is a moral art that uses science. It is not a science:

Since the physician deals directly with the welfare of individuals, medicine must be recognized as a moral profession whose tools are, in part, technical. I say in part, rather than entirely, technical because one of the most important tools of medicine is the person of the physician himself. Medicine is concerned with the care of persons *by* persons, as simple as that (Cassell 1976).

Like Kathryn Montgomery Hunter, Cassell is reclaiming medicine as teleological. His aim is to restore the patient's health, relieve suffering, and allow patients to regain control of

their lives. The focus of medicine must be the patient, not the disease. As Cassell points out, the physician's role is most critical when there is nothing that can be done about the disease.

If medicine, as a scientific enterprise, was correct that the treatment of disease is central to physician care, the physician could excuse herself when she has no therapeutic treatment to offer. But nothing is farther from the case. When I was a medical student I worked for two months on an oncology unit (cancer) at my medical school. The unit was at that time full of young patients with chemotherapy -resistant lymphoma (cancer of the lymph nodes). They were participating in a clinical trial of a new medication that might reverse chemotherapy resistance, allowing other conventional medications to kill their cancer. The trial was a failure, at least for this group of patients. None of them responded, and they all needed to be told that there were no other effective treatments available to them—they would all be dead within a few weeks. The doctor who led the trial chose not to break the news to his patients; instead, he left it to the new doctor coming on the service after the trial had been stopped. I remember the new oncologist's anger at him for failing to explain to the patients the results of the trial. But what I remember most is the Saturday when it took her the whole day to sit with each patient and deliver the terrible news. She spent as long with each patient as they needed; she answered the same questions over and over, sometimes with the same patient wondering why there was nothing left to be done. She held their hands, she cried with them, and she only moved on when the patient she was with was ready to be alone, or with family. The time she spent that day, and the following days, gave each of those patients an opportunity to accept and face their impending death. It was the only effective therapy

they received in the hospital, except perhaps for the medications that eased their pain in their final days. If medicine is a science, she did nothing. If medicine is a moral art, as Cassell claims, she was a healer. To answer this question, we need only reflect on which oncologist we would choose for our family or ourselves.

Returning now to Cassell's second point:

- 2) The role of medicine is the care of other persons (patients). This is often accomplished by treating disease, but the treatment of disease has wrongly been moved to the center of medicine:

...there must be a similar distinction between healing and curing. If a sick person indeed presents two different aspects of his sickness—the illness and the disease that caused it—the doctor must respond with two separate functions, no matter how closely connected they may be or how the curing function may conceal the healing function. To the doctor who does not distinguish between illness and disease, making a patient with pneumonia better means curing the pneumonia—killing the bacteria, bringing down the fever...but there are other aspects of the illness that the doctor may ignore: the patient may be frightened about what is happening in his body; he may feel cut off from his family and friends, and he may find himself painfully dependent on other people. Healing those aspects of pneumonia is also part of the doctor's job, a part of the healing function... (Cassell 1976).

Healing is care of the person, directed at the person and the needs and fears brought on by the illness; curing is activity directed at the disease itself that can at times seem to leave the patient feeling superfluous.

Forty years after writing *The Healer's Art*, Cassell argued that an autonomy model of the patient-doctor relationship actually prevents the caring function of the physician, and the full benefit of a therapeutic relationship:

Taking care of the sick must have been a heavy responsibility for doctors, or they would not have been so eager to get out from under it and let patients make health care decisions on their own—what I think of as the cafeteria model of medicine...therapeutic relationships can bring about biological changes in the body and therefore affect healing. If this is so, then some currently popular ways of thinking about autonomy may have negative effects on patients' well-being (Cassell 2007).

The direction of medicine since the writing of *The Healer's Art* has been away from the lessons that Cassell tried to teach. The autonomy model, as Cassell writes, impedes the kind of relationship that he and I both believe to be the most therapeutic. The reasons for this will be explored further in chapter 2, but now it is time to look at the historical reasons for the rise of the autonomy model to the center of the doctor-patient relationship.

The Rise of Autonomy

Medical ethics arose as a discipline in response to serious medical and scientific misconduct at the expense of patients and study subjects. Two events that were pivotal in the development of the discipline of medical ethics, and that gave impetus to placing respect for autonomy at the center of ethical principles within the field are the “God Committee” in Seattle and the Tuskegee syphilis experiment.

The God committee was created after the development of the first dialysis machines in the early 1960s. A group of laypeople was chosen to determine who would receive dialysis and thus live, and who would be denied this treatment and then die of end stage renal failure (Jonsen 2007). Many of the criteria they used have been judged as both discriminatory, for example, favoring married over single persons, churchgoing over

nonreligious, and utilitarian, for example, how many children would be left behind to be supported by the state. News of the criteria used by the committee to select who would receive this scarce treatment option provoked outrage among both ethicists and the general public (Jonsen 2007).

The Tuskegee experiment was a longitudinal observational study of 399 Black men in Alabama infected with syphilis (CDC 2011). They were observed as study subjects without treatment from 1932 until 1972. Effective treatment for syphilis was developed in 1947, but the study subjects were not told of their condition, and treatment was never offered. When the study was made public, one of the researchers defended the men's lack of treatment, saying, "The men's status did not warrant ethical debate. They were subjects, not patients; clinical material, not sick people" (Tuskegee 2011). The Belmont Commission was established in response to the outcry over the Tuskegee syphilis experiment. A group of researchers, philosophers, and theologians met over a four-year period and in 1979 produced the Belmont Report (Ryan et al. 1979). It established the Office for Human Research Protections and led to the development of Institutional Research Boards that would be established wherever human research is conducted within this country. The board also established principles, which it believed would be useful guidelines for determining whether a proposed study involving humans was ethical. These three principles were: respect for persons, beneficence, and justice. The description of "respect for persons," however, was immediately equated with "respect for autonomy," which is how this principle has since been understood:

Respect for persons incorporates at least two basic ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons

thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.

An autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show a lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so (Ryan et al. 1979).

Given its nature as a response to serious ethical lapses, it is not surprising that “respect for autonomy” became the central principle guiding the doctor-patient relationship. This ascendancy continued with the publication of Beauchamp and Childress’s *Principles of Biomedical Ethics*, beginning with its first edition in 1979. This text has been central to medical education and medical ethics (Beauchamp and Childress 1979). Its four principles are based upon the three principles of the Belmont Report, but non-maleficence is made a separate principle in this work, rather than being subsumed under the principle of beneficence as it is in the Belmont Report.

I taught medical ethics seminars to students at Oregon Health Sciences University during their third and fourth years in medical school for several years. My students have already received lectures on medical ethics during their first two preclinical years. I never encountered a medical student who knew any methodology for deliberating on medical ethical issues other than the principlist theory put forth by Beauchamp and Childress. Although bioethicists are divided in their loyalty between different schools of thought regarding methods of deliberating medical ethical cases, by and large medical students and physicians learn only the principlist method.

The four principles of this theory are: autonomy, beneficence, non-maleficence, and justice. The authors describe these four principles useful for resolving bioethics dilemmas as *prima facie* but non-hierarchical—that is, no principle takes priority over another until the actual case is presented, and it is the particulars of the case that decide which principle is most important in each instance. Despite this, autonomy has been widely regarded as the principle least justifiably abrogated by the other principles, regardless of the circumstances of the case. For example, Raanan Gillon argues that autonomy makes ethics possible, so to fail to put autonomy at the center of medical ethics, and by implication at the center of the doctor-patient relation, is to fail to be moral (Gillon 2003).

In the most recent edition of *Principles of Biomedical Ethics* (PBE), Beauchamp and Childress define autonomy as “self-rule that is free from both controlling interference by others and from certain limitations such as inadequate understanding that prevents meaningful choice” (Beauchamp and Childress 2009). In light of much of the critique that their principle of autonomy has received over the last thirty years they also stipulate that:

We attempt to show that, in a properly structured theory, respect for autonomy is not excessively individualistic (thereby neglecting the social nature of individuals and the impact of individual choices and actions of others), not excessively focused on reason (thereby neglecting the emotions), and not unduly legalistic (thereby highlighting legal rights and downplaying social practices and responsibilities) (Beauchamp and Childress 2009).

In this description of autonomy can be read the lines of attack that the principle has received since the first edition of PBE in 1979. Unlike their description above, in 1979 Beauchamp and Childress drew explicitly on the ethical writings of philosopher

Immanuel Kant for their notion of autonomy. That is, in 1979, Beauchamp and Childress used a directly Kantian sense of autonomy:

Kant contrasted heteronomy (rule by other persons or conditions) and autonomy. Autonomy is governing oneself, including making one's own choices, in accord with moral principles which are one's own and which are universalizable... a person who acts out of desire, rather than reason, is not acting autonomously (Beauchamp and Childress 1979).

Although they are expousing Kant's conception of autonomy in this quotation, they go on to affirm it as their own, writing that, "This notion of self-directed action based on a rational principle accepted by the agent is the central ingredient in 'autonomy' in the rest of this chapter" (Beauchamp and Childress 1979). Like Kant, Beauchamp and Childress initially tied the concept of autonomy to both reason and morality—to be autonomous, a decision is based upon reason and consistent with the moral law discernible through reason.

The evolution of the principle of autonomy within PBE was necessary to respond to salient criticism. A notion of autonomy that links autonomy to reason and following "moral principles," as Kant does, potentially makes many patient decisions non-autonomous, and therefore subject to be overridden by the physician, if the physician judges the decision to be not "reasonable," rational, or morally correct. For example, a patient who declines an elective but clearly beneficial surgery out of fear of pain could be judged non-autonomous because her decision is based upon an emotion (fear) rather than rational grounds. Given that the principle of autonomy arose in biomedical ethics as a safeguard of patient rights, it can only serve this purpose if physicians are not empowered to overrule patient decisions that they disagree with on the grounds of reason and

morality. In fact, the most accepted standard for judging whether a patient is making an informed, competent decision now rests upon the patient being able to describe the circumstances of her illness, give the options presented to her, and then give an answer as to what she chooses and why. The *why* can be based upon completely irrational beliefs or values that some would judge to be immoral; it still must be respected (Beauchamp and Childress 2009). In a recent example of this, communicated to me by a medical student, a patient chose to reject amputation of a gangrenous leg because she believed angels would help her. She was still judged competent because she could repeat the options given by the surgeon, and she also stated that if the angels did not save her she was likely to die of her disease, which was later the outcome.

The expansion of Beauchamp and Childress's meaning of autonomy, to include patient decisions based on emotion and other motives not founded solely upon reason, also includes recognizing that patients do not always desire to be treated autonomously, and that whole cultures do not value autonomy. Furthermore, patients may choose to give decision-making power to other members of their family, or even ask the doctor to decide for them (Beauchamp and Childress 2009). Additionally, many patients treated by physicians are non-autonomous because they lack the capacity for medical decision making as the result of impaired cognitive status or simply severe illness. There is an obvious problem with trying to characterize the doctor-patient relationship by way of a principle that is not applicable to many clinical encounters, and which may be undesired or culturally inappropriate for many more.

Autonomy in the Doctor-Patient Relationship

The focus of *Principles of Biomedical Ethics* is the four principles that they determined are most central to resolving biomedical questions and dilemmas; it is not the doctor-patient relationship. For this reason, Beauchamp and Childress do not explicitly describe the doctor-patient relationship wholly in terms of autonomy; but Robert Veatch does in *The Patient-Physician Relation* (Veatch 1991). Here, the principle of respecting patient autonomy is translated into a guiding standard for conduct in the clinical encounter. Veatch's contract theory of the doctor-patient relation takes the autonomous selfhood of both the physician and the patient as the starting point for his description of the proper clinical relation:

If it is true that medical ethics involves the stances of lay people as well as health professionals, and that patients (or their surrogates) are often healthy enough to be substantially autonomous agents, then the patient-physician relation ought to be one in which both parties are active moral agents articulating their expectations of the interaction, their moral frameworks, and their moral commitments. The result should be a partnership grounded in a complex contractual relation of mutual promising and commitment (Veatch 1991).

I have already addressed how the autonomy model is empirically limited in failing to be applicable to many medical encounters, including virtually all cases of serious illness, but Veatch does not address this concern in his writing. He does, however, argue that the contract, or partnership, model is most compatible with modern medicine, in part because it can accommodate the increasingly common circumstance in which the patient and doctor are strangers to one another (Veatch 1991).

Veatch defends the need for his model precisely in an aspect of the clinical encounter that others consider a problem of modern medicine that needs to be remedied, rather than accepted. Many see the lack of continuity and enduring relationships between doctors and patients as a problematic and unfortunate emerging norm in clinical settings. But Veatch argues that there are potential advantages to a “stranger-physician relationship,” over one where patient and physician share a friendship or mutual knowledge of one another. One problem with the physician-as-friend model that is avoided by a more distant contract model is that the physician-as-friend may presume knowledge that is incorrect, or worse, try to speak for the patient based upon the closeness of the relationship. It is certainly true that once a physician has spoken for a patient, given the social power of the physician’s voice, it is hard for a patient to regain her standing and correct the physician’s conclusions. But it seems equally true that details not shared by the patient, because the relationship is too distant, also may produce decisions that do not reflect patient preferences. For example, is a woman more likely to share her new need for contraception because she is having an extramarital affair with a doctor who knows the circumstances of her life, or with a stranger-physician? Either answer could be correct, depending on the circumstances and judgment of the patient, but I also believe it is equally likely that sharing this information with a physician who knows her may actually be easier than sharing it with a stranger who she may fear will then judge her. Certainly the physician as friend is someone to whom she may feel comfortable offering a justification for her actions, whereas with the stranger-physician she must rely upon a more generalized nonjudgmental attitude.

The point is not to refute Veatch's claim, but rather to note that lapses in the knowledge necessary for good decision making will occur in any model, although perhaps for different reasons. Later, when discussing the narrative model in Chapter IV, I will return to this point, because proponents of narrative medicine seem to sometimes view themselves as invulnerable to the problem of presuming too much knowledge of the patient, a significant danger of their approach if not corrected. An epistemological humility is crucial to good medicine, and no model of the clinical encounter is immune to mistakes made from not knowing what is not known.

Veatch breaks with Beauchamp and Childress in that he places respecting patient autonomy over the principle of beneficence in the medical setting. Whereas PBE regards the four principles as having equal value, so that only in an actual individual clinical case can one principle override another, Veatch places autonomy permanently over "producing good" for the patient (Veatch 1991). Furthermore, Veatch argues that maintenance and respect for physician autonomy is crucial in a well-functioning clinical encounter, and he believes that approaching the relation as a "contract" offers the best way of respecting both parties.

The only problem Veatch identifies with a model based upon autonomy is its potentially excessively individualistic focus that may obscure the fact that physicians must sometimes choose to balance social justice concerns over the needs of an individual patient. Veatch writes that:

If a clinician has entered into a partnership with a patient in which he or she is constrained by a promise to protect that person's rights and welfare, it would appear that any pressure to have the clinician reduce expenditures is really a pressure to violate that promise (Veatch 1991).

It is outside the scope of this work to fully review the debate regarding the physician role in the doctor-patient relationship when there is a conflict between what is best for the patient and what is cost-effective or financially responsible. Paul Ricoeur, however, places issues of social justice outside the center of the doctor-patient relation, but within the domain that physicians must consider in medical decision making (Ricoeur 2007). That is, although a physician's primary concern must be the patient at that moment, the physician must not lose sight of the larger community of patients, and some consideration must at times be given to preventing a harm to others, if treatment to one potentially leaves others without care. Although this is a relatively underdeveloped consideration in the developed world currently, it is becoming an important issue globally, and medical ethics will increasingly have to contend with this balancing of individual and community needs.

In Veatch's most recent book, *Patient, Heal Thyself*, he takes the more radical step of suggesting that the doctor-patient relationship should, in a sense, be a non-relation. His argument has four parts:

1) Doctors are committed to a set of moral values by being members of their profession.

This is also MacIntyre's argument in *After Virtue* (MacIntyre 2007). Professions have a set of values that must be accepted as part of being a member of that profession. Therefore, the values of the medical profession are both incommensurable to patient values, and also largely unknown to patients:

...as medical professionals become specialized and separate themselves from the broader community of laypeople, in a sense they become alienated from the patient perspective. They think about medical choices

differently and choose options based upon values that are not shared by others. In fact, the Hippocratic notion of professionalism suggests that by taking an oath, the physician sets himself or herself apart from other citizens. He or she “professes” a set of obligations that require loyalty to the profession. Just as patients cannot think like health professionals, who have been trained to view medicine with asset of concepts and theories unknown to laypeople, so, likewise, physicians...lose the capacity to think like a patient (Veatch 2009).

While MacIntyre recognizes that professions have a set of values unique and definitive of their roles, Veatch argues that these values prevent physicians from communicating with patients. But the examples he uses to illustrate this actually suggest a different, less discouraging situation. He describes an orthopedic surgeon telling a young college student that in his opinion it would be safe to take the cast off after only four weeks, rather than the standard six weeks for this fracture (Veatch 2009). I believe this example reflects a doctor trying to place himself in the role of the patient, and thinking that the small additional risk of reinjury would be mitigated by the patient’s youth and excellent health, and justified by the patient’s desire to return to a normal life as soon as possible. While I agree with Veatch that it would have been better for the physician to explicitly lay out options for this patient, or at least explain the basis of his reasoning, I do not see this as supporting medical values that are in principle unknowable to the patient. The doctor is seeking to think from the patient’s perspective, even if he has made unwarranted assumptions about what he thinks the patient would want. The leaps in the physician’s thinking do not arise from his medical values so much as they arise from his memory of being a young college student or a sense of what the patient is like from his interactions with him.

2) Patients have their own values, and doctors cannot know them.

The first part of this is undoubtedly true, but the second part is suspect and simply untrue at times. Although doctors do adopt a certain set of values, they also maintain a set of values that are outside medicine. Physicians often have values derived from their religion, their class, and even their upbringing, which may or may not coincide with a patient's values. Sometimes it is easy for physicians to recall other value sets because they have held them themselves, or have family members or friends with similar beliefs. Even when it is a stretch, it seems implausible for Veatch to claim that physicians are able only to see the world through the value set imbued by medicine. But Veatch holds the view that to know how to best benefit a patient, the physician must understand the patient in a way that he believes is impossible, or at least highly unlikely in modern medicine:

Physicians no longer can be expected to be able to do what is in their patients' best interest just because they are competent physicians. They cannot be expected to do what best serves patient interests because they cannot be expected to know what the patients' interests are (Veatch 2009).

There are problems with this at several levels. Firstly, it is the responsibility of "competent physicians" to seek to understand their patients' values and interests. Secondly, without this understanding, and the ensuing dialogue that seeks to match patient interests and medical choices, a dialogue that must be physician led, it is wholly unrealistic to expect patients to make choices in their best interest. A common example from clinical practice explains what I mean by this. Since the Women's Health Initiative study linked hormone replacement with higher rates of heart disease and breast cancer, many women suffering from symptoms of early menopause have come into my office asking for natural hormones to relieve their symptoms. Although some popular media

figures have made claims about the safety of natural, plant-based estrogen, the data do not support their claims that some forms of estrogen are safer than others. It is a simple discussion to elicit why a woman wants natural hormones. If it is because “natural” feels better to her than “artificial,” this is a value that needs no correction or revision, provided she does not labor under an illusion that “natural” also implies “safer.” I have heard women say that they understand there is no proven benefit to natural hormones, but they feel more comfortable with them, and this seems unproblematic. Women, who claim that even if there were no proven benefit, they would still like natural hormones, because they believe a benefit may still be shown in the future, similarly hold a value that does not contradict what we know. But a woman who thinks that natural hormones do not cause cancer needs to hear that early menarche (the age of the first menstrual period) and late menopause both increase the risk of breast cancer, because they increase the total time of exposure of breast tissue to estrogen—a natural estrogen produced by the woman’s own body.¹ This discussion only occurs, and could only occur, when the physician has asked the woman about the values and thinking behind her choice for natural hormones.

There is often no uncomplicated way for a patient’s values to justify a given medical choice, without the physician taking a role that clarifies and translates between the patient’s values and medical choices. To do this, physicians must begin a discussion of patient values, and must then test the patient’s statements against examples pertinent to the decision that needs to be made. (e.g., the value of natural remedies, against information about what is actually safe or not.) This dialogue often reveals that the stated values of a patient are not actually consistent with her choices when given full

¹ For matters of clinical practice, particularly when referring to relatively noncontroversial claims within medicine, I will not cite standard medical texts as support.

information about the likely consequences of her choices (e.g. that natural or plant-based estrogen will have the same side-effects as artificial or animal-based estrogen). Veatch's claim that the patient must make these choices unaided by a dialogue with the physician that clarifies the medical facts and patient values leaves the patient completely unaided by physician knowledge and experience (phronesis). If this is actually the direction of medicine, as Veatch claims, it is unclear why physicians could not be replaced by Internet sites for medical information and technicians performing procedures selected by patients unaided by any expertise other than their own.

3) Physicians must cede decision making to the patient, as only she knows what she actually needs or wants.

Much of this claim has already been addressed by the arguments above. But an additional response that needs to be made is this: Veatch conflates making the decision with a dialogue about making the decision. No one seeks a return to paternalistic medicine, but there is a wide gulf between doctors making decisions for patients, and patients making medical decisions unaided by physicians. It is within this wide gulf that I believe effective, humane medicine resides and must continue to inhabit.

Veatch's position in *Patient, Heal Thyself* can be seen as the culmination of an autonomy model of care for conceptualizing the physician-patient relationship. The result is a nonrelation in the sense that the physician is not expected to seek to understand the patient, and the patient should not expect to receive any assistance other than medical information from the physician in medical decision making. This does not even represent dialogue, in the sense that there is really no exchange that could not be accomplished by

interfacing with a computer. The physician lists choices and risks and the patient has an internal dialogue that includes values, but there is no point in sharing this inner discussion with the physician, because the physician lacks the skills to help or correct a patient in her decision making, in her matching of choices and values, options and interests. Furthermore, Veatch's model is inconsistent with both patient and physician expectations of how the clinical encounter should proceed. Empirical research shows that over three quarters of patients value empathic care from their physicians (Mercer et al. 2004; Mercer et al. 2005). The paternalistic model of "detached concern" is replaced by Veatch with a model of total detachment, as expressed by the title, *Patient, Heal Thyself*. It seems hard to conceive that meaningful empathy could find a place in an encounter in which physicians are no longer even expected to engage patients at a personal level.

The Aim of This Project

It might seem that the goal of this critique is to "turn back the clock" to a time when physicians took the time to know their patients and treated every patient as a person, not as a disease, as Cassell describes. This would be an incorrect statement of my goals for two reasons. The first is that medicine never was that humane profession. When Cassell tried to humanize medicine beginning in the 1970s, medicine was already in the thrall of technology, and the predominant mode of doctor-patient interaction was paternalism. As Albert Jonsen explains, even critics of autonomy-based medicine, including himself, need to recognize the benefits it has provided by moving medicine

beyond a “doctor knows best” attitude in regards to patient communication and decision making (Jonsen 2007).

Furthermore, although I endorse the position of Cassell, Montgomery, and many others, a full description of how this is to be achieved, and how it would actually be accomplished in each clinical encounter, has not yet been articulated. When Ricoeur writes that the “just distance”—the relationship in each clinical encounter—needs to be set by the singular narrative of each patient, her illness, and the physician receiving the request for help, he gives an answer, but it is an answer that must be further developed to be of any use to practicing physicians, patients, and medical students who wish to receive meaningful guidance for how they should proceed (Ricoeur 2007). An explication of this relationship of the just distance is my goal. The resulting description and prescription for the doctor-patient relationship must recognize and be capable of functioning within medicine as it is currently practiced, even if it simultaneously works to critique many of the problems and failings of our current system. It must address every clinical setting, from the ICU and emergency room, to the prenatal visit and well child checkup.

