

An Affair of the Heart

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At the University of Kentucky Albert B. Chandler Medical Center, Integrative Clinicopathological Conferences are held regularly to explore various dimensions—economic, psychosocial, ethical, preventive, and medical—of health care. They are organized by Dr. Engelberg, Professor of Physiology and Biophysics. This conference was moderated by Dr. Bosomworth, Chancellor of the University Medical Center. The proceedings were edited by Maitland DeLand.

Dr. Bosomworth:

We are going to discuss a 15-year-old girl, Mary, who died during her second pregnancy, three years after she had had an artificial heart valve installed. Dr. Jacqueline A. Noonan [Chairman of Pediatrics] will review the history.

Dr. Noonan:

This patient had a heart murmur noted at birth, which suggested congenital heart disease. Approximately eight of 1,000 babies are born with a heart defect, so it is a relatively common problem. When our patient was four months old, she was seen for a cardiac evaluation because the murmur persisted. We diagnosed congenital aortic stenosis. She was followed regularly and all her appointments were kept. The cardiac condition was followed by regular physical examination and by electrocardiography.

She did well until she was 5½ years old, when the ECG showed cardiac strain from increasing left ventricular wall hypertrophy. Cardiac catheterization confirmed that she had severe aortic stenosis. She was referred for surgical repair. Although the abnormality could not be completely corrected, the surgeon was able to enlarge the aortic valve opening. When the valve is significantly malformed, it does not close well after repair, so

some retroflow will develop, as it did in this case. On follow-up she continued to be asymptomatic. Although she was very small, she did quite well until she was about 12 years old.

At that time she began to display some emotional instability, manifested by suicidal gestures at school and poor academic performance. Although she did not express firm ideas about suicide, she threatened to take an overdose of penicillin. We then referred her to our psychiatry clinic for counseling, but she kept only one appointment.

With respect to her home life, her mother used the child's heart disease to obtain special privileges—a more comfortable apartment, a more convenient school, etc. Even as the daughter began to manifest emotional instability, her heart condition worsened. Her heart had become enlarged. When valve leakage increases, left ventricular volume loading leads to increased heart size, and a prosthetic heart valve is required to correct this problem. This is a major procedure, and we hesitate to recommend it unless the symptoms warrant such surgery.

In October 1980, she was hospitalized with severe chest pains. Serum enzyme studies and radionuclide scanning showed that she had myocardial ischemia. The poor perfusion of her heart muscle was the direct result of the severe leakage of the heart valve. The cardiac findings indicated that we could no longer delay surgery. After a complete catheterization, which confirmed our diagnosis, she underwent replacement of the aortic heart valve with a prosthetic valve. An artificial valve may become obstructed by clots unless the blood is kept thin, so we put her on anticoagulant medication. The anticoagulant generally used is warfarin, which is taken orally. She improved clinically—i.e., she no longer had chest pain, and her heart became smaller—but her family and school

problems became more serious. She was demonstrating significant emotional instability, and her mother was continually calling on the school personnel for help.

When she was 14, the patient indicated at one of her follow-up visits that she was sexually active and asked for birth control pills. She didn't want to tell her mother but was going to tell her father so that he could pay for the pills. Her parents had been divorced, and the girl was living with her mother but maintained contact with her father. She told the cardiac nurse that she was going to get the birth control pills. We asked her to come to the cardiology clinic for counseling, because the birth control pills could interact with the warfarin and accentuate blood clotting. She did not come for counseling and she became pregnant. We referred her to the obstetrics department.

She elected to continue the pregnancy, which posed two problems. Warfarin causes malformation of the fetus, while pregnancy itself is procoagulant. Consequently, pregnant patients are switched to heparin. Unlike warfarin, heparin cannot be taken in pill form; it must be administered subcutaneously. The patient and her mother were taught how to inject heparin. Fortunately, I thought, she had a spontaneous miscarriage early in her first trimester, and we hoped that this experience would discourage further pregnancies. A very short time later, however, she again became pregnant.

