

# Virtual Mentor

Ethics Journal of the American Medical Association  
July 2005, Volume 7, Number 7

## Clinical Case

### When Diagnosis Becomes Unaffordable

Commentaries by William Hensel, MD, and Justin List, MAR

The waiting room is packed at the Urgent and Family Care office. Dr Garrison picks up the chart for the next patient, Mrs Williams, who has come in because of cough, fever, and chills.

“Good morning Mrs Williams, I’m Dr Garrison, how can I help you?”

Mrs Williams looks older than the 50 years listed on her chart, and Dr Garrison is struck by how gaunt and pale she appears. Mrs Williams reports that she has had no serious illnesses or surgeries but admits that she has been a 2-packs-per-day smoker for the past 30 years.

After performing a physician exam, Dr Garrison tells Mrs Williams that she would like to order a chest x-ray and a complete blood count because she is concerned about the possibility of pneumonia.

“Pneumonia? Again? I’ve had that 2 times in the last year.” Mrs Williams exclaims. Dr Garrison flips back through her chart and sees that Mrs Williams was treated for pneumonia in their office 4 months ago. Dr Garrison orders the chest x-ray and the labs and reviews Mrs Williams’ previous films. She sees an abnormal area in the right middle lobe. In the previous film it had been read as “anatomic variant, likely related to pectus excavatum,” with an infiltrate distally. Today’s results show that the distal infiltrate is gone, but the area originally read as “anatomic variant” appears larger and more defined. Mrs Williams’ white count is in the high normal range. Given the patient’s smoking history, Dr Garrison is concerned about the possibility of a mass. Could this be lung cancer or is it just another pneumonia?

“Mrs Williams, I was just comparing your chest x-ray to the one you had before in our office. I am concerned about an area that just doesn’t look right to me. It could be that you have pneumonia again in an area of your lung that is a little abnormal and prone to getting infections. I’m going to treat you with antibiotics, but, given your smoking history, I’m also worried, honestly, about the possibility of a cancer. I’d like to do a CT scan of your chest, so we can get a better idea of what’s there.”

Mrs Williams is silent for about a minute. “Dr Garrison, I’ve thought about lung cancer because my cousin just died of that, and he smoked a lot too. But I don’t have any health insurance. I just started a new job and I’ll be eligible for health insurance in 6 weeks. I started in the middle of the month, and they don’t count part of a month when they figure eligibility for benefits. So in 6 weeks, I’ll see which plan I can afford

to be in. I don't know what my rate will be when they find out that I smoke. So, can we wait to get the CT scan until after I have insurance? My cousin didn't have insurance and their family went bankrupt paying for his treatments. Now he's dead and his wife and kids got nothing. I don't want to do that to my family. Plus, you said it could just be another bout of pneumonia.”

### **Commentary 1**

by William Hensel, MD

Physicians must balance their ethical obligations to patients with those to society at large. Society trusts the profession of medicine to self-regulate the care it delivers, but it has strict rules for reimbursement of that care, especially when it comes to caring for those who are unable to pay. Physicians work within those reimbursement rules, attempting to meet patients' needs and preferences whenever possible. But what if society's rules are unjust? What then is the physician's obligation? These ethical dilemmas frame the problem confronted by Mrs Williams and Dr Garrison.

Ethically, Dr Garrison cannot simply blame our US health care system, which seems to accept as inevitable 43 million uninsured patients, and leave Mrs Williams to fend for herself [1]. Instead, she must advocate for Mrs Williams and help her navigate through the barriers to her care.

All patients, and especially those who are seriously ill, need health care professionals whom they trust to guide them through our complex system and to assist them with the difficult decisions they face. In this case, Mrs Williams has been seen in the practice before, but not by Dr Garrison. I will resist the temptation here to comment on the decline in continuity of care. Focusing on the situation at hand, Dr Garrison should discuss with Mrs Williams which doctor in the practice she would prefer to see for her subsequent care.

What else should Dr Garrison try to accomplish during this initial visit? The answer is not much. Mrs Williams has just received shocking news: she might have lung cancer. She knows full well the potential horror of the disease—she has witnessed the tragedy of her cousin and his family. When confronted with such devastating news, rational thought typically takes flight and is replaced by confusion and denial. This is not the time to discuss rationally Mrs Williams' request to wait 6 weeks before further testing.

Dr Garrison's best strategy is to schedule a follow-up visit in 1 to 3 days with Mrs Williams' doctor of choice. She should encourage Mrs Williams to bring a trusted friend or family member to that visit. The simple act of deciding which doctor she will see and identifying a support person can help Mrs Williams reestablish some control over her life, control that was lost moments earlier when the possibility of cancer was mentioned. Dr Garrison should then conclude this initial visit as empathically as possible.