Chapter Overview

In Chapter II, I summarize the critique of an autonomy model for the doctor-patient relationship. The gist of this argument is that this model of care is founded upon an outdated and flawed view of selfhood: the autonomous subject. Alfred Tauber, physician and ethicist, argues that medicine embraced the autonomy model, long after the social sciences and philosophy had moved beyond it, because it actually strengthens

physician power and allows an abdication of responsibility justified on the basis of patient's rights (Tauber 2003; Tauber 2005). The version of selfhood it is predicated upon is the independent, self-ruling individual who both seeks, and is capable of making, medical choices without any coercion or assistance from her physician, except for the provision of information.

As the autonomy model of care has slowly lost ground over the last thirty years, other ways of configuring the relationship have emerged. The two most prominent of these are shared decision making and narrative medicine. While narrative medicine incorporates an implicit and explicit critique of the autonomy model (in part because it relies on a wholly different view of selfhood), the shared decision-making model can actually coexist with an autonomy model. Perhaps for this reason, shared decision making has recently received widespread endorsement from several major medical societies (Kon 2010). But, shared decision making has philosophical underpinnings as suspect as the autonomy model of care. Its philosophical foundation is logical positivism, which like an autonomy model of selfhood, is largely rejected by current philosophical thinking.

Chapter III addresses the other model of care that is growing in prominence: narrative medicine. It is derived from narrative philosophy and seeks to correct the problems it sees in the current medical environment, brought on in part by an inflexible adherence to the principle of autonomy. Beginning in the philosophy of Ricoeur, MacIntyre, and other narrative philosophers, narrative medicine and narrative ethics teach that the self is composed and known to itself and others through narrative structures: we are in a real sense our story (Ricoeur 1984, 1992, 2007; MacIntyre 2007). Medicine as a

healing art must then learn to elicit and heed the story of the patient, if it is to really serve to end or reduce personal suffering and restore health.

Narrative medicine is the strongest contender for overthrowing the dominance of autonomy in determining the clinical encounter, but I believe it suffers from both practical and philosophical problems that need to be addressed prior to its ascension.

Chapter IV addresses issues with narrative medicine that need to be resolved. There are both practical and philosophical problems with its current formulation. Philosophically, a narrative version of selfhood raises questions of how closely or neatly we are to understand the equation between self and story to be. Within narrative philosophy, there are also different claims about who the privileged narrator is, and whether the story composes or constitutes selfhood. That is, do we need story to know ourselves (the position held by Hannah Arendt and Adriana Cavarero), or do we need stories because these narratives actually represent our selfhood (the position held by most narrative philosophers)? This is not an irrelevant philosophical detail. The implications of this difference are that a too-facile equation of self and story may actually lead narrative physicians to be overly optimistic or confident in their ability to know and speak for the patient. Using the work of Adriana Cavarero and Emmanuel Levinas, I seek to supplement and delimit the claims of narrative medicine. Cavarero's understanding of narrative selfhood does not render the self of the other transparent through narrative. This perspective on narrativity defends narrative approaches without encouraging an overreaching attitude among narrative practitioners. Levinas's suspicion of narrative and ultimately of our ability to fathom the other before us completes the discussion. If physicians see their role as striving to understand, Levinas, I will argue, can defend this

as “proximity”—an open, caring approach to the patient. While proximity never results in complete resolution of the opacity of another, the commitment to receptivity that it represents returns a sense of caring to the clinical encounter. Taken together, the claim is that physicians must strive to know the narratives of the patient, the story of the illness, and must have already mastered the narrative of disease, but they must not conclude that they have closed the distance between physician and patient in doing this. The just distance, to return to Ricoeur, is always some distance; it is never a complete closure or fusion.

Chapter V seeks to define, or describe, how a physician can engage in the phronetic act of finding the right relationship. There are four central issues that must be addressed in each encounter, and these four issues can be understood to define it. The first is the act of diagnosis, or at least a decision about what kind of disease is probable, even when the exact diagnosis need not or cannot be made. The second question involves choosing therapeutic options and discussing them with the patient. Some patients need significant support to proceed through the process of medical decision making; some require only clearly explained facts and statements of risks, benefits, and options. Deciding how to assist a patient in medical decision making without unduly influencing her decision is the third issue that requires practical judgment within the clinical encounter. The fourth aspect of the relationship is the level of emotional support—care and empathy—requested or needed by the patient, and the physician’s assessment about whether this can be achieved, and whether it will in fact serve the goal of promoting healing and ending suffering. Each of these four factors influences the other three, and the physician-patient relation is not static, so each of the four remains in flux and may

alter the other three as conditions change. Physicians must re-embrace medicine as a moral activity if we are to expect them to consciously reflect on these issues in each clinical encounter. But I also believe we must expect nothing less than this.

CHAPTER II

AUTONOMY: CRITICS AND REFORMERS

Introduction

In the last chapter, I reviewed how the autonomy model of care came to be the most widely accepted view of how the clinical encounter should proceed. Despite its widespread acceptance within the medical world, it has received withering criticism from philosophers, ethicists, and even physicians who argue against it on several grounds.

The arguments against the autonomy model have shaped the chapter dealing with this principle in Beauchamp and Childress's *Principles of Biomedical Ethics*. This text, which stands at the center of the debate regarding patient autonomy, details and defends the use of the principle of autonomy in medicine, to the point that much of the sixth edition's discussion of autonomy seems focused on answering its critics (Beauchamp and Childress 2009). The medical community seems unaware or unaffected by this, however, in the sense that discussions such as whether midwives or physicians are better adherents to the principle of autonomy are still commonplace (see beginning of Chap. I). Specialty societies, including my own in obstetrics, have monographs in ethics that follow the principalist method and begin with the importance of respecting patient autonomy at all times (*Ethics in Obstetrics and Gynecology* 2004).

The critics of the principle of autonomy do not deny its positive results or important contributions to ethical practice. It has been especially successful in undermining the paternalistic approach that had previously dominated the field. This was an important advance, given the authoritarian mindset of many physicians. Many authors

have sought to limit, reform, or reframe the principle of autonomy to preserve its benefits while limiting its harm. In one sense, this is the only reasonable response a critic can maintain, given that respecting the decision-making capacity of a patient capable of making her own decisions is now taken for granted.

This chapter's critique of the autonomy model of care focuses on two problems of its current formulation and consequences. I introduced the first problem in Chapter I: Autonomy must be seen as a rule of the medical encounter that should only rarely be transgressed, rather than as a shaping or defining feature of the relationship. The second problem is that prioritizing autonomy in the relation implies, by the importance we have now given it, that we should see ourselves as autonomous beings: an autonomy model of selfhood. Prioritizing autonomous individuality in *clinical practice* then supports the continued centrality of autonomy as a guiding principle describing who we are. The result is a self-reinforcing circle that is perhaps most easily interrupted in the concrete, everyday relations between physicians and their patients. That is, most no longer see autonomous selfhood as a defensible philosophical position; we should therefore no longer regard it as the centerpiece of the clinical encounter.

If we accept an autonomy model of selfhood, then placing autonomy at the center of the relation makes sense. If, however, we believe selfhood to be narrative and relational, then these values should be central, even if autonomy remains a shorthand reminder that physicians have a duty to respect their patients' decisions, and in fact have a responsibility to aid patients (without coercion) in making difficult medical decisions.

Autonomy as a Constraint

Paul Ricoeur describes the medical decision making involved in a clinical encounter as having three levels: prudential, deontological, and reflexive (Ricoeur 2007). Although he is not explicitly addressing the principlist theory or an autonomy-based model of care, I would like to engage his threefold distinction to argue that the principle of autonomy in the doctor-patient relation should be placed at the *deontological level* of judgment, not as a primary descriptor of the relationship. The deontological level of judgment involves testing the decisions made at the individual patient level (the prudential level) against the rules and duties proper to being a physician. Autonomy is thereby a rule to be considered *after* the physician-patient relation has been established; it is a limit that functions more as a rule to be only rarely transgressed, rather than the grounds upon which the relation is established. Respecting autonomy is a *duty* for the physician, and autonomous patients have rights that need to be valued, but this is secondary to the needs that brought the doctor and patient together, in the first place.

Prudential Judgment

Ricoeur places at the center of the clinical relation the *telos* of medicine--to diminish the patient's suffering and help obtain her desire to return to health. He defines suffering broadly as both mental and physical. Further, he suggests that suffering is not

only pain, but also *incapacity*: illness implies a certain loss of ability, for example, to take care of oneself, work, or do the things that bring one pleasure. Illnesses also may result in the loss or shifting of important relationships. This suffering, Ricoeur says, is *singular*. He uses this term in two senses—one positive and one negative. Singularity in the positive sense refers to the uniqueness of each patient, each illness, each situation; singularity in the negative sense specifies the potential isolation of the patient from her job, goals, friends, and family—from her everyday life brought on by illness.

Ricoeur writes, “medicine is...a social relation for which suffering is the basic motivation...” (Ricoeur 2007). The obvious observation here is that patients never go to a physician for the purpose of having their autonomy affirmed; they go to a doctor seeking health and relief of suffering. The first level of decision making must therefore address this request from the patient. The aim of the principle of autonomy is to protect patients, but if they are kept at too great a distance—due to excessive focus on respect for autonomy—they are no longer being protected, and the *telos* of medicine cannot be fulfilled. Furthermore, respecting autonomy should not be at the center of the relation, because although every medical encounter involves a suffering person, or a person seeking health, not all clinical relationships involve autonomous patients. Children and patients with Alzheimer’s disease or other mental illnesses or incapacities may be unable to make decisions alone or unaided. Many others, including those from some Asian and Hispanic cultures, may not desire to make decisions without the aid of family members or other social supports (Beauchamp and Childress 2009). A principle that excludes so many cannot be a good starting place for the description of the relation. In some cases, autonomy is a capacity that may be returned to the patient through the caregiving

relationship, but it is one ability among many, and some never possess it, even in a state of health.

Ricoeur recognizes that to care for a patient requires that several interrelated perspectives be addressed and valued. The physician must recognize the patient as singular in the positive sense of her unique individuality, and in the negative sense as suffering and separated from her life goals and other people by her illness. Secondly, the physician must approach the patient *holistically*, not by fragmenting her into a disease or organ, but always by regarding her as a person with an illness. Lastly, the physician must see the relation as one that affirms *self esteem*, a technical term for Ricoeur that can be understood in the commonplace sense of respecting the other as a person with value, but which also means that this respect given to another affirms ourselves as a person worthy of respect, and capable of entering into mutually meaningful relationships with others. The patient is affirmed as worthy of care; the physician is affirmed as capable of providing care, both by way of her medical skills and through seeking to understand the patient's needs.

In Chapter V, I will reformulate these precepts into a practical approach for determining how the clinical encounter should proceed. For now I would like to return to Ricoeur's conclusion of what constitutes the *prudential* (or *phronetic*---see Chapter I) level of the doctor-patient relationship, the establishment of the caregiving partnership and finding the *just distance*. For Ricoeur, the just distance is the nature and limits of the relationship that will best facilitate the goal of giving care to the patient. This distance, in Ricoeur's spatial metaphor, must be uniquely determined by the patient and her illness, with the considerations just given, namely that the patient is unique, the patient is a whole

person and not a disease, and the doctor and patient share the goal of affirming each other's worth.

Deontological Judgment

After the doctor-patient relationship is established, the second level of medical judgment is deontological, and it is here that “respect for autonomy” belongs. It is the physician's duty to respect patient autonomy, when patients are capable and desirous of substantial autonomy in their decision making. To accept this as a principle is in agreement with much that Beauchamp and Childress write in the *Principles of Biomedical Ethics* regarding autonomy, including that respect for autonomy is one principle, not an overriding principle, but one that creates a *prima facie* duty when a physician is relating to a patient who wishes, and is capable of, autonomous decision making. The duty to respect autonomy can be understood as having the *negative constraint* of not abrogating the wishes of autonomous patients, and the *positive duty* of seeking to enhance or return autonomy to those who temporarily lack it secondary to illness, fear, or lack of information regarding options. It is important to emphasize that with these considerations, the autonomy principle consists of not doing some things and doing others. The process of obtaining informed consent, for example, involves both not performing procedures without patient permission, and giving patients enough information to guide decision making.

Ricoeur describes the move from the first level of medical judgment, the prudential level, to the second level, the deontological, as a move from focusing on the

particular to a shift to the universal. The philosophical background to his reasoning here is that in the tradition of Immanuel Kant. Deontological or duty-related moral principles are universal, abstract, and absolute (Kant 2008). This is not to say that the physician puts all particulars out of mind, but rather that the physician must now test her singular judgment against universal principles that generate rules of behavior in the medical relationship. For example, because humans are rational and free they (as patients) must be given every opportunity to understand and participate in decision making when possible. That is, the *rule* of informed consent flows from the concept of humans as rational. The rule is universal in the sense that it follows from who we are. Although Ricoeur takes this from Kant, he is not strictly Kantian in his application, because whereas Kant believes the moral principles that follow from human nature (as rational and free) must never be abrogated, Ricoeur argues that the third level of judgment actually involves deciding when to choose the particulars of a situation over a universal rule. In a classic example from *Principles of Biomedical Ethics*, giving informed consent to a traditional Navajo is actually inappropriate because her culture believes that speaking things makes the events more likely to occur—to name a risk is to make it happen (Beauchamp and Childress 2009). Ricoeur and Kant have different views of moral decision making with Kant favoring that morality is always universal and impersonal—a lie is a lie, regardless of how pressing a need we may have to forgo telling the truth. One aspect of this universality is that morality admits no exceptions: a lie is always wrong (Kant 2008).

Ricoeur, on the other hand, in trying to marry Kantian and Aristotelian ethics, recognizes that although there are universal moral laws that can be derived from our

nature, ultimately ethics must serve the goal of “the good life.” Thus, the rules are universal in one sense, but not in another. That is, informed consent is a rule that applies to the medical encounter because humans, as rational animals, deserve the respect of being given the opportunity to make medical decisions after being adequately informed. But if following this rule would actually harm another, then the goal of helping another achieve her “good life” supersedes the need to follow the rule. On points of dispute, Ricoeur places the ethics of Aristotle, the teleological aim of a “good life,” over the morality of Kant, the need to follow the rules of universal laws derived from our nature (Ricoeur 1992).²

There is an important sense in which aspects of the relationship realized at the first level are preserved and raised to the second level. For example, respecting persons in a medical environment must almost always include truth telling, and the exceptions even affirm the rule. Truth-telling may only be overridden by a strong and well-founded fear that to inform the patient completely would result in substantial harm to the patient, which is a rare circumstance. Respecting autonomy, however, can only be universalized in one sense: we must respect the autonomy of people who are substantially autonomous, and who desire autonomous decision making in their medical care. It is not universal in its application to all clinical encounters, because depending upon the specialty or practice of the physician, it may apply as a norm to few, if any, of the patients that an individual physician treats.

² Ricoeur writes in depth on the relationship between “ethics,” which for him is an Aristotelian concept, and “morality,” a Kantian concept, in chapter seven of *Oneself as Another*. What is most important in this discussion, however, is that the ethical aim is primary, and moral norms “constitute only a limited, although legitimate and even indispensable actualization of the ethical aim.”

Pediatricians treat a substantial portion of their practice without recourse to autonomy, although the surrogate decision making made by parents or family is often described within the context of autonomy. Beauchamp and Childress, although they do describe surrogate decision making within the chapter on the principle of autonomy, do so in part to explain how decision making may still occur with a patient who lacks autonomy. In surrogate decision making involving an adult patient, with a narrative history to fall back upon, the surrogate decision maker can arguably be extending the patient's autonomy by providing the answer that she would have given if she could. But in a pediatric population, particularly with very young children, surrogate decision making really involves "best interest" decision making—what is the right choice for *anyone* in this circumstance, because the individuating life and personality of the patient has not yet been revealed.

The duty to respect autonomy is only on the side of the physician. Patients have a right to autonomous choice when possible; they do not have a duty to choose autonomously:

Health professionals should always inquire in general terms about their patient's wishes to receive information and make decisions... The fundamental requirement is to respect a particular person's autonomous choices, whatever they may be. Respect for autonomy is not a mere *ideal* in health care, it is a professional *obligation*. Autonomous choice is a *right*—not a *duty*—of patients (Beauchamp and Childress 2009).

Although physician autonomy is not unimportant, physicians can protect their own autonomy and the patient is not responsible for preventing breaches in physician choice. The power relation between physician and patient *always* allows physician

decision making to take precedence over patient choices. If I do not perform abortions, I can (and must) offer this as an option to patients seeking alternatives when faced with an unexpected or undesired pregnancy, but I would never be required to perform a procedure I find morally unacceptable, simply because the patient requests it. Threats to physician autonomy come not from clashes with patient values, but rather from the increasingly corporate nature of medicine. Physicians may be unable to provide what they consider the best option for care secondary to financial constraints on the patient's side, insurance coverage, or practice agreements. Although a noncompliant patient may be understood as interfering with physician autonomy, physicians can always choose to terminate patients in nonemergent circumstances, and many episodes of seeming "noncompliance" actually represent physician failures of communication (Burcher 2011).

So respecting the autonomous choices of patients who are substantially autonomous in their decision making, and enhancing the autonomy of those who were autonomous but have lost this attribute through illness, must remain a rule within the medical encounter. Beauchamp and Childress, and the Belmont Report before them, did medicine a service by rejecting paternalism as the dominant mode of engaging in a clinical encounter. But Ricoeur's point here is one that we will return to again in this chapter: the principle of autonomy must be understood as a rule to be considered, after the relationship is established. It does not describe how to approach a patient. As Tauber will describe later in this chapter, the autonomous patient is too often perceived as the patient that *must not be touched* by the encounter, a belief that is at least partially based in the history of the principle of autonomy (Tauber 2003).

Reflexive Judgment

The third level of medical judgment is *reflexive*. The reflexive level involves mediation between the first two levels when they conflict with one another. There are two possible types of conflict. The first is when a rule or duty is inappropriate, or needs to be overridden by the particular circumstances of a given case. A classic example of this, although also one that provokes significant controversy, is the decision to withhold a bad prognosis from a severely depressed individual at risk for suicide: by this reasoning, beneficence overrules patient autonomy in this circumstance. The other source of possible conflict requiring mediation is when the care of one patient must be weighed against the consequences of that care for others. This can include the need for triage in disasters or times of medical scarcity, as well as more mundane circumstances such as deciding how much time to spend with the complicated or distraught patient before moving on, because there are other patients also waiting for your care.

Ricoeur is not using the term “reflexive judgment” in a Kantian sense. For Kant, reflexive judgment involves a decision in which there is no “determinant concept” to follow; classically, he is referring to aesthetic decisions. In deciding that something is beautiful, we are not classifying it under the concept of “beauty” because there is no set of rules to follow to describe what is beautiful, and what is not (Kant 1987). But Ricoeur uses “reflexive judgment” in two ways that are quite different. He writes that when physicians override a rule based upon the particular situation, that they are using reflexive judgment. But he also describes reflexive judgment as the kind of reasoning used when the particulars are more known than the universal, a point that is much less clear (Ricoeur

2007). I take this to mean that the universal is unclear in its *applicability* rather than its meaning. For example, physicians understand well the rules regarding informed consent, but deciding which aspects of informed consent can still be maintained in a traditional Navajo setting may be tricky, and here the particulars become more clear than the nuanced version of informed consent that must be sought after.

Let me return to the case that I presented at the opening of Chapter I to illustrate how these three levels can be understood within one medical encounter. This time, the woman with the breech baby (a baby presenting buttocks or feet first rather than the more common head first) is in my office seeking care. She values and desires a natural birth with a minimum of medical intervention, but the risks of vaginal breech birth are substantially greater for the baby than a planned cesarean birth. This case is complicated by the fact that in a full-term pregnancy, there are really two patients, the mother and the fetus, although only the mother is capable of expressing choices. The first level of judgment involves the patient's particular situation, her values, and her expressed wishes. At the second level, rules such as respecting her autonomy come into play. But in this case, the third level of judgment is perhaps most crucial. I would not accede to the wishes of the patient, even if the risks and benefits of vaginal birth versus cesarean had been explained and she were still choosing a vaginal birth. This reasoning, which involves a *mediation*, as Ricoeur calls it, can be understood two different ways that both render the same conclusion.

One way of parsing the decision in favor of a cesarean birth is that it would violate my physician autonomy to perform a procedure, that is, a vaginal delivery, which I believe carries substantial and unnecessary risks to the fetus. This reasoning would

apply even if the excessive risk were to the woman herself. (For example, a woman requesting a hysterectomy for benign menstrual bleeding would and should be denied the surgery if her other medical conditions render the surgery quite risky, particularly if there are other, safer options available to her). This is a reflexive judgment in the sense that there is no rule to follow. Rather, the physician must decide between a rule (respect patient's autonomous choices) and a particular situation, or between two rules that are in conflict with one another—respect autonomy versus “do no harm” (the principle of non-maleficence).

The other sense in which my refusal to perform a vaginal breech delivery on the woman requesting it represents reflexive judgment is that it involves a mediation between the rights of the woman and the rights or safety of the fetus. This could be understood as a question of justice in that no right is absolute, particularly if exercising that right harms or even risks harm to another.

There is yet a third level of reflexive judgment that a physician could make in this breech case, which is the decision to violate his or her own physician autonomy for the benefit of the fetus. Suppose that it is against the physician's best judgment to perform a vaginal breech birth, but the physician knows that he/she has greater skill in vaginal breech birth than the midwife from whom the patient reports she will now seek care, having been refused her choice by the physician. Should the physician then provide care to improve the likelihood of a good outcome? If the physician knows that the midwife will not refuse the vaginal birth, and the physician knows the midwife lacks skill in this area, it could well be reasonable to choose to provide care. Weighing against this decision would be the liability in rendering care that falls outside normal standards of medical care

(that is, willfully choosing a risky procedure over a safer one), as well as the possibility that by refusing care and expressing concern, the patient will eventually decide to accept your recommendation. No rule or principle alone will answer this dilemma—it must be a weighing of rules and the particular case that produces a judgment, a decision regarding what care should be rendered.³

By describing three levels of judgment, and placing rules at the second level, Ricoeur is explicitly acknowledging that sometimes the circumstances will warrant ignoring or breaking rules in order to do what is best for the patient. This affirms the proper place of autonomy once again, and limits its scope even further. In the case of the women requesting a vaginal breech birth, the physician is likely not to accede to her autonomous choice. Whether this is framed in terms of physician autonomy, fetal right to a safe birth, or weighing the *principle of non-maleficence*, or as placing greater importance on the rule of seeking to do no harm than the principle of respecting autonomy, the end result is the same: the patient's autonomous choice is overridden. The fact that the patient-doctor relationship may continue, and even function well, to a mutually satisfactory end, speaks to the peripheral nature of patient autonomy in this encounter.

³ This case recalls the deontological versus consequentialist debate that Bernard Williams discusses in his article, "A Critique of Utilitarianism," in *Utilitarianism: For and Against*. The debate involves whether moral decision making should focus primarily upon achieving the desired outcome (as utilitarianism does), or whether the action of the agent must be intrinsically moral (as Kantian ethics insists).

Critics of the Autonomy Model of the Doctor-Patient Relationship

Tauber: the Critique of a Physician/Philosopher

Before returning to the critique of the autonomy model of the doctor-patient relationship, I want to emphasize the sense in which autonomy should be understood and the way it can continue to function, even if its centrality to the physician-patient relation has been rejected. Using Ricoeur's framework for medical judgment, we can still understand the respect for autonomous choices to be a rule, among a group of rules that need to be considered within the context of a medical relationship, and as a possible constraint within medical decision making.

Determining whether autonomy should remain at the center of the clinical encounter poses the question of whether it is central either to the relation or to our selfhood. If either of these conditions pertains, then autonomy's current standing as the primary determinant of how the physician-doctor relationship should be conducted would seem justified. I have already argued against its centrality within the relationship, because patients do not seek out physicians to affirm their autonomy; rather, they seek care and relief of suffering.

