

MEDICAL FUTILITY AND THE SOCIAL CONTRACT (WHO ARE THE REAL DOCTORS ON HOWARD BRODY'S ISLAND?)†

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INTRODUCTION

The term futility seems to capture something that has gone wrong with medicine in the United States. Driven by a technological imperative, fear of litigation, and a misunderstanding of patient rights, too often physicians have abrogated their clinical good sense by offering, or caving into demands for, end-of-life interventions that are "futile." However, a satisfactory operational definition of futility remains elusive.¹ Complicating matters further, futility has been co-opted by and confounded with other agendas. One of those agendas is rationing, society's perceived need to save scarce resources by refusing to provide marginally beneficial treatments. Another agenda is that of physicians who see futility as an opportunity to assert a power and authority that is slowly ebbing away from them.

I am convinced, however, that the original alarm about futility arose from physicians and nurses who were genuinely concerned that demands for aggressive interventions like cardiopulmonary resuscitation (CPR) were sometimes part of a desperate ritual of denial, a ritual that caused unnecessary suffering by dying patients and robbed them of their last vestiges of dignity. Advocates of the position that physicians can and should act unilaterally on their own futility judgments have used the concept of professional integrity to justify their position. They recognize the centrality of patient autonomy, but argue that it should not always trump professional judgment.

For example, Schneiderman, Jecker, and Jonsen call for "restoring a common sense notion of medical duty."² "So powerful

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¹ John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81, 82 (1989); Robert D. Truog et al., *The Problem With Futility*, 326 NEW ENG. J. MED. 1560, 1560 (1992); Stuart J. Youngner, *Who Defines Futility?* 260 JAMA 2094, 2094 (1988).

² Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERN. MED. 949, 950 (1990).

has this notion of autonomy become," they argue, "that its glare often blinds physicians (and ethicists) to the validity of earlier maxims that had long defined the range of physician's moral obligations toward patients."³ What are these moral obligations? The American Thoracic Society identifies "the ethical principles of beneficence and nonmaleficence that underlie the practice of medicine and define its goals," and argues, "[t]o force physicians to provide medical interventions that are clearly futile would undermine the ethical integrity of the medical profession."⁴ Echoing these words, Tomlinson and Brody write that "[a] principle that denied the physician any power to act on his or her professional values, rather than the patient's, would leave the physician powerless to refuse to perform actions that harm patients."⁵

These authors support the notion that society has granted the medical profession the responsibility and authority to make certain kinds of *medical* judgments. These inevitably but necessarily involve values about quality of life and judgments concerning likelihood of success.⁶ Without the ability to exercise such judgments, physicians would be more like automobile mechanics or lab technicians. None of these authors argue that physicians' judgments should be above the law or that physicians should not be accountable to society for their actions. However, society must allow physicians sufficient leeway to exercise professional judgment because any other course of action would jeopardize their role and status as professionals.

Tomlinson and Brody also argue that offering patients and their families interventions that the physician knows will not work actually undermines autonomy by implying a choice when none exists.⁷ As several authors have pointed out, desperation born of denial and guilt often motivates families' demands for futile treatment.⁸ To cave into such demands would serve only as a "high-technology placebo."⁹

³ *Id.* at 949.

⁴ American Thoracic Society, *Withholding and Withdrawing Life-sustaining Therapy*, 115 *ANNALS INTERN. MED.* 478, 481 (1991).

⁵ Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 *JAMA* 1276, 1278 (1990).

⁶ *Id.* at 1277.

⁷ *Id.* at 1279.

⁸ Schneiderman et al., *supra* note 2, at 949; Stuart J. Youngner, *Futility in Context*, 264 *JAMA* 1295, 1296 (1990); Leslie J. Blackhall, *Must We Always Use CPR?*, 317 *NEW ENG. J. MED.* 1281, 1283 (1987).

⁹ Blackhall, *supra* note 8, at 1283.

Howard Brody makes an eloquent and even romantic plea for professional integrity:

Suppose that a new island has just been discovered, and explorers from various nations are eagerly planting their flags and laying claim to various pieces of territory. I am trying to plant the flag of professional integrity somewhere on this island. I am not claiming that, compared with the territory claimed by autonomy, the territory in which professional integrity rules will be very large at all; indeed it may turn out to be very small and hardly worth fighting over. It is simply my goal to establish that *somewhere* there is a set of treatment decisions over which professional integrity will hold sway, even against contrary claims of patient autonomy.¹⁰

I. THE FLAG OF PROFESSIONAL INTEGRITY

The following case illustrates the responsible exercise of professional responsibility and integrity in refusing a demand for futile treatment.