She returned to our clinic, and we sent her back to the obstetrics department. A heparin regimen was again prescribed, to be administered twice daily, but she was noncompliant. On one occasion I had to send her to the emergency room for heparin. I hoped that this extreme action would make her understand how vital it was that she take the heparin. At 12 weeks of pregnancy, however, she came to the pediatric cardiology clinic complaining of shortness of breath and chest pain. I discovered that the valve was not working well. The normal clicking sound was no longer present, and I detected a murmur indicating that the valve was now leaking. I suspected that the valve was affected by thromboemboli and that she hadn't been taking her heparin. We hospitalized her immediately.

Our studies indicated that the valve was moving, although some clotting had occurred. We found no evidence of a myocardial infarction. She was given intravenous heparin to dissolve the clot. She did moderately well for about 24 hours, but then she quite suddenly complained of severe

chest pains. She had become hypotensive and appeared very ill. Preparations were made for surgery, but she had a cardiorespiratory arrest on the way to the surgical suite. She was resuscitated, put on a heart-lung machine, and a thrombus was removed from the aortic valve. She could not be removed from the heart-lung bypass, and she died.

In retrospect, I believe the better decision would have been to have sent her to surgery when she came to the clinic with chest pain. However, since the clot was not completely developed and because of the risk to the baby, we felt a conservative approach was a better choice.

Question:

Why was an abortion not recommended when she became pregnant the second time?

Dr. Noonan:

We do not perform nontherapeutic abortions at the university medical center, and the patient did not want an abortion. She chose to have the baby.

Question:

Suppose she had decided to have an abortion: What influence would her parents have had on her decision?

Dr. Noonan:

As far as I know, no one suggested she have an abortion.

Question:

You mentioned that she had an unstable family background. Her parents were divorced and apparently were not very supportive.

Dr. Noonan:

The divorce of her parents was a source of problems, which are common in today's society. Her family is typical in many ways. Interaction between mother and father was negative, and continuous support was not available.

Question:

What would be your recommendation to teenagers with artificial heart valves regarding pregnancy? If they become pregnant, how many of them successfully carry the child to term?

Dr. Noonan:

You must remember that I am a pediatric cardiologist. I take care of children. Unfortunately, children get pregnant, which is one of the other

problems we must handle. The decision to have a baby is very personal. Some patients do what they want to do, regardless of the recommendation of their physicians. If a woman has an artificial heart valve and she wants to have a baby, the physician must help her. In such a case this takes a serious commitment. To follow a woman with an artificial valve through pregnancy to a normal delivery is very demanding. With this particular heart problem there is a high risk to the baby and to the mother because of the need for anticoagulants. We certainly do not encourage patients to become pregnant; however, some women with similar cardiac problems have carried to term. We do point out to patients with artificial valves that pregnancy poses a high risk, and many women elect to have a tubal ligation to prevent pregnancy.

Question:

Do we know the magnitude of this risk when the mother has an artificial valve?

Dr. Noonan:

The risk depends partly on the patient's general cardiac status. Some patients with an artificial valve are able to exercise and are in good physical condition, while others have cardiac symptoms. A woman with an artificial valve who decides to become pregnant must make a major commitment. She must be mature, responsible, and compliant regarding heparin therapy, and she needs a supportive husband—none of which applied in this case. Generally, we discourage women with artificial valves from planning to become pregnant. For women of childbearing age, we try to use a pig valve that does not require anticoagulation so that pregnancy can be an option.

Dr. Bosomworth:

Dr. John W. Greene, Jr. [Chairman of the Department of Obstetrics and Gynecology] will discuss the likelihood of someone in this situation having a normal pregnancy and healthy baby.

Dr. Greene:

In the past 10 years I have had five or six patients with similar medical conditions who successfully carried a pregnancy. There are no medical or surgical indications for voluntary interruption of pregnancy in such cases. That is a rather strong statement when we consider that we used to interrupt some pregnancies because of severe heart disease or other serious illnesses. Sometimes, if a woman has terminal carcinoma, the pregnancy

may be interrupted because the mother will not live to care for the child. The point I am making is that if this young woman had desired proper care, it was available and she would have had a successful pregnancy. Be careful in telling a young lady that she cannot or should not ever have a child. If a patient does get pregnant, she has to be mature and motivated to take care of herself—not only to eat properly but also to come to the clinic. The patient we are discussing today was a member of a high-risk group.

