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How Right Are Patients' Rights?

Curriculum Unit 01.01.01
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The goal of this unit is to encourage students to think and to focus that thinking on the future of their health and that of their loved ones. Most of the students we come in contact with have had nothing more serious health-wise to contend with than a sprained ankle or a bout with the flu. They consider themselves to be invincible. But, if you probe, they will recall an aunt with cancer or a cousin with sickle cell anemia, and they can be slowly brought around to seeing the relevancy of health care concerns. In your discussion of these issues, ask them to relate their experiences and those of family members and friends to help them to associate themselves with the subject. This unit is based primarily on discussion and on activities designed to keep them personally involved. These are serious issues that will at some time in their lives affect every single student.

Activity One

Early in the unit, I would suggest a field trip to the children's ward at one of the local hospitals. They will see children their own age and the age of their siblings, battling serious injuries and life-threatening illnesses. This will help to "make it real" and it will also prove invaluable in writing their feelings in the journals you will be asking them to keep throughout this unit. Note: You will need to closely monitor any remarks made to or about the patients by the students. Have them save up their questions for your guide.

Activity Two

Along with other briefer activities, I am going to suggest that you break your class up into groups of five students each and provide each with a small journal. Ahead of time, make up a series of 3x5 cards. Assign each student a disease/condition/problem that you are aware of and he is not. Each day he is given a new card with a continuing serial of symptoms/problems for him to react to and record in his journal. Some suggestions might be: Condition 1)

> Card A: You have just been in an automobile accident (driving drunk after a party), broken your neck, rushed to the hospital.
> Card B: Paralyzed from the neck downwait to see if it is permanent. Doctor is too busy to answer questions.
> Card C: In ICU; specialist says maybe surgery would relieve pressure on the spine or it could

make it worse. Second opinion?
Card D: Informed consent for surgerydo you have enough information? Should you sign?
Card E: Surgery didn't workparalyzedwhat is going to happen to you? Nursing home? Do you bother with rehab? Who's going to pay for it?

Condition 2)

Card A: Symptomsfatigue, vague aches and pains, want to sleep all the time, pale and rundown.
Card B: Go to the doctorflu. Seems worse than that to youcan't get well.
Card C: To another doctorsays you need tests. Will insurance cover them? He's scaring you, but you're afraid to ask what you might have.
Card D: Doctor says you have leukemia. He explained chemotherapy, but you were too upset to understand what he was talking about. You hate needles and don't know what to do. You're too young to die.
Card E: You started chemo and threw up for three days. Nothing tastes right and you feel sick all the time.
Card F: Your hair is starting to come out in clumps. You don't want to go out of the house where anybody will see you. You want to know if you're ever going to get well, but nobody will say.

Condition 3)

Card A: You and your friends were snorting coke and the couch caught on fire. You went up like a human torch and were burned over 70% of your body. You were taken to a burn unit.
Card B: You are in constant, terrible pain. Your whole body is bandaged, including your face. You can't see, but you can feel the bandages being removed and replaced and you know there is very little area not affected. You ask questions, but you keep being put off.
Card C: You must be dipped every day into a tub of disinfectant to kill the bacteria which would otherwise kill you. It is extremely painful and you must be sedated in order to endure it. You wonderwhy bother?
Card D: You know now that you will be blind and that you will require years of treatments and

multiple surgeries to regain even partial use of your hands and feet. You will never be able to resume the active, athletic life you once had. You sink into a deep depression.

Card E: You demand that the treatments be stoppedyou just want to go home and die with your family in peace.

Condition 4)

Card A: You are African American and kidney function problems run in your family. You begin to experience symptoms of renal dysfunction.
Card B: Tests reveal that both of your kidneys are malfunctioning and you must go on a dialysis machine three times a week.
Card C: You have asked to be put on a waiting list for a kidney trans-plant, but you are told that you probably will not get one because you are black and there are very few black organs donated. Experience has shown that there is a better rate of compatibility and success if a black person receives a donated organ from another black person.
Card D: You are angry that you may very well die because you are black and can't get a transplantwhat can you do about it?

Condition 5)

Card A: Your father lives alone; he has chronic bronchitis, which is not covered by insurance. He is unable to work and can't pay his bills. Are you going to let him starve and/or cough himself to death?
Card B: You feel obligated to take your father in to live with you-your brother has moved to California and your sister has four children and no room.
Card C: Your father's condition is worsening. He's very forgetfulleaves the gas on, the front door open, wanders off in the street and gets lost. He gets angry when you try to talk to him about it.
Card D: Doctor says your father may have Alzheimer's Disease and there is very little he can do about it. The medicine is expensive and Medicare does not cover it. What are you going to do?

These are only suggestions for the cards to get you started. Use your imagination and make the unit last as long as you want. The unit itself will be taught a little each day and the students will write in their journals, based on what they have heard taught and on what they are personally experiencing through the cards. At some point, switch the groups so that all the leukemia patients are together, all the burn victims together, etc., allowing them to compare notes. Assign one group member to be the doctor. The others will ask him questions about their treatment, his attitude/attention, etc., and he will defend his busy schedule, financial pressures, need to distance himself from his patients and whatever he feels will alleviate the patients' fears and concerns. This will give everyone a chance to hear both sides. You might also invite a doctor to join the class and field questions. Conclusions from these discussions should be noted in their journals. At the end of the unit, have a general discussion on patients' rights and responsibilities and doctor/patient relationships, with each telling what he has learned and how it will affect his future health care.