A. *The Case of Mr. A*

Mr. A was a successful biomedical researcher in his early sixties. He had been diagnosed with an aggressive cancer of the bladder two years before I became involved in resolving the ethical implications of his treatment. From the moment of diagnosis, Mr. A. and his wife clearly informed his physician that they wanted to "do everything" to treat the cancer aggressively. They had no children. He had undergone surgery to remove his bladder, chemotherapy and radiation treatments. These treatments slowed but did not stop the progression of his cancer.

From the beginning, the patient had one oncologist who served also as his primary care physician. Both Mr. A and his wife had read extensively about his illness and often had suggestions or advice for the oncologist who was always available to answer their questions and fill their need for advice and support. When the couple asked for an experimental chemotherapy protocol, the oncologist explained the risks and poor likelihood of success, but provided it. They had excellent insurance that paid well for both outpatient and hospital treatment.

As the patient became sicker and sicker, the degree of his wife's emotional dependency on him became evident and her de-

¹⁰ Howard Brody, *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRIC Soc'y 875, 876 (1994).

nial grew more extreme. She began investigating unconventional therapies and discovered a vitamin which, used in high doses, could "cure" various types of cancer. When Mrs. A demanded that the oncologist treat her husband with the vitamin, the oncologist took her request seriously. She reviewed the evidence for efficacy and found that the Federal Drug Administration (FDA) had determined that there was none. On the other hand, the oncologist concluded that administration of the vitamin would not harm Mr. A and therefore supported the treatment.

Not surprisingly, the patient continued to deteriorate. The cancer spread to his spine and throughout his abdomen. He was in a great deal of discomfort, but neither he nor his wife acknowledged that he was dying. "We are going to beat this thing," they repeatedly told the oncologist. Mrs. A became obsessed with the details of her husband's care, calling the oncologist late at night and on weekends because the oncologist had given Mrs. A her beeper number. The oncologist spent hours talking with Mrs. A.

When the patient was hospitalized with pneumonia and acute renal failure and admitted to the intensive care unit at his wife's insistence, radiological studies demonstrated that the malignancy, which had continued to grow and spread, had now invaded his kidneys. The wife insisted that this was a temporary setback. The patient experienced increasing pain but his mental status had deteriorated to the point that he could not understand or respond to questions. His wife was becoming more and more distressed but insisted that "with a little more time" he would begin responding to the megavitamin doses that he was now receiving via rectal enemas because he could no longer take them by mouth. Some nurses objected to providing this "futile" intervention because of the obvious discomfort it caused him (he had to be turned onto his side in a painful position) and were not assigned to his care.

All but the wife clearly understood that the patient was dying. However, she continued to spend almost all her time in the hospital ministering to her husband, focusing on small details of his care such as lab values and doses of medicine. When it became clear that his kidneys had shut down, the medical director of the medical intensive care unit (MICU) and the patient's oncologist met with Mrs. A to discuss how they might make Mr. A's death as comfortable as possible. She would have none of it, insisting that the hospital put her husband on dialysis, fully resuscitate him if he suffered cardiopulmonary arrest, and attach him to a mechanical ventilator if necessary.

The treating physicians called the Ethics Consultation Service to help them resolve the situation. As a consultant with that service, I met with the wife, the oncologist, and the ICU director. The wife adamantly insisted that her husband was getting better. She claimed that the vitamin was working because she could see that the necrotic tumor "was being expelled from his body in his sputum and stool." I have rarely seen desperation this great or denial this extreme. When the oncologist gently told her this was the end of the line, Mrs. A accused her of "treating us like we are a number." Mrs. A turned a deaf ear toward any concerns about her grief and need for support, refocusing the discussion on "curing" her husband.

The oncologist and ICU Director held fast. They said Mr. A was dying and that dialysis, intubation or full resuscitation would, at best, extend his life for a brief time at the expense of great suffering. They told Mrs. A that they would do everything to keep him comfortable. When they took this firm position, Mrs. A did not argue. She turned to other matters over which she still had control. "I want him to keep getting the vitamin," she insisted. The physicians agreed. Two days later, Mr. A died a relatively peaceful death, with his wife present. Her relationship with the ICU staff remained good throughout.