Question:

Are data available on the mortality of pregnant women with artificial valves?

Dr. Noonan:

In some countries where abortions are not freely done (e.g., Mexico), there are data for a large number of women with artificial valves, many of whom have had normal infants. I think if a woman has had a good result from aortic valve surgery, she would have a reasonably good chance of getting through a pregnancy.

Question:

What procedures are performed to diagnose heart problems in a baby?

Dr. Noonan:

When a baby presents with cyanosis, a heart murmur, abnormal heart rate, or congestive heart failure, we suspect a congenital cardiac malformation. We then evaluate the infant to determine the nature and severity of the lesion. Electrocardiography, echocardiography, cardiac catheterization, and angiography provide the diagnostic information. Sometimes listening to the heart with a stethoscope is all that is necessary, as it was for this patient. Aortic stenosis was diagnosed with this simple clinical procedure. However, we eventually performed invasive tests to determine our plan of treatment.

Question:

If this were not a university medical center but rather a hospital with some religious affiliation, would there be very much difference in the way you would handle such a case and in the judgments you would make?

Dr. Noonan:

No. Our practice of medicine here is very similar to that of most religious hospitals. In some of

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INDICATIONS AND USAGE

Anxiety disorders, short-term relief of the symptoms of anxiety, and anxiety associated with depression. Anxiety or tension associated with the stress of everyday life usually does not require an anxiolytic. Effectiveness for more than four months has not been established; periodically reassess the usefulness of the drug for the individual patient.

CONTRAINDICATIONS

Sensitivity to XANAX or other benzodiazepines, and in acute narrow angle glaucoma.

WARNINGS

Benzodiazepines can cause fetal harm in pregnant women, hence women who may become pregnant should be warned. Avoid during the first trimester. Withdrawal seizures have been reported upon rapid dose reduction or abrupt discontinuation, thus reduce dose gradually. (See Drug Abuse and Dependence and Dosage and Administration.)

PRECAUTIONS

General: If XANAX is combined with other psychotropics or anticonvulsants, consider drug potentiation. (See Drug Interactions). Use the usual precautions in patients with renal or hepatic impairment and regarding prescription size in depressed and suicidal patients. In elderly and debilitated patients, use the lowest possible dose. (See Dosage and Administration.) Hypomania and mania has been reported in depressed patients.

Information for Patients: Alert patients about: (a) consumption of alcohol and drugs, (b) possible fetal abnormalities, (c) operating machinery or driving, (d) not increasing dose of the drug due to risk of dependence, (e) not stopping the drug abruptly. **Laboratory Tests:** Not ordinarily required in otherwise healthy patients. **Drug Interactions:** Additive CNS depressant effects with other psychotropics, anticonvulsants, antihistamines, ethanol and other CNS depressants. Plasma levels of imipramine and desipramine are increased. Pharmacokinetic interactions with other drugs have been reported. Cimetidine can delay clearance of benzodiazepines. **Drug/Laboratory Test Interactions:** No consistent pattern for a drug or test. **Carcinogenesis, Mutagenesis, Impairment of Fertility:** No carcinogenic potential or impairment of fertility in rats. **Pregnancy:** See Warnings. **Nonteratogenic Effects:** The child born of a mother on benzodiazepines may be at some risk for withdrawal symptoms, neonatal flaccidity and respiratory problems. **Labor and Delivery:** No established use. **Nursing Mothers:** Benzodiazepines are excreted in human milk. Women on XANAX should not nurse. **Pediatric Use:** Safety and effectiveness in children below the age of 18 have not been established.

ADVERSE REACTIONS

Side effects are generally observed at the beginning of therapy and usually disappear with continued medication. In the usual patient, the most frequent side effects are likely to be an extension of the pharmacologic activity of XANAX, e.g., drowsiness or lightheadedness.