The doctor that Mrs Williams chooses must carefully plan the next appointment. A well-structured visit with information regarding her options for determining a

definitive diagnosis will help give Mrs Williams the confidence that she will need to deal with her health crisis. It should begin with the doctor's asking what thoughts she has had since the last time she was at the office. If Mrs Williams remains focused on financial concerns and reiterates her request to wait 6 weeks until she has insurance before pursuing any further diagnostic tests, the doctor must gently outline the problems with this approach:

- The insurance delay will probably be longer than 6 weeks. It is unlikely that Mrs Williams will be able to sign up, on day 1 of her eligibility, for a plan that will immediately cover a CT scan of her chest. Realistically, as much as 4 to 8 weeks should be added to her estimated 6-week delay.
- The insurance company will most likely consider this a pre-existing condition. Even though Mrs Williams does not have a definitive diagnosis, she does have symptoms and objective x-ray findings that point to a possible neoplasm. Thus, waiting may not achieve the desired result of having her tests and treatments covered.
- Any delay in the diagnosis and treatment of lung cancer may affect the treatment outcome. Delaying 6 weeks or longer could decrease the chances of a cure if the suspicious area turns out to be cancer.

Given that the risks involved in waiting are great and the benefits uncertain, the doctor should advise Mrs Williams to proceed with the CT of her chest. Psychologically, patients deal better with known problems than with uncertain fears. So, even if the CT scan confirms that Mrs Williams has a lung cancer, the conclusive diagnosis will take her out of limbo and allow her to begin to deal with her cancer. I would recommend that the physician schedule the CT scan before Mrs Williams returns for her follow-up—within 48 hours of the initial visit, if possible—so that she can say to Mrs Williams, “I took the liberty of making you an appointment for tomorrow. It can be cancelled or postponed, but I wanted to give you the option of immediate care.” This paternalistic approach can be justified in times of crisis but must be judiciously balanced with efforts to empower the patient’s own decision making so that she can regain a sense of control.

Anticipating that Mrs Williams might ask, the doctor should know the approximate cost of a chest CT (\$850-\$900 for scan and radiologist’s interpretation at my institution) and be able to direct her to the hospital’s financial counselor or other community resource to help resolve some of her financial concerns. The doctor could also offer to make this appointment for Mrs Williams.

A timely follow-up appointment should be scheduled to review the CT results and to discuss options with the doctor. At some point, the doctor should address end-of-life issues with the patient. The recent Schiavo case emphasizes the importance of discussing advance directives regardless of the test results. Because it is difficult to prognosticate without an accurate diagnosis, a tissue biopsy is typically necessary before Mrs Williams and her physician can have a serious discussion about the risks and benefits of the various treatment options. Should the tests confirm cancer, and depending on her prognosis and personal values and beliefs, Mrs Williams might

choose palliative care over aggressive curative care. Shamefully for this country, her lack of insurance may influence that decision.

The physician will face an unfortunate dilemma if Mrs Williams insists on waiting until she has insurance. The insurance company may contact the practice and ask if there is evidence that this was a pre-existing condition. Physicians must respond truthfully to such direct questions; to do otherwise is unethical and constitutes insurance fraud.

How forthcoming should the doctor be if the insurance company does not ask direct questions? Suppose Mrs Williams asks the doctor for advice on how she might get around the pre-existing condition clause in her insurance coverage? The central point of this commentary is that ethical physicians should advocate for their patients and help them negotiate the health care system. To what lengths individual physicians are willing to take their advocacy depends, in part, on how fair they think our current system is. America stands alone among industrialized nations in its failure to ensure that all its citizens receive basic health care. I believe that it is unjust to limit access to care for 43 million Americans because of their inability to pay. Therefore, I would do all that I could legally and ethically do to help Mrs Williams obtain access to care—access that should be her right.

### **Reference**

1. Institute of Medicine. Insuring America's health: principles and recommendations. *Acad Emerg Med.* 2004;11:418-422.

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### **Commentary 2**

by Justin List, MAR

This case illustrates some of the frustrations experienced by patients and physicians due, in large part, to systemic shortcomings in health care delivery in the US. It also raises questions about the professional obligations and limits of care Dr Garrison owes to her patient, and it vividly portrays how financial concerns may critically impact health outcomes. To be sure, there is medical uncertainty about Mrs Williams' actual illness, but there are tests available to help Dr Garrison rule out or confirm the presence of a malignant mass. A delay in the diagnosis of lung cancer could result in a poorer outcome for Mrs Williams, and, unfortunately, she cites financial not clinical or personal concerns for postponing testing. Determining Mrs Williams' illness expeditiously using the standard diagnostic procedures seems ethically imperative for optimal patient care, but prudential concerns and the wishes of the patient must be seriously considered, despite the potentially tragic outcome of delayed testing.