The case of Mr. A is an excellent example of the responsible exercise of professional responsibility. Mrs. A, desperately fearful of her husband's death, was using invasive end-of-life medical interventions as a way of supporting her denial, which had assumed almost psychotic proportions. The interventions she demanded were not benign. Mr. A's oncologist had provided excellent technical and emotional care. She had functioned as both a specialist and primary care physician, working diligently and compassionately with the patient and his wife. She had supported their decision to go for the outside chance of a recovery, and had even acquiesced to an unconventional therapy that was ineffective but minimally harmful. As the patient neared death, however, the oncologist was unwilling to participate in Mrs. A's nearly delusional denial at the expense of her husband's unnecessary suffering. By drawing the line, Mr. A's physicians acted responsibly and with integrity.

Consideration of another case in the same hospital, however, reveals the elusive nature of a clear definition of professional integrity.

B. The Case of Mr. B

A nurse from the surgical intensive care unit (SICU) requested an ethics consultation regarding the care of Mr. B. Mr. B was a man in his early seventies who had undergone coronary artery bypass surgery. Although he had been otherwise healthy when he entered the hospital, one thing after another had gone wrong following the surgery. He developed a pulmonary embolus (blood clot in the lung) and then suffered a myocardial infarction. Five weeks later, his kidneys had failed and he was receiving renal hemodialysis three times a week. He was intubated and attached to a mechanical ventilator. Because he was semiconscious and unable to eat or drink, the staff provided nourishment intravenously. The surgeon was unwilling to consider pulling back from an aggressive stance. He made daily rounds, but often when the patient's wife and three children were not present. The patient's family conversed largely with the nursing staff and expressed their opinion that the patient would never leave the hospital alive. During infrequent conversations with the surgeon, the family was told that the patient remained in stable condition and that he was hopeful the patient would pull through. The family complained to the nurses that the surgeon was not answering all their questions and worried that Mr. B was suffering and would not recover. However, they were unwilling to confront the surgeon with these concerns.

The nurses, who would be responsible for attempting to resuscitate the patient if he suffered cardiac arrest (i.e., would have to administer chest compressions), urged the surgeon to write a do-not-resuscitate (DNR) order. The nurse who called me for an ethics consultation said the surgeon was annoyed, but had reluctantly agreed to write the order. However, the next day the surgeon had still not placed a DNR order in the chart or talked with the family. When the patient's blood pressure began to drop, the nurses talked to the surgical resident who was covering for the surgeon while he was in surgery and asked him to write the DNR order. He demurred. The patient stabilized, however, rendering moot the issue of resuscitation. The nurse requested that I talk with the surgeon about his failure to write a DNR order in the chart. The hospital policy clearly states that DNR orders are not valid unless they are written by a physician in the medical record.

The surgeon returned my phone call and I met him the next day in his office. He maintained that the patient's situation was not hopeless. He reluctantly accepted that he should write a DNR order because if the patient's heart stopped, it was unlikely that the

staff could restart it. However, the surgeon stated that he was unhappy with the nurses who, he felt, were "too negative and should get back to taking care of patients rather than worrying about the things that are really the business of physicians." He noted that the surgical intensive care unit had a different "philosophy" from the medical intensive care unit (where Mr. A had died). "They kill people in the MICU," he said. When I pressed him to explain this provocative statement, he backed off a bit, "The MICU physicians are ready to give up too early. They pull the plug when they should be trying to save life."

I did not ask the surgeon to defend his aggressive "philosophy," but I am sure that if I had he would have done so, much as Mr. A's physicians did, by appealing to the internal values and goals of medicine and a sense of professional integrity. How are we to understand the notion of professional integrity when the only common ground between the physicians treating Mr. A and Mr. B is their conviction that their judgment and experience should prevail? Schneiderman and his colleagues argue that physicians should be true to the goals of medicine by refusing to provide treatments that fall below a certain threshold of quantitative or qualitative benefit to the patient. The physicians of Mr. A and Mr. B had very different conceptions of that threshold. In fact, the judgments about qualitative and quantitative futility vary from physician to physician¹¹ and often from service to service.¹² A more disturbing issue is that demographic factors such as the specific illness or age of the patient may inequitably influence physicians' futility judgments.¹³ A recent study by Curtis et al. found that the non-white race of the patient independently predicted a futility judgment resulting in a DNR order.¹⁴

These observations raise the question: if you are a patient in

¹¹ J. Randall Curtis et al., *Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders*, 273 JAMA 124, 128 (1995); S. Van McCrary et al., *Physician's Quantitative Assessments of Medical Futility*, 5 J. CLIN. ETHICS 100, 100-105 (1994).

¹² See generally Stuart J. Youngner et al., *Resolving Problems at the Intensive Care Unit/Oncology Interface*, 31 PERSP. BIO. & MED. 299 (1988) (describing the different clinical perspectives and experiences that exist in the hematology-oncology unit and the medical intensive care unit at University Hospitals of Cleveland).