Central nervous system: Drowsiness, lightheadedness, depression, headache, confusion, insomnia, nervousness, syncope, dizziness, akathisia, and tiredness/sleepiness. **Gastrointestinal:** Dry mouth, constipation, diarrhea, nausea/vomiting, and increased salivation. **Cardiovascular:** Tachycardia/palpitations, and hypotension. **Sensory:** Blurred vision. **Musculoskeletal:** Rigidity and tremor. **Cutaneous:** Dermatitis/allergy. **Other side effects:** Nasal congestion, weight gain, and weight loss.

Withdrawal seizures with rapid decrease or abrupt discontinuation. (See Warnings.)

The following adverse events have been reported with benzodiazepines: dystonia, irritability, concentration difficulties, anorexia, transient amnesia or memory impairment, loss of coordination, fatigue, seizures, sedation, slurred speech, jaundice, musculoskeletal weakness, pruritus, diplopia, dysarthria, changes in libido, menstrual irregularities, incontinence, and urinary retention.

Paradoxical reactions such as stimulation, agitation, rage, increased muscle spasticity, sleep disturbances, and hallucinations may occur. Should these occur, discontinue the drug.

During prolonged treatment, periodic blood counts, urinalysis, and blood chemistry analysis are advisable. Minor EEG changes, of unknown significance, have been observed.

Liver enzyme elevations, gynecostasia and galactorrhea have been reported but no causal relationship was established.

DRUG ABUSE AND DEPENDENCE

Physical and Psychological Dependence: Withdrawal symptoms including seizures have occurred following abrupt discontinuance or rapid dose reduction of benzodiazepines. (See Warnings). Dosage should be gradually tapered under close supervision. Patients with a history of seizures or epilepsy should not be abruptly withdrawn from XANAX. Addiction-prone individuals should be under careful surveillance. **Controlled Substance Class:** XANAX is a controlled substance and has been assigned to schedule IV.

OVERDOSAGE

Manifestations include somnolence, confusion, impaired coordination, diminished reflexes and coma. No delayed reactions have been reported.

DOSAGE AND ADMINISTRATION

Dosage should be individualized.

The usual starting dose is 0.25 to 0.5 mg, t.i.d. Maximum total daily dose is 4 mg. In the elderly or debilitated, the usual starting dose is 0.25 mg, two or three times daily. Reduce dosage gradually when terminating therapy, by no more than 0.5 mg every three days.

HOW SUPPLIED

XANAX Tablets are available as 0.25 mg, 0.5 mg, and 1 mg tablets.

CAUTION:

FEDERAL LAW PROHIBITS DISPENSING WITHOUT PRESCRIPTION.

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April 1988

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those institutions, however, the hospital board and the physicians in consensus may set guidelines that would preclude the termination of pregnancy. Also, we freely do tubal ligations here, and some religious hospitals do not approve of this procedure.

Dr. Bosomworth:

Dr. Eugene B. Gallagher [Professor, Department of Behavioral Science] will review the psychosocial history of the patient.

Dr. Gallagher:

A psychosocial history can be as broad or as narrow as one chooses. In this case, we elected to limit our discussion to two salient issues concerning Mary's behavior in the patient-illness context. We shall explore some possible reasons why Mary became pregnant a second time and why she resisted taking the prescribed dosage of heparin during that pregnancy.

In the first pregnancy, the father was a 17-year-old boy who wanted to marry the girl, and she wanted to marry him. The two young people were, however, caught in a conflict between Mary's divorced parents, whose hostile relationship and struggle over parental control persisted six years after their divorce. There had been a custody dispute, and the father had lost. Mary's father gave written permission for the couple to marry, but her mother opposed it; the court decided that the father's permission for the marriage had no legal validity. Mary's father felt that she was not doing well in her mother's custody and that she could be better off married to the young man who was the father of the baby. According to Mary's father, at the termination of the first pregnancy, the boyfriend phoned and said that he had broken off his contact with the patient. The implication was that if she became pregnant again, he was not the father.

Mary's second pregnancy followed closely on the termination of the first. She sought no contraceptive assistance this time. Indeed, it was her mother's opinion that Mary had deliberately become pregnant again because she wanted to have a baby. She had, in a sense, at the time of the miscarriage lost two potential relationships—the possibility of having both a husband and a child. I think the observation by Mary's mother that the second pregnancy may have fulfilled some wish to

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restore at least one of those lost relationships is probably accurate. Having a baby to her meant having someone to love and being loved in return.