Alfred Tauber, a physician who practiced oncology for over thirty years, now writes on topics in the philosophy of medicine. In his first book critiquing the autonomy model of care, *Confessions of a Medicine Man*, he makes both a historical and philosophical argument against autonomous selfhood, and then he argues that this misconception of selfhood has created distortions and harms within medicine and the

clinical encounter (Tauber 2003). Tauber responds to those who hold to autonomous selfhood that “the autonomous individual was invented” (Tauber 2003). By this, he means that a sense of humans as autonomous first arose with the scientific method of Bacon, Newton, and others, and this scientific position was then extrapolated to political philosophy, and eventually to philosophy of medicine. In science, the dispassionate observer, isolated from the object of study, became the paradigm for how science should be conducted—an independent subject who can study objects without affecting them:

The scientific ideal—unfettered rationality, objective experimentation, autonomous observation—translated into the political and moral ideals of seventeenth century England. Locke’s philosophy hinged upon the ability of the individual to detach himself from the world, indeed from his very self, and observe each objectively, just as Newton regarded apples falling and planets orbiting. The individual then becomes an independent consciousness relating to the world through “objectivity.” Self-conscious efforts to be objective dominated the birth of modern science, and it was this same concern for establishing independence of the thinking subject—with attendant legal rights—that dominated Locke’s own thinking of the political, moral agent (Tauber 2003).

Tauber traces how the presumed autonomy of the scientist first moved into the political realm, with the beneficial effect of establishing a basis of rights, and then into ethical philosophy with “profound...ramifications” (Tauber 2003).

The contemporary sense of self is still informed, particularly in the political and human rights arenas, by this seventeenth-century sense of self that led to political liberalism, where it had a significant influence on the founding fathers, the U.S. Constitution, and the first ten amendments to the U.S. Constitution, the Bill of Rights. Despite this, in the twentieth century, both philosophy and the social sciences have moved beyond this stable, individualistic sense of selfhood created by the autonomy model. Chapter III describes this evolving understanding of self, as narratively

constituted and relational. In opposition to the autonomous self, many now argue that it is through others that we both come to know ourselves and even develop a selfhood by coming to possess a story of self.

However, Tauber claims that medicine adopted the autonomy model long after other social spheres had recognized, adopted, and then moved beyond this individualistic model of selfhood. That is, autonomy is consistent with seventeenth-century scientific and political thinking, and the nineteenth-century ideals of populism and romanticism, but it was not incorporated as a principle in medicine until almost a century later. This places medicine behind the times, because we have philosophically and culturally “moved on,” and the defense of autonomy as a model of selfhood is one that has long been viewed as deeply problematic in other relevant areas.

Although Tauber ultimately seeks to reform rather than reject autonomy as a central principle in the clinical encounter, he acknowledges that there is a particular version of selfhood that is affirmed and necessary, beneath assertions of autonomy. That is, one cannot divorce the principle of autonomy from a certain conception of self. One can only respect autonomy if it means something to say that we are autonomous.

Although Beauchamp and Childress back away from a Kantian version of rational selfhood between the first and latest editions of *Principles of Biomedical Ethics*, ultimately they cannot completely separate the principle from the philosophically suspect ontology of an isolated, independent, rational self (Beauchamp and Childress 1979).

Tauber shows how autonomy as individualism actually works counter to the therapeutic relation of medicine. If respect for the other person is construed as keeping a “hands-off” approach to clinical decision making, then the patient may very well not

receive the care or support that she needs because the physician is too distant in the relation to be of any real service:

This understanding of persons has profound moral implications, because the idealized autonomous person forfeits trust, friendship, loyalty, caring and responsibility as secondary attributes to those primary values of self-direction, self-determination, and self realization (Tauber 2005).

Tauber is arguing here that not only are we not accurately understood as autonomous, but also that it is wrong to hold up autonomy as a value to be respected, or an ideal to be attained. Autonomy should not be central to the doctor-patient relationship, not only because it represents a historical fiction, but also because it is a fiction that does not serve us. Medicine must also recognize that the illusion of the physician interacting with the patient while remaining apart from the interaction is neither possible nor desirable.

While Tauber's claims regarding the evolution of autonomy are not universally held, they are important to this discussion for another reason. It is certainly not impossible for physicians to respect patient autonomy while maintaining close, supportive relationships with patients at the same time. The two are not logically exclusive, but in practice, physicians often seem to jump from "respect autonomy" to "hands off the patient"—in the sense of providing support or expressing empathy. Regardless of whether Tauber is historically correct, physicians are usually scientists first as undergraduates in college, and then physicians. Their understanding of autonomy may well be informed from science, and the detached observer status may be too easy for them to understand and maintain. If so, this argues against attempts by Tauber and others

to reform the principle of autonomy, because physicians may yet again distort it. We can respect patient decisions without recourse to this principle and its history.

In *Patient Autonomy and the Ethics of Responsibility*, his second book on the subject of patient autonomy, Tauber goes beyond his previous arguments to explain why medicine has continued to cling to an autonomy model of selfhood, while philosophy and social sciences have moved on (Tauber 2005). One reason, of course, is that medicine often misunderstands itself as science, and so to the extent that the autonomy model arose from scientific underpinnings not wholly rejected by science (the view of the isolated subject), medicine may still hold a worldview that continues to be prevalent among many scientists. But the other, more sinister reason that physicians may embrace the autonomy model of care is that it shifts responsibility to the patient, away from the physician.

Tauber argues that the autonomous patient is a consumer, and the physician is a shopkeeper, offering products to the patient, explaining each one to the consumer and letting her choose. If the product does not serve, the physician is blameless, provided the explanation of the product was adequate (informed consent), and the product is not defective (absence of negligence). While the demand for patient autonomy arose from excesses and abuses of medical power, Tauber argues that this shift to a jurisprudence theory of medical ethics, based in part upon patient rights, has only ultimately strengthened physician authority:

Patient autonomy, rather than being corrosive of professional privilege, may actually reinforce physician authority: autonomy tends to be a negative right (in that a person has the right to refuse treatment) rather than a positive right (a person cannot generally demand a particular treatment). Physicians are translators and filterers of information to their patients, who generally defer to physician recommendations regarding definitions of disease and its treatment (Wolpe 1998, 52). Indeed, physicians have incorporated informed consent into

their practice as a means of improving patient satisfaction, and perhaps most importantly, in shifting responsibility to the patient, often a potent tactic to combat malpractice suits (Tauber 2005).

Thus, according to Tauber, physicians are wrong to think that they have gained from this consumerist model of care perpetuated by the principle of autonomy. Although perhaps physician prestige and power have been strengthened, it has been at the cost of reducing physician satisfaction. Medicine as a moral practice has the end of caring for patients. While physicians may secondarily gain power and economic security through their profession, they are still drawn to medicine by a desire to care for and heal others. Unfortunately, the empathy for others actually diminishes as medical education progresses (Garden 2008). Although there are many factors that may play a role in this detachment, students are taught and presented with the model of an autonomy perspective on patient care. Tauber argues that empathy and relation, not reductionism and autonomy, must return to centrality in patient care:

Without prioritizing empathy, we doom ourselves to a myopic technocratic medicine. This is not to say that there is no place for the highly technical solution to certain problems. We have come to expect no less. But this is not an either/or selection. Why not demand humane *and* scientifically competent care? Beyond technical expertise and performance, medical ethics must face the more difficult challenge of establishing the physician's identification with the patient (Tauber 2003).

This “empathetic identification,” Tauber continues, allows the physician to “experience...herself” (Tauber 2003). Tauber means this in two senses. Physicians experience themselves in the unique relation that medicine represents—an asymmetrical, but mutually respectful relation founded in trust. But this can also be understood in the broader sense beyond professional identity. As human beings, physicians seek

meaningful relationships, and an autonomy model of care inhibits the establishment of real relationships, blocking the caring and responsible attitude that physicians should achieve. Tauber ends *Patient Autonomy and the Ethics of Responsibility* by arguing that although medicine is a moral practice, it becomes “amoral” under the principle of autonomy (Tauber 2003).

Jean Keller: Care Ethics and the Feminist Critique

Care ethics, and feminist philosophy more generally, have also played an important role in the twentieth-century intellectual movement away from an autonomy-based notion of selfhood. The foundational ontology underpinning care ethics is a relational selfhood that stands as a phenomenological response to autonomy. That is, we find ourselves, and experience ourselves and others, as both encumbered and defined by our relationships (Keller 1997). Jean Keller argues that care ethics and autonomy present incompatible versions of selfhood. She claims that care ethics, “has been used to criticize the philosophical tradition for exalting an individualistic conception of autonomy that is attained at the cost of denying our relations with others” (Keller 1997). Keller’s argument against autonomy is that it fails to accurately describe our selfhood as relational beings deeply embedded in the lives of others, and furthermore, that it offers an ideal that we should not in fact be seeking. That is, to strive to be autonomous is actually to create a sense of self at odds with our social nature. The third aspect of her critique, and one that I believe is crucial to the position I offer, is that autonomy should not have attained the status it holds:

...care ethics also criticizes the status the Western Tradition has granted to autonomy. Autonomy has been thought of as the pinnacle of human achievement, the source of human dignity, *the* mark of moral maturity. Yet the capacity to form and maintain relationships, which has received little attention in the Western philosophical tradition, is arguably just as much of an achievement as autonomy, and just as important for moral maturity (Keller 1997).

Keller concludes, like Tauber, that the concept of autonomy need not be abandoned, but rather modified and perhaps de-emphasized, as one aspect of our selfhood, rather than its central nature. Her arguments are more persuasive than Tauber's, in part because she successfully argues that care ethics must incorporate some sense of personal choice and moral agency into the decisions one makes about with whom to form or break relations, and how these relations should proceed.

If we shift back from "respect autonomy" to "respect persons," then autonomy can be seen as an aspect of personhood, provided it has been dethroned from its current status in American medical ethics. Keller ends with a tantalizing suggestion that autonomy can be understood as the competency to make choices, a description she takes from Diana Meyers. Moreover, she claims that close relations can actually enhance autonomy: a thinking through and envisioning choices together (Kittay and Meyers 1987). To the extent that this is true, then physicians have often done little to aid their patients' sense of autonomy by distancing themselves from the decision-making process and leaving patients alone to make hard choices, aided only by the bare facts provided by the emotionally remote doctor.

Relational Autonomy

However, if autonomy must be twisted or massaged to be best understood or enhanced by close, supportive relations, it leads me to then ask whether we should be characterizing this debate in terms other than autonomy. Are we torturing autonomy, simply because of its historic role in medical ethics, to mean more than it should mean?

Both Keller and Tauber embrace a concept of “relational autonomy,” a term that seems to represent an oxymoron at its outset. It seems more straightforward to value relationality, and to acknowledge that healthy caring relations allow us to make choices that reflect our values and are coherent with our sense of selfhood. This sense of relationality, I will later argue, can be derived from *narrative*, a synthesis of our internal capacity for narrative unity, and the narratives of ourselves that others give us.

Furthermore, Beauchamp and Childress’s response to “relational autonomy” represents a concession that changes nothing:

Some feminists have sought to affirm autonomy but to interpret it through relationships. These conceptions of “relational autonomy” derive from the conviction that persons’ identities are shaped through social relationships and complex intersecting social determinants. . . . Such a relational conception of autonomy is illuminating and defensible as long as it does not neglect or obscure the main features of autonomy that we analyze. . . . (Beauchamp and Childress 2009).

As long as the language of the doctor-patient relationship is described in terms of autonomy, regardless of how nuanced this term can be in philosophical discussions, the effect for clinicians will be no effect. As Tauber concludes, we need a new description of the relationship, one that again makes central the ethical nature of the relationship, and of medicine itself.

Susan Sherwin

Susan Sherwin, feminist medical ethicist, argues against an autonomy model for the medical encounter, not only because she also espouses a relational model of selfhood, but also because an autonomy model covers over the oppressive power dynamics that she believes is central to the relation:

Similar claims (of autonomy) are found within the literature of medical ethics, where it is widely recognized that the relationship between physician and patient is far from equal (especially if the patient is very ill) and that the model of contracts negotiated by independent, rational agents does not provide the ideal perspective... (Sherwin 1992).

She is arguing that autonomy is a fiction at yet another level. How can a patient exercise autonomous choices in her relationship with a physician, when the physician may literally hold the power of life and death over her? Although Sherwin and Tauber reach radically different answers about how to heal the current healthcare environment, they agree on this one point: physicians do have enormous power by virtue of their knowledge and their ability to perform procedures with the potential of great benefit or harm. Patients, by comparison, have no such power. Patients who believe themselves to be autonomous in a medical environment are failing to recognize this power disparity, a disparity that is only covered over by talk of autonomous decision making..

Sadly, although Sherwin affirms that we are relational beings, and that trust would be a better model for the relation between physician and patient, given the unreformed nature of medicine, she believes it is necessary for medical encounters to be conducted in an atmosphere of “anti-trust.” The patient’s relationships to friends and family are then

necessary to protect the patient from the relation with the physician, who seeks power and control over, in Sherwin's primary example, the female patient (Sherwin 1992).

Tauber and Sherwin divide most strongly on the question of paternalism. Tauber believes that the last forty years represent an erosion of physician responsibility, as physicians have willingly given the power and responsibility of decision making to patients, and that physicians must once again help patients make decisions, and even sometimes make decisions for patients. Sherwin, on the other hand, still believes that physician paternalism is a major problem, and that patients need to guard themselves against physicians in a climate of "anti-trust." As a physician, I realize that my opinion is naturally suspect, but I see little support for Sherwin's position in current medical practice. As Christina Sinding's study of female cancer patients shows, patients have trouble getting answers regarding best treatment from physicians, and even try to trick their physicians into helping them make decisions for them (Sinding et al. 2010). Sherwin's voice in this debate is important for two reasons. Although she perhaps overstates the dangers of paternalism, it is important to remember that the goal is not a return to physician power and decision making. Secondly, like Keller, she affirms that the principle of autonomy is in many ways inconsistent with feminist ideals that value relation over individual power.

This debate of how the doctor-patient encounter should be conducted can, as Cassell suggests, proceed without making reference to autonomy (Cassell 1976, 1985). As Albert Jonsen has argued, perhaps autonomy has done what benefit it can by moving medicine beyond a paternalistic stance, but it is now time to reconfigure the entire

discussion to allow growth of the physician-patient relation in ways that placing autonomy at the center simply does not allow (Jonsen 2007).

Empirical Critique

Anthropologists now seem to accept as a given that selfhood is a construct, which arises from the social. That is, our own sense of our selves (and this sense is the only meaningful site of selfhood) is derived from our place in society, and this can be distilled further to represent the relations with others in which we participate. Although one can have an atomistic, isolated, individual sense of selfhood, this itself arises within a historical/cultural framework, and so is itself constructed from our relation to a larger whole. Debhora Battaglia, anthropologist, writes:

The self is a representational economy: a reification continually defeated by mutable entanglements with other subjects' histories, experiences, self-representations; with their texts, conduct, gestures, objectifications; with their "argument of images" and so forth...Selfhood...is a chronically unstable productivity brought situationally—not invariably—to some form of imaginary order, to some purpose, as realized in the course of culturally patterned interactions (Battaglia 1995).

The anthropological evidence for this position is the differing senses of self evident in members of different cultures, and even in different people within the same culture. The autonomous self is then one historical construct in Western culture, and should not be aggrandized by placing it at the center of a theory that purports to describe how the patient-doctor interaction should be conducted. A sense of self that is both

relational and not fixed or essential has become the predominant view of both philosophers and anthropologists. Autonomous selfhood is essential in the sense that rationality is posited as the essence of human beings—humans are rational and therefore autonomous. It is a version of selfhood that is independent of culture, history, or life story. To be human is to be autonomous.

Eva Kittay provides a phenomenological argument against an autonomous self, based in part on relationality. She argues that few *experience* themselves as autonomous, but rather we see ourselves as bound to others by relations that both define us and limit our choices in ways that make autonomy a philosophical construct alien to our experience of our lives (Kittay 1999). If patients do not see themselves as autonomous, how can physicians place this value at the center of the clinical encounter?

Only someone who perceives herself to be autonomous would then wish her autonomy to be respected in a medical setting. But if we instead see ourselves as intertwined in the lives of others, isn't this relationality what instead should be respected? Would the mother of a disabled child feel more respected by a physician who ignores this crucial aspect of her life in seeking to plan elective surgery, or by a physician who sees her *as the mother of a disabled child*, that is, not as an isolated, autonomous individual, but as someone whose plans must always incorporate the needs and care of another?

Kittay's critique can be seen as empirical: if few live lives that parallel the construct of an independent monad, but we instead generally live as deeply connected selves, who cannot choose for ourselves without considering the implications of this choice on others, then the autonomy model fails to describe the person who confronts a physician in a clinical encounter. Furthermore, there is no reason to believe that the

mother who sees her life as one lived largely to help her children grow and flourish would feel more respected by being treated as a solitary being capable of deciding for herself without consideration of others, when that is not how her life is lived. She may be perfectly capable of making decisions without aid from her physician, but her decisions in an important sense are still not autonomous—they are made in consideration of, and constrained by, another person (her disabled child). One could use the language that the physician is respecting her autonomous choice, while still recognizing that in an important sense she does not see herself as autonomous.

Autonomy and Shared Decision-Making

The American Medical Association and the American Academy of Pediatrics have both recently endorsed Shared Decision-Making as the proper model for conducting the doctor-patient relationship (Kon 2010). Shared decision making is not a rival to an autonomy model; rather it is in a certain sense an elaboration of the model. It sets the bounds of what appropriate assistance can be within an autonomy model of care. It shares similar presuppositions to Veatch's description of the relationship in *Patient, Heal Thyself* in that both place a demarcation between the physician's values and patient values. That is, physician values should not play a role in shared decision making. For Veatch, this amounts to a very limited exchange with the physician offering information. The patient need offer nothing about herself at the level of personal values because the decision is solely hers to make. The physician cannot help in the decision-making process

because any assistance would amount to physician values being reinserted inappropriately into the patient's decision regarding care.

Shared decision making gives the physician a larger role than Veatch permits, but it is still a role bounded by the constraints of respecting autonomy. Part of what is meant by respecting autonomy in shared decision making is that the physician may learn of the patient's values, but only to assist in mating those values with the medical facts of the situation. The physician's responsibility is to provide choices and evidence—value-free “facts;” the patient's role is to explain her values. Together they seek an option that is consistent with the evidence, while also being in harmony with patient ideals.

This model arises from a decade of psychological research, although some of the research actually highlights the problems and shortcomings of shared decision making (Frosch and Kaplan 1999). In this model, there is bilateral information sharing: the physician shares technical information, and the patient shares her preferences, values, and plans (Charles, Gafni, and Whelan 1999). After the sharing of information, the decision is then negotiated between patient and physician. This interaction can involve an actual seeking of a middle ground that satisfies both parties, but more often it represents working together to decide how evidence-based medicine and patient preferences can be best combined in a manner that suits the patient (Elwyn, Edwards, and Kinnersley 1999).

Although shared decision making is appealing in its mutuality and non-hierarchical model of the doctor-patient relation, in that both parties contribute to the relation and both are involved in shaping the final outcome, it suffers from at least one shortcoming that it shares with the autonomy model: it lacks universal, and perhaps even widespread, applicability. The old, the very ill, and the poorly educated neither want this model nor

thrive in it (Frosch and Kaplan 1999). In fact, like the autonomy model, it seems to serve the healthy, well-educated population better than those who need physician care the most.

Even within a population of affluent, well-educated women with breast cancer, some patients report “opting out” of the shared decision making model of care. In a study by Christina Sinding et al. that recorded patient narratives using “institutional ethnography,” one patient describes how she manages to avoid the decision making thrust upon her by the oncologist, regarding the future of her chemotherapy:

Robyn: He (the oncologist) said, ‘Well, what do you want to do? Do you want to go back up to the full dose and risk having another episode or do you want to stick on the 15%, the reduced by 15%?’ And I remember thinking, don’t ask me that, you decide. But then I got crafty and I figured...just keep him talking for two and a half minutes min and they’ll figure out what it is they (the physicians) want to do. So that’s what I did (Sinding et al. 2010).

This study gives many reasons why the women sought directly or indirectly to get greater assistance in decision making from their physicians, but two are particularly noteworthy. The first is that making truly informed medical decisions required so much time and research from the patients that they found themselves exhausted, sleeping poorly, and unable to function in other aspects of their lives. That is, even with the physician presenting facts to the patient, for the patient to fully utilize those facts in intelligent decision making, she needed to spend additional time, on her own, familiarizing herself with the background knowledge needed to make sense of what she had been told. Many chose to just “trust the doctor,” rather than face this daunting task, *while already facing the daunting task of living with cancer.*

The second reason women wanted their physicians to make decisions for them is related to the sense of responsibility associated with decision making. This study

provides empirical support for Tauber's claim that physicians abdicate responsibility in a strong autonomy model of care. In the cancer narratives from Sinding's study, she found several women who did not want to make decisions regarding treatment options, precisely because they felt that they would then blame themselves for a recurrence of cancer, feeling that they should have then made another choice (Sinding et al. 2010). This equation of decision making and responsibility is seemingly both natural and present for patients and physicians alike. Furthermore, the "sharing" of shared decision making is clearly insufficient to "share" a sense of responsibility, at least in this study. This is unsurprising, because the sharing is so constrained—the decision is still the patient's. Thus, providing facts and interpretation is inadequate to making the patient feel fully cared for and supported.

Shared Decision Making and Logical Positivism

Also in common with the autonomy model, the origins of shared decision making theory can be traced back to a widely discredited philosophy. As Dan Brock describes, shared decision making is an outgrowth of logical positivism, which may explain why its support is from the psychological sciences rather than from medical ethics literature—which is more tied to the history of philosophy (Brock 1991). The assumption that shared decision making has in common with logical positivism is the fact/value distinction. The physician is supposed to contribute value-free facts to the encounter; the patient shares her values (which are purely subjective and therefore not subject to scrutiny), and then these two components are parsed into a decision that is consistent with the facts, and yet

reflective of the patient's values. As Brock shows, both sides of this equation are problematic, because the medical "facts" are not value free, and it is not the role of the physician to take the patient's value statements as "incurable." By this Brock means that logical positivism sees values as nonempirically verifiable or noncontestable inner states. Values are personal, and not open to another's critique. Facts are impersonal, testable, and the grist of science and medicine. A fact can be found to be wrong and therefore replaced; a value cannot.

The sharing that is presumed in shared decision making is not an open two-way sharing, but rather two one-sided exchanges in which the physician provides the facts, and the patient adds her values to the mix.

By seeing facts and values as fundamentally different and of separate realms—that is, facts and values are not permitted to somehow speak to each other shared decision making replicates the error of logical positivism that teaches a fact/value separation. But as Brock argues, medicine, even more than basic science, is committed to a set of values, and disease and health cannot be defined in a value-neutral fashion. Furthermore, it is crucial that physicians not merely elicit patient preferences, but actually engage patients when possible, in examining whether their values contribute to or harm their overall health and sense of well-being.

Ethical Critique of Shared Decision-Making

If ethics is to be understood as the pursuit of “the good life” or human flourishing, then physicians must at some level be ethicists; to do less is to not fully connect with the patient in every aspect of what they may need to achieve health. Georg Gadamer describes the physician’s role as having both a short-term and long-term viewpoint. In the long-term viewpoint, physicians must use their sense of “health” to help patients correct values, beliefs, or behaviors that stand in the way of this, while still respecting a patient’s sense of self:

We know the routine formulas with which doctors normally fulfill their obligations toward their patients. But when doctors genuinely succeed in leading a patient back into his or her own life-world, they recognize that they are called on to provide help not just for one particular moment but over the long term as well. Here doctors are called on not merely to ‘act upon’ their patients but to ‘react to’ them by treating them in a proper manner (Gadamer 1996).

This “react(ing) to” patients must include the type of responses that shared decision making would disallow. To treat a patient “in the long term” means to confront her at times with the values and behaviors that she exhibits that are self-defeating and diminish her health and well-being. While Veatch is correct that physicians must recognize their own values, and recognize that at times medical values are themselves not always conducive to human flourishing, many of the values affirmed by medicine such as eating well, avoiding tobacco, and reducing stress are values consistent with health. Often the most important step in improving the health of a patient is pointing out the contradiction between, for example, desiring long life and a pack-a-day habit of smoking

cigarettes. This is challenging patients in a way that neither Veatch nor shared decision making seems to wish to allow, and yet it is one of the most important tools physicians have to improve their patients' long-term well-being.