¹³ Kevin M. McIntyre, *Failure of 'Predictors' of Cardiopulmonary Resuscitation Outcomes to Predict Cardiopulmonary Resuscitation Outcomes*, 153 ARCHIVES INTERN. MED. 1293, 1295 (1993); Mark Rosenberg et al., *Results of Cardiopulmonary Resuscitation: Failure to Predict Survival in Two Community Hospitals*, 153 ARCHIVES INTERN. MED. 1370, 1374 (1993); Carlo Vitelli et al., *Cardiopulmonary Resuscitation and the Patient With Cancer*, 9 J. CLIN. ONCOL. 111, 114 (1991).

¹⁴ Curtis et al., *supra* note 11, at 128.

need of hospitalization and wash up on the shores of Dr. Brody's island, which flag of professional integrity will fly over your beach?

II. DOCTOR/PATIENT RELATIONSHIP (SOMETIMES THERE IS NO FLAG)

When physicians use the notion of professional integrity to defend their unilateral treatment decisions, they do so in the context of a presumed ideal physician/patient relationship. Such a relationship implies continuity over time, good communication, and a general sharing of basic values. The following cases illustrate how far short of this ideal we can fall.

A. *The Case of Mrs. C*

A medical resident, who described Mrs. C's family as "making unreasonable demands" on the staff to treat her aggressively, requested an ethics consultation. Two years before my involvement with the case began, Mrs. C had suffered a severe stroke which left her in a persistent vegetative state. Since that stroke, she resided in a nursing home where she was fed through a gastrostomy tube. She was admitted to the hospital several times with pneumonia. This time she was quite unstable; her blood pressure was low and it appeared that she might be developing a blood infection (sepsis). Her family insisted that the hospital transfer her to the medical intensive care unit. Mrs. C's physicians opposed the transfer to intensive care as inconsistent with their role as physicians. They cited an assertion in the medical literature that persistently vegetative patients placed in intensive care fall below a minimum acceptable threshold quality of life.¹⁵

Mrs. C was an African-American. Her family was from the inner city. The county nursing home had assigned a physician to Mrs. C's care, but that physician did not have admitting privileges at the hospital and was in no way involved with her care there. When I met with the family, the only physician present was an "acting intern," a fourth year medical student who, with added supervision, had taken on the responsibilities of an intern. This student was especially competent and concerned. The patient's husband and son were clearly angry. "Why don't you want to save our mother?" they asked. When the physician explained that there was no chance that the patient would ever regain consciousness, the family was unmoved. "You just don't want to spend the money on

¹⁵ Schneiderman et al., *supra* note 2, at 952.

her," they replied. In fact, the patient's physicians had raised the waste of resources issue, although not in the family's presence. The physicians replied that they thought aggressive treatment was futile.

The patient's son complained that they never met with the same physician when they came to the hospital. "And look at what we have now. A medical student!" he exclaimed. "He's not even a real doctor. How can we trust what he tells us?" When the medical student offered to remove himself from the case, the family became visibly shaken. "No. Don't do that," they pleaded. "He's the only one who spends time with us and our dad. The other doctors are too busy. Why can't he be our doctor all the time?" The medical student explained that he would be leaving in five days because it was the end of the month and he had to "rotate" to a different ward at a different hospital. "Who will take your place?" they asked. The answer was a simple "I don't know."

When I tried to find a senior physician who would follow the patient and family through this hospitalization and probable others, I did not succeed. Physicians with offices outside the hospital could not afford the time it would take to come to the hospital to manage this case, which would also compensate them very little for their efforts. Full-time staff physicians had clearly defined months during which they had responsibility for the care of inpatients. They were busy doing research and writing grants to support that research during the remaining months.

B. The Case of Mr. D

Mr. D was a fifty-five-year-old man with leukemia. He had received high dose chemotherapy and a bone marrow transplant. He had a difficult course with recurrent pneumonia and gastrointestinal bleeding. His own bone marrow had not yet begun to make white blood cells. It was not clear if this situation was secondary to the chemotherapy or if his leukemia had become active again. The patient was on an experimental oncology unit where the patient, family, and health professionals knew they were going for a "long shot." When the patient became severely ill, the physician transferred him to the medical intensive care unit (MICU). There, the hospital could more effectively monitor his vital signs and employ aggressive life-sustaining interventions such as mechanical ventilation and drugs (vasopressors) to maintain blood pressure.

