Pharm 543 Laws & Ethics, Autumn 2006 -- Ethics Cases: Autonomy

Of the four principles of bioethics (autonomy, beneficence, nonmaleficence, and justice), autonomy is of primary importance in the United States.

Autonomy -- inherent individual value and right to self determination

One way to analyze autonomous action is in terms of "normal choosers" who act:

1. intentionally
2. with understanding
3. without controlling influences that determine their action

Respect for Autonomy – in order for a person to be considered an autonomous agent, at minimum, the person's right to hold views, to make choices, and to take actions based on personal beliefs and values must be acknowledged.

Consider the case with regard to each of the following ethical principles and theories:

1. Nonmaleficence -- do no harm
2. Beneficence -- promote good, and to remove or prevent harm
3. Autonomy -- self determination, individual control
4. Justice -- fairness and equality, including access and rationing
5. Virtue -- focus on virtue in the conduct of your profession, including compassion, discernment, trustworthiness, and integrity

Please read all of the cases before class.

Two project groups will be selected at random each week to present a case. During discussion, each of following presentation responsibilities should be assumed by a group member:

1. Perspective – patient, care-giver, family member, health care provider, etc.
2. Nonmaleficence
3. Beneficence
4. Autonomy
5. Justice
6. Virtue
7. Root cause

Focus on autonomy.

Case 1

Susan was found at a local HIV center, complaining of shortness of breath for most of the day. The staff called 911 after noticing her "bluish" skin color and distressed breathing. The paramedics put her on an oxygen mask and took her to the emergency room of a nearby hospital, where she reported feeling much better. But when the mask was removed, her oxygen saturation fell from 94 percent to 50 percent within five minutes. Oxygen was reintroduced and her status quickly improved. Tests revealed a profuse, bilateral pneumonia, more than likely a *Pneumocystis carini*, common in HIV-infected patients. Her white blood cell count was elevated, supporting the diagnosis of a respiratory infection. Hospital admission was strongly advised to treat the underlying infection with intravenous antibiotics and for respiratory support until she could breathe independently.

Susan had contracted HIV through illicit drug use or the promiscuous sexual behavior that financed her addiction, but had been in a rehabilitation program and claimed she had not used drugs for several months. She had arrived t the emergency room hostile and defensive because of the paramedics' many failed attempts to initiate an IV. As many addicts do, she directed the emergency room staff to the best site for venous access and insisted that Monique, the primary nurse, had only one opportunity to establish an IV. Monique succeeded and Susan seemed to calm down. Having won her patient's trust, Monique was then able to talk with Susan about her life experiences and perspective about her current situation. Susan told a common story about failed marriages, estrangement from family, and unfulfilled dreams, all leading to self destructive behavior. However, she seemed to express some hope about getting her life in order, despite her diagnosis. And she was anticipating a visit from her teenage son the following day, whom she had not seen in two years.

As their conversation ended, Susan asked if she could smoke a cigarette. Monique deferred to the physician's judgment, but the physician refused -- would pose an immediate health risk. Upset, Susan threatened to leave. Monique managed to calm her down, gently telling her just how fragile her condition was. Susan changed her mind and decided to say; however, when the emergency room physician, intern, and attending physician returned to discuss admitting her to the hospital, Susan again asked to smoke. They refused, and she refused to be admitted. The physicians bluntly discussed the likelihood that she would die if she did not stay. Monique too tried to persuade Susan to stay. But Susan demanded to be discharged.

After removing her oxygen mask and discontinuing the IV, Monique helped Susan dress because she was too short of breath to do it herself. Monique wished her well, but said she was disappointed with her decision.

Twenty minutes later the paramedic unit responded to an emergency call. Susan was brought in with respiratory and cardiac arrest; she was pronounced dead within minutes.

Adapted from *Hastings Center Report* 1997;27(6);23-4.

Case 2

Mr. S is a seventy-four-year-old resident of a skilled nursing facility who is visited regularly by his wife of five years. Mr. S has a cardiac condition that required one bypass operation eighteen years ago and a second with placement of a pacemaker five years ago. Mr. S also has had progressive dementia (Alzheimer type) for eleven years and he no longer recognizes his wife, two sons, or the staff. He expresses no willful desires, including desires to use the bathroom or his formerly distinctive preferences and revulsions to particular foods. He is incontinent and diapered, and confined to bed other than at mealtime, when he is fed in the dining room. Mr. S does not resist being moved, though a staph infection in his foot makes movement quite painful. He never initiates any activity and does not communicate at all. There is a DNR[1] order, and instructions prohibiting placement of a feeding tube, both signed by Mrs. S.