The Existing Health Care System

"The millions of uninsured Americans and the spiraling cost of health care received progressively more attention through the last half of the 1980's. But what finally pushed health care reform to the top of the national agenda, many believe, was the discontent of the middle class. Middle class families with sick children were being priced out of group insurance, even plans offered by large companies; others were stuck in dead-end jobs because 'pre-existing medical conditions" prevented them from getting insurance from a new employer; and still others lost medical coverage when they were laid off during the economic recession that began in mid-1990. (1)

"Medicaid, the state and federal health care program for the poor, has never lived up to its promise to eliminate the country's two-tiered system of health care. Medicaid income restrictions are so tight that the program covers less than half the poor, defined as those Americans who fall under the federal poverty level. Most of the working poor were and still are excluded from Medicaid and are thus uninsured, although some of their children are being progressively added to the program under reforms that began in the late 1980's. Those who manage to get Medicaid have struggled to find decent doctors. Medicaid pays physicians well below the rates of commercial insurers, and doctors perceive the poor as 'difficult' patients, sometimes with reason. Poor patients' ailments are made worse by delays in getting care, and they show up at doctors' offices with more of what one physician calls 'sociomos', social problems that range from not having a ride to the doctor's office, to drug addiction, to homelessness, to the despair that accompanies miserable life circumstances. As for the physicians who do practice in poor neighborhoods, they may be there only because they are not good enough to work anywhere else. Poor families usually have no way of knowing whether local doctors are up to snuff, even when they have been disciplined by state medical regulators. (2)

"While Medicaid recipients are exceedingly vulnerable to the vagaries of state and federal budgetsbenefits are cut when times are tight or whole categories of people are eliminated from the programMedicare is an entitlement program that covers most Americans who are older than 65 and certain disabled people. Because Medicare is an entitlement, the federal government cannot cut people from the program willy-nilly. Payments to doctors and hospitals can be reduced, however, and they have been, though Medicare still pays much better than Medicaid, and its lower rates have not seriously curtailed the elderly's access to doctors and hospitals. What bedevils the poor...is Medicare's gaps. It does not pay for medication, for transportation, for many basics that may sound wholly affordable to those with generous pensions or insurance to supplement

Medicare. But such essentials strap the poor, who often end up going without. (3)

Millions of Americans find themselves in the position of needing health insurance, but not knowing which kind will best fit their needs. "New health plans offering some form of 'managed care' beckon to workers and retirees alike. These plans are frequently known as health maintenance organizations (HMO's) or preferred provider organizations (PPO's). Not only are such plans cheaper than traditional insurance, they offer reduced paperwork and assurances that they can guard members against overtreatment. The advantages sound irresistible. But the choice isn't that simple. Managed care plans save money by limiting patients' choices and by installing overseers who restrain what doctors can do. Those restrictions can lead to painful breakdowns in medical care just when patients need help the most." (3A)

"The trillion dollars that Americans spend on health care should be more than enough to provide all our people all the care they need. An equal amount would be enough to provide care for 750 million Britons, 620 million Japanese or 500 million Germans. But in the American way of health, a trillion dollars isn't sufficient to treat 260 million Americans. Instead we waste some $250 billion. We are buying billions in bureaucratic waste. America spends some $200 billion on administrative costs borne by private insurers, Medicare, and Medicaid, as well as the doctors, nurses, hospitals and nursing homestheir secretaries, assistants, and accountantswho handle the paperwork created by four billion insurance claims each year." (4)

"Hospital 'dumping' is repeated 250,000 times a year in the United States, when hospitals turn away sick and injured people or women in labor, due to lack of medical insurance or inability to pay their bill. There is no justification for emergency rooms to refuse treatment to the poor. Hospitals that wish to make money in a community have a responsibility to help care for all its sick and injured. And that community has a responsibility to help that hospital meet the expense of patients who cannot pay. The decision to treat a patient should be a medical decision based on moral and ethical principles, not on an economic decision based on profit. " (5)

Dr. David Hilfiker, who practices in Washington, D.C., states, "Private medicine is abandoning the poor....There are, of course, many complex factors that have precipitated (this). The urbanization and anonymity of the poor, the increasingly technological nature of medicine, and the bureaucratic capriciousness of public medical assistanceall these serve to make private physicians feel less responsible for the medical needs of those who cannot afford the going rate. But the cause that is most obvious to the lay public is singularly invisible to the medical community: Medicine is less and less rooted in service and more and more based in money. With many wonderful exceptions all over the country, American physicians as a whole have been turned away from the ideals of service by an idolatry of money. Physicians are too seldom servants and too often entrepreneurs. A profitable practice has become primary." (6)

"More than 23,000 Americans await a suitable cadaveric kidney, fewer than 8,000 receive transplants each year (originally published in JAMA 270, No. 11, Sept. 15, 1993). Approximately one-third of end-stage renal disease (ESRD) patients are African American, but blacks are less likely than whites to receive a transplant, with almost double the waiting time. Allocation is done by a federally-mandated system based on HLA matching. This puts potential black recipients at a disadvantage, especially with the critical shortage of transplantable kidneys. Minority populations (American Indians, African Americans and Hispanics) are at increased risk of developing ESRD relative to whites, with blacks having the highest incidence. Black ESRD patients are less likely to have a relative who can donate a kidney and also may have socio-economic reasons for being unable to travel to a transplant center in a timely fashion. There is also a shortage of black donors. Nationally, blacks make up 12% of the population, 8% of the donors, but 34% of those with ESRD." (7)