To return to the example of a planned breech home birth, it is clear that it would not be acceptable within the shared decision-making model for a physician to point out to the patient that she has values in conflict with one another: the desire for both a safe birth and the hope for a vaginal breech home birth. These patient values conflict because the facts supporting safety do not support a home birth in this setting. But what if the patient responds that it is her "feeling" that the baby is safer at home? That is, physicians must be able to address patients at the level of questioning values, or the assumptions that lead to value judgments, to fully engage patients' decision making. It may seem paternalistic to claim that sometimes a patient hasn't fully thought through the implications of her value system, but physicians must speak to these values in order to use their experience fully in the clinical encounter. This may be as simple as responding to the patient who claims that home birth in this circumstance "feels" safer, with an acknowledgement that this may be emotionally true for the patient, but that the risks are approximately 4% of a bad outcome for the baby if she proceeds with a breech home birth, and that the safety of the baby is of greater value than her desire for a vaginal birth.

"How can we make you feel safe *in the hospital*, so that you both feel good about your decision, and your baby can receive the best chances for an injury-free birth?" is a way to acknowledge the patient's belief system, while factually correcting it. For the physician to respond this way, and I believe that it is the physician's responsibility to respond in some similar fashion, is to address value statements with value statements.

The physician is not simply correcting values with facts here; the physician is also by implication asserting that the facts regarding the baby's safety are more important, to be valued more, than the patients' feelings on matters of safety. This is not the nice neat model of shared decision making, in which facts and values and physician and patient contribution are added like ingredients in a recipe. Here, the physician is challenging patient values with facts *and values*, and the physician may ultimately choose not to follow the patient in her choice. To concede that one outcome is no agreement is to recognize that the physician also brings values to the discussion, and that physician values may also play a significant role in determining the outcome of decision making.

To put this in the language of narrative medicine, (Chapter III will translate the clinical encounter into narrative terms), the physician and patient both arrive in a clinical encounter with their own stories. The physician's goal is to coauthor a narrative with the patient that meets her needs, without violating the physician's account. While many have argued correctly that the physician's viewpoint has been too dominant in the past, and that the patient's narrative is crucial to good decision making (both are points I would readily concede), shared decision making makes the patient a sole author of the ongoing narrative of her illness, while the physician's role is not to coauthor but merely to research source material, providing "just the facts." This is just a restatement of the autonomy model, and it is time to examine other approaches to the clinical encounter that do not suffer from the shortcomings I have described.

CHAPTER III

MEDICINE TAKES A NARRATIVE TURN

Introduction

In Chapter I, I described medicine as having prematurely settled the nature of the doctor-patient relationship in favor of a model that places respect for patient autonomy at its center. I argued that this has exacerbated problems in medicine by actually encouraging, or mirroring, a consumerist version of medical care that leaves patients feeling neglected by the emotionally distant physician, who offers choices, but leaves patients feeling ultimately responsible for their own care. As shown in Chapter II, shared decision making offers no advance or improvement over this scenario. By remaining wedded to the centrality of the principle of respecting patient autonomy, it fails to escape its significant shortcomings, such as essentially prohibiting physicians from taking a truly beneficence-based role in patient care, accepting responsibility, and guiding patient decisions in a substantive manner.

As Chapter II also illustrates, there has been substantial critique of the principle of autonomy, but much of this critique has actually sought to reform or refine the principle, rather than seek an alternative perspective on the nature of the doctor-patient relationship. Even Alfred Tauber, who is sharply critical of autonomy-based care, from both a theoretical perspective and from his own experience as an oncologist for thirty years, eventually concludes that autonomy is too entrenched in bioethics and physician training to be supplanted. This leads him to redefine autonomy in terms of relationality: he

argues that relationships, caring, and beneficence actually strengthen patient autonomy. While I believe this is true, I think it misses the point that placing autonomy as the descriptor of the patient-doctor relation cannot lead to a relational view of the clinical encounter without forgetting or ignoring a long history in philosophy and political science of what *autonomy* has meant. The word means what it means, and it cannot be changed by our wishes.

Narrative medicine, unlike shared decision making, is not an attempt to reform, or specify, how patient autonomy can be respected and remain central to the doctor-patient relationship. By offering a positive alternative, and showing how it can function differently and lead to outcomes distinct from an autonomy model of care, narrative medicine is able to critique the current model of care while allowing us to envision a radically disparate view of the clinical encounter. In this chapter I will explain how narrative medicine, like the autonomy model of care, is ultimately grounded in a view of selfhood, but that in contrast to the autonomous self, the narrative self readily accommodates relationality, care, and empathy. The narrative self is not only more “philosophically fashionable,” it is also a model of selfhood supported by both cognitive science and phenomenology.

The translation of narrative philosophy into narrative medicine is an ongoing project, but I will argue that narrative selfhood is more compatible with medicine as a profession that offers care and relief of suffering to its patients than the juridical model of autonomy-based care could ever be. Although Chapter IV will point out the practical flaws and philosophical questions unanswered by narrative medicine, my goal is ultimately to address these concerns, rather than suggest yet another model. I will argue

that narrative medicine, still in its infancy, has growing pains, but that the project needs refinement, not replacement.

Narrative Selfhood

Getting an accurate model of selfhood to be foundational for our understanding of the clinical encounter is neither an esoteric nor irrelevant philosophical exercise. The autonomy model of care, in my estimation, fails, not because it does not or can not respect patient autonomy, but rather because patients are often unconcerned with questions of autonomy. More central to patients are concerns regarding loss of health, pain, and death, and these are not readily made relevant by an autonomy model of care. Yet, they are central to every human narrative and so come to the forefront with narrative selfhood and narrative medicine. If autonomous decision making is a historically achieved right of patients, but not fundamental to how they see themselves, or even to what they seek and desire from a clinical relationship, then autonomy is an inappropriate foundation for the physician-patient relationship.

It is, however, a different question whether the narrative view of selfhood facilitates the doctor-patient encounter more successfully than autonomous selfhood, and whether it represents a model that we should embrace beyond its instrumental value in medicine. I will argue that its instrumental value resides in its more accurate description of our lived experience. Medicine is more able to address the concerns of the patient when the patient is more accurately understood. Paul Ricoeur's intimate linking of

narrative selfhood and suffering answers why a narrative approach addresses patient concerns more directly by *addressing the actual patient more directly*.

In the work of Ricoeur and others, a view of selfhood arises that challenges the autonomous self without making the postmodern move of either abandoning or relativizing selfhood. For Ricoeur, the self is constructed or organized through narrative, and to be a person is to see the world, to emplot it, to create stories and to share stories with those with whom we live and to whom we relate (Ricoeur 1984, 1992). In *Time and Narrative*, Ricoeur develops his thesis of the threefold mimesis in which experience is described as fundamentally narrative in nature. That is, we perceive certain things in a pre-narrative but symbolic plane, which we then represent through narrative structures. This is the first and second mimesis; the third mimesis occurs between the storyteller and the other. What Ricoeur sets out in *Time and Narrative*, he develops further in *Oneself as Another*: we experience and communicate the world to others in narrative structures, *because we are narrative*.

Alasdair MacIntyre writes that, “Stories are lived before they are told,” meaning that we live inescapably in narrative structures, and only understand others and ourselves through this prism (MacIntyre 2007). This does not deny the role of others in the development of self through narrative. While the exact nature of this influence varies among narrative theorists, none would defend the view that narrative is solely the story we tell about ourselves to ourselves, that is, the view that narrative is purely subjective. Others are critical in our life story, and our narrative is something we share with others, and it is informed by the views of others regarding ourselves. This means that a narrative sense of self is always and already a relational self—the narrative is about our

relations with others, informed by their sense of us, and communicated to, and lived out with others.

Valerie Grey Hardcastle suggests that the narrative structure of selfhood is no longer a point of significant debate; in fact, it has been embraced and confirmed across many academic disciplines:

Indeed, there is remarkable consensus regarding what the human self is. For the last century or so, the sciences and humanities have operated somewhat removed from one another, with little overlap among either individual research projects or larger conceptual frameworks. But studies within disciplines as diverse as anthropology, artificial intelligence, cognitive science, communication studies, history, law, linguistics, literary theory, philosophy, political science, psychology... all converge on or around the idea that a narrative structure unites our fleeting and fluttering Humean perceptions into a single self (Hardcastle 2008).

Hardcastle's claim is not simply that a narrative structure of selfhood is widely accepted, but also that this broad agreement has occurred because the support for a narrative structure of selfhood is both empirical and philosophical.

The Narrated Self as Private or Public

However, while there is broad consensus about the self as narrative, I believe that across the varying disciplines, and even within them, there is less agreement about the actual details of narrative selfhood. As one example that will become more important as we move to a discussion of narrative medicine, the relative contribution of others in the composition of the narrative self is not uniformly described even within the group of philosophers who agree upon narrative selfhood. Thus, while Hardcastle describes the

self as, “we are who we say we are,” Hannah Arendt and Adriana Cavarero would argue the inverse—that we are largely who others claim we are (Hardcastle 2008; Cavarero 2000).

In order to successfully apply narrative philosophy to medical practice, physicians ought to bear in mind that there is an important difference between the self as the *story I tell about myself* and the self as a story told about me by others. Furthermore, John Arras argues that there is a difference between the story of self we tell ourselves, and the story we tell others—and the story changes again depending on who the other is, and the role she occupies (Arras 1997).

The relationship between a person’s view of herself, even if informed by others’ observations, and the stories others tell about her, is an important distinction within attempts to translate narrative philosophy into medicine, because the clinical encounter usually has no access to the public narrative of a person—the private narrative, the story the patient tells about herself, is the only story that the clinician will hear. If this is not the privileged locus of selfhood, then the physician cannot “know” the patient, the selfhood of the patient cannot be revealed in the clinical encounter, and therefore the patient’s self must not be a concern of medical care. Furthermore, while my story of self may largely coincide with the story others would tell about me, there are many instances where the public narrative and private narrative can be widely divergent. Which version to privilege may not be decided by any rule other than hearing both, and deciding which coincides to other observable or verifiable facts, again, a possibility outside the scope of medicine. Only if the self can be revealed, wholly or largely, within the doctor-patient

relationship, can narrative selfhood serve foundationally in describing the proper nature of the relationship.

Both extremes of narrative selfhood---a total identification with the individual story or the public narrative---are counterintuitive when examined closely, or held to be true for every person. We would not agree that Ted Bundy was the person he described himself to be. Furthermore, his self-description was also seemingly self-deceptive, in that he believed his own lies about himself. Similarly, many stories told about ourselves reflect a truth that we wish to reject, even though they may describe us better than we wish to admit. My provisional answer to this quandary is that for most, personal narrative and public narrative mutually inform one another. We listen to what others say about us, and incorporate or reject these stories, and others listen to us and incorporate or reject how we describe ourselves. Many patients are also able to give multiple perspectives on themselves to the physician. For example, a woman may tell her doctor both that she believes her loss of libido is from lack of sleep and that her husband thinks it is from no longer feeling attracted to him.

But self-deception, and also willful, knowing deception of the physician by the patient, are important for the physician to recognize as critical to the clinical encounter, beyond the difficulties these obscurations present for the physician seeking to obtain an accurate history of the patient's symptoms or disease. It says a great deal about a patient if she believes she is seriously ill when she is not, or if she knowingly deceives the physician about the extent of her illness. The physician must address both the illness as she sees it, and the patient's misperception or misrepresentation of her illness. In this

circumstance, where there is no underlying disease creating the symptoms of the illness, the illness *is* the symptoms.

When the patient's illness narrative is at odds with the physician's view, the patient's self-understanding and the physician's perspective must be brought into alignment in order for them to work together as a team. As Ricoeur describes, the clinical relationship must be two people with the same goal for the relation to function properly (Ricoeur 2007). The point here is that the patient narrative is important even when it sheds no light on the illness directly, but rather informs the physician about how the patient understands, and even incorporates, the illness into her life, as both gain and loss. For example, experts in chronic pain write about how finding and addressing the secondary gains of chronic pain is important to ameliorating it for suffering patients (Glajchen 2001). Patients cannot directly tell physicians how they benefit from their chronic illnesses, but their narratives will often provide these answers to the skilled reader of the patient "text" (Anderson and Montello 2002).

So, returning to whether the narrative self is private or public, I respond that the physician must address the patient in the examining room. The narrative provided by the patient may not even perfectly coincide with the view of self she holds privately, but it is still the starting place physicians are given, and it is adequate to many clinical encounters. Sometimes, particularly in cases of mental illness or drug-seeking behavior, the physician must corroborate the story of the patient with the perspectives of family members or friends. But even in these circumstances, the patient narrative speaks volumes, if only in terms of what the gaps and gulfs reveal.

Medicine and the Self as Social

While Hardcastle argues that the self is the story we tell about ourselves, often to ourselves, she is neither denying the impact of other people's narratives upon our own, nor is she neglecting the way in which the social-cultural narrative plays an important role in shaping personal narratives. Using the work of George Mead, Hardcastle states that "we need our social group in order to tell stories about ourselves in the first place" (Hardcastle 2008). This would seem to create a problem for narrative within the doctor-patient relationship. Isn't this just another distortion, yet another reason why personal narrative is unreliable and therefore unimportant in taking care of patients? In the simplistic model of medical care now known as the *biomedical model*, that would seem to be both a fair and damning critique of the utility of patient narrative in the clinical encounter.

The biomedical model views the patient through a reductionistic, even mechanistic paradigm: The body is a machine that when broken or infected with a hostile, invading organism needs fixing or treatment to restore proper function. The biomedical model has been prevalent for the last one hundred years, and part of its longevity is attributable to its success in dealing with many common medical problems including infection, injury, surgically treatable disease, and even cancer to some extent.

Persistence of the biomedical model is an obvious threat to incorporating narrative techniques in medicine, because there is no place, need, or standing for narrative in medicine conducted in this manner:

According to the biomedical model, the patient is a machine composed of individual body parts that, when broken or lost, can be fixed or replaced by new parts. Moreover disease, whose cause can be identified by scientific analysis, is an objective entity. It is often organic and seldom, if ever, psychological or mental. The notion of health involves the absence of disease or the normal functioning of body part... Thus the physician is a mechanic or technician, whose task is to determine which part of the patient's body is broken or diseased... (Marcum 2008).

As James Marcum points out in this quotation, the physician is in a certain sense diminished by this view of medicine, but the patient as a person disappears completely. If the patient is merely a collection of body parts to be fixed, it is easy to see why narrative would have no role. The patient history is important only insofar as the symptoms provide clues for the physician trying to determine "what is broken." Disease and ill health are not simply objective and purely physical; they are also impersonal. One of the simplest critiques of the biomedical model is that it seems to have no answer as to why the same disease manifests so differently among different people, and perhaps even less understood, among different cultures or populations of people.

Marcum credits George Engels and Eric Cassell as the two physicians who successfully challenged and exposed the flawed presuppositions of the biomedical model, proposing and defending a *biopsychosocial model* by Engels, and a *humanistic model* by Cassell. Humanistic medicine returns the patient to the encounter:

What is a person? Cassell initially treats the questions two separate questions, one concerning the particularity of the person *qua* person and the other in terms of the measure of a person. Importantly the initial discussion is embedded in the nature of suffering, especially with respect to the illness experience. ..

The features that make up Cassell's first category of person in terms of his or her individuality include an individual's body, personality or character, regular behaviors, activities, public and secret life, past, future, and transcendent dimensions. Each of these features has an important impact (Marcum 2008).

Although Cassell is not explicitly a narrativist, it is clear from this account of his thinking that a narrative approach to medicine is both justified and necessary within his thinking about the clinical encounter. Illness and the patient response to it are affected by far more than the body parts that make up a human being. Although Marcum writes that the biomedical model is still the prevalent model in medicine, the challenge to it that humanistic medicine presents has been growing since the 1980s, as medical schools have sought to produce physicians who see patients as persons, rather than as collections of body parts, and medical schools have openly sought ways to increase student empathy toward patients (Benbasset and Baupal 2004; Hoja 2007; Halpern 2003).

The rise of humanistic medicine is complementary to narrative medicine in that there must be an engagement with the patient as a person to have any interest in narrative. The self as including or incorporating the social is similarly resonant in both humanistic and narrative medicine. As Marcum describes it, the social affects how disease is translated into illness in an individual, and the choice of therapies is also socially constrained.⁴ One commonly cited example of this is that Japanese patients with lower - back pain exhibit much less physical and vocational disability than their American counterparts (Brena, Sanders, and Motoyama 1990). Narrative theory makes sense of this in that illness is the interaction of disease with the individual, and in turn the individual understands herself through stories of self that follow certain patterns that are socially constructed. Thus, back pain in Japan would not be expected to be the same as in America, because the Japanese person understands herself through a different lens. The American with back pain who must see herself as either a success or a victim can choose

⁴ Marcum does not define “social,” but does define “the social construction (of medicine)” which he writes, “(is)...a specific social or cultural context.” In this same section, he seems to equate the social with the societal perspective, as opposed to a biological or biomedical viewpoint.

to be a victim and emphasize disability, particularly when her job or life is unsatisfactory. That is, she is not a success, but it is not her fault—the reason is outside herself (even though in a real sense, her back pain is her own). The Japanese are more inclined to blame themselves for failure, so are less likely to be disabled because they would have to see this as a personal failing.

Physicians should take into account that narratives not only incorporate and depend upon societal views and values, but are also constrained by social mores. As Arthur Frank, sociologist and survivor of cancer, writes in *The Wounded Storyteller*, the patient's story is personal, embodied, but also shaped by the social:

The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to “tell the doctor what hurts” and had to figure out *what* counted as the story that the doctor wanted to hear. From their families and friends, from the popular culture that surrounds them, and from the stories of other ill people, storytellers have learned formal structures of narrative, conventional metaphors and imagery, and standards of what is and what is not appropriate to tell (Frank 1995).

As Hardcastle describes, the narrative must make us look good by societal norms, or at least innocent. Mark Johnson writes that through our stories we morally justify ourselves—we frame things and find our lives both meaningful and good (Johnson 1993). The patient with a sexually transmitted disease will either explain that her boyfriend was unfaithful, or that she made a mistake—from which she has already learned the lesson. To know what cannot be said within the social rules of narrative is a critical skill. The patient with a sexually transmitted disease may tell you that she has learned the appropriate lesson, because she believes that this is the correct answer socially, but she may very well not have actually learned the lesson that you feel is most

important. Thus, to take her at her word is to miss an important counseling opportunity, exactly because she gave the socially correct story.

Medicine has for too long ignored the social. Narrative technique is one remedy to this insofar as the impact of the social on narrative is appreciated. But if physicians have failed patients by ignoring the way in which illness and personhood are in part socially constructed, we have failed patients to an even greater degree by being blind to the impact of the socially constructed physician narrative upon the clinical relationship. Walter Robinson, a narrative ethicist and practicing pediatrician, describes how physician narratives are crucial for allowing physicians to hurt others in an effort to heal them, but that blindness to narrative prevents doctors from recognizing when these same narratives are dysfunctional, and actually prevent good patient care (Robinson 2002). Using the example of the “rescue narrative,” the story of how medicine can either with progress or high technology save a child at the brink of death, he shows how many family or individual narratives and choices get overridden by the physician version of the story, even when there is no plausible rescue to be made. Robinson describes how parents with children suffering from cystic fibrosis, a chronic lung disease that usually leads to an early death, often in a child’s adolescence, have been given the hope that a cure is coming, and that it is likely before the disease takes their child, only to see their children die with no new treatment yet in sight.

The harm of this is at least twofold, according to Robinson. First, by giving the family a narrative that fails to be realized, the doctor is depriving the family of constructing their own narrative about the disease that is likely to end their child’s life prematurely—a narrative that would incorporate their own values, spiritual beliefs, and

sense of family. The denial of a family narrative may leave families feeling even more bereft at the death of their child, because they have not yet started to make sense of it.

Secondly, physicians are often too aggressive in end-of-life care with children because they are unable to let go of their own myth of progress or the possibility of cure, even when it is clear that further efforts would only prolong suffering and death, not prevent it. The point of revealing physician narratives is not to try to get physicians to practice without them, because it is with narrative that we structure experience and determine what is meaningful, and what is forgotten. Rather, physicians must become more aware of our own narrative foundations so that we can more consciously examine when we are literally telling ourselves the wrong story for a given situation. The rescue narrative is neither bad nor good, but it is often the wrong story to be telling when the patient has little real hope of a rescue. The tragedy is only heightened when the promised *deus ex machina* fails to arrive, and the treatment may reflect the plot of the story rather than an evidence-based response to the actual medical circumstances.

Robinson's argument could be understood as a choice for physicians: either understand narrative and its centrality in the meaning-making of life, and therefore our profession, or be doomed to fail your patients because you cannot see the mismatch between your narrative and the specific circumstances of the medical encounter. Ricoeur argues in *Oneself as Another*, following MacIntyre, that not only is narrative the inescapable lens through which we view all experience, but that also we need narrative to give meaning to the events in our lives: "By narrating a life of which I am not the author as to existence, I make myself its coauthor as to its meaning" (Ricoeur 1992).

We are not author of our lives because we do not choose the circumstances of our birth, and many things happen to us that we do not choose (for Ricoeur, we are either acting or suffering). Nonetheless, we do act, and we act according to a vision of the “good life” that we construct:

First, between our aim of a “good life” and our particular choices a sort of hermeneutical circle is traced by virtue of the back-and-forth motion between the idea of the “good life” and the most important decisions of our existence (career, loves, leisure, etc.) This can be likened to a text in which the whole and the part are to be understood each in terms of the other (Ricoeur 1992).

We make our professions meaningful within this plan, especially professions such as medicine that are always chosen and struggled for, never entered into lightly or by default. Furthermore, the overall values of a physician and the values of the profession must be consistent for the narrative to be consistent. But the profession, as Robinson shows, also has a narrative, or narratives, and this may at times not further the values of the profession, as well as the personal narrative of the person entering the profession.

The life-made-meaningful function of narrative is a necessary prerequisite for the ethical life—we must make sense of our professions in order to make them an aspect of our lives that contributes to our overall life goals. Robinson’s cautionary tale of conflicting narratives has another dimension when Ricoeur’s analysis of the role of narrative and meaning is considered. The rescue narrative is a professional narrative of physicians precisely because doctors want to help their patients, and need to feel that they are benefiting, not harming, their patients. But when physicians blindly play a role in this narrative, they may in fact violate their own goal of caring for others. Thus, blind

adherence to a social narrative not only harms the patient at times, but may thwart the physician's own life plan of reducing the suffering of others.

Narrative Medicine

Hardcastle, in *Constructing the Self*, her recent book defending and explaining narrative selfhood, begins the chapter that makes the case for narrative selfhood against arguments raised by Galen Strawson by commenting that she was surprised that an explicit defense of narrative selfhood was necessary—it seems so self-evident to her (Hardcastle 2008). The proponents of narrative medicine would appear to have the same attitude toward narrative medicine—it is of such evident value that an explicit justification is unnecessary. However, narrative medicine is far from a widely accepted technique of approaching the clinical encounter, and although it has some obvious problems with universal applicability, I would like to make the case for narrative medicine, before discussing how it needs to be reconfigured to address these concerns.

I have four overlapping arguments for narrative medicine and each can be stated as a simple proposition:

- 1) Our selfhood is narrative. Medicine must heed narrative technique to treat the whole person, which is the goal of humanistic medicine.
- 2) Illness and treatment both represent a threat to, or loss of, selfhood. Narrative returns the voice of the self, restoring a self beyond the self as merely patient.
- 3) Medicine, also, has an implicit narrative structure, as Robinson described with his discussion of physician “rescue narratives” (Robinson 2002). Making this

explicit, that is, acknowledging the competing narratives within a clinical encounter, provides the best opportunity for allowing the most important narratives, rather than the most powerful narrative, the physician narrative, to be heard.

- 4) Medicine is a moral art; ethical reasoning and understanding take place within narrative structures. To pursue the moral art of medicine without narrative is to approach the clinical encounter without the skills necessary to achieve the goal of serving others.