Mrs. S is a devoted spouse who cared for her husband at home for several years until he became verbally and physically abusive, then moved him to a nursing home and later to a group home living environment. The foot infection precipitated transfer back to the skilled nursing facility for antibiotic therapy. Mrs. S is quite saddened by these developments, and is convinced that her husband would not desire to continue to live in this condition and would want his physician to discontinue his medications and pacemaker. She has mentioned this belief many times to the staff on her alternate daily visits, adding that she also had discussed Mr. S's medical situation with her

[1]DNR – do not resuscitate

daughter-in-law who is a nurse, and received her strong support. Both of Mr. S's adult sons recall a remark their father made some years earlier when he could not name the woodworking tools he was using and, very frustrated, told them, "Boys, if this gets worse I'm going to take myself out."

Mrs. S has discussed her husband's probable desires with Dr. N, a close personal friend who, until he retired, was their longtime family physician. Though he admits never discussing advance directives with his patient, Dr. N concurred that Mr. S would not want to be medically supported under the current circumstances.

Mr. S's internist has agreed to withhold the cardiac medications, but is unwilling to discontinue the pacemaker without the cardiologist's concurrence. The cardiologist refused to discuss turning off Mr. S's pacemaker, ordering Mrs. S to “get out of my office” when she sought his help. Mrs. S's daughter-in-law then approached the pacemaker manufacturer and was told that discontinuation of an implanted pacemaker is “not an uncommon request, and a service we will provide if we have a physician's order to do so.” Dr. N is willing to assume Mr. S's care if that is the only way to get the order to discontinue the pacemaker, however, he is very reluctant to do so.

Adapted from *Hastings Center Report* 1997;27(1):24.

Case 3

Mrs. R, an eighty-one-year-old woman with a five-year history of dementia, was admitted to the nursing home after being hospitalized for a stroke. On admission, Mrs. R was responsive at times but unable to communicate in any meaningful fashion. She was incontinent and needed maximal assistance with activities of daily living, but was somewhat resistant to care. Although she was ambulatory when she first entered the home, she was unable to participate in a formal rehabilitation program. Two months later she developed pneumonia and, after an extended period of bed rest, was unable to walk.

Within six months Mrs. R again developed pneumonia, along with congestive heart failure, and was treated with antibiotics. Because she had stopped eating, a nasogastric tube was considered. Her husband, a member of the home’s geriatric outreach program, wrote a letter with the assistance of his social worker. In the letter, which was forwarded to the ethics consult team, Mr. R asked that his wife not have a feeding tube inserted, stating that he knew she would not want to be fed in this manner. The primary care team responsible for Mrs. R's care was informed of Mr. R's request soon after his letter was received. Though the staff had somewhat mixed feelings at the time, they felt professionally obligate to honor the request. Their greatest concern centered on whether Mr. R could speak for his wife since there were no advance directives in place. Another concern was the issue of not providing food. However, at this time the question of the – feeding tube was secondary, since Mrs. R was able to be fed with a syringe and was taking sufficient amounts of a nutritional supplement.

Since there were no advance directives in place, and there was doubt about how closely Mr. R's statement actually reflected his wife's wishes, corroborating statements were obtained from Mrs. R's brother and two of her friends. The ethics consult team felt these statements were sufficient to substantiate Mrs. R's wishes, and that a feeding tube should not be inserted when Mrs. R became unable to take nourishment by spoon or syringe feeding. This was communicated to the members of the primary care team, who did not voice objections at this time. About six weeks after Mr. R's initial request, Mrs. R stopped eating, and no feeding tube was inserted. After Mrs. R had taken nothing by mouth for five days, it became apparent that several members of the primary care team were uncomfortable with this decision, and the ethics consult team was called in.

Members of the three disciplines with the greatest involvement in the case – nursing, social work, and medicine – all expressed concerns regarding the decision to withhold treatment. Nursing staff

seemed to have a particularly difficult time with the idea that they were just "letting Mrs. R go." Many felt that by allowing a resident to die they were not doing their jobs. At the same time, Mr. R's visits and calls to inquire about his wife's condition decreased in frequency. The nursing staff perceived this not only as an abandonment of Mrs. R, but also of them.