According to data from the UCLA Transplant Registry, HLA matching may not be a significant factor for black recipients, as the matching has no consistently documented benefit on graft survival. The estimated five-year average cost of a transplant (including return to dialysis in the event of graft failure) is $98,300 for a black recipient and $90,700 for a white recipient. Unfortunately, blacks have a lower rate of success, which leads to the ethically unacceptable practice of higher transplant allocation to whites." (8)

High Drug Prices

"The United States harbors the world's most sophisticated and successful pharmaceutical industry. Its discoveries have provided some of the nation's and the world's most cost-effective medical miraclesfrom vaccines for childhood diseases to hypertension, cholesterol, and ulcer pills that have eliminated the need for billions of dollars of risky medical procedures. These research investments have also produced some of the world's most expensive drugs, such as Genzyme Corporation's Ceredase for Gaucher's Disease, which can cost $300,000 a year. Genentech's Pulmozyme, a drug for cystic fibrosis victims, costs $10,000 a year. Dr. David Wolf, one of the nation's top hematologists, points out that the drug Levamisole is used to treat dogs for worm infestation. When research found it effective in treating colon cancer in humans, he prescribed it for his patients. But they had to pay one hundred times more than the veterinary price when the cost was jacked up to $1,200 a year for consumption. Most prescription pharmaceuticals cost more in the United States than in any other nation on earth." This is reported by Joseph A. Califano, former Secretarty of Health, Education and Welfare. He adds that the United States is the only industrialized country that does not control prescription drug prices. (9)

Senator David Pryor, Chairman of the Special Senate Committee on Aging, on the subject of ever-rising drug costs, "Any time Congress is critical of the enormous profit margins of the pharmaceutical industry to raise prices in excess of three times the rate of inflation, the industry argues that they need these exorbitant profits and high prices to finance research and development. However, it is clear their well-worn and recycled research and development argument is not going to sell anymore. Consider these facts: Americans are already providing hundreds of millions of dollars in tax breaks annually for the industry's R&D investment. According to a 1991 Forbes Magazine article, the drug industry is spending a BILLION DOLLARS MORE a year on marketing than it is on research; that is, the industry will spend $10 billion on marketing and advertising this year, but only $9 billion on research and development. After accounting for the investment in research and development, the pharmaceutical industry still earns an annual Fortune 500 industry-leading profit of 15.4%. This industry profit average is triple that of the average Fortune 500 club member, which is 4.6%. (10)

"The drug industry says it needs such profits to attract capital. Yet they certainly do not need a return on shareholder investments (return on equity) that industry analysts say is consistently 50% higher than the average Fortune 500 company to attract capital....In addition to the hundreds of millions of dollars in direct research and development tax breaks given to the drug industry each year, a significant amount of research on drug products occurs in federal facilities or with grants provided by federal agencies. For example, most of the research on the drug AZT, used to treat symptoms of AIDS, was conducted at the National Institute of Health (NIH), yet a private drug company holds the patent on the product and has used the patent to charge exorbitant prices for the drug. The drug companies whose R&D investments brought no new breakthrough drugs to market are the very same companies that are increasing prices at some of the highest rates....Drug manufacturers have been increasing prices, on average, at three times the rate of inflation for the last eleven

years. (11)

"One of the largest investors in R&DMerckis holding its price increases to inflation. If the world's most research-intensive drug company can adopt this responsible public policy, the others should be able to do the same. In Canada, the drug industry has voluntarily agreed to limit its price increases to the inflation rate, while substantially increasing its investment in research." (12)

If Merck and Canadian drug industries can keep prices down, why are we allowing the majority of pharmaceutical companies in this country to get away with price-gouging, especially when we know that thousands of elderly people are in a financial situation of having to choose between buying food and buying prescription drugs?? We need to make these companies accountable and likewise the congressmen that are enabling them to continue to pocket these huge profits.

We also need to investigate the health care frauds that are helping to raise medical costs across the board. "Health care provides many opportunities for kickbacks for steering business to suppliers, pharmacies or laboratories. A medical equipment supplier might pay off a hospital to get a monopoly on its business, or slip cash to a doctor in return for patient referrals; a pharmacy may pay 'incentives' for a nursing home to steer patients its way; labs may reward doctors for a stream of patient referrals." (13)

"We are buying billions in fraud and abuse. Health industry officials and government watchdogs agree that as much as $100 billion a year is lost through fraud and abuse, including padded bills, charges for tests and procedures never performed and double billing." (14)

Universal Health Insurance

"Univeral health insurance is an imperative of social justice, because no one has complete control over whether or when illness will strike"Joseph A. Califano, Jr. (15)