There are at least 3 potential dilemmas for Dr Garrison. First, her clinical encounter with Mrs Williams is encumbered by nonclinical financial, family, and insurance matters that could impact her patient's health. Thus Dr Garrison finds herself in a situation where prescriptions for standard and advisable medical tests butt up against systemic injustice in the delivery of health care that make getting such tests difficult. As a result, it is likely that Dr Garrison's ethical duties in this encounter will include helping her patient navigate the insurance and payment system. Second, Dr Garrison must establish trust with Mrs Williams early in the clinical encounter, a potentially difficult task, given Mrs Williams' lack of continuous care from a single physician. Third, Dr Garrison must resolve conflicts among respect for patient autonomy, clinical judgment, and the economic and social realities of the health care delivery system. A form of soft paternalism in response to the injustices of the system may seem appropriate, eg, pressing Mrs Williams to get the testing, while at the same time searching for or directing Mrs Williams to financial assistance opportunities. But such actions have an impact on a key principle of medical ethics—respect for patient autonomy.

Examining the dynamics of the patient-physician interaction more closely allows for a greater understanding of the possible relationships between patient autonomy and professional duties. In "Four Models of the Physician-Patient Relationship," Ezekiel and Linda Emanuel compare paternalistic, informative, deliberative, and interpretive models of patient-physician relationships, taking into account in each model the (1) goals of the professional interaction, (2) physician obligations, (3) role of patient values, and (4) notions of patient autonomy [1].

The paternalistic and informative models are undesirable approaches in this case. In the paternalistic model, the physician decides the best course of action almost unilaterally, and patient autonomy is relegated to patient assent. Using the informative model, the physician acts as a technical expert, providing facts and information to the patient but offering little overall guidance. With this approach, physicians' values and assessments of their patients' values are supposed to be absent, and patients have more or less complete autonomy in medical decision making. Both of these are inappropriate models for Mrs Williams because they entail what many consider unacceptable and unequal levels of knowledge, power, and decision making within the patient-physician relationship.

The remaining models—deliberative and interpretive—may better help Dr Garrison share her knowledge and professional opinion with Mrs Williams while simultaneously discerning Mrs Williams' values and honoring her autonomy.

Using the interpretive model, Dr Garrison would limit the expression of her own values and desires as they bear on the clinical decision. Rather, her responsibility is to elucidate her patient's preferences in order to match them with medical actions that accommodate them. Dr Garrison would act like a counselor, trying to understand the underlying reasons for Mrs Williams' unwillingness to undergo a CT scan, but she would ultimately make recommendations based on Mrs Williams' preferences. Dr

Garrison's belief in the injustice of the health care system will likely remain deeply troubling to her if Mrs Williams opts to forgo further testing.

Following the deliberative model, Dr Garrison would act as a teacher or friend, aiming to help Mrs Williams determine the most important health-related values in the clinical situation and then correlating those with the options available to her, all things considered. Most likely, the options would include treating possible pneumonia and pushing Mrs Williams to get a CT scan, despite her financial reasons for not wanting to do so. Of course, Dr Garrison cannot force Mrs Williams to get the scan, but she can make her professional advice explicit and underscore the importance of placing one's health above other factors that can, lamentably, devalue it. Dr Garrison's responsibilities under this model are to advocate for the most clinically relevant medical choices and explain the implications of those and any other alternative treatments.

Dr William Hensel's adjoining discussion of this case reflects the deliberative approach to the encounter between Dr Garrison and Mrs Williams, the one also most favored by Ezekiel and Linda Emanuel. Although this model may best allow Dr Garrison to persuade her patient to go ahead with the CT scan, Mrs Williams will still ultimately have to decide what to do. The cardinal principle of respect for individual patient autonomy in Western medical contexts requires that the physician honor the patient's wishes. According to a biopsychosocial understanding of health care decision making, Mrs Williams may reasonably hold nonmedical values that support a decision to delay or deny further testing. In this situation, Dr Garrison should convey compelling arguments that might assuage Mrs Williams' financial concerns without making her feel guilty about deciding to forgo testing. When financial concerns stand in the way of adequate diagnostic procedures despite the serious health consequences at stake, physicians often feel helpless within the health care system.

As if working to decrease medical uncertainty about Mrs Williams' condition were not enough for Dr Garrison to do in this clinical encounter, her ethical responsibilities also include actively helping Mrs Williams navigate the health care system. From her physician's perspective, Dr Garrison probably hopes that all her patients rank their personal health as a priority. In this particular case, however, the physician has no choice but to honor the autonomous decision of the patient, despite the potentially unfavorable health consequences. Mrs Williams' concern for her family and their finances seems to outweigh her concerns for her own health, even though these considerations should not be at odds with each other. Dr Garrison's awareness of medical uncertainty may help her feel more comfortable with Mrs Williams' decision to delay testing. Before Mrs Williams makes a final decision, though, Dr Garrison's duties as a patient advocate lie in vigorously challenging the forces that, and negotiating with the people who, may be leading Mrs Williams to minimize the importance of her health.

## **Reference**

1. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267:2221-2226.

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