The issue of her noncompliance with heparin administration is more speculative. This could be considered rebellious acting-out behavior or—recalling the earlier suicide gesture—her noncompliance with the medication and even the second pregnancy might have been similar gestures.

A few facts about the final episode: The patient had been absent from school for some time. One morning a truant officer came to the apartment and abruptly told the mother that if her daughter did not attend school that day, the mother would be brought to court. To prevent her mother's arrest, the patient tried to walk to school, as transportation was not available. A few blocks from the house, she was unable to go on. She sat down to rest and then managed to return home. When the mother came home from work, she found the girl on the floor and took her to the emergency room. Thirty-six hours later she was dead.

Question:

Is there any history of sexual abuse of this patient?

Dr. Gallagher:

At age 13, the patient told her father that the nephew of a friend of the family had raped her.

Question:

Was the father of the child of the second pregnancy involved in the problems that developed?

Dr. Gallagher:

In strong contrast to the father in the first pregnancy, who was emotionally involved and wanted to marry the girl, the second young man, who was 19 years old, rejected the patient.

Dr. Bosomworth:

Dr. Alan K. David [Associate Professor, Department of Family Practice] will discuss facts surrounding the pregnancy of this patient.

Dr. David:

My comments will deal with three problem areas: physiologic changes in pregnancy, anticoagulants, and teenage pregnancy.

First, pregnancy alters the function of much of the endocrine system. Thyroid function increases, which results in increased heart rate and heat in-

tolerance. Cardiac output increases by 30% to 50% as the placenta and fetus grow. These changes are usually well tolerated. Had this patient with a prosthetic valve been able to manage her anticoagulant therapy, she might have done quite well. She certainly would be classified as a high-risk patient, however.

Second, the anticoagulant used, warfarin, passes through the placenta into the infant. During the first 12 weeks of pregnancy, it causes specific congenital abnormalities; after about 16 weeks, there is an increased risk of fetal bleeding. Heparin is therefore prescribed for pregnant patients, but it must be administered subcutaneously every six to 12 hours. Our 15-year-old patient had psychologic problems and little or no family support; yet we expected her to inject this medication on a twice-daily basis. In a situation analogous to that of an adolescent diabetic, a certain amount of rebellion can be expected. All teenagers need to develop a body image. Do they "look good"? An injection with a needle leaves a small mark or may cause bruising. It's not surprising that problems with compliance develop.

Third, there is the epidemic of teenage pregnancy in this country. Of the world's developed countries, we have the highest rate of teenage pregnancy. The medical statistics in this age group are alarming. Girls who become pregnant under the age of 15 have a 60% higher mortality than older pregnant women; the incidence of low-birth-weight babies and infant mortality is twice as high. Toxemia of pregnancy, hypertension, abruption of the placenta, and kidney problems develop more frequently in this underage group.

Abortion is a highly charged issue in our society. It is not funded by the federal government, and legislatures continually pass laws to limit abortion. It must be extremely difficult for a 15-year-old to contemplate such a course of action. She has little money, and good advice is often unavailable to her. Some doctors may discuss abortion as an available option; others will not discuss it with patients, because they believe it is immoral or inappropriate. This procedure does, in fact, raise complex ethical questions. In a woman on anticoagulants, an abortion after eight weeks is very risky because of the danger of hemorrhage. If this procedure were to be considered, it would have to be done early. Thus, abortion is neither likely to be suggested nor financially feasible for a poor 15-year-old.

Prevention of pregnancy is not only a medical problem; it is a societal, educational, and economic problem as well. This youngster's need to

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be pregnant prevailed over seemingly more basic needs. She miscarried at 12 weeks into her first pregnancy, but within eight weeks she was pregnant again. Obviously, she did not adhere to a birth control plan.