Of the two social workers intimately involved in this case the first, Mr. R's social worker, focused on his well-being. She was particularly concerned about his failing health and the deleterious effect his wife's condition was having on him. The other social worker was assigned to Mrs. R's primary care team. When Mrs. R stopped eating and no feeding tub was inserted, this worker worried about the impact this was having on the primary care team, especially the nursing and medical staff. She expressed the opinion that the staff had become family to Mrs. R, and watching her die was very difficult or them. Of particular concern was the staff perception that a decision had been made by administrative staff, and that the unit team was not given enough time or opportunity to participate in review and discussion before the consult team had reached its own conclusions.

Mrs. R's primary care physician was involved in the process from the beginning, meeting with the consult team and Mr. R after his initial request not to insert a feeding tube, and also participating in the first unit team meeting. From the outset, he expressed a very strong opinion that Mr. R wanted to "starve his wife to death," and was clearly very uncomfortable with the request. He seemed to feel that Mr. R was not speaking for his wife, but rather for himself. The psychiatrist on the team was distressed that he had not been included in the earlier stages of decision making (he had been absent from the first unit team meeting). In addition, he had a long-standing relationship with Mr. R as his psychiatrist in the geriatric outreach program. He felt that Mr. R's lengthy history of depression precluded his ability accurately to articulate his wife's wishes. In addition, this physician also expressed doubts concerning the validity of the corroborating documents.

Adapted from *Hastings Center Report* 1992;22(6):26.

Case 4

Mrs. B is an eighty-six-year-old widow who lives in a California retirement home. She is a gentle, sociable lady and likes to reminisce about her work doing make-up for movie stars. She has no family locally but does have one good friend nearby and a 101-year-old sister on the East Coast. She is in the hospital for treatment of an infection, from which she is recovering. She also has chronic kidney failure, however, and has been on dialysis for about eighteen months.

For at least the past eight months, Mrs. B has told her doctors, her nurses, and her friend that she wants to stop the dialysis. She understands that her life depends on receiving it, but she hates the process and does not want to live this way. Yet she continues to board the van that takes her to the dialysis center three times each week. She claims that every time she tells her doctor she wants to stop, he describes the risks of falls, fractures, and a miserable end.

Even with the dialysis, Mrs. B has been hospitalized three times after falls or for pneumonia. In fact, the current hospitalization occurred after a fall in the dialysis center. Each time she is ill, her statements about discontinuing are stronger, although when her nephrologist comes by on his rounds, she is quiet and appears to accede to treatment. With others, however, her cries to stop the treatment are ever more persistent, emphatic, and emotional. She complains that this is not what she wants, that her doctor frightens her and makes her feel guilty, and that some of the nurses encourage her to hold onto and to try to enjoy her life. She says that her wishes are clear and her instructions ignored, but she also admits that she is confused about whether it is truly right to exercise her will to discontinue the treatments.

A consulting psychiatrist concludes that she is oriented, competent, and severely depressed, as evidenced by her wish to discontinue treatment. He prescribes Prozac.

Adapted from *Hastings Center Report* 2000;30(6):24.

Case 5

An 800--gram male infant, 28 weeks gestation, was born to a 31--year--old G_6P_{3114} [2] mother by caesarean delivery because of breech presentation. The rupture of membranes occurred 22 hours prior to delivery. The APGARS[3] were 1, 2, and 8 at 1, 5, and 10 minutes respectively. The maternal history was significant for active and continuous drug abuse (opiates, cocaine, alcohol, and tobacco) for a period of twelve years. She had no prenatal care. In fact, she lived on the street, but had recently been taken in “for the last time and only temporarily” by her sister and her sister's family. Her parents had long ago disowned her. She had two children from a first marriage. They both now live with their father. She has no contact with them. A third child was taken from her by the Department of Child and Family Services and put into foster care. This is her fourth pregnancy.