Dr.Steffie Woolhandler and Dr. David U. Hummelsteen, who teach at Harvard Medical School, state the case for the United States' nationalizing health care. They say that "uncontrolled increases in health care costs have caused millions of Americans to forego needed health care or to be bankrupted as a result of health emergencies. For federal and state budgets, the increases mean less money available for investment in education, infrastructure and other needs. For business, especially small business, the burden of health insurance has become increasingly difficult to bear....The abolition of billing for service would with a single stroke eliminate the need for the entire insurance industry and much of doctors' office and hospitals' administrative expenses. Distribution of funds based on health care needs, rather than market forces, would save the money now spent on marketing. Eliminating corporate profit from the sale of health care would free up money for expanded health services and research. And abandoning litigation in favor of no-fault compensation for medical errors could direct remuneration to victims rather than attorneys and insurance companies....The extent of waste in our current health care system is much greater than most people realize. Conservatively, we estimate that 30% of health spending ($226 billion in 1991) is wasted on administration, profits, high physician incomes, marketing and defensive medicine, none of which goes to improve health care. Everyone now acknowledges that health care costs are higher in the United States than in other industrialized nations. One of every seven dollars spent in the United Statesfourteen percent of our gross

national productgoes to the health care industry. This compares to six percent in Britain and eight percent in Canada. And both of these countries promote free care to all. Nationalization of the health care system would save both lives and money....Nearly every poll in the past thirty years has shown that a majority of Americans support a universal, comprehensive, publicly-administered health service of the kind that exists in Canada and western Europe." (16)

So, why don't we have it? Because it would eliminate health insurance companies, half the staff in doctors' and hospitals' offices (administrative costs consume over 15% of our health care costs), huge promotion budgets of pharmaceutical firms, lucrative services now done only in hospitals (such as renal dialysis which could be provided at home), and it would reduce physicians' incomes. Overall, this would save the public a tremendous amount of money, but the ones who are accustomed to living high on huge profits, strongly oppose a system that would give free health care to all.

Those who argue against universal health care claim that it results in large caseloads for doctors, less exam time, long waits to see a doctor, more people seeking free treatment for minor ailments, less money for tests, procedures and instruments, deteriorating facilities and long waiting lists for surgery. There is concern that cutbacks would affect the elderly and seriously ill.

According to Elaine Bernard, Past President of the New Democratic Party of British Columbia, Canada, and currently Director of the Trade Union Program at Harvard, Canada, after 40 years of universal health care, has waiting lists for surgery, but not for immediate or life-threatening needs. Canada has fewer high technology facilities, but the United States probably has more than it needs. Canada has a higher life expectancy and lower death rates from heart disease and infant mortality. (17)

"Primary and emergency care, universally insured, are readily available. No financial or administrative barriers prevent patients from seeking the services of any family doctor. Canadians visit physicians more often than Americans do and are highly satisfied with the service and the system. With a single insurer, the provincial government, there is far less paperwork for patients and doctors. More important is the widespread sense of security that comes from knowing that illness, however catastrophic, never results in financial disaster." (as quoted from Theodore R. Marmor and John Godfrey, *The New York Times* , July 23, 1991) (18)

"We need to return hospitals, medical supply companies, and pharmaceutical firms to the status of servants supported by the community or, in poor communities, by the state. Once deep interdependence exists between community and hospital, the community can create humane ways to care for needy members of society. If all healing systems were shifted to the service sector, competition among health care providers could disappear and everybody could work together to bring the best possible care at the lowest price." (19)

Since 1974, in Hawaii virtually all employers are required to provide health insurance for their employees. Small businesses form a large risk pool and get reduced insurance rates. The state provides health insurance for the poor, elderly and disabled. So far it is working well and could be used as a model for other states as an alternative to universal health care. (20)

Oregon had proposed a rationed care health plan, which listed 709 medical procedures and ranked them on the basis of their costs and benefits. If the treatment was too costly in that it was not likely to sufficiently to improve the patient's condition or was deemed of insufficient value to society, then it will not be paid for. It was to bring 120,000 poor people into Medicaid, but it also cut off other poor people who had received services before. (21)

"Oregon's cost-effectiveness list failed miserably. It had almost no published cost-effectiveness analyses to help it make its ranking....The rejection of the list as a priority-setting tool resulted from a wide array of moral controversies which Oregonians had not adequately sorted out." A highly publicized refusal of a bone marrow transplant for a seven-year-old leukemia patient embarrassed the Oregon legislature into dropping the plan. They had also been "accused of violating the Americans With Disabilities Act." (22)

"Patients and clinicians, especially physicians, form a moral relationship that goes beyond that of most professionals and clients. Patients often come to physicians in stressful, compromising situations. They usually rely on physicians to give them advice and counseling regarding their options, and to help them understand their clinical situation. They often feel vulnerable because of their illness (Pellegrino 1979). Sometimes they must reveal intimate secrets so that physicians can diagnose and treat them....With such knowledge and power come moral duties....Physicians are given special power by society: to prescribe medicines and to cut open people's bodies (with their permission, of course). With this knowledge and power comes a duty to advocate for patients' interests. Any decision to stray from absolute patient advocacy must be done with great caution and with significant moral justification....Because physicians have more knowledge than patients about clinical issues, patients have learned to trust physicians to recommend what is best for them, or to describe the risks and benefits of treatment alternatives in ways that will help them decide what is best for themselves. If physicians ration care costs, patients will no longer know how to interpret their recommendations: did the physician recommend conservative treatment to help me, or to save money?" (23)

Former U.S. Surgeon General, Dr. Everett Koop, stated, "I would rather ration greed than ration health care." (24)

Activity 3

Divide the class into two groups for a debate. The topic: "The United States should adopt a universal health plan." The students can draw upon their newly-acquired knowledge of both universal health coverage and rationed care to debate and rebut.