Could this tragedy have been prevented? In St. Paul, Minnesota, a group of health education facilities were established adjacent to high schools. Students received free health education, diet information, and contraceptive counseling. The number of pregnancies at the schools decreased 50% in the next three years, no repeat pregnancies occurred in the adolescent girls who had previously become pregnant, and less than 10% of those who became pregnant and had children failed to finish their high school education. Before the project was organized, 45% had failed to finish high school after pregnancy. A similar study in western Massachusetts yielded comparable results. Appropriate information apparently makes a difference in the teenage pregnancy rate.

If birth control information and materials are available, why don't people avail themselves of them? In one college, 50% of sexually active women do not avail themselves of birth control services offered on campus. A partial explanation relates to the adolescent's romantic ideas that sexual intimacy should be spontaneous. She may not be willing to define herself as being sexually active or committed to nonmarital sexual intimacy before the first act. The possibility that she could become pregnant is not seriously considered. Only when friends become pregnant does reality strike home. Yet, instructing teenagers in birth control measures is very difficult. Often they are unable to manage the contraceptive techniques or comply with the need for consistent use.

We have been discussing a teenage pregnancy complicated by medical problems—a compromised heart, a prosthetic heart valve, anticoagulation medication, and a nonsupportive environment. In my opinion, she risked her life by becoming pregnant because this fulfilled a need for her, a need to be seen, a need to care for someone. In her mind those needs outweighed the risks to her life.

Dr. Noonan:

I think that the programs Dr. David described would be valuable. Programs are successful when the community admits that some teenagers are sexually active. Once this assumption is made, a clinic offering contraceptive information and service provides an excellent opportunity for coun-

seling girls about their sexuality, their sexual activity, and other social and family problems. Often, counseling reveals family pathology that has resulted in the teenager's loss of self-esteem. The girl responds to psychologic conflicts by rejecting established moral standards.

We all are very concerned about the teenage pregnancy problem, and we do have a teenage pregnancy program. Pregnant girls are followed very closely by a group of nurses, nutritionists, and social workers. The youngsters are encouraged to stay in school, receive good medical care, and are taught parenting skills. After the baby's birth, they are followed for six years; we observe that the mothers in our program make fewer visits to the emergency room than do those who have not received training and care.

Question:

The United States has the highest teenage pregnancy rate. One reason given is that the United States doesn't provide sex education classes, as is done in European countries. How do you feel about that?

Dr. David:

Lack of education is only part of the problem. In our society we are bombarded with sexual messages from the media—soap operas, movies, commercials, and magazine and newspaper advertisements. We can educate our teenagers about sexual anatomy and physiology, but how do we counteract the pervasive message of advertising?

Another study suggests that teenage pregnancy correlates with the distribution of wealth. Countries in which wealth is not evenly distributed have a high rate of teenage pregnancy in the lower socioeconomic strata. The United States has the greatest maldistribution of wealth among the developed countries. People at the bottom of the scale have a hopeless outlook; the future seems to hold little opportunity for them. Pregnancy seems to provide an opportunity for a change in their lives.

Dr. Bosomworth:

Dr. Laurie L. Humphries [Assistant Professor, Department of Psychiatry] will give a psychiatric evaluation of the patient.

Dr. Humphries:

I would like to suggest that this patient died from a cause other than her medical condition, that this case is an affair of the heart. We know that

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Mary died even though she had all possible medical advantages—the most advanced technology, eminent and caring practitioners. The patient died, I believe (and Dr. Noonan and others have reiterated this point), because her mother did not nurture her and give her a sense of being loved. She exploited and abandoned her daughter.

When she was six years old, Mary was a Heart Fund poster child. On examining that photograph of her, we see at once that no one was really taking care of her. Her hair is uncombed, her clothes unkempt, and her crooked smile is more a grimace than a grin. She seems to shrink from the world as though scarred by the trauma of life. It is an eloquent portrait with much to tell us.

Mary was born imperfect; she had a heart defect. Bonding of mother and infant from birth appears to have been inadequate, and we know that later her mother did not convey a sense of love and caring. Rather, she used Mary's illness to gain certain advantages for herself. Mary was

"used" even on the final day of her life. She agreed to go to school, even though she was feeling ill, to protect her mother from legal action. In spite of the mother's inadequacies (I believe she had a serious personality disorder), the courts awarded her custody of her daughter. The only consistent caring and emotional support Mary received was her medical attention. Even her teachers, unable to communicate with the child's mother, resorted to telephoning Dr. Noonan when Mary had problems at school.