I will further explain these four propositions in the rest of the sections of this chapter.

Medicine and Narrative Selfhood

As I previously discussed in this chapter, there are ambiguities and even controversies within *narratology* regarding the precise relationship between story and self.

Nonetheless, I take it as largely settled that both our experience and our sense of self is narratively structured and understood. Medicine needs narrative competence to better understand both the patient, and the nature of medicine. In Chapter IV, I will discuss what I see as the primary limitation of narrative medicine, namely, exaggerated claims about the extent to which the patient can be fully understood via narrative. But here, I wish to emphasize that narrative medicine addresses the important deficit left by the biomedical model of medicine, which is to fail to see and address the whole patient.

In simplistic terms, if we accept selfhood and experience as narratively structured, then it is through narrative approaches that we will best come to know our patients, and

even our own profession. This is less self-evident, however, than it first appears. If we experience the world narratively, why do we need a narrative approach? Don't we always and already have it without labeling it so? The answer as to why we must learn to be consciously narrative in our approach when we are already unconsciously narrative can be seen in Robinson's critique of the rescue narrative in medicine. The autonomous self is an historical story, a narrative about ourselves that is more or less true, depending upon the person it describes and her history, culture, class, and gender. To understand it as a story is to see it and value it very differently than to understand it as an essential unmediated truth about ourselves as human. Similarly, to know about the predilection of physicians to see ourselves as rescuers is to be largely freed from adopting that narrative unthinkingly. It may still be chosen, but now consciously, and it may then be examined as to whether it continues to fit or be appropriate to any given clinical encounter.

The point is that it is very different to unconsciously inhabit the world of narrative than to recognize the importance of story to selfhood, and critically choose the right story. With this recognition comes the responsibility to seek the narratives important to each patient, because only by sharing these stories can we hope to know the other well enough to treat her illness or suffering. Illness is the unique interaction of disease and an individual person—to treat illness and relieve suffering requires a narrative approach, consciously chosen:

As medicine matures, perhaps its practitioners will develop the skill to register singular contexts that donate meaning to each clinical situation and will take upon themselves the responsibility to learn about singular aspects of their patients' lives. Such efforts are bound to enhance clinical effectiveness, not only by guiding choices of treatment interventions but also by alerting doctors to all considerations that might help or hinder patients from following medical recommendations and becoming true

partners in achieving and maintaining the best health within their reach (Charon 2006).

Narrative selfhood emphasizes the singularity of each self, the uniqueness of each of our stories. It serves as a constant reminder or response to the reductionistic tendencies of the biomedical model that focuses on the universal aspects of disease, rather than the uniqueness of each person's illness.

Narrative Treats the Loss of Selfhood Associated with Illness

Arthur Frank describes how illness represents a threat to selfhood on several levels. The first, and the one most obviously connected to narrative selfhood, is that we lose or must reconfigure our sense of the future when faced with serious or chronic illness. Sometimes this includes recognizing that a future we considered central to who we are is no longer possible; sometimes having a future is itself threatened. Frank writes that a “disjunction” between our story and reality can be worse than having no story at all, and that healing must include narrative repair:

Stories have to *repair* the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations (Frank 1995). (Italics original)

In most cases, patients are capable of reorienting themselves as their capacities change, but at times they can be overwhelmed by the task, and physicians may play an important role in imaginatively envisioning new futures, along with a patient. When the fictional surgeon Charles Emerson Winchester on “MASH” shows his wounded

soldier/concert pianist patient that there is great classical music that he could still play despite his wounded hand, he enters the narrative future of another with the goal of restoration.

Frank recognizes the value of narrative repair, yet also warns against a too- facile response to the dissolution of selfhood that comes with serious illness. To seek solutions in response to another's description of chaos and narrative breakdown can represent a denial of the other's experience. When the suffering person seeks to speak of the chaos she is experiencing and the loss of self, Frank argues that the correct attitude on the part of the listener is to witness and accept this ineffable aspect of illness as part of the real that cannot be narratively fixed or understood. The move to repair, or even to reformulate it narratively, is to deny the chaos antinarrative:

The challenge of encountering the chaos narrative is how not to steer the storyteller away from her feelings...the challenge is to *hear*. Hearing is difficult not only because listeners have trouble facing what is being said as a possibility or a reality in their own lives. Hearing is also difficult because the chaos narrative is probably the most embodied form of story. If the chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate (Frank 1995).

Listening without fixing, Frank argues, is hard for physicians, not simply because we see our role as healers, but also because the chaos narrative challenges medicine at its core—it lacks rationality; it is what must be accepted without being understood.

Physicians have the ability to respect, and at times help repair the patient's narrative that exists apart from illness, or help patients construct a new narrative that incorporate illness without being only a medical narrative. But physicians must also recognize that they represent the human voice of the medical institution, and that our

address of the patient as patient represents an interpellation—medicine creates a new subject, the patient, by addressing the person in the clinical encounter:

Waitzkin describes how medicine *creates* a new person, a new “subject” in its work of hailing... This creation of the patient is based not on a politically and morally neutral science, but on the social need to keep people “performing reliably” in what they are “expected to do.” The patient is hailed to “march [not walk] down a more straight and narrow path.” Whether this path is what the patient needs is not the present issue... how can we possibly say what anyone “needs” when ideology—whether medical, legal, educational or religious—has already defined the terms of what people “need” (Frank 1997). (*Italics original*)⁵

This new subject represents yet another threat to the selfhood of the person now addressed as patient. The patient self carries much information about the illness, but little other personalizing information besides smoking, drinking, and drug habits. Many physician interviews dichotomize the patient as either single or married, as if this describes the wide range of personally intimate relationships. The person in the physician’s office, already struggling with the loss of self that illness can precipitate, now faces a new threat from the person she approached for help. Frank writes that patients, “resist medical interpellation ambivalently and ambiguously,” because they want what medicine has to offer, but they do not want the new subjectivity associated with the medical encounter (Frank 1997). This is less crucial when that subjectivity is temporary, and represents only a small counter narrative requiring incorporation into other life narratives. But some patients become “career” cancer patients; the subjectivity of being a patient becomes a significant burden and affront to a sense of self that they wish to preserve apart from their medical subjectivity. Frank writes that patients have found

⁵ Arthur Frank is drawing from the work of Howard Waitzkin, *The Politics of Medical Encounters: How Patients and Doctors Deal with Social Problems*, New Haven: Yale University Press, 1991. Waitzkin’s work in turn draws from the Marxist social philosophy of Louis Althusser.

ways to subvert or reclaim themselves while continuing to be patients in an institution that can be both dehumanizing and literally lifesaving. But physicians have two possible responses to this issue of conflicting narratives, and I believe both represent insights of narrative medicine.

The first helpful response of physicians is actually an old technique of medical history: seek as much detail as possible about the patient, and incorporate it into the medical narrative. This attention to detail both makes the patient feel more seen as a person, and also may uncover diagnostic possibilities that otherwise would not have been considered. Eric Cassell describes how knowing that the elderly patient has recently lost his wife and lives in a walk-up apartment with stairs now too difficult for him to manage represents more than personalizing narrative about the patient hospitalized with pneumonia and malnutrition. These facts are actually crucial details to understanding why he is malnourished, and what services he will require before he can safely be discharged from the hospital (Cassell 1979). Cassell argues that these details of his life are as causal to his pneumonia admission as the bacteria *pneumococcus* that is the proximate cause of his admission. Physicians need to return to an ethic that knowing the patient as a complete person aids the diagnosis and treatment as much or more than a CT scan, or even the physical exam. The complete and personalized history produces both better medical care (and more cost-effective care), and also make the patient feel less dehumanized by medical interpellation.

The second way physicians can reduce the burden of medical narrative on our patients is by acknowledging the personal details of the patient's life that are irrelevant to medical treatment. That is, when physicians greet patients by asking about their knitting,

their volunteer work in church, or their children, we are acknowledging the life, joys, and obligations that this person has outside the sphere of medicine. Such “small talk” represents a gesture beyond the medical narrative, to the stories inhabited by that person. It represents a value statement that there is more than the illness that is important, even if our business in the clinical encounter is to focus on the illness. To ask whether the patient has pets may, of course, be relevant to a medical visit, but to ask the name of the patient’s dog can only be understood as stepping outside medical fact finding and seeking to know the patient as a person.

Medicine as Narratively Structured

Narrative medicine can be simply characterized as an effort to privilege the patient narrative, and to get physicians to appreciate that respect for patients must begin in allowing patients to be fully human in medical encounters, rather than biomedical machines that require “fixing.” Kathryn Montgomery Hunter argues that medicine, and medical knowledge, rather than being a scientific enterprise, is actually a narrative project. That is, physicians are already trained to take the patient narrative of illness and reconstruct a narrative from these clues, which fits a medical framework:

The practice of medicine is an interpretive activity. It is the art of adjusting scientific abstractions to the individual case. The daily life of a practicing physician is made up of observing, testing, interpreting, explaining as well as taking action to restore the patient to health. Much of this routine, the exercise of clinical judgment that has been acquired, first, by a thorough education in human biology and then, by participation in the care of a myriad of single cases that are narratively described and studied one by one. The details of individual maladies are made sense of and treatment is taken in light of the principles of biological science. Yet medicine’s focus on the individual patient, fitting general principles

to the particular case, means that knowledge possessed by clinicians is narratively constructed and transmitted (Montgomery Hunter 1991).

Montgomery Hunter is arguing that medical training and knowledge is a narrative enterprise rather than a purely scientific one, and that physicians construct an illness narrative for the patient, beginning with the patient history, and then return this narrative to patients as a way for them to now understand their illness. Montgomery Hunter describes how the patient history is treated as the most valuable piece of information, the most important clue in solving the mystery of the diagnosis. She writes, “This is often stated as a statistical rule, one that is noteworthy for its approximate probability: ‘Eighty percent [in some versions 90%, but always at least three-quarters] of your patients can be diagnosed from the history’” (Montgomery Hunter 1997). While touting the importance of the history, physicians have learned that it offers clues that often need to be reinterpreted to be made meaningful within a medical framework. For example, the elderly woman who describes her vasculitic rash as “scratches from picking blackberries,” when it is neither blackberry season nor a rash from contact exposure, *is* telling me about her level of dementia, but she is not telling me the cause of her rash.

There are two tensions here that need to be addressed. The first is between singularity and universality; the second regards the status of the different narratives. Rita Charon argues that physicians have not respected the uniqueness, the singularity, of each patient they encounter—they tend to focus on the universals of disease, rather than the individuality of each person who seeks their care:

When patients complain that doctors or hospitals treat them like numbers or like items on an assembly line, they lament that their singularity is not valued and that they have been reduced to that level at which they repeat other human bodies. It

is in the sphere of narrative that patients, of late, have attempted to take back their singularity, their subjectivity (Charon 2006).

But if patients desire the singularity of their subjectivity to be recognized, they also seek to escape the singularity of illness. Ricoeur writes that illness singularizes in that it separates the patient from her activities and from other people, to leave her in a place where she worries that there is something uniquely wrong with her (Ricoeur 2007). Here, the physician rescues the patient by universalizing, or generalizing, her illness into a disease that can be known and treated. The patient goal is to be unique but not isolated; individual, but with a recognizable ailment. Even giving name, or conceptualizing the individual symptoms within a taxonomy, is often of great relief to patients. “I thought it was just me,” and “I thought I was going crazy” are two common responses to giving name to a patient’s condition. While Charon is right that patients wish to be seen as unique, they do not wish their illnesses to be unique, and patients can get significant comfort by discovering that there are others suffering from the same affliction. The status of the various narratives coexisting within a clinical encounter needs to be noted here as well. Montgomery Hunter is correct that the practice of medicine is inherently narrative, but it has also been an enterprise that often devalues the patient narrative, even while mining it for important clues that may lead to a diagnosis. The goal, she writes, is to value the patient narrative, but from this narrative a physician constructs a new medical narrative, and returns this respectfully to the patient:

[Here is]...a model for the right relation between general biomedical rules and the particular circumstances of illness. It is an epitome of the physician’s threefold task: to acknowledge the subjective experience, to reconstruct it as a medical version that can be matched to taxonomic abstractions and explicated with

biomedical laws, and returning that interpretation to the patient, still to understand and affirm the life narrative of which it is now part (Montgomery Hunter 1991).

To solely privilege the patient narrative is to fail to engage in medicine. Medicine is a narrative undertaking that hermeneutically works uniting the particulars of the patient case with the generalized knowledge base of medical science. But the new narrative, as formulated by Montgomery Hunter, must be understood as something to be reintegrated into the patient's life narrative—a narrative in which, hopefully for the most part, she sees herself as one who is acting rather than suffering.

Medicine as an Ethical Art: The Role of Narrative

In Chapter I, I explained Montgomery Hunter's argument that medicine is a moral art and an interpretative enterprise, not a science, but I believe that by using Ricoeur's *Oneself as Another*, this case can be made most directly (Ricoeur 1992). Here, Ricoeur separates ethics, which sets the goals of a good life, from morals, which provide the necessary norms to avoid harms to others. Strictly speaking then, medicine is ethical rather than moral by this reasoning, because it is the practice of medicine that returns people to health so that they may continue to be productive, aspiring members of a community. Medicine then is an ethical art in two senses: it is part of what is necessary for living well, and it takes up, sometimes directly, the question of what living well actually means.

The practice of medicine is crucial to living well, and living well with others is the goal of ethics. But how a physician perceives the role of medicine affects the

decision making she then makes within a clinical context. The physicians responsible for refusing to take Karen Ann Quinlan off the ventilator, despite her persistent vegetative state, argued that medicine had the duty to preserve life, any life (Pence 2008). In contrast, many in medicine now argue that helping patients die well is part of the larger goal of medicine, which is to help people live well. The conversation about whether the goal of medicine is to preserve life at any cost, or to help others live well, is of course ethical, and when physicians question how to best help others live and die well they are asking an ethical question of medicine—what is its goal, and how do we best achieve it?

As Hilde Nelson Lindemann argues, physicians need narrative skills to help patients achieve goals of health and living well. The narrative skill is not the inculcated practice of taking the patient narrative, physical exam, laboratory and radiological tests, and fashioning a new narrative that follows the conventions of medical narrative. Rather, it is the narrative skill of looking backward at the patient's life, looking sideways at the current circumstances, and projecting possibilities forward, with the patient as partner in this enterprise (Nelson Lindemann 2002). To relieve suffering, as Jon Arras points out, it is necessary for physicians to narratively discern the *meaning* of the illness for the patient:

Although the chart and other forms of medical discourse, such as the truncated language of clinical rounds, pretend to have achieved a high level of universality and scientific objectivity, they often screen out the very meanings that disease or illness has for the patient. In the absence of an understanding of the existential implication of the patient's condition and the meanings of various treatment alternatives, the physician is likely not even to recognize moral tensions or problems latent in the medical encounter (Arras 1997).

When physicians slip into a universal sense of what is good for humans, they risk no longer being beneficent to an individual patient. My medical ethics students argue with near-unanimous agreement that the physicians who kept Dax Cowart alive after being burned severely over most of his body, and despite his pleas to have treatment withdrawn so that he could die, did him no favors, and certainly did not act beneficently (Pence 2008). The consensus in medical ethics has been toward a gradually increasing awareness that doing good for another, or harm, must take into account the patient's wishes and story. To do the right thing, especially in medicine, requires more than a knowledge of principles of ethics and the idealized human subject. It requires a sensitivity to the uniqueness of each person's story, and a willingness to look deeply into what each person needs to be made well again.

While respecting individual choice is part of an autonomy model of care, taking an interest in determining who the individual is has not been. Respect for autonomy only gives voice to those who already have it; the narrative model seeks to empower all patients.

Narrative Medicine: But What Is It?

Just as I think that narrative medicine has been less propositional and more, well, narrative, in its justification of itself, I think there is not a simple answer as to what narrative medicine actually represents as a movement. In fact, as I have already suggested, the narrative nature of our selfhood and experience cuts both ways in an argument for why we need more narrative technique in medicine. Aren't we narrative to

the core already? Does narrative medicine simply mean we should listen better to our patients, and not replace their story with our medical story, or see their story only through the lens of the narratives that we have acquired in our medical training? While all these statements are true, narrative medicine is asking more of physicians than to simply improve their listening skills with patients. Much of what it asks of physicians has been alluded to directly or indirectly in my treatment of it so far, but I would like to make explicit what I believe the central claims of narrative medicine to be.

The Central Claims of Narrative Medicine

- 1) **To treat the patient requires knowing the patient.** This, in turn, requires being a skilled reader of the patient as text—a narrative told, inferred, or enacted. The first way that the narrative aspect of medicine must be complicated is in expanding what is meant by narrative. It is already clear that I am not referring to narratives as written autobiographies; few patients arrive with their life story written for the physician to interpret (I say few, because I have received written narratives from patients on a couple of occasions). It is also not just the story told, drawn out by the physician’s questions in the exam room. Arthur Frank writes that stories are “enacted” in our lives, in our bodies, and that both of these senses are at times available to the physician if she is a generous reader of the text, now understood as body, before her (Frank 1995, 1997).

I also wish to be clear that I am excluding the directly literary aspects some, particularly Rita Charon, have included in their description of narrative

medicine—that is, using literature as a moral or character-building exercise to improve patient care, or journaling as a method of exploring one’s thoughts about an individual patient’s story (Charon 2006). This is not to deny the potential value of these techniques, but I choose to focus on the aspects of narrative technique that pertain directly to the patient-physician interaction.

If the sense of narrative is more expansive than one unfamiliar with narrative theory might first assume, the notion of being a reader is equally rich. Reading the patient as narrative, or reading the patient narratively, is much more than simply being a good listener or even questioner. Charles Anderson and Martha Montello describe both literary theory and their expectation that doctors must learn to be good “readers” of the patient “text”:

The subjectivity of the reader, not the autonomy of the text, is the center of this critical attention. Meaning is understood to take shape—for different critics in different ways and to different degrees—in the symbolic space that reader, text, and other elements create during the reading process and does not exist without the subjective activity and the contextual elements brought to the text by the reader (Anderson and Montello 2002).

Two aspects of creating this shared symbolic space that they explain further in this article are imaginatively looking at possible futures together with the patient, a technique they ascribe to Socrates’ method of examining another’s position, and, finding a shared aspect of history or value with the patient. Their claim that finding “consubstantiality” with patients as a way of creating a symbolic space where the text of the patient can be shaped and understood together strikes me as overreaching, and I will discuss some of the issues it raises in the next chapter. Nonetheless, engaging a patient in a discussion about the

future, now personalized by the patient story, rather than a generic discussion of risks and benefits, is an underappreciated art in medicine.

Although there are many controversies in bioethics regarding the nature of informed consent, including whether it is even possible or meaningful, one issue is whether it should be personalized or generic. I worked for years with a physician who gave *exactly* the same discussion of risks and benefits to each patient before a given surgery. Not only did he not personalize the risks to the clinical aspects of the case—a hysterectomy for fibroids has a different risk profile than a hysterectomy for endometriosis, for example—but he also ignored any personal or historical aspects that the patient had shared with him. I have always taken the opposite view. Although I try to discuss each risk and benefit, or at least mention the significant ones, I focus on aspects that are particular to the individual clinical scenario, and even more so focus on concerns the patient has already raised. If a patient says that she fears the postoperative pain of surgery, or if I have clues from her history that this might be the case, then this point receives more attention than a discussion of blood transfusion if that seems to raise little concern.

Anderson and Montello’s discussion of “consubstantiality” has both value and limits. They describe an example in which a young medical student and an elderly woman discover a common past in cotton picking. Through this sharing, the student is then able to care for her patient more successfully, and the patient in turn responds more favorably to the treatments offered. By moving closer to one another in this recognition of shared experience, she becomes a better patient, and

he becomes a better healer (Anderson and Montello 2002). While it may be true that every physician and every patient can in the course of the clinical encounter discover some area of shared history or value, I do not think physicians must assume the presence of some common experience, let alone search for, or find one, in order to be good physicians or even good “readers” of the patient. One of my favorite novels, *A Fine Balance*, follows the lives of two homeless men in India. While it is hard to imagine a life more different than my own, I enjoyed the novel precisely because it showed me the lives of two men with whom I shared little but common humanity. Part of what has drawn many physicians to medicine is the intimate knowledge of others’ lives that we receive in the course of our work. Even when these lives strike us as radically other, we must find ways to care for them. Furthermore, I believe it is possible to enjoy the way a patient, like a novel, may open us to something completely new, rather than familiar.

2) **A skilled narrativist recognizes the multitude of narratives at play in a clinical encounter, and makes conscious choices about which narratives should be privileged, and which should be suppressed at any given moment.**

Narrative physicians must recognize the power of the medical narrative, and its relationship to patient narratives. While Montgomery Hunter has emphasized the potential benefit of organizing and making sense of a patient’s symptoms, these same impulses may also lead to harm or unnecessary treatment.

Michael Balint, a psychiatrist and psychotherapist, wrote extensively on the doctor-patient relationship. In research derived from primary care physicians in the United Kingdom, he found that physicians often unwittingly reshaped the

patient narrative of life dissatisfaction into a medical narrative of recognizable clinical entities, often with disappointing results for both parties:

We think that some people who, for some reason or other, find it difficult to cope with the problems of their lives resort to becoming ill. If the doctor has the opportunity of seeing them in the first phases of their becoming ill, i.e. before they settle down to a definite “organized” illness he may observe that these patients, so to speak, *offer or propose various illnesses*, and that they have to go on offering new illnesses until between doctor and patient an agreement can be reached, resulting in the acceptance by both of them of one of the illnesses as justified (Balint 1964).

Although Balint’s research was in the 1950s, well before the rise of narrative medicine, his point here can be easily understood using narrative language. The patient feels bad, and goes to the doctor seeking a physical cause for this. The doctor’s history-taking shapes the patient’s vague somatic complaints, reshaping a personal narrative into a medical narrative that can now be accepted, even embraced by the patient. But if the patient finds the medical narrative a poor fit to her own, she may continue to provide more detail, new complaints, hoping that the physician will return with a story that fits her own. From the physician’s standpoint, when a patient continues in this searching mode for an extended period of time, the relationship becomes unsatisfactory and frustrating.

Balint is not claiming that all illness is psychosomatic, but he does claim that much of the task of primary care physicians may be recognizing the psychological components of illness. He addresses yet another problematic relationship between the medical narrative and the personal narrative: the

entrained facility with which physicians translate the patient narrative into medical narrative. As Balint makes clear, patients come to the doctor expecting this transformation of vague symptoms or anxiety into a medical diagnosis, so they are at times complicit in this process. Whereas Arthur Frank focuses on how patients may feel colonized by this transformation of the personal into the medical, Balint examines how at times patients seek this out, sometimes to their detriment. Medical narrative can so easily turn somatization into unnecessary medical treatment, and physicians can only prevent this by not making the translation of personal into medical so reflexive. Balint describes one physician who refers a patient for appendectomy, only to later realize that her pain had been a response to family stressors (Balint 1964). Recognizing when a personal narrative should not be transformed into a medical narrative is a skill in which physicians receive no training. Years ago, I had a young woman complain of postpartum depression—she actually used those words. When I asked her what she meant she gave symptoms completely consistent with postpartum depression: she wasn't sleeping well, nothing gave her joy, and her energy was low. But when I asked her about how much her partner was helping with the newborn, she replied that he rarely came home, and that when he did, he was drunk and abusive. As her story unfolded, it became increasingly clear that her partner gave her no support except financial, and that she wanted to leave but feared the break-up. I said as a near-joke that she suffered from “postpartum oppression,” not postpartum depression, and that my treatment recommendation was leaving her partner, frightening as that

must be to a woman with a newborn baby. I saw her frequently over the next few months as she left him, found a job, and returned to college. I believe that her understanding of that time is now not one of a medical illness, but of a difficult period in her life when a physician offered support. Perhaps we need to remember, as Balint remarks, that a physician's time is often the treatment patients seek.