The MICU physicians and nurses were not enthusiastic about the transfer. They had seen many such patients die in their "high

tech" environment. These deaths were often prolonged, uncomfortable, and "undignified." Mr. D and his family had grown used to the physicians and nursing staff on the oncology unit. Now they had an entirely new group of physicians and nurses with whom to interact. Mr. D's oncologist remained active in the case, visiting every day, briefly reviewing the patient's progress and speaking with the family. There were other physicians involved in the case as well—consultants from gastroenterology, infectious disease, and cardiology. For the MICU staff, Mr. D was a dying patient who had been sent to die a high tech death because his oncologist was unable to confront his family with the "truth." Continued aggressive intervention was "futile." To his oncologist, Mr. D was very sick and might well die, but was still "salvageable." Each view was presented to Mr. D's family, either directly or by implication.

To the various consultants, Mr. D was not so much a whole patient as he was an organ or organ system. Every day the consultants came by with a group of fellows, residents and medical students in tow. They examined the "appropriate" part of the patient, examined the "relevant" lab tests, and answered questions from the family about his bleeding gastric ulcer ("He is showing no evidence of blood in his stool."), his blood infection ("Good news. The blood cultures are not growing any bugs."), and his irregular heart beat ("Good news. His heart is responding to medication.").

To make matters worse, there was a complete turnover of intensive care unit and consulting physicians at the end of the month. A new "rotation" of attending, resident, and student physicians from each service "took over" the care of the patient. Nursing provided the greatest continuity of care, but the nurses worked shifts and took days off. When they were not on duty, the nurses were not available to the family or patient. Mr. D had a family doctor who lived in a city ninety miles from the hospital. He had not been involved in the case for over three months. When the family became so confused and full of despair that they demanded outside intervention, the physicians called for an ethics consultation.

The cases of Mr. C and Mr. D illustrate structural problems of the medical care system. When patients are in the hospital for two or three days and have a straightforward medical condition, these problems may not surface. However, during prolonged hospital stays with high diagnostic and therapeutic uncertainty and marked social and ethnic disparity between patients and staff, the short-

comings of the system come out in bold relief.¹⁶ Can physicians eschew responsibility for these shortcomings while at the same time using the trump of professional integrity to deny patient and family requests for life-sustaining interventions? Can they appeal to the physician/patient relationship as the cornerstone of the health care system when it is increasingly hard to come by? I think not.

CONCLUSION

Defenders of futility argue that a physician's refusal to provide "futile" treatment at the end of life serves a patient's interests. This claim rings hollow when those same physicians "hand off" their dying patients to other physicians at the boundaries between months, services, or hospital and community—returning to their laboratories, teaching responsibilities, or busy office practices. The claim further loses force in the face of multiple simultaneous physician/patient relationships, none of which are focused on the patient as a whole. The claim of professional integrity seems particularly ironic when physicians and their institutions use market values to determine which patients will or will not receive the benefits of their professional integrity.

As we attempt to restructure our health care system, these problems are receiving little attention. Health policy experts extol primary care as a cost-saving strategy, yet often seem oblivious to its real meaning and value. Managed care frequently forces patients to switch physicians as health management organizations (HMOs) and corporations play musical chairs. Managed care can surreptitiously (without patient knowledge and consent) place the physician in a conflict of interest between benefit to the patient and cost savings to the managed care entity.¹⁷ As physicians increasingly view themselves as employees, they will opt for smaller work loads and less demanding schedules. Perhaps the notion of "my patient" or "my doctor" will only exist during "eight to five" office hours. At night, weekends and in the hospital, strangers will take care of strangers. Of course, many patients will continue to have little or no access to physicians unless they are deathly ill, a circumstance in which they are unlikely to be receptive to physicians' futility judgments.

¹⁶ Stuart J. Youngner, *Applying Futility: Saying No Is Not Enough*, 42 J. AM. GERIATRIC SOC'Y 887, 887-889 (1994).

¹⁷ Susan M. Wolf, *Health Care Reform and the Future of Physician Ethics*, HASTINGS CENTER REP., Mar.-Apr. 1994, at 28; Ezekiel J. Emanuel & Allan S. Brett, *Managed Competition and the Patient-Physician Relationship*, 329 NEW ENG. J. MED. 879, 880 (1993).

Development of a system that provides and nurtures real physician/patient relationships for all of our citizens may simply not be possible. If this is so, the assertion of professional integrity will become irrelevant to everyone but the physicians who cling desperately to their dwindling authority and prestige. The flags of professional integrity may become rare indeed.