Doctor/Patient Relationship

Do you have the right to expect your doctor to treat you as a individual human being, rather than as a statistic, a set of symptoms or as a monetary gain? I myself have often been made to feel as though I were on an assembly line conveyor belt with the doctor checking his watch ready to push a button to move me to the next station for bloodwork or an X-ray. We all need to feel that what we have to say is important and worth listening to and that we ourselves are important. Illness is frightening because it opens up all sorts of possibilities for an uncertain future. Our fears need to be addressed and alleviated, rather than exacerbated by unanswered questions and the indifference of an over-scheduled physician.

"Something is happening to American health care. It's been happening for some time now. Right before our eyes. As national attention is focused on containing spiraling health care costs, the hidden price of that containment eats away at the very heart of our medical delivery system. The price of containment may be the doctor/patient relationship, unless the danger of its erosion is recognized and certain misguided attempts at reform are redirected. In more than fifty years of medical practice, I have been dismayed at the recent

escalating tragic conflict between medical and financial priorities." (25)

Dr Jeffrey M. Thurston goes on to state, "As President and Chairman of the Department of Surgery at Baylor College of Medicine for many years, I have supervised the training of thousands of physicians. The disparate goals of physicians who were trained to put the patients' welfare first and those of the profit-driven, insurance-owned medical corporations are rapidly disillusioning physicians and patients alike. Increasingly, the sanctity of life is being subordinated to Mammon, and medical decisions are being dictated by those unqualified to do so. The patients' choices are being wrested, and the physicians' authority is being expropriatedto the detriment of all....So-called managed care, as it is already evolving even without government intervention, is severely altering the doctor/patient relationship, transforming what can be a very special personal interaction into a business transaction. It is usurping the doctor's decision-making power, forcing diagnostic and treatment decisions to be made by a third party whose central concern is cost. Costnot the patient's welfare." (26)

"Many of us entered medicine out of deep altruism," says Dr. David Hilfiker, "wanting to be of service, only to discover that the daily crush of dozens of sick and needy souls left us exhausted. Under such circumstances, we found ways to detach ourselves from the emotional turmoil of the sick. We may have become physicians desiring to enter deeply into our patients' lives, but we soon discovered that the long line of patients waiting to be seen encouraged us to be more efficient and cost-effective. We discovered that the economic pressure to see 30 or more patients a day did not allow for the kinds of relationships we had envisioned." (27)

Physicians can charge more money for procedures, such as suturing a wound or ordering bloodwork, than they can for just talking or listening to a patient; the interaction is cut short so that the doctor can move on to a more profitable patient. The first patient feels shortchanged and may not even have had a chance to inform the doctor of pertinent issues that could affect his future health. His experience could very well discourage him from seeking medical assistance when next needed. (28)

"The blight of burnout is so pervasive in the health care system that everyone expects it to happen," says Dr. Adam Patch. "Most health care professionals I have met tell me that burnout damages their personal as well as their professional lives....The first cause is poor communication. The joys of relationships are lost if a physician can spend only short periods of time with patients; gone is the thrill of intimacy. If physicians could really delve into their patients' lives and take time to understand the whole person, all-important lifestyle issues could be addressed. Medications are often substitutes for what the patient really needs. Longer visits make physicians' and patients' lives more real, because shared time is a key ingredient in friendship. Without this kind of friendship, 'bedside manner' can feel impersonal and superficial. An imbalance between work and personal time can also foster burnout....A third cause is that medicine operates as a business, thereby inviting all the stresses of a business....Any health care professional who entered medicine to serve humanity is pained every day by its business aspects. Health care is denied to the poor and limited to many others....Healers wear down as their dreams of serving humankind become compromised....Anxiety about malpractice suits also breeds blame and inhibits intuition, creativity and scientific investigation. (29)

"The greatest shock I experienced in medical school came during discussions with teachers about the doctor/patient relationship. The overwhelming majority emphasized the importance of professional distance. This meant maintaining a scientific detachment and dealing with patients as if they were experiments in a laboratory. The 'distance ethic' was extended to the wards where doctors described patients as diseases, lab values, signs, symptoms, or treatments. I was amazed that a group of doctors 'on rounds' could hover around the bed of a human being, staring at, poking, or even undressing him or her with little more consideration

than was given to dogs in the physiology lab....None of these conditions improved during my internship; in fact, they grew worse. Under intense time pressures, the human component was confined to simple answers for extremely complex questions....as I discovered this cancer in my profession, I started to wonder what it was doing to the patients. So I asked them. I heard anger, fear and despair flow out in a torrent of frustration. Rarely did I see their eyes sparkle for their doctors. If they did light up, it was more often for the professional's reputation than for his or her compassion....After more than twenty years of searching for one, I still have not found a happy hospital setting. (30)

"Medicine, you are blowing it! Bedside manner has nothing to do with information about the patient! Bedside manner is the unabashed projection of love, humor, empathy, tenderness and compassion for the patient. Scientific brilliance is an important tool, but it is not the magic inherent in healing....Doctors should never buy into the lie of professional distance....Every human being has some kind of impact on another....Don't we want that in the doctor/patient relationship?" (31)