- 3) **Narrative medicine fosters clinical empathy.** The effort to “read” the patient is to take both the verbal and nonverbal cues, words, and body signs to understand as best as one can what the patient feels. I will discuss the idea of “just distance” in greater detail in Chapter V, but the skilled reader neither remains detached from the text, nor fuses with it. Jodi Halpern, a physician and philosopher whose interest is clinical empathy and emotions, describes how being open to the patient can allow a “resonance” where the physician can read the patient emotions in herself:

Emotional attunement operates by shaping what one imagines about another person's experience. In trying to imagine what the patient is going through, physicians will sometimes find themselves resonating. This is not an additional activity to imagining, but rather a kind of involuntary backdrop to it. Further resonance is not a special professional skill, but a part of ordinary communication. While listening to an anxious coworker, one feels heavy, depressed feelings. Importantly, attuning to patients does not involve resonating with strong feelings, but is often a subtle nonverbal sense of where another person is emotionally (Halpern 2003).

Halpern is describing how being fully open to the patient includes seeking to imaginatively understand the feelings and emotions either verbalized or physically “enacted,” to use Frank's descriptor. Her argument in this paper is that medicine has taught “detached concern” rather than emotional attunement, so physicians are

actually taught to not engage patients at a level that allows real empathy. Medical student empathy scores do decrease with training, although the attitude of “detached concern” taught in medical school is probably not the whole cause of this (Garden 2008). The long work hours, the biomedical model of care, and the sometimes-inhumane treatment of medical students and residents by attending physicians, may all play a role in the decline of empathy. But equally important to this loss of empathy, I believe, is the structured interrogation form of the history taught in medical school and practiced by most physicians, rather than the more open-ended narrative approach to history that has been taught by Charon and Cassell (Charon 2006; Cassell 1985).

The structured history is antithetical to a narrative approach because it prevents patients from revealing themselves in the discussion with the physician—little personal detail is requested, and patients are certainly never asked how they *feel* about anything. Not only is there little space for patient feelings to be revealed, there is little space for the patient as person to be revealed. While I would hold open the possibility that one could feel empathy toward a stranger, it is clearly the case that as the patient moves from stranger to a person whose stories have been shared, the possibility of empathy rises.

But if the claim that empathy is enhanced with narrative technique is accepted, the question then arises of why empathy is important in a clinical encounter. Cassell argues that it requires empathy to understand what a suffering person needs, because she is often unable to tell you directly:

While suffering persons are no longer autonomous, they usually are not aware that alone they cannot best represent their own interests. Like all who are very sick, they require the help of others to represent themselves, but it is the nature of this assistance that is key. The suffering person is helped, through the process of interaction and probing by the caregiver, to make decisions (to pursue purposes) that are authentically coherent with the pattern of purpose that has characterized his or her previous life (Cassell 1991).

Rebecca Garden similarly argues that empathy must be understood not only as an end in itself, but as the first step in developing an action plan that addresses the patient as person most completely (Garden 2008).

Lastly, as I have argued elsewhere, while physicians may have lost sight of the importance of empathy in the clinical encounter, patients have not (Burcher 2011). In a study by Stewart Mercer of the importance of clinical empathy in primary care encounters, over three-fourths of patients surveyed from a diverse socioeconomic population of over ten thousand patients reported that physician empathy was “very important” to good medical care (Mercer et al. 2005). Other empirical studies have demonstrated that both patient and physician satisfaction are increased by empathy, and that patient compliance and outcomes are improved (Garden 2008).

The narrative goal of being a good reader creates an opening into the patient world not offered by traditional biomedical medicine. To seek to understand what is said, and what cannot be said, and to act upon this understanding is of demonstrated benefit, and narrative approaches provide the best opportunity to reaching this type of relationship with the patient.

- 4) **Narrative medicine recognizes that illnesses have meaning for the individual patient, and that discerning this meaning can be critical to achieving**

treatment goals. While this is related to the previous point, because it may be an empathetic response that allows a physician to recognize the meaning of an illness for a patient, this discernment may also come from appreciating the social context of narrative, and the work or family dynamics that she lives within. Arthur Kleinman, a physician and medical anthropologist, has written extensively on how while illness is personal it also reflects a larger context, and that there are layers of meaning, particularly in chronic and serious illness (Kleinman 1988). He argues that medical schools produce “naïve realists,” who believe in only a single objective meaning to illness, to which medical terms and taxonomies correspond. But Kleinmann argues that it is only by looking at the patient narrative, and family and social narratives, that some illnesses can be understood and treated:

From an anthropological perspective and also a clinical one, illness is polysemic or multivocal; illness experiences and events usually radiate (or conceal) more than one meaning. Some meanings remain more potential than actual. Others become effective only over the long course of a chronic disorder. Yet others change as changes occur in situations and relations... The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history (Kleinman 1988).

Because chronic illness enfolds itself into a life, with the development of secondary gains occurring unconsciously for the patient and sometimes for her family, chronic illness is rarely successfully “cured.” Without understanding the role the illness plays in a patient’s life, it is often frustrating and futile to treat chronically ill patients.

In a classic example I first heard in medical school, while the young, overworked mother may hate her frequent migraines, she may appreciate that

it is only when she has a migraine that she receives help with the children from her husband. To miss this meaning is to miss why treating her migraines has been so difficult, or her symptoms so recalcitrant. Her migraines are not less real by recognizing that they may be triggered by the stress of a difficult family situation, but they cannot be addressed only with a prescription for migraine medication.

Conclusion

Narrative medicine offers an approach to the clinical encounter that stands in opposition to both the biomedical model of care and to an autonomy-based perspective on the doctor-patient relationship. Beginning in narrative selfhood, it recognizes the complexity of the encounter in its multiple narratives, and seeks to privilege patient narrative as the source of, or starting point for, a healing therapeutic relationship. Capable of supporting empathy, and seeking social, familial, and personal meanings to illness, narrative techniques give physicians therapeutic options not available in a biomedical model, because the patient is approached as a complete person embedded in relationships and a culture. In Chapter IV, I will address the limits of narrative medicine, and seek to reformulate it in a way that addresses these concerns.

CHAPTER IV

THE LIMITS OF NARRATIVE MEDICINE

The principle of autonomy arose as the primary determinant of the doctor-patient relationship in an era when patient rights, as well as civil and voting rights, were championed. Although it has prevented many of the abuses of the past, the principle of autonomy has also been seen, as Howard Brody writes, “{as} an excuse to avoid relationships with patients” (Brody 2009). Because of this unintended and unforeseen consequence, many in bioethics have sought to either reform or replace autonomy with a more relational principle.

Although narrative medicine has not been tested on the same scale as the principle of autonomy, I believe that in looking at the writings of its proponents, one can see possible problems, if narrative medicine is expanded to become the dominant method of conducting the clinical encounter. These are both practical and philosophical problems, but the philosophical issues also have real-world implications. If narrative medicine is “not yet ready for prime time,” I believe, as stated at the outset of Chapter III, that addressing these concerns is a more fruitful way to address the problems in the clinical encounter than reworking the principle of autonomy one more time.

Practical Issues

As a clinician with sixteen years of practice, I read Rita Charon’s description of narrative medicine several years ago with a skeptical eye. Her description of long, unstructured initial meetings with patients, unrushed and open-ended, had little in

common with my own practice, where I see often thirty people in a day. It is not personal greed that dictates my schedule. Like many physicians today, I work in an employed setting, and my schedule is largely out of my control. Primary care physicians often have even busier schedules, and here there is the additional problem of a shortage of primary care physicians. If primary care doctors adjusted their schedules to follow Dr. Charon's model, the shortage in primary care physicians would be even more acute. Although patients do desire empathic physicians, I believe they would rebel against a proposal that made it even harder to see their doctors when they need them.

Obviously, narrative medicine as described by Charon cannot simply be imported into the current health care environment without causing serious issues in physician access and cost containment. Reading Charon, one wonders whether she intends narrative medicine as an alternative to the currently structured medical encounter or only sees it as a critique by example, namely that this is what medicine could be, if only we were willing to make the changes necessary. But if these changes include training twice as many physicians, physician assistants, and nurse practitioners, then narrative medicine is truly DOA—dead on arrival.

It does not need to be all or nothing, however. In the years since first reading about narrative medicine, I have learned that it can be adapted to a busy office schedule, and also that a busy office schedule can be tweaked in ways that then foster narrative techniques. Charon's book on narrative bioethics is titled *Stories Matter*, but amidst my own busy practice, sometimes the story doesn't matter, which is to say that narrative can be used selectively. Here is where the *phronesis*, practical wisdom, of the physician is crucial. I discuss *phronesis* at greater length in Chapter V, but for now it can be thought

of as the skill for finding the best response to a particular circumstance, guided by experience, knowledge, and moral character.

Just as physicians must weigh how much medical care each patient requires, and this phronetic task includes looking at multiple factors—the patient, her illness, her family supports, etc.—the physician can learn to recognize how much story needs to be told to successfully navigate each encounter. I realize that the rejoinder from a fully narrativist physician would be that you cannot know this without first knowing the whole story, but my experience argues against this. Just as you do not need to read the whole novel to decide if it is worth your time and attention to read completely, it is possible to discern in a clinical encounter how much of the patient needs to be “read.” The happy young couple presenting for a prenatal visit with smiles and a list of questions need less discernment than the homeless prenatal patient whose mother comes with her to prenatal visits, but refuses to let her come home. The mother and daughter present two stories, at least, that need addressing, and narrative may be the first step in family healing, or in sorting out new options for housing when the family is too broken to be the answer. Narrative authors seem at times to lack a certain flexibility in their expectations of physician response. It is as if the answer is always more narrative, regardless of the question being asked.

The narrative approach in medicine may be an overreaction to what Arthur Frank describes as a “lack of generosity” in medicine (Frank 2004). One aspect of this lack of generosity is a refusal by physicians to enter into true dialogue with their patients. By this, Frank means an openness that transcends playing roles, an authentically human encounter:

Normative self-disclosure requires dialogue: the person who we see ourselves revealed to be is seen most fully in others' responses to us. Yet what dialogue enables, refusal of dialogue can deny. This self-disclosure that dialogue makes possible can be impeded when some people refuse to accept others as partners in dialogue (Frank 2004).

While the openness to dialogue and self-disclosure that Frank speaks of is certainly engendered in a fully narrative approach, it may also occur in more constrained conversations. In the vignette that introduces this topic in his book *The Renewal of Generosity*, it is the refusal of a medical resident to speak with his patient about an incident when they walk past a corpse being taken to the morgue, which prompts Frank to regret the lack of dialogue in medicine. He wishes the resident had just addressed the incident with the patient, but to do so would have been to step out of his role as physician, and to address the patient, person to person, about the striking image of death they had both just witnessed.

Most human dialogue is circumscribed; it is not the complete opening of ourselves to another. Can we encourage the real human dialogue that Frank feels medicine now lacks without believing that narrative can or should be an all-encompassing encounter where the patient is laid bare as a text for the physician reader?

Perhaps it is the significant advances of medical science, and the attendant biomedical model, that has made it so hard for physicians to treat patients as persons, as equals. In one sense, physicians feel elevated, or made different, by our training and skills. Physicians occupy their role more completely than most professionals—we can be called upon to be doctors at any time. In my first job, I was the only physician in town who could perform certain surgical procedures, and I could be asked to come to the

hospital and perform surgery literally at any time, day or night, during those nine years. Part of my reasons for leaving included the burden of never feeling completely at rest. But if we are physicians more than we choose, I believe it also makes it harder for us to be simply human, and relate to another, particularly a patient, at a level unfiltered by our role. Yet patients want both a technically proficient doctor, and also someone who feels like a neighbor, a person like themselves.

My concern is that too strict an adherence to the rules of narrative medicine may simply become a new role for physicians, which inhibits rather than facilitates an authentic relationship with the patient. Frank argues that physicians need to step out of the role of physician at times and dialogue with the patient. When I meet a new patient, some have much to tell me about themselves, and some are strictly business. Sometimes they leave as still strangers, sometimes they leave feeling closer to friends, and sometimes I find their stories difficult to accept or understand. Sometimes I am tired, and simply cannot put the effort needed into drawing them out. Sometimes a Pap smear is just a Pap smear.

Being open to encounter is different than trying to make every visit significant at a human level. I hate talking to my dental hygienist—I just want her to clean my teeth. Some patients want a problem fixed, without any deeper interaction, and this too should be accommodated. The secret is understanding when to be a full-fledged narrator, and when to prescribe and move on. When Frank speaks of generosity, he has the right idea: being open, giving and willing to be more than a physician, and yet still being a physician first, for those who need only this. Narrative medicine may be a reaction to biomedical medicine, which is needed, but is still reactionary. The phronetic act of being what the

patient needs, up to the ethical and professional limits of being a physician, is what doctors need to become more nimble at achieving. Narrative techniques are part of this, but may represent just one skill among many.

Undermining Narrative Confidence

The impression of Rita Charon from *Narrative Medicine*, particularly the clinical vignettes of her patient encounters there, as well as her other writings, is that she is an excellent and humble clinician (Charon 2006; Charon and Montello 2002). Yet at times in her writing, I find myself uncomfortable with claims she and others in narrative medicine make about the power of narrative technique to both know, and merge with, the patient as other. I say this as a sympathetic critique in the sense that I am persuaded that physicians have much to learn from Charon and other narrativists, but that it is important for physicians in repairing mistakes of the past to avoid replicating them. There is a tension in Charon's writings about how much power narrative medicine wields in terms of knowing and merging with the patient. This is an important point, because as Frank writes, it is a very different thing to speak with someone than to speak about someone, and different yet again to believe that you can speak *for* another (Frank 2004).

We could draw the "bright line" that narrative medicine means being in dialogue with the patient, showing interest and willingness to engage at a human level, but that it must never be about claims of fully comprehending or uniting as one. When Martha Montello describes narrative medicine as having the power of finding "consubstantiality," that line seems to have been crossed (Anderson and Montello 2002).

Here, to use the language of Emmanuel Levinas, narrative has become totalizing, focused on the oneness and shared similarities of being human, rather than on the ways in which we may be unique or singular. Some physicians would prefer to emphasize how narrative has the power to frame our singularity, how each of us has a unique story, rather than the ways in which narrative can make us all feel as one. This tension between singularity and unity is not unique to questions of narrative medicine, although in this case, the rush to unity may be less respectful of persons than emphasizing our uniqueness.

Early in her defense of narrative medicine, Charon offers an interesting metaphor of human relationality:

We are at the same time *alone* and *with*, strange and similar. The presence of the other is both mystery and identity. We are simultaneously outside the obscurity and within the familiarity of another's being. Like planets in a solar system, we revolve around and are warmed by a common sun while hosting lives of absolute distinction. In the end, we live with one another as best we can, trying, as health care professionals, to receive what our patients emit and trying, as patients, to convey these all but unutterable thoughts and feelings and fears (Charon 2006). (Italics original)

But at other times, Charon seems to step outside this view into a position that, continuing the metaphor started above, would be planets colliding or fusing with one another:

To know what patients endure at the hands of illness and therefore to be of clinical help requires that doctors *enter* the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patient's point of view (Charon 2006).

Later she writes:

Narrative competence permits caregivers to fathom what the patients go through, to attain that illuminated grasp of another's experience that provides them with diagnostic accuracy and therapeutic direction (Charon 2006).

And further:

Anterior to our differentiating into doctors, nurses, and patients, that is, we are united *and can be re-united* (Charon 2006).(Italics original)

The most striking example of narrative overreaching, however, comes not from Charon, but from Charles Anderson and Martha Montello in a chapter on the reader's response (in an anthology edited by Charon). Here, the authors describe the transformation of a medical student and elderly woman when they reach the point of realizing their narratives have shared elements:

Over the course of his treatment of Mrs. Green, the student, who grew up on a farm in the same area of Arkansas Delta, finds himself transformed by the narrative *consubstantiality* they share. As he resists and finally discards the normative medical narrative of the "train wreck" and opens himself to the possibilities, the medical student comes to know that what has been derailed is not Mrs. Green's body, but the story that gives meaning to the events...As he enters the world her story offers him, he meets her authentic, historic self and understands that she and he, as different as they might seem, are indeed of the same substance at the deepest level of human experience (Anderson and Montello 2002).(Italics original)

Arthur Frank, in contrast, describes a perhaps more defensible view, when describing the work of David Hilfiker, a physician who works with underserved patients in urban Washington D. C.:

David Hilfiker's choice not only to care for the poor but to live among them is grounded in his religious faith, that "each of us is inextricably bound to—indeed, tangled up with—the pain of the poor," with whom we share a "common community." Yet Hilfiker emphasizes the eternal gulf between himself as host

and his guest. He speaks of the need for *identification* with the poor, giving this phrase a particular meaning, for his *identification* is not being *identical with*. What he means by identification begins with recognizing the fundamental difference between people...and rejecting the dangerous fantasy of merging consciousness with the other (Frank 2004).(italics original)

The goal of this chapter is to explain and argue why Frank, a narrativist himself, holds a more defensible view of the limits of narrative than Montello, and even Charon at times. These limits must be embraced for narrative medicine to understand the relationship between self and other, which is at the center of understanding the physician-patient relationship.

Narrative Overreaching

It will be helpful to begin again with Valerie Hardcastle's definition of selfhood, which is the story we tell ourselves about ourselves (Hardcastle 2008). Even this simple, perhaps too simple, understanding of narrative selfhood should not necessarily lead physicians to a place of confidence regarding their ability to understand the person before them through narrative techniques. Although this should be complicated by questioning her direct equation of narrative and selfhood, even this simple version presents problems for claims of knowing the other.

John Hardwig identifies two epistemic problems with the privileging of patient autobiography at the heart of narrative medicine. He argues that narrativists do not recognize or adequately account for these problems, because they are unknowingly still under a "Cartesian spell." This is the unjustified belief that our thoughts are transparent to us, so that when we tell others our story, we actually know how we think, and feel, and

in short that we can tell others who we are, because we already have a meaningful answer to this question (Hardwig 1997).

The first problem has already been touched upon when I discussed the social context of narrative. People tell the story that they believe the other wishes to hear, and the story of ourselves generally makes us look good, or at least innocent. The validity of autobiography, which is the primary narrative in narrative medicine, because multiple perspectives are rarely available in the clinical encounter, is suspect. Hardwig argues that medical narrativists conflate two narratives: the story of our self that we tell ourselves, and the story about ourselves we tell others. These are not the same story, and the patient may be revealing less of self than narrativists presume, when they take her story at face value:

The fact that we tell—and perhaps must tell—ourselves stories about our lives introduces an important ambiguity into what we mean by autobiography. The story I tell myself about my life is not an autobiography to which you can have access—probably not even if we are intimate, certainly not if we are strangers. We all have secrets. So you must be content with the story I tell for public consumption. That will not normally be exactly the way I see my life (Hardwig 1997).

The point is not that we should again devalue the patient story revealed in the clinical encounter; patients do often reveal significant truths about themselves to physicians that they would not share with others, sometimes even loved ones. In the quotations given previously, Charon and Montello have drawn a straight line from the story told to the selfhood of another. This is a dangerous and unwarranted assumption. It is not that patients routinely lie to their physicians. The difference between the internal story and the story told may largely be the result of unconscious forces and social

pressures. At times, Charon makes clear that what a patient tells us is not necessarily to be understood literally—this, of course, is the point of being a good reader. Sometimes the narrator is unreliable, but even recognizing this can provide meaningful information about the patient, and it actually argues for, rather than against, narrative technique.

The second epistemic argument against privileging too directly the patient narrative is the problem of deciding to what degree a person can even know herself—still understood narratively. There are gaps in our stories from external information we do not possess. There are also lacunae from our ability or inability to “read” our internal states and emotions:

Of course, telling the story of my life requires knowing much more about me than my present state of consciousness. And as we move into less basic though equally critical elements of my account of myself, the likelihood of errors multiplies rapidly. I am quite capable of major mistakes about my beliefs and values. My own account of my intentions, my motives, my character, my personality are all extremely unreliable. The rage I feel is unnoticed, my desire for revenge is unexperienced, and consequently my account of what I was up to is...not only fallible, not only faulty or flawed, but fundamentally wrong and wrongheaded. I used to divide the world into “settlers” and “explorers” and thought of myself as an explorer. My partner just hooted at the idea. And she was right (Hardwig 1997).

The argument here is that narrative medicine and technique are most valuable when it is recognized that they are tools for learning much about the patient, and conveying to the patient a sense of caring and engagement. But being a good reader is never straightforward, and we should not oversell the ability of narrative medicine to remove epistemic problems and allow us to “fathom” the inner worlds of our patients. When proponents of narrative medicine claim to see into the hearts of others, they have ventured into a place that seems both false, and dangerously close to being able to make

claims of speaking *for* others, rather than speaking *to* others. Frank regards this as an unwarranted usurpation of power—a full-circle return to physician paternalism done under the guise of giving voice to the patient story.

Is the Narrative Self Enough?

The last section cast doubt on the degree to which the story told can actually reveal the self of the other. Closely related to this is the question of whether we wish to privilege narrative, any narrative, as fully capturing our selfhood. Adriana Cavarero takes the position that while narrative is crucial to our development of selfhood, there remains a difference between story and self. We are more than our stories, despite the crucial relationship between self and story. V. S. Pritchett, writer and literary critic, wrote that, “We live beyond any tale that we happen to enact” (Pritchett 1979). Although Galen Strawson has quoted Pritchett often in his critique of narrative, Strawson’s argument against narrative is actually different from what Pritchett means (Strawson 2004).

Strawson’s attack on narrative selfhood is that some people probably are narrative in their composition of self, but that others, including himself, are more episodic, or living in the moment, rather than unified in the temporality of narrative. Hardcastle’s response to Strawson adequately addresses this critique. She points out that to see oneself as unconcerned with the past, as a “happy-go-lucky-fella” as Strawson sees himself, is a narrative construction in itself (Hardcastle 2008). But Pritchett is not

implying that some are narrative, and others are not, but rather that narrative, the story, cannot fully capture what we mean by self.

Cavarero makes a distinction between the narrative and the self, even while acknowledging that without narrative we cannot know ourselves, and that this narrative of self is largely a gift from others. Following Hannah Arendt, she writes that we begin as actors, and from this a story emerges that allows us to understand who we are. We are “narratable selves” who come to know ourselves in the personal relations where others give us back our story—show us to ourselves (Cavarero 2000). With memory we are able to compose a self-narrative, but only because others have revealed us to ourselves. We need the text of our story, and yet remain apart from it:

...the narratable self is not however the *product* of the life-story which the memory recounts. She is not, as the experts of narratology would say, a construction of the text, or the effect of the performative power of narration. She coincides rather with the uncontrollable narrative impulse of memory that produces the text, and is captured in the very text itself...

The ontological status of the narratable self becomes distinguished, therefore, from the text of her story; even if it is irremediably mixed up with it. Such a distinction is neither separateness nor self-sufficiency, because the self cannot lie in perfect isolation outside, or beyond, the text of her story...the text of the story is inessential to the self-sensing of the self as narratable (Cavarero 2000).

The self is the activity that generates the story, and the story reveals the self to itself. Because we are “narratable,” it is only through narrative that we come to understand ourselves, but because the text is the mirror, there is still the prior actor who moves before and beyond the story. Cavarero writes that the text is “reifying,” which means that the self prior to the text should be understood differently. The self is not a

stable substance, but an activity. To focus on the text is to make the self a thing that can be wholly known. Cavarero writes that the text “consists in a reification of the self that crystallizes the unforeseeability of the existent” (Cavarero 2000), meaning that to identify the text as self produces a thing that can be understood, even predicted, whereas the narratable self remains a potentiality beyond the text. Narratable selfhood implies this potential, although Cavarero is quick to point out that this potential is always being actualized—it cannot be mere potential. To live is to generate story, to create text, and to interact with others. who may then show us the text we have generated. As narratable, we desire what others give us—a return of ourselves to ourselves.