The infant was born with minimal heart rate requiring intubation, ventilation with 100% oxygen, cardiac massage, two doses of epinephrine, and a dose of bicarbonate. The infant was admitted to the special care nursery, where he was placed on a ventilator (100% oxygen at a rate of 62 breaths per minute and pressure set at 20/5). He was also started on intravenous fluids, ampicillin, gentamicin, and then transferred to the tertiary care unit. The first blood gas showed a pH of 6.9, the blood culture grew ß hemolytic group B streptococci. The infant started having seizures at 12 hours of age and was treated with phenobarbital. Because of uncontrolled seizures, phenytoin was added and lorazepam was used on an as-needed basis. The infant was treated with ampicillin for 10 days. The hospital course was complicated because of grade IV intraventricular hemorrhage as demonstrated on a CAT scan of the brain taken on day 2 of his life, and the possibility of ischemic areas on a CAT scan of the brain taken on day 10 of life. A pediatric neurology consult was obtained, with the report of severe damage to the brain. The EEG was abnormal for increased seizure activity on days of life, 2, 5, and 10. By 24 hours of age, the infant was weaned down from the initial vent settings to 43% inspired 0_2, a rate of 40, and pressure of 14/4 on the ventilator. By 22 days of age, further weaning down of the ventilator took place to 23% oxygen at a rate of 30 and pressure of 13/4. We considered this to be good progress. Nasogastric tube feedings were started with 1 SCF on day 5 of life. The infant's nasogastric tube feedings were slowly increased over the next two weeks to bring them up to full volume. The chest X ray was consistent with chronic lung disease at day of life 15. After the initial conference with the mother and a clinical ethics consult discussion with the care team, phenobarbital was stopped on day 16 of life, although other antiseizure medications were continued. This decision was based on a goal of trying to finalize our neurological assessment while still controlling the infant's seizures and his suffering. We instinctively rejected the mother's request [to remove the child from the ventilator] at the time of the consult, although her request at the time of the initial conference to terminate life support still hung in the air over the baby's treatment plan.

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[2]Gravida (G) -- number of pregnancies; para (P) -- subscript 1 -- number of full term infants delivered, subscript 2 -- number of premature infants, subscript 3 -- number of abortions, subscript 4: --number of children now alive

[3]Ap.gar score (pgär) n. A system of assessing the general physical condition of a newborn infant based on a rating of 0, 1, or, 2 for five criteria: heart rate, respiration, muscle tone, skin color, and response to stimuli. The five scores are added together, with a perfect score being 10. [After Virginia Apgar (1909--1974), American physician.] [American Heritage 2000]

From R Jain and DC Thomasma. Discontinuing life support in an infant of a drug--addicted mother: whose decision is it? *Cambridge Quarterly of Healthcare Ethics* 1997;6(1):48.

Case 6

Ying Chang Liang age 43, developed a severe headache following the birth of her fourth daughter, now age 2. She was eventually diagnosed with adenocarcinoma metastatic to the brain. She has been in the United States for about 10 years, following a path from Southern China to Hong Kong to the United States. She has a junior high education and worked as a chef, providing a large part of the financial support of her family, prior to becoming ill. Her husband, who has some college education, has had a more difficult time maintaining steady employment.

Mrs. Liang was described by herself, husband, and physician as the primary decisionmaker about her medical care. "I personally made the decisions about most things in my family. For my treatments, even for the Chinese medications (and I had several different kinds) I would take whichever I trusted more." Describing her discussions with her doctor about treatment, she said "If I did not feel good, I asked to stop, and the doctor would stop."

The interviews reveal striking mistrust of the western physicians involved in Mrs. Liang's care. She not only returned once to China for therapy with a doctor in Shanxi, but took traditional medicines provided by family members and friends remaining in China. Her husband believed firmly that his wife would have died if they had relied on western medicine, and complained, "I don't trust the doctors here; doctors here with an MD degree are not even as good as bare-foot doctors in China."

Fully in control, Mrs. Liang used western therapies when they suited her needs, and refused them when she found them ineffective. One of our researchers once observed a complex negotiation between patient and husband, interpreter, and physician, during which the patient requested a CT scan of the brain in order to determine whether the Chinese medicines she took were working. The physician – who was never informed about the patient's use of alternative therapies (and the interpreter was party to this mis-communication) – could not understand why she wanted a CT scan when, she was refusing radiation therapy to further shrink her brain tumor. Dr. Ingle, her oncologist, described her as "clearly in control; she had no trouble speaking her mind." Nonetheless, he had lingering doubts about her understanding of her illness, complaining that she never understood the connection of her brain metastases to the primary tumor and that she was never "completely accepting" of her illness.

From H Hern, Jr., BA Koenig, U Moore and PA Marshall. The difference that culture can make in end-of-life decision making. *Cambridge Quarterly of Healthcare Ethics* 1998;7(1):27-40.