Senior Concerns

"By simple virtue of their age, seniors are more likely than others to become sick in the first place, to be confronted with issues of care in general, and life-sustaining care in particular....By the time that seniors come under a doctor's care or enter the hospital, they are far more likely to be significantly debilitated. Often, they have suffered for years from chronic conditions like arthritis, diabetes, and heart or kidney problems, which have taken a significant toll. They are also more likely to manifest what are termed 'toxic metabolic reactions' to illness. For when older people get sick, they look, feel and act very sick, very quickly....The fact that seniors get so severely ill so quickly means that they often cannot effectively advocate for their own careas one must in a hospital. Their voices are weakerliterally and figurativelyso that they may not be readily heard or heeded in the din of the modern medical center. This in turn subtly skews how doctors and nurses treat them...Consciously or unconsciously, doctors, especially those in training, may put older patients lower on the list for attention and treat them less aggressively. A senior patient may be disdained, explicitly or implicitly, despite the admonitions of senior physicians, as a 'GOMER'Get Out of My Emergency Room'that class of difficult, unpleasant, unrewarding, or hopeless patients. GOMER's are the first to be shunted aside, medical pariahs in the whirl of a busy hospital." Montefiore Medical Center Staff Bioethicist Nancy Dubler learned that her own mother was admitted to the hospital labeled as a "LOLFOF"a Little Old LadyFound On Floor. (32)

"The rampant ageism of our larger culture becomes a particular danger in medicine. Care providers may write off the older patient as disabled, confused, or 'senile'; they may believe that chronological age necessarily determines a person's ability to function. In fact, these are useless, unsupported generalizations, medical myths. In reality, a given senior's individual abilities and the rate of psychological and physical aging are unique, and they can vary widely from person to person. Ethically and medically, we are required to assess each individual's function fully as the foundation of her personal care plan. And, for the elderly, even more so than for younger persons, an assessment must include knowledge of the person's level of function before the event or illness that brought the person to the hospital....Some caregivers may simply not be willing to put in the time and effort required for communicating with the elderly. For the older patient, the modern medical center can be a frustrating and dangerous place. No wonder so many older patients slip through the cracks. (33)

"All of these elements combine to remove decisions from the hands of seniors. Families and doctors start talking around them and deciding without them. Older people, if they are not strong, determined and forceful, get bypassed in decision-making all the time. It is standard procedure for doctors to turn to loving and involved relatives to make decisions for the older person, even when that person is perfectly capable of deciding for herself. (34)

"No matter who practices it, whether family or physician, excluding the elderly patient from discussions and decisions is both very common and ethically unacceptable. The golden rule calls for us to do to the one in the bed as we would want done to us were we in that position. That means our first impulse must always be to include, not exclude, the patient in decision-making as long as possible." (35)

The key word here is respect. The day will come, sooner or later, when we are the ones in that bed and we will have earned the right to have our dignity preserved and our opinion respected. "Being old, after all, is no reason to be deprived of the ability to control your life." (36)

Teen Concerns

"Teenagers....raise serious questions for those responsible for their physical or educational well-being, and those who care for them....The central ethical question we face with teenagers is'Who decides?'....Adolescents, with one foot still in the land of children they were, the other in the realm of the adults they will become, inhabit a challenging niche in our culture. Are these beings great big children or little adults? In fact, they are both and neitherand therein lies the confusion....Nobodynot adults, not the courts, and certainly not the teenagers themselvescan agree on just what capabilities they do, or should, have. (37)

"In general, society is torn between permitting teenagers to decide and permitting the parent to decide even over the objection of the adolescent. We let teens go to war and vote for president, yet in most states they cannot drink alcohol. In California, prosecutors have attempted to hold parents responsible for the gang behavior of their children. In New York, on the other hand, adolescents who commit horribly depraved and shocking crimes are now tried in adult criminal court where they cannot hide behind the curtain of protection of the juvenile justice system. The same confusion runs through our health laws. In Alabama, a 14-year-old can choose her own medical care; in Oregon, she must wait until age 15; in most other states she must be 18, and in Nebraska and Wyoming, she is not legally able to do so until she's 19. (38)

"Our legal system struggles to keep pace with the massive social changes our culture has undergone. Never before have so many adolescents made their own decisions, lived apart from their parents and families. Tens of millions more are independently engaging in 'adult behaviors', earning money, having sex, conceiving and bearing children, using and abusing drugs and alcohol....Such decisions carry medical implications. They raise complex questions for doctors, nurses, and social workers, questions that arise every day in our clinics, doctors'offices, hospitals and courts." (39)

"The specter of HIV-related disease has made things more complex around adolescents and sex. Where once these decisions involved only the teenager and the family, in the age of AIDS, they involve our whole society. Personal health now blurs into public health, which raises the stakes enormously....Often, adolescents' newfound right to make sexual and health decisions outstrips their willingness to take responsibility for those

decisions. Where once that meant 'shotgun weddings', today it can mean death. (40)

"Many adolescent medical doctors will likely tell parents and the teenager that what happens between the child and the physician is confidential unless the child is in direct physical or psychological danger of harmin which case the protections for privacy will be breached and the parents involved....It also makes pure medical sense to try to include young people to the degree that they can participate....this is particularly true for older chronically ill children and teenagers. These young patients are often remarkably wise and perceptive. They alone know the pain and suffering that disease has brought into their lives, and this knowledge can powerfully inform their decisions...America has come a long way from the days when a child was considered a parent's property, to be dealt with, decided for, and disposed of at the parents' whim. Collectively, we still wrestle with the roles of parent and child, struggling to assure our newborns, children, and our youngest adults of the rights they deserve, while affording them the protections they require." (41)