There are several implicit critiques of narrative medicine within the philosophy of Cavarero. They can be made explicit by returning to the quotation from Anderson and Montello, where they describe how a medical student and elderly woman recognize “consubstantiality” by finding commonality in their life stories. Cavarero would separate herself from this position at two levels. Firstly, by denying that we are our life stories, she would deny that a union of stories represents a union of substances, or at least that what have been united are the two stories, not the two selves. But furthermore, she opposes the position that narrative shows us our commonality; rather she argues, narrative differentiates us into absolutely unique beings:

The first consequence of this perspective is that, by swallowing life, the text also risks swallowing the unrepeatable uniqueness of the existent. Omnivorous texts, hungry for life and ready to offer themselves as the more dignified replacements of an all-too-human corporeality... (Cavarero 2000).

To find similarly in our texts, and to thereby leap to “consubstantiality,” is to ignore both that we are more than our stories, and also to gloss over the huge disparities

between the story of a young medical student and an elderly woman, even if they can find areas of overlap in their texts. One can hold the position of Hardcastle that we are our stories, and still reject Anderson and Montello's claim, on the grounds that each person's story is individuating, rather than evidence of our oneness. Nonetheless, Cavarero distances herself yet again by denying that the story captures who we are: The story told about a self is the product, not the producer, of selfhood.

If physicians see narrative as a way of moving closer to their patients, emotionally and empathically, then narrative serves a beneficial function within medicine. Cavarero argues that it is not the similarities between life stories that unite us but the desire to share and relate to another:

No matter how much you are similar and consonant...your story is never my story. No matter how much the larger traits of our life stories are similar, I still do not recognize myself in you and, even less, in the collective we. I do not dissolve both into a common identity, nor do I digest your tale in order to construct the meaning of mine...Put simply, the necessary other corresponds first of all with the *you* whose language is spoken by the shared narrative scene (Cavarero 2000).

This is a radically different view of the function of narrative than the one put forth by Anderson and Montello. Rather than creating a shared "life-world" with another, we share our unique world with another, and by this dialogue we do not merge, but rather show care for another, while remaining separate from that person. Cavarero is rejecting both an epistemic claim to know the other, and an ontological claim of our oneness. Levinas, as I will discuss later, accepts both of these conclusions and similarly argues that the real basis of care is recognizing the other as other, not making claims of "consubstantiality"—a term that arose in Christology to describe the singular substance of the Trinity (Bridge 1910).

If narrative is presumed to show our oneness, then the details of any one life are less important, and we have come full circle into no longer needing to hear the patient out. We can simply find our areas of commonality, claim to then understand the other, and proceed with business as usual. It is only when narrative emphasizes the unique that it can function as a countermeasure against the biomedical claim that humans are all variations of the same machine with a finite number of ways of becoming broken and a predictable number of strategies for getting fixed.

Frank decries medicine's propensity to "finalize" the patient. Finalizing, much like Levinas's use of "totalizing," occurs here when one person claims to merge, or know, or be able to speak for another:

...unfinalizability recognizes that milieu is not destiny, any more than personal history is not destiny. The others whose voices are in our voice, through whose eyes we see ourselves, do not determine us. As Clark and Holdquist write, I go out to the other in order to come back with a self that retains its own horizons. The objective of going out is not to be limited by my own horizons: the object of return is not to exchange my limitations for those of someone else (Frank 2004).

Like Cavarero, Frank believes that our relationships and dialogue with others are crucial to our self-understanding; through dialogue we come to know ourselves by glimpsing how others see us. But using the metaphor of mirrors, he argues that although we may at times see ourselves as others see us, we can never see all the mirrors of another: they remain separate. But it is also true that although others tell our story, give it back to us as Cavarero shows, we can never be fully limited or trapped by this story—we can always be different, and we are always more than the story so far.

This retention of “horizons” is what makes us unfinalizable, and Frank observes that medicine has a tradition of speaking “about” the patient, rather than speaking “to” the patient. The concern is that narrative medicine may only reinforce this, when it seeks narrative merger, when it claims to “fathom” the patient, and certainly when it claims that we are all one, if only we look hard enough. But just as Frank has shifted in his own writing from narrative to dialogue, perhaps out of suspicion that narrative at times claims too much, encouraging narrative technique may be a move toward real dialogue between patient and physician, so long as the narrator does not hold the goal of “consubstantiality.” When Charon writes that we all live lives of “absolute distinction,” she is describing a narrative medicine that holds no risk of “finalizing” the patient before her. But perhaps it is the insidious return of medicine’s impulse to claim knowledge of, and knowledge over, all things, that has allowed narrativists to move from metaphors of separate planets orbiting the same sun to the metaphor of one in being, one substance, united in three persons.

When Cavarero describes us as narratable, in contrast to Hardcastle’s equation of self and story, she creates the distance that justifies Frank’s claims of a self that retains horizons beyond the story. I see this as a philosophical defense of one kind of narrative technique, not a rejection of narrative medicine. To humbly engage patients, to draw out their stories, to address them outside the role of physician, as person to person—all of this remains valid, even supported, by Cavarero and Frank’s views of our selfhood. We must constantly seek to know about our patients; we must never assume, however, that we are done.

Levinas, Proximity, and Caring for the Patient

The conclusions reached so far in this chapter are consonant with the philosophy of Emmanuel Levinas. Elsewhere I have argued that narrative medicine can slip into “totalizing” the patient, which is essentially the same critique Frank makes in his concern regarding “finalizing” the patient (Burcher 2011). Perhaps it is the close connection between science and medicine that permits or even encourages a slippage from the power to treat the patient to an ethically indefensible power over the patient. The first step in this downward movement from an ethical relationship with the patient, to a dominating one, is for both Frank and Levinas a belief that one can truly know the other. This is an easy mistake in medicine, because it is so important that we know as much about the patient as possible, and from there, the step to the larger claim seems small. But while too simple an understanding of the relationship between self and story may lend itself to this concern, Cavarero offers an understanding of our narrativity that successfully resists any slide into totalization of the patient.

To return to the example of Anderson and Montello’s vignette about the elderly woman and medical student, there is yet another lesson that those who wish to apply narrative technique to medicine must still learn, and here the philosophy of Levinas adds to this discussion in new ways. The implicit viewpoint of Anderson and Montello is that we must find areas of commonality in order to truly care for one another—seeking a sense of oneness is what allows the development of compassion, empathy, and desire to help another. At some level, this is true. For example, the commonalities we share with those of our community, social class, race, perhaps even gender, make them easier to

treat. However, physicians must constantly provide care to strangers who will remain strangers; to the other, who despite our narrative inquiries, remains other. Is this a project doomed to failure? Must physicians begin in a search for common ground as the first effort in providing compassionate care to our patients?

Levinas has two implicit responses to Anderson and Montello's view of the clinical relationship. The first is that care and responsibility must and do arise prior to the narrative encounter, not within it or from it. The second lesson is that seeking "consubstantiality" in narrative actually effaces the alterity of the patient-other, and is not a mark of respect or care, but actually a debasement of the other's unique humanity.

Responsibility before Narrative

This critique of narrative can be described both at a purely philosophical level, and also within the medical context. Philosophically, Levinas argues that there must be an openness to an encounter that grounds, or permits the encounter. Without this "proximity," the openness to the other, we can listen to the other without the slightest possibility of caring. Most of our conversations with others occur at a level where there is no genuine opening to the other. However, Levinas writes that this potential for relation precedes actual relations, and is always possible when we face another. Most of the time when we speak, we have little interest in whether we are actually heard by the other, and much of our listening involves little true engagement with the other. We listen only for details that may affect us; we do not actually care what the other is communicating about herself, because we do not care about her. But we can also speak and listen in a way that

conveys, and begins in a real engagement with the other as a person. We can greet the other with a “hello” that is already a response to the other—that contains within it an acknowledgment of our responsibility for the other (Levinas 1985). Frank’s story about the resident who fails to address with his patient the corpse in the hallway that they both observed represents a refusal to speak to the patient as another person—a refusal to relate to the patient outside of their designated roles as physician and patient.

The claim of narrative medicine that duties arise from the narrative, a point Charon explicitly makes, is wrong in its ordering, because there can be no narrative, no dialogical encounter, unless there is care, openness, and acceptance of responsibility as the gateway for the encounter to then occur (Charon 2006). It is important to remember that medicine, as an ethical art that seeks to relieve suffering, must always place responsibility before narrative; and physicians must recognize that sometimes the patient narrative may generate emotions in the physician that can diminish his or her desire to help, but that physicians must resist this if they wish to remain ethical physicians. It is simply untrue that the story always unites. Physicians must at times ignore the story and care, despite the narrative, not because of it. The mistake of narrative medicine here is twofold: the responsibility in medicine precedes the narrative, and it is in no way dependent upon it. The narrative may determine the level of responsibility or the nature of the response from the physician, but narrative cannot be the source of our ethical response to the patient.

The priority of care and responsibility is evident within the movement to make medicine more narrative in its approach to patients. The physicians who are proponents of narrative technique are embracing this response as an alternative to a biomedical

model of care, precisely because they wish to take good care of their patients, and they wish to encounter them as complete humans rather than metonymies, e.g. ,“the kidney in room seven.” The embrace of narrative is then preceded both temporally and ethically by a commitment to caring for others.

There is confusion on the part of Montello and Charon between care as an emotional feeling and care as responsibility for another. Physicians must not provide better care because they feel more for the patient, and less care when they feel emotionally distant. Even when narrative leads us to revile another, an uncommon but not rare response that some may have in listening to patient stories, physicians must treat the patient, and even use the narrative to best treat the patient. The narrativist seems to suffer from an optimism born out of the claim of “consubstantiality,” that narrative always unites, and always engenders care in the sense of an emotional desire to help others. Because this is not true, Levinas’s point is important: Physicians must enter each patient room already seeking what is best for that patient.

To hope that narrative will generate responsibility is unethical, because it holds the possibility of having different levels of care for different patients, depending on how far we find ourselves resonating with them. While few would deny spending more time with patients they enjoy listening or speaking to, physicians provide sometimes heroic care for patients whom they personally dislike. Placing duty after narrative gives license to the natural human response of treating best those most like ourselves. Rather, physicians must resist that tendency, and render care based primarily on the need for care. The narrative is important in that it helps us determine the level of care required, but it must not determine whether to care.

While Levinas hopes for an increase in our sense of responsibility toward each other, as the basis for a better world, grounded in a recognition of our innate “sociality,” there is also a special responsibility incurred on those who witness suffering. In the essay “Useless Suffering,” he describes how suffering is absurd for the one experiencing the suffering, but is a call that must be answered for the medical profession:

Is not the evil of suffering—extreme passivity, helplessness, abandonment and solitude—also the unassumable, whence the possibility of a half opening...the original call for aid, for curative help, help from the other me whose alterity, whose exteriority promises salvation? Original opening toward merciful care, the point of which—through a demand for analgesia, more pressing, more urgent, in the groan...the anthropological category of the medical, a category that is primordial, irreducible, and ethical, imposes itself. For pure suffering, which is intrinsically senseless and condemned to itself with no way out, a beyond appears in the form of the interhuman (Levinas 1998).

Like Ricoeur, Levinas is seeing the solitude of suffering as a great part of what makes it intolerable. The half opening is that suffering is both “unassumable,” and yet also something that pushes us to be with others for the relief provided simply by not feeling alone in our pain, even though we ultimately do experience it on our own. But medicine is an “anthropological category,” precisely because we are called by the pain of others, and we seek to end, reduce, or be with others in pain—this is the foundation of medicine, grounded in what it means to be human. Levinas gives two injunctions against medical overreaching. The first is seen above, where the opening is described as a half-opening. We cannot assume, imagine, or experience the pain of another. We can be with the patient, and this is mercy, but it is not taking on her burden. I believe patients receive more relief from hearing from their physician that their burdens are “unimaginable,” than they do from expressions such as, “I feel your pain.” The first acknowledges their

suffering without claiming knowledge of it—we do not experience the pain of another. To claim otherwise makes the patient feel that her pain is commonplace, rather than the extraordinary affront to her life that she is experiencing in her suffering. For one cancer patient to commiserate with another is more justified than for a healthy physician to claim an imaginative understanding of his patient's suffering, but even the suffering of two cancer patients is unique to each of them.

The second injunction provided by Levinas is that just as the patient's pain remains her own, it is the recognition of alterity, and not claims of unity, that best describe the asymmetrical relation between physician and patient. The physician gives "analgesia," relief from pain, to the one experiencing the pain. By fulfillment of her vocation, the physician is made more human, in her response to another. But even if both are given something by the relation, the relation is profoundly non-reciprocal in the sense that they cannot "switch places" or describe the exchange with any kind of equality.

Embracing Alterity

In my first reading of Levinas, as a physician, I was struck by how different from narrative medicine his answer is as to why we must care for each other. Montello and Anderson give an answer that I have since characterized as a "Walt Disney response" because it reminds me of the ride and song, "It's a Small World after All." In both we are exhorted that we "share" so much that we must care for each other; we are really all the same. Levinas's answer to this is that believing we are all one also makes us each interchangeable, and therefore unimportant, and that this belief justified, not prevented,

much of the violence of the last one hundred years (Levinas 1961). His phenomenological critique of the we-are-all-one philosophy is that when we encounter the other we are not struck by sameness, but rather by alterity—the shocking sense that there are others whom I cannot control, grasp, or even fully know. The other shows herself as “unforeseeable,” but not a “privation” of knowledge (Levinas 1985). That is, we sense how the other is beyond our power to manipulate like a thing or tool in the world, but other people are not wholly other—they are both beyond our world and yet encountered within it. Michael Morgan explains Levinas’s sense of alterity while quoting from Levinas’s *Time and the Other*:

“The Other is, for example, the weak, the poor, ‘the orphan and the widow,’ whereas I am the rich or the powerful.” In social life, I am always confronted by another particular person, who is near or far, friend or foe, present or absent, but always in the world with me and more importantly over against me or before me. This person is different from me fundamentally—prior to considering her features or character, her height, or complexion, her features, the color of her hair, her humor and mood, whatever. And her difference is all about what she imposes upon me simply by virtue of being there, before me. What she imposes is dependence and need, integrity and demand. Her presence, before it says anything else to me, says “let me live,” “let me be here too,” “feed me,” “allow me to share the world and be nourished by it too.” I am imposed upon, called into question, beseeched, and commanded, and thereby I am responsible... (Morgan 2007; Levinas 1987).

His claim here is the opposite of Anderson and Montello’s view of responsibility. We are struck in our encounter with others by their need, a need that we do not share with them, but which rather differentiates us. This is not to say that it is particular differences that matter, only that every person makes a demand of us to “share the world.” What we see when encountering an other is that she is not me, but that I must acknowledge and

care for this other person even though the experience is one that shatters my sense of the world as serving me alone, or being there just for me.

Levinas describes the other as both excessive and infinite to convey the sense, born out of this alterity, that we can never claim to be able to speak for another—we may only speak to the other. If Cavarero's point about narrative demonstrating the absolute singularity of the other is remembered here, then narrative technique involves a sharing that never means merging. This is Levinas's stance as well:

The relationship does not *ipso facto* neutralize alterity, but conserves it. The other as other is not an object which becomes ours or which becomes us, to the contrary, it withdraws into its mystery (Levinas 1985).

Because there can be no identification or merging, dialogue always involves distance, a closeness or proximity, that remains and respects the other:

Directness of the face-to-face, a “between us’ [*entre-nous*], already conversation [*entre-tien*], already dia-logue and hence *distance* and quite the opposite of the contact in which coincidence and identification occur. But this is precisely the distance of proximity, the marvel of the social relation. In that relation, the difference between the *I* and the other remains (Levinas 1985). (Italics original)

For both Levinas and Cavarero, we can come to know about the other, but we must never claim to fully know the other. If narrative medicine is to replace an autonomy model of care, this stance that respects alterity provides the safeguard necessary to reformulate the clinical encounter, without placing autonomy at the center. Autonomy forbids speaking for the other on the basis of a right that I have argued is historically founded, but not based upon a contemporary sense of selfhood.

Narrative medicine argues for narrative selfhood, and respect and care for the patient grounded in seeking the story of the other, and thereby coming to know them in both their uniqueness and commonality. In contrast, both Levinas and Cavareto support a view of selfhood that emphasizes our singularity and potentiality, beyond the story we tell about ourselves, or the story told about us. If this is embraced by medicine, then we must respect the patient-other precisely because we cannot possibly hope to speak for her. Respect for alterity, unlike respect for autonomy, can be understood as being operative in every clinical encounter. Although the young, infirm, elderly, or demented may lose their status as autonomous, they remain other. Indeed, if the claim is that alterity demands respect and responsibility, then the weak remain in a place of maximal protection rather than diminished status.

The threat implicit in claims of unity or consubstantiality is that if we can capture the essence of another by hearing her out, by listening attentively to her stories, then we may seemingly justifiably leap to speak for another that we now know so well. If narrative claims that the perfection of narrativity allows us to render transparent the person of another, then it has come full circle and becomes again a justification of medical paternalism. On the other hand, if we see narrative as a technique for expressing interest and care for the other, who always remains more than her story, no matter how completely it is told, enacted, or intuited by the physician, then the story exhibits the other in her “absolute distinction” (to return to Charon), rather than a tool for “fathoming” another, in the sense of measuring and drawing the limits of another. Narrative need not diminish alterity; it can illuminate it.

In any given patient encounter, I can find myself struck by either alterity or commonality, but the tendency to embrace commonality, I believe, should be resisted. I have noticed over the years that when I am the patient, physicians are quick to assume they know my wishes precisely because we are both physicians. The effect was not to feel known in a positive way, but to feel unseen, because although we are both physicians, we are not therefore the same person, and my wishes as a patient do not all emanate from my profession.

Narrative medicine so far has vacillated between claims of singularity and consubstantiality. These claims are mutually exclusive, and only a narrative medicine that moves away from claims of knowing or merging with the patient offers the safeguards patients should expect in a clinical relationship. When Ricoeur writes of the “just distance,” it is clear that there is always “distance.” Determining how to gauge this distance is the topic of the next chapter. Here, I have tried to establish that this distance includes the humility to never speak *over*, or *for* another, while always seeking to speak *with*, and listen to, the patient and her story.

CHAPTER V

PHRONESIS AND THE JUST DISTANCE

Returning to the themes of the first two chapters, one of the issues of medicine as it is currently practiced is that the principle guiding the clinical encounter, respect for autonomy, lacks the flexibility to allow physicians to be responsive to many of the circumstances they face in patient care. Narrative medicine seems to offer a ready-made solution to this in that by understanding persons as narratively derived, the clinical encounter must then first discern the narrative, and then respond to the individual now made more visible by the attention to narrative, and seek the means to reduce her suffering and restore health. But narrative medicine has issues as well, including a seemingly inflexible demand that every encounter be narratively conducted, regardless of the patient complaint, and also that some of the narrativist claims seem to actually reduce the individuality or singularity of each person which narrative techniques should actually highlight.

While narrative medicine has gained some attention in philosophical discussions of how the doctor-patient relationship should be conducted, so has an appreciation that the Aristotelian concept of *phronesis* is important within medical decision making. But *phronesis*, the practical wisdom of applying knowledge, experience, and wisdom to a particular circumstance that lacks a rule-oriented or “cookbook” answer, has been understood as primarily relevant to medical diagnosis and secondarily to treatment decisions. I believe that the lesson of narrative medicine is that every aspect of the medical encounter is open to this kind of judgment, and that physicians must learn that

this approach is crucial not only for proper diagnosis, but also for other aspects of medical decision making.

When a patient seeks care from a physician there are at least four aspects of phronetic judgment, or to use Ricoeur's term, four distinct areas of the clinical encounter where finding the just distance is important. While interrelated, they are separate enough to be treated individually. In patients with significant illness, or significant pre-existing medical or social issues, each of these four categories must be ascertained and addressed. Phronetic judgment, however, can only be attempted when the patient is approached narratively. Although the limits of narrative knowledge must be respected, as discussed in Chapter IV, it is only by engaging the story of the patient that physicians can obtain the individual details important in guiding phronetic judgment on the multiple planes of decision making within the clinical encounter. Before describing this dissection of medical judgment, let us return to phronesis and review the recent literature linking this Aristotelian concept to medicine.

Medicine and Phronesis

In the last twenty years, there has been a significant discussion in the philosophy of medicine involving the question as to whether the practice of medicine should be regarded as phronetic or not. Most authors who have discussed medicine and phronetics, including most notably Hans-Georg Gadamer, have argued in favor of seeing medicine as a phronetic activity, and encourage explicitly teaching it as such, and emphasizing the attributes of medicine that support this claim (Gadamer 1996). The practice of medicine,

using this reasoning, is enhanced by focusing on its differences from scientific pursuits, and emphasizing the practical wisdom brought to bear in the clinical encounter, and the moral origins of medical practice—moral in that relief of suffering and restoration of health are the goals of medicine, rather than knowledge for the sake of itself. Kathryn Montgomery Hunter has argued that the judgment involved in medical decision making is phronetic judgment, both because it is a moral decision at its roots, and also because so much medical judgment involves strict attention to the particular and cannot be subsumed under rules or universal concepts:

It is not that certainty or fixed and invariable knowledge is undesirable, but that *episteme* or scientific reason is not “appropriate to the occasion” in fields like medicine or morals, law or meteorology, that are themselves uncertain. *Episteme* is proper to stable physical phenomena that can be known through necessary and invariant laws. *Phronesis*, or practical wisdom, by contrast, is the virtue of working out how best to act in particular circumstances that are not (and cannot be) expressed in generally applicable rules. Scientific reason has as its goals precision and replicability; practical reason enables the reasoner to distinguish the better from the worse choice in a given situation. The first is lawlike and generalizable, the second is inescapably particular and narratable (Hunter 2002).

Hunter makes the connection that Ricoeur also makes in his description of medical judgment as seeking “the just distance,” that phronesis and narrative are dependent upon one another (Ricoeur 2007). To make good decisions in the particularity of the moment requires attention to narrative detail, or the singularity of the situation is not actually revealed. This does of course presuppose a narrative understanding that the story emphasizes our individual lives as ones of “absolute distinction,” to return to Rita Charon’s descriptor, rather than an attention to story that seeks a narrative merging of identities (Charon 2006).

Critics of viewing medicine as a phronetic activity point to Aristotle's own description of medicine as *techne*, an art that produces a product, health, rather than an activity that is an end in itself, which is part of his definition of phronesis (Waring 2000). While it is clear that Aristotle did not regard medicine as phronetic, others have argued that this reflects his own lack of appreciation for the moral aspects of medicine and the complexities and vagaries of diagnosis and treatment. To return to Eric Cassell's story of the elderly man with pneumonia (Chapter III), if medicine is understood as *techne*, then the diagnosis of pneumonia and treatment with antibiotics fulfills the role of the physician (Cassell 1979). But the phronetic physician sees more than pneumonia, and her treatment addresses the particular circumstances: the grief, malnutrition, and housing conditions that all contributed to *this* pneumonia in *this* person.

Duff Waring argues that applying phronesis to medicine represents too liberal an appropriation of the term (Waring 2000). Fredrik Svenaeus responded to Duff by arguing that it is Aristotle's sense of medicine that may have been too limited, and that Aristotle's use of *techne* at times clearly overlaps with his use of phronesis (Svenaeus 2003). For example, Aristotle does seem to appreciate that medicine requires experience and attention to the particular to be practiced well:

If, then, a man has the theory without the experience, and recognizes the universal but does not know the individual included in this, he will often fail to cure; for it is the individual that is to be cured (Barnes 1984).

Medicine requires *techne*, but although Aristotle opposes *techne* and phronesis, the good physician clearly utilizes both.

Diagnosis

Kathryn Montgomery Hunter alternatively describes the diagnostic process as phronetic, hermeneutical, and narrative in *Doctor's Stories: The Narrative Structure of Medical Knowledge* (Montgomery Hunter 1991). This work is significant in that diagnosis would seem to be the least phronetic activity that physicians perform. Placing the particular illness within a taxonomy of disease appears to represent the precise meaning of *techne*— understanding the individual by way of knowledge of the universal.