Women's Concerns

"The problems women experience in the health care system reflect the problems of the system in general. Women, however, are impacted on a scale that is disproportionate to their numbers. Whether you are talking about unnecessary surgery, inappropriate treatment or testing, lack of preventive care, lack of consideration in research, allocation of dollars, or simply being milked for dollars by physicians, women are mistreated on a major scale," states Dr. John M. Smith, Gynecologist. "They experience these abuses far more frequently than their male counterparts, regardless of economic or work status or any other factor. Gender alone is the determinant.... (42)

"One of the conclusions of the AMA report of the Council on Ethical and Judicial Affairs was that: 'Gender bias may not necessarily manifest itself as overt discrimination based on sex. Rather, social attitudes, including stereotypes, prejudices and other evaluations based on gender roles may play themselves out in a variety of subtle ways. For instance, there is evidence that physicians are more likely to perceive women's maladies than men's as the result of emotionality. Also, many researchers have noted the greater utilization of health care services by women than men and have attributed this difference to 'overanxiousness' or overutilization on the part of women without supporting evidence.' In other words, the prejudice is there, and it is real and it means that women are treated differently by male physicians." (43)

Know Your Rights

"Most people are not aware of their medical rights. And what you don't know can hurt you....Doctors must provide you with complete information about your condition, including diagnosis and prognosis. If the doctor fails to do soand especially if that failure results in additional medical, financial or personal problemsyou have the right to sue him for malpractice. (44)

"Most people assume that once they are hospitalized, they can only leave the hospital when given permission to do so...The hospital isn't a prison and the doctor isn't your jailer. In fact, if they try to keep you there

against your will, you have the right to sue them for false imprisonment. If a hospital administrator tells you that you can't leave until you've paid your bill, don't believe him. You can leave any time you want. Here's another assumption related to hospitals: you have to submit to examination by all medical personnelinterns, residents, medical studentswho come into your room. You can refuse to be a training device for future doctors. In fact, you can say no to any order, whether you're in the hospital or in the doctor's office. Remember, it's your body; you have not donated it to science. Unless you give your permission, no one can do anything to you." (45)

"Informed consent is a two-step process, in which the physician is supposed to provide information about a medical condition and the treatment he proposes, and the informed patient is supposed to give (or withhold) consent. Ideally, the consent form serves as a reminder or summary of information already understood by the patient....However, many doctors are too busy to take the time to fully explain, so they give patients reading material on the subject. Many patients lack the education and/or are under such stress from the situation, that they are unable to understand either what is said or what is given to them to read. In a medical situation requiring consent, the patient should have a basic understanding of the following points:

The diagnosis or nature of the medical problem.
The purpose of the proposed procedure or treatment.
The significant risks involved in the procedure and the likely consequences and side effects.
The expected benefits of the procedure and the likelihood of success.
The nature of the procedure, including its length, discomforts, preparations required on the part of the patient and the expected recovery period.
Reasonable alternative methods of managing the problem, including no treatment and and the pros and cons of each." (46)

Do not hesitate to get a second opinion if you have been told you need major surgery or any treatment or test that could be risky, or if you have been told you have a potentially fatal disease/condition.

"If you are considering consulting a new health care professional, check that person out before you visit his office....If you have been harmed or suspect quackery or health fraud, write to the National Council Against Health Fraud, Victim Redress Committee, 3251 Broadway, Kansas City, MO 64111." (47)

ASK QUESTIONS! If you know ahead of time that there will be tests/treatments discussed, make a list of questions and take it with you, along with a list of symptoms and problems, so you won't forget what you want to say. If you don't know ahead of time, try to stay calm and keep your brain in gear. Don't just accept what is being said to you; ask if the tests are really necessary and if there are any risks. Ask how the test is being done and how you need to prepare for it. Make sure you know if your insurance covers the testsome tests cost hundreds of dollars. If you are given a prescription, ask what the side effects areall drugs have side effects. Be sure you understand the dosage and what the medicine is for. Ask what will happen to you if you don't take it.

There are alternative forms of medical treatment available to you also. "Most of the public debate over health care reform and financing relates to the established medical system....yet a huge number of Americans are turning away from conventional medical care to try other approaches. Many of these alternative pathways have roots that antedate modern establishment medicine by centuries. Entire civilizations in the East, in Africa, and in America use and have faith in forms of treatment that are effective in ways that American medicine ignores, to its own detriment. Thousands of practitioners study and believe in a variety of approaches and they have millions of satisfied patients." (48)

These alternative approaches include diet, vitamin therapy, herbal therapy, aromatherapy, acupressure, acupuncture, chiropractic, homeopathy, reflexology, massage therapy, hydrotherapy, yoga, meditation and naturopathy. Some of these treatments are covered by insurance, but, more often they are not, which makes it financially prohibitive for many patients to utilize anything other than standard medical treatments.