Hunter undermines the simplicity of this schema without ever completely refuting that medicine at times does bear resemblances to, and is reliant on, basic science. But just as phronesis is the practical knowledge of determining the best action in a particular circumstance, the physician does not seek diagnosis for the sake of knowledge, but rather to guide therapeutic action. The diagnosis is not an end in itself; it is the beginning of, or transition to, the treatment. Although patients can be frustrated by a lack of clear diagnosis, a diagnosis that has no treatment is an unsatisfactory result for patient and physician alike. The stark division between treatment and diagnosis is also false for two reasons. As Hunter explains, a diagnosis is often an educated guess that allows the move to treatment, which may, depending upon the result, alter the understanding of the diagnosis. This interpretative circle may play out several times before a satisfactory diagnosis and treatment are finally arrived upon. So the diagnosis is neither fixed prior to, nor independent of, treatment and response to treatment.

To place the practice of medicine firmly in the arena of *techne* is also at odds with a current understanding of disease. Hunter argues that seeing disease entities as “objects in nature” ignores the substantial evidence that points to the concept of disease as a

schema of useful generalizations, not an independent reality that medicine discovers (Montgomery Hunter 1991). The “ontologists,” those who see disease as having a reality apart from our classification, persist because their concept of disease is useful, even if it has been undermined by further research:

The apparent triumph of ontology, following the development of germ theory later in the century and abetted by the practical demands of medical education and daily practice, is rather like the persistence of Newtonian physics in daily life: except in special cases the old generalizations work. Whether patients or physicians, we tend to ignore much that our reified concept of disease does not account for, and, although the cultural determinants of disease are well known, we live—and physicians practice—as if diseases were objects in nature (Montgomery Hunter 1991).

The move from diseases as fixed entities to loose categories shifts further the practice of medicine toward a phronetic practice. But in the sense that diagnosis is never the end of medicine, only a part of the art, even when diagnosis is simple, straightforward, and points to a real entity such as pneumococcal pneumonia, medicine remains phronetically practiced. Although a particular diagnosis may yield a particular treatment most of the time, no diagnosis leads lockstep to one treatment. Pneumococcal pneumonia responds most of the time to antibiotics. But in one instance I remember well from medical school, it led instead to a discussion between the ninety-two-year-old rancher and his physician about whether it was “time to go.” Rather than antibiotics, he received comfort care, and died peacefully a short time later from a potentially treatable disease. The “good” in this circumstance is, in a certain sense, largely undetermined by diagnosis. The patient was an elderly man, a widower, who had lived a good life and who now faced a serious illness. Regardless of the specific diagnosis, the patient and

physician would have arrived at a similar plan. He was not going to struggle against any life-threatening illness; he was ready to die, and the treatment plan was comfort, not cure.

There is also the issue of how specific a diagnosis needs to be, and when a diagnosis need not, or should not, be obtained prior to moving on to treatment and management issues with the patient. Frequently, gynecologists treat benign menstrual bleeding either medically or surgically without ever reaching a diagnosis. Patients are often troubled by physicians' inability to explain why their periods are abnormal. However, given that the treatment options do not necessarily change with a more specific answer than benign menstrual bleeding, pursuing a more specific diagnosis only delays treatment, which does not benefit the patient. In the case of abnormal menstrual bleeding, there are two diagnostic questions that need to be addressed, first, establishing that the bleeding is not caused by a gynecological malignancy, and second, determining whether there are any large anatomic abnormalities of the uterus that would change the treatment options. Once these questions have been answered, it is usually most fruitful to move to a discussion of treatment options with the patient.

There are many similar examples in medicine, where diagnosis need not yield a specific disease before the clinician moves on to treatment considerations. It is an axiom in medicine that if answering a question yields no new options, then the question need not be answered. This can be frustrating at times for both physicians and patients, but the wisdom of this is also borne out by considering that diagnostic testing is never wholly without risk. A woman with chronic cyclic pelvic pain has a seventy percent chance of having endometriosis identified if a diagnostic laparoscopy is performed (a surgery that places a scope into the woman's abdomen and pelvis to examine the exterior surfaces of

the uterus and ovaries). But laparoscopies carry a surgical risk, and if the woman responds to medical therapy, there is in most cases no benefit to making the diagnosis. Returning to the axiom that the options must change for a procedure to be worthwhile, the medical therapy that is working will remain the correct therapeutic option, whether she has endometriosis or not. Laparoscopy becomes justified when a nonspecific medical therapy does not work, because then the surgery may be therapeutic by directly treating the medically unresponsive endometriosis, or may yield a new diagnosis that needs a different therapeutic modality.

Too much attention to diagnostic specificity not only potentially delays treatment, it may also actually harm patients by subjecting them to excessive testing, much of which carries direct or indirect risks. Even a test with no risk in itself carries risk if an abnormal result will be evaluated by another test that then carries risk.

Montgomery Hunter is correct in differentiating medicine from science, and remembering the end of diagnosis is one example of this. The goal of diagnosis is not knowledge for its own sake; it is having a response that can guide therapy and answer questions of prognosis. Sometimes this answer is a specific disease, sometimes it is a range of disease possibilities, and sometimes it remains quite open. The joke of dermatology is that an actual diagnosis is rarely necessary, “if it is wet, dry it. If it is dry, wet it.”

Treatment

Edmund Pellegrino and David Thomasma dissected the phronesis of medical judgment into three questions: what can be wrong, what can be done, what should be done? (Pellegrino and Thomasma 1981). The first question addresses the diagnostic issues of judgment, but the next two are both therapeutic questions. While these two therapeutic questions are undeniably different, it is the second question that requires phronetic judgment, and it is here that narrative attention and phronesis can be so critical. Although physicians are not uniform in this regard, most physicians only offer treatment options that they believe to be appropriate for the specific circumstances of the patient situation. This is precisely what Robert Veatch argues physicians should not do, because the medical values and decision-making algorithm remain opaque to the patient (Veatch 2009). The patient is presented with choices that represent a series of decisions already made by the physician about risks and benefits individualized to the particular patient.

While Veatch sees this as problematic, I regard it as both inevitable, and actually a desirable aspect of medical care. That is, patients expect physicians to filter choices for them, and give them the options most likely to be successful, well tolerated, and appropriate for their individual lives. Here is where medicine benefits most directly from narrative attentiveness: individualization of choices can only occur when the patient has become an individual, with a story, family, career, and values that the physician appreciates. Here also is where medical judgment needs to be hermeneutical, circling recursively between the patient's story and the problem at hand. Although the physician

can justifiably first filter the choices offered the patient based on both medical knowledge of the problem and narrative knowledge of the patient, the physician needs to present the remaining choices to the patient, and engage her in a discussion involving which option is actually best for her.

Simon Whitney and Laurence McCullough defend these “silent judgments” that occur prior to the presentation of options to patients even within an autonomy- based model of shared decision making (Whitney and McCullough 2007). They argue that physician judgment precedes the shared process between patient and physician where options are then discussed and chosen. They give a compelling example of their thinking that bears repetition and discussion. They argue that it is completely appropriate for a physician to withhold any discussion of isotretinoin to a young, sexually active teenage girl with severe acne who has had two unintended pregnancies in the last year, despite prescription contraceptives. Isotretinoin is an extremely effective antiacne medicine that can cause severe birth defects if the woman conceives a pregnancy while taking it. While she would potentially benefit greatly from the drug, they argue that the physician has enough history to realize that she cannot be trusted to reliably prevent pregnancy.

This raises several important issues. Patient rights advocates could argue that the physician misses an opportunity to explain why she feels uncomfortable prescribing the medication for her, and then seek to form a compact that would allow future use if certain conditions are met (such as a year without any further pregnancies, or the placement of an indwelling contraceptive such as an IUD or an implanted contraceptive that requires no patient compliance once it is in place). But it is also true that such an approach could backfire in dangerous ways—it could undermine their relationship by seeming too

parental, or it could even encourage the teenager to seek another provider with fewer scruples about prescribing the medication. Whitney and McCullough justify this filtering process based upon “professional integrity,” but it is equally clear as they discuss their reasoning that it also relies on a detailed knowledge of patient history that comes from narrative attentiveness:

There is another possibility. Perhaps this young woman is so irresponsible and impulsive that the physician judges that she is not currently capable of undertaking reliable contraception and that a conversation about this aspect of her life would not educate or inform her. If this is the situation, it would be irresponsible to prescribe isotretinoin, and there would be no benefit in discussing it. This silent decision is noteworthy in that the physician, after considering this individual patient’s circumstances, does not disclose the reasoning or invite the patient to participate in the decision, which is the opposite of what strong advocates of shared decision-making would regard as good clinical practice. However, the physician’s choice is forced by the catastrophic consequences of an isotretinoin-affected pregnancy. The consequences fall primarily on a future child who cannot consent and to whom the physician has a professional obligation to protect from such harm. A physician must withhold isotretinoin if there is serious doubt about a patient’s ability to avoid pregnancy and the far-reaching and irreversible teratogenic effects of this medication. In this case, the patient’s maturity and capability of changing her behavior is the determining factor.

Clinical decisions are regularly affected by the physician’s estimate of the patient’s ability and intentions to follow medical advice and avoid predictable and undesired consequences. (Whitney and McCullough 2007)

This case illustrates Pellegrino and Thomasma’s point about the difference between “what can be done” and “what should be done” (Pellegrino and Thomasma 1981). Although I argued in Chapter IV that presuming too much knowledge of a patient through narrative medicine has the potential for overreaching, and even a return to paternalism justified in this knowledge, Whitney and McCullough are correct in their assessment that this case does not represent paternalism, but rather that it exhibits good physician judgment grounded in knowledge of the patient history. While they may be missing the possibility of first discussing the patient’s willingness to use an implanted

contraceptive, and then discussing isotretinoin only if she first agrees to effective contraception, their overall reasoning is both sound and justified. To offer isotretinoin to an impulsive teenager with a record of contraceptive failure is to honor patient autonomy over patient well-being, and to ignore what the narrative is telling you about her life so far. But just as we always may live beyond our narrative, to paraphrase Pritchett, the possibility of a future time where isotretinoin could be discussed must still be held open.

The distance metaphor of Ricoeur is wholly apt here, because there is a continuous spectrum of possibilities for this interaction between two poles of decision making that should generally be avoided. At one end is physician paternalism, presuming too much knowledge of how the patient thinks, the worry expressed in the last chapter. In the case above, while isotretinoin may not be offered, the physician should still be discussing the other, more appropriate options for the patient's acne. At the other end is classical shared decision making in which the physician presumes nothing about the patient and merely offers options without truly engaging the patient as a person. This would include offering isotretinoin, even though it poses great risk to a developing fetus if she becomes pregnant. Here, the physician ignores what narrative has provided, and uses no judgment prior to the shared decision making. The choices offered are generic, the same set offered to any patient with the same diagnosis. The biomedical model, which discounts the importance of individuating detail, encourages an approach in which each disease or pathology yields the same set of treatment options.

These three failures, or extremes, presuming too much about the patient, presuming too little, or failing to engage the patient as an individual, fit well with Ricoeur's metaphor of the "just distance," and the necessary connection between

phronesis and narrative becomes equally evident. Without narrative, phronetic judgment has no individual detail upon which to act. Without phronesis, narrative loses relevance in the clinical encounter except as evidence of physician care. Together they function to establish where the conversation should begin, and what choices should be offered and discussed.

Decision-Making Support

So far, this account of the clinical encounter has proceeded from diagnosis, to physician judgment or “silent decisions,” to shared decision making, once choices have been filtered using phronesis and narrative. But there is a different type of judgment that comes into play within the discussion of treatment options with the patient. This is the judgment about how much support a patient, or patient and family, will require for making a good decision. The nature of the decision and the person making it are both important. Beauchamp and Childress point out that the complexity of a decision is actually distinct from the risks involved in the decision (Beauchamp and Childress 2009). Thus, it may be hard to choose between open- heart surgery or medical management of heart disease, because the risk of a wrong choice may well be death, but the information necessary to make the decision may be relatively straightforward. Many decisions are both complex and risky, but a patient may only be struggling with one aspect of the decision—the acceptance of risk, or the cognitive task of weighing medical details. To support a patient, without overriding her autonomous choice, requires ascertaining where

support is needed, and how much assistance is needed to arrive at a decision. Narrative helps with both aspects of this task.

The patient who sees herself as “in control” and detail oriented may need more detail and more information, whereas a patient who tends to make decisions at a more intuitive level may want less detail and a more emotionally responsive approach to decision making. Elsewhere, I give the example of helping an elderly, schizophrenic woman decide among surgical options by recalling her own statements regarding fear of pain and dependency (Qualtere-Burcher 2009). Although Hardwig is correct that we do not always know ourselves as well as we think we do, and we do not always present ourselves honestly to others, using the narrative detail obtained in the clinical encounter to determine how much and what kind of support a patient needs in decision making is certainly a better approach than withholding support out of fear of influencing a patient choice (Hardwig 1997). Patients often ask what their physicians would choose if the decision was theirs to make. Although I was taught to avoid answering this question in medical school, because the answer could have too much influence on the patient’s thinking, I have at times answered it when I thought it could be helpful. On one occasion, I told a patient that I would not choose surgery to investigate a probably benign pelvic mass because I would fear the risk of surgery more than the small risk of cancer posed by the mass. My opinion clearly did not unduly or wrongly influence her, because she then chose to have surgery. Furthermore, she said my answer clarified her thinking because she realized that, unlike me, she feared cancer more than surgery. While my answer was helpful in this instance, I would have declined to answer if I felt that she would have taken my answer as her own, rather than an example of how I would weigh

the decision. But I knew her to be a strong, intelligent woman whose problem was not cognitive or related to lack of information. Her issue was how to weigh two risks, both significant—the risk of cancer and the risk of surgery—and yet quite different.

Authors who support the autonomy principle have correctly argued that support of patient decision making need not violate patient autonomy. In fact, support may lead to autonomous choice that may have been otherwise impossible. Still, this example underscores the importance of narrative as a tool necessary to provide meaningful support (Beauchamp and Childress 2009). Support must be personalized, informed by narrative, and with phronetic judgment determining the nature and degree of support offered.

Emotional Support

While I have emphasized that patients seek medical care to obtain relief of suffering and restoration of health, the relief of suffering must not be understood only in terms of medical treatment and cure. Ricoeur is empirically justified in his description of suffering as loss of relation with others, and with our own abilities (Ricoeur 2007). In one study of patients seeking primary care, over three quarters responded that physician empathy was the most important quality for a good doctor to possess (Mercer et al. 2005). Given a choice between a cold but excellent surgeon, or an incompetent but empathetic one, we would probably choose competence over empathy, but this study reveals how important emotional support is to patients seeking medical care. They are not simply seeking answers and cures. Many feel alone, and the presenting complaint has often separated them from their friends, family, and jobs. While they want to be reunited

with their friends and family, they also seek to feel less alone *in their illness*. This at face value seems like an unreasonable request to be made by the patient of the doctor; after all, the patient is alone in her illness—the doctor does not share it with her. But Ricoeur recognizes that at another level, the clinical encounter does represent a commitment to sharing the burden of illness, and creates a partnership with the common goal of relief of suffering and restoration of health:

On the one side is someone who knows what to do; on the other, someone who is suffering. This moat gets filled, and the initial conditions become more equal, through a series of steps beginning from each side of the relationship. The patient—this patient—“brings to language” his suffering in speaking of it as a complaint that includes what will become a descriptive element (a symptom) and a narrative one (an individual entangled in these details). In turn, the complaint becomes more precise as a request: a request for...(healing and, who knows, health and, why not, in the background, immortality) and a request to...(addressed as an appeal to some physician). To this request gets grafted the *promise* to carry out the protocol of the proposed treatment...

At the other pole, in passing through the successive stages of accepting a client, formulating a diagnosis, and finally offering a prescription, the physician makes up the other half of the path leading to that equalization of conditions... In this way, the caregiving agreement becomes a *covenant* sealed between two people against a common enemy, the disease in question. This agreement owes its moral character to the tacit promise shared by the two protagonists faithfully to fulfill their respective commitments (Ricoeur 2007).

This partnership is the first action that treats suffering by ending the “singularity” of suffering. But this is a partnership founded on a shared goal, even if the roles within the relationship are nonreversible. The patient needs the physician’s skills and knowledge, but also hopes to feel support from the physician, *especially* when medicine offers no ready answer or cure. Physicians are only physicians because and when there are patients to serve, so there is mutual if not reciprocal need in the clinical relationship. While the exact nature of clinical empathy is a matter of much debate, and a discussion that is outside the focus of this work, there is no debate regarding whether empathy

exists. It would probably surprise many doctors to see how much patients desire and seek empathy from their physicians, but the role of empathy in the clinical encounter should not be assumed to be straightforward. That is, some emotional support is probably appropriate in most encounters, but the degree and type of support must vary, must be judged anew, in each encounter. Furthermore, there are at least two potential dangers to empathy that both need to be recognized and respected.

The first issue is creating dependence, rather than giving support that promotes return to independence. Patients with chronic illnesses can come to view their physician as part of their social circle, a friend of sorts. This is potentially detrimental to any progress if a patient believes that “getting better” can also mean losing the support the physician provides. Chronic pain patients often have limited social interactions, suffer from secondary depression, and can easily make their physician visits the center of their limited sociality. Providing meaningful emotional support while maintaining professional boundaries is a daunting task, but narrative plays a crucial role in getting the right balance. Knowing the level of support that a patient receives from family and friends, how this support is perceived, and how it is evolving with the demands placed upon it by the illness are all aspects that give light to the question of how much support truly benefits the patient.

But it is also too simple a response if physicians fear and avoid patient dependency. As Robert Bornstein has shown, patients with dependent personalities are often more compliant with treatment, and are better about seeking needed medical care (Bornstein 1998). Furthermore, patients that are critically ill are dependent by necessity,

and their dependence is directly correlated with their degree of illness. Ricoeur writes that physicians must recognize this and respond appropriately:

The caregiving agreement ideally implies a correspondence between two partners in this agreement. But the regression to a situation of dependence, once one enters the phase of serious treatments and situations that may be lethal, tends insidiously to reestablish the situation of inequality that was supposed to be set aside by the caregiving agreement. It is essentially the feeling of personal esteem threatened by the situation of being dependent that prevails in hospital. The patient's dignity is threatened not only at the level of language but by all the concessions having to do with the familiarity, the triviality, and the vulgarity of everyday relations between the medical personnel and hospitalized patients. The only way to fight against such offensive kinds of behavior is to return to the exigency at the base of the caregiving, that is to the associating of the patient with the carrying out of his treatment or, in other words, to the agreement that makes the physician and the patient allies in a common struggle against disease and suffering. I want to emphasize again that I am placing this concept of self-esteem at the prudential level, reserving the concept of respect for the deontological level (Ricoeur 2007).

Many of Ricoeur's words here are self-explanatory, but the end deserves additional explication. I take "associating...the patient with the carrying out of his treatment" to mean that the physician must continue to engage the patient, speak to the patient, as a partner in the struggle against illness, even if the patient is too ill or medicated to truly be making medical decisions. This stands in contrast to an autonomy model, in which the patient is engaged as a partner only when she is capable of this role. Ricoeur seems to suggest that the struggle against excessive dependency can include treating a patient as less dependent than she actually is. He justifies this not on a deontological level, which as described in Chapter II is where the principle of autonomy resides, but rather at a prudential level—the level of singular judgment founded in the

encounter between two unique individuals. The significance of this is that he is arguing that it is not for the benefit of a universal principle that we must treat patients as persons, even when they may lack the capacity to behave as fully autonomous beings. We must remain partners with patients, so that we do not compound their sense of dependency when the circumstances are diminishing them in every other way.

The other danger of excessive emotional support or empathy for a patient is that too much emotional merging can impair physician judgment. This has long been the logic behind medical prohibitions against treating family or even close friends. A certain amount of detachment is necessary, even if physicians today have in general taken this too far. But physicians need to be careful not only of pre-existing relationships, because sometimes the clinical encounter produces strong ties that need to be guarded against as well. I am not referring to the pathological relations, such as becoming romantically involved with patients. Even the ordinary, seemingly healthy yet close relationship can impair judgment at times.

I took care of a couple with twins a few years ago. They were both scientists, and the pregnancy was the result of in-vitro fertilization—highly desired and sought after. They wanted a birth as natural as possible, and greatly feared a cesarean section. Their visits were often long and somewhat social, as we discussed everything from biology to car seats. When the mother went into labor, I hurried over to the hospital, anticipating a nice birth. Instead, I was greeted by a nurse warning me that the “tracing on Baby B did not look good.” The monitor tracing of the second baby did look worrisome, but it had been a completely normal pregnancy up until then, and there was no reason to believe that the second baby could not tolerate labor. Furthermore, I reassured myself, fetal

monitoring has a high “false positive” rate; that is, many babies give worrisome tracings despite normal fetal well-being. But this tracing, as I looked at it more, was not just worrisome; it was a classically bad tracing that could not be ignored. I did eventually walk in and give them the news that it looked as if there were a problem with the second baby, and that we needed to do a cesarean section as soon as possible, but the decision was remarkably hard despite its straightforward nature. The second baby was depressed at birth although she recovered uneventfully, and the reason was also discovered: the placenta had started to separate prematurely from the uterus (an abruption). Medical decisions are often hard, and physicians often have to recommend precisely what the patient fears most.

While I am not suggesting that we cannot befriend our patients, we must be aware that there is both a potential risk, and cost, in doing so. Furthermore, if we reach a point at which we feel that we can no longer function with enough objectivity to render good care, then we must cease being that person’s physician.

Conclusion

As medicine expands its capabilities—especially the costly capability to keep more people alive, longer, with more debilitating conditions—institutional reform will always be a work in progress. No one should have any illusions about the capacity of institutional reform to bring about a renewal of generosity. It is the reverse: personal acts of generosity have the potential to affect the values that determine what goals are sought by reform. In clinics, at the bedside where it counts, a health care system is people touching each other. Everyone who touches anyone affects that person’s healing, and affects the further demoralization of medicine—or its remoralization. In the moral moment of that touch, there is no system (Frank 2004).

Just as the critique of narrative medicine includes a concern for the practicality and widespread applicability of its methods, there is a possible response to this new conception of the clinical encounter that needs to be addressed. Frank addresses one of these concerns in the preceding quotation. Any method that relies upon broad institutional reform of medicine has little likelihood of ever being implemented, but organic change, encouraging physicians and medical students to approach patient care with a new set of skills and attitudes, is clearly possible. The widespread adoption of the principle of autonomy beginning forty years ago is evidence of this. Although Alfred Tauber argues that autonomy was accepted because physicians actually saw it as a way of reducing their burden of responsibility, narrative technique and phronesis both tap into physician desire to have better and more meaningful relationships with their patients (Tauber 2005). Frank is also correct that institutional change may actually follow attitudinal change, as more physicians demand the resources, time, and even reimbursement for providing “high touch” care, rather than procedure-driven medicine.

The other concern that needs addressing is the critique that this represents nostalgia for a time of more humane medicine that cannot return again. To be clear, there are aspects of medicine as once practiced that do inform any attempt to re-humanize medicine. But this is not a nostalgia for a past that never was. Patient autonomy swept into medicine on a wave of disgust and distrust that physicians brought upon themselves by failing to respect patients in fundamental ways. In every generation of physicians, there have been Albert Schweitzers and Josef Mengeles. Good physicians took good care of their patients, even though physician paternalism was the rule prior to the ascendancy of the principle of autonomy. The goal is to explicate, teach, and affirm the skills that

good physicians have always intuitively used. Neither physician paternalism nor respect for autonomy does this. Narrative medicine does, when it does not overreach in its claims, and when it is combined with prudence to achieve the balance and flexibility that narrative alone seems to lack.

Physicians can and must incorporate these techniques into medicine as practiced today. This is not a manifesto against the technological advances in medicine that have saved so many lives, or even the growing shift in physician employment from private practice to employed status. Physicians face constraints on their behavior and time regardless of the model under which they work, and the goal of providing good care and having genuinely therapeutic relationships with patients is not actually harder today than in the past. No scientific advance will change the practice of medicine from the ethical enterprise that it fundamentally is. To best care for patients, physicians must seek better diagnostic tests and treatments, but they must also remain engaged in finding the best methods of patient care grounded in the clinical relationship.

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