Personal Responsibility

"Medical decisions always rest on somebody's value judgment. If you are aware and educated, the values will be yours; if not, they will be the values of othersgood people, but strangers. Whether you will be hospitalized or medicated; should an operation be performed and, if so, which one; will your mother be given CPR; can a bed be found for your child, experimental drugs for your lover, or a transplant for your uncle: these judgments are based as much on values as on medical knowledge and skill. But whose? The impersonal policies of institutionshospitals, insurers, courts; the flesh-and-blood individual values shared among you and your family; the personal values of your doctors and nurses? Who, ultimately, will prevailyou or somebody else? (49)

"Technology, legality and cost containment. Together they have forever changed the ground rules for how you are treated when you are sick. Together, they have made doctors' offices, hospitals and clinics vastly different places from the comfortable world of solace and succor most of us envision. Amid all this complexity, in most places, it is still true that if you don't stand up for your own values and rights, nobody else will." (50)

"The single best hope for health promotion, disease prevention and extending the years of independent, healthy living lies in ourselves and our behavior. As a culture and as a community, we need to make tobacco, alcohol and illegal drugs as difficult to obtain as possible, especially for children. Those who are addicted to them and abuse them fill our emergency rooms and hospital beds. They spawn mental and physical illness not only among themselves, but among others, ranging from family and friends to victims of their crimes and reckless conduct. Violence, poverty, environmental conditions such as lead poisoning and air pollution, and unsafe sex crank up the speed of health care spending....With our vastly increased knowledge of what constitutes healthy diet, laws relating to military rations and school lunch and breakfast programs should require that meals be low in fat and high in fiber and protein....We must deliver the message that healthy habits such as a sound diet and regular exercise can offer years of additional independence and vibrant living. For each of us, young or old, black or white, poor or rich, the message should be to take personal responsibility....for our own health and future." (51)

Activity 4

Check your library for videos available on teen health issues, such as smoking, drinking, STD's, AIDS, nutrition, etc. Also see the list of suggested videos at the end of the unit. If you plan on showing several, they could be scattered out through the unit as relevant. The purpose is to emphasize the responsibility each person has for his own health.

In Conclusion

All rights are inevitably attached to responsibilities. Our rights as patients depend at least in part upon our responsibilities as patients. The rights of patients have been outlined in this unit, but there is no guarantee that we will be freely handed these rights unless we are alert to any possible violation of them and are ready to stand up and defend them. We need to let our legislators know how we feel about health care reform and be watchdogs against greed and fraud in the industry that escalate costs. On a personal level we need to regulate our own lives with self-control, self-discipline and common sense, in order to avoid many of the reasons that bring patients to doctors and hospitals in the first place.

"Despite the superb achievements of medicine, our best hope for a healthy life is not medical care, but self care. Current medical evidence, which implicates violations in lifestyle, environment and diet as the driving forces in chronic disease, shows that many of us are not conducting our lives in a healthy way....This abdication of responsibility undermines the development of healthy attitudes and healthy behavior. Kidding ourselves that we are forever young, or that the doctors will take care of us if something goes wrong, keeps us from doing what we can, learning how to take care of ourselves. It jeopardizes our healtha little more each day." (52)

Reinhard Priester, "Focus on Values in Health Reform", *Minneapolis Star-Tribune* , March 3, 1992: "A new values framework, reflecting a new blend of ethical priorities, is needed to serve as the moral foundation of our health care system and to guide reform. Community-oriented values should be added to help us break out of the 'narcissistic individualism' that, in the words of one bioethicist, 'makes us forgetful of our interdependence and social connectedness.' We need a value of social advocacy which calls on health care providers to take seriously their obligation to advocate for the needs of underserved people and of society as a whole. We need a value of personal financial responsibility and a value of social solidarity to engender a sense of community." (53)

"Skepticism is the highest of duties, blind faith the one unpardonable sin." Thomas Henry Huxley (54)

Videos

"DUI - Dead in Five Seconds". Turner & Assoc. Dist. By Goldhil Video, Thousand Oaks, CA 91360 www.goldhil.com

"Drugs: This Is the Way It Is". The Robert James Corp. 1990.

"Right Decisions Right NowDon't Be Clueless About Teenage Smoking". APC Productions. 1998.

"You Don't Have To Drink To Suffer From AlcoholismAl-AnonIs It For You?" Al-Anon Family Groups

"The National Nutrition Quiz". Produced by KERA-TV. 1985. Distributed by PBS Video.

The Schlessinger Teen Health Video Series. 1994. Produced by InVision Communications, Bala Cynwyd, Pa.

AIDS	Nutrition and Diet	Teen Pregnancy
Birth Control	Peer Pressure	Teen Sexuality
Eating Disorders	STD's	

notes

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(20) McCuen, Page 109, 110.

(21) Bender, *Health Care* , 192.

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(23) Ubel, 101, 102.

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(29) Adams, 31.

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(33) Dubler, 203.

(34) Dubler, 206.

(35) Dubler, 214.

(36) Dubler, 215.

(37) Dubler, 285.

(38) Dubler, 288.

(39) Dubler, 288.

(40) Dubler, 293

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Internet

Search for topics such as Patient Rights, Bioethics, Health Care Rationing, Doctor-Patient Relationship, Organ Transplants, Medical Rights, Managed Health Care, Women's Health Concerns, Teenage Health Problems, etc.

A few sites to get you started:

http://www.cal.nurse.org/cna/new2/sjm9999.html

http://www.grohol.com/ptright.htm

http://www.cp.duluth.mn./~ennyman/DAS-1.html

http://www.yourhealth.com/ahl/1201.html

http://encarta.msn.com/find/print.asp?&pg=8&ti=761575709&sc=0&pt=1

http://www.religioustolerance.org/euthanas.htm

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