Mary's suicide threat at age 12 must be considered a cry for help. What would have helped her? Certainly, an emotionally stable environment would have helped. The major issue in this case appears to have been the lack of adequate nurturing: Both emotional stability and the ability to care for oneself are learned through the child's early interaction with the mother. Mary's behavior in relation to her illness and herself was learned from her mother.

Finally, until we recognize the importance of a person's emotional needs in the context of the patient-illness relationship, all the technology in the world is meaningless.

Question:

Dr. Humphries, when we consider that the patient had displayed some suicidal tendencies and that she had a girlfriend who had become pregnant and died of complications, could she perhaps unconsciously have wanted to become pregnant because death resulting from that would be a way to commit suicide?

Dr. Humphries:

I believe we could view this death from that standpoint. This youngster displayed real ambivalence about living and dying. The most ambivalent statement she could make was to become pregnant—i.e., giving birth to life, when the pregnancy represented something that could cause her death.

Dr. Gallagher:

Because the patient had a friend who became pregnant and died, she had a sense of dread during the second pregnancy that things were not going well. There was some indication that she had become involved in a subculture where pregnancies were more or less common and conferred status on adolescent girls. When I talked with the mother, I was struck by the fact that she seemed to know a lot about her daughter and sympathized with her medical problems when some

material advantage for herself was to be gained. Although she told me that she was trained in the administration of the injectable heparin, the mother had a blind spot about that. She was very vague as to whether the daughter had been taking it. This ambiguity stood in contrast to her very detailed knowledge of other areas of her daughter's life.

Question:

Dr. Gallagher, what can you tell us about the patient's father?

Dr. Gallagher:

I visited the father in the counseling center. He had remarried but maintained very active contact with his daughter. He tried to help her as much as he could. He has a relatively well-integrated personality and is a responsible person. He exhibits a great deal of antagonism toward his former wife, but he loved his daughter.

Question:

What more can you tell us about the mother?

Dr. Gallagher:

I was not able to interview her face-to-face, but I talked with her twice over the telephone. When you don't know a person, it's very difficult to form an accurate perception of that person's sense of responsibility. Even in my limited contact, however, I got the impression that she had a dependent personality. She had a real problem in that her daughter was disabled; nevertheless, she used her daughter to manipulate the welfare system to gain advantages she could not otherwise obtain. She justified her actions by indicating that they were obtained for her daughter's sake.

Dr. Bosomworth:

Dr. Glenn C. Blomquist [Professor, College of Business and Economics] will discuss the economic impact of this patient's illness.

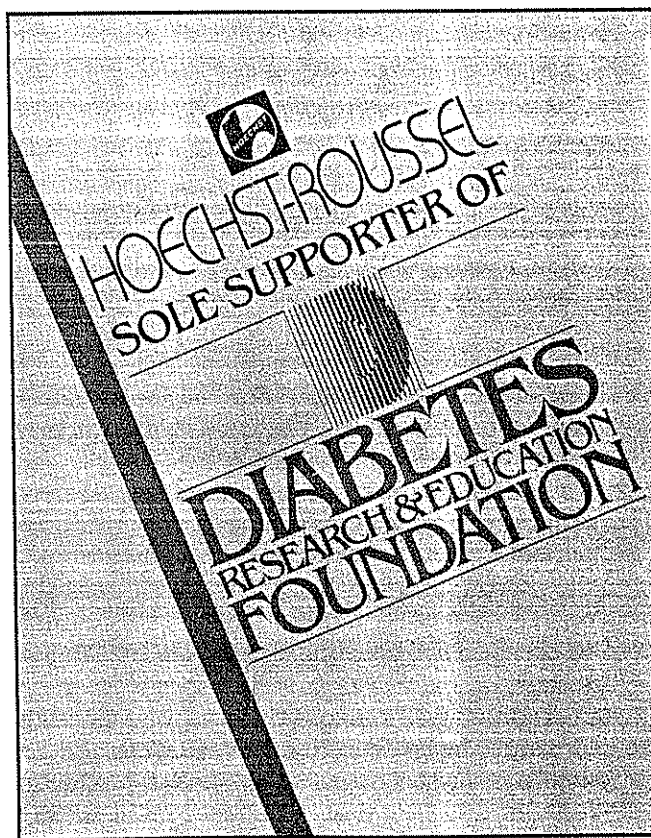
Dr. Blomquist:

My economic analysis of this case is divided into two parts. The first is the accounting of the medical center costs incurred because of this young woman's health problems. It is well documented and rather straightforward. The second part concerns the production of health in our health care delivery system. It is more illustrative in nature.

Accounting analysis: Dr. Noonan indicated that the patient could have expected to lead a rather normal life after the implantation of the plastic

heart valve. The major qualification was that the patient should avoid pregnancy because it would endanger her life. She became pregnant. Her pregnancy had several consequences, including an increase in medical care. She was hospitalized four times here at the medical center: to replace warfarin with heparin, for the miscarriage, for the heparin regulation with the second pregnancy, and finally for her chest pains and surgery. During the six-month period the cost of the four hospitalizations amounted to \$10,041. Of these costs, \$5,576, approximately one half of the total, was for the final hospitalization. Private insurance covered 87% of the costs, Medicaid paid for 9%, and the patient's family paid the final 4%. Although we may have missed some costs incurred by the family in settling the final bill, this accounting picture is pretty clear. Hospitalization costs amounted to approximately \$10,000, half of it for the last admission, and about 90% of the total was covered by insurance.

Health production analysis: This economic analysis is based on a simple concept, which is some-



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times referred to as "a health production function."¹ The idea is that a person's health depends on a variety of factors, including heredity, professional health care, life-style, and the time and energy an individual devotes to health. For this woman an obviously crucial determinant of her health status was the time and energy devoted to compliance with medical advice and regimen, particularly with regard to pregnancy and anti-coagulant medication.

Although the pregnancy decision is complicated, the "economics" of compliance with the anti-coagulant regimen is clear. When faced with the need to administer the heparin subcutaneously, she found it inconvenient, uncomfortable, and occasionally disfiguring (bruising), and she responded negatively. She perceived an increase in the cost of producing health and lowered her target level of health. If we are fatalistic, we must view the \$10,000 in medical costs as an unavoidable component of the vicissitudes of life. Perhaps with regard to this 15-year-old woman, such a view is appropriate. If we are more optimistic, however, we can envision a change in our health care delivery system that would compensate for increased patient costs, so that compliance would not deteriorate.

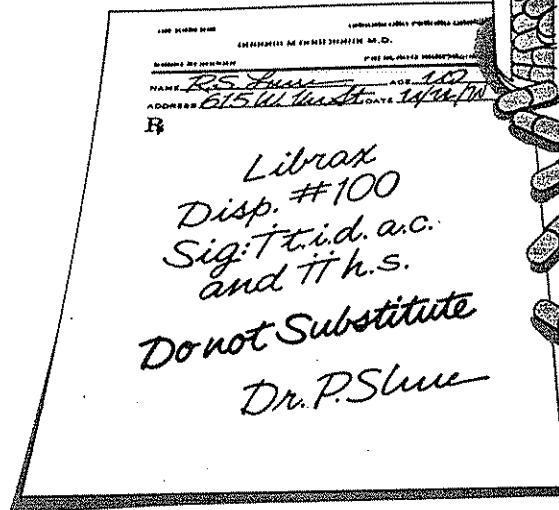
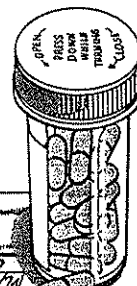
If a health care professional, such as a visiting nurse, could have developed a successful health promotion program for this patient through continuous, personal follow-up, she might have had an opportunity to lead a normal life. How much should we spend on this level of compliance in cases such as this one? If we make use of the concept of discounting, which implies a dollar in the future is worth less than the dollar today, we can correctly compare a flow of future annual expenditures with a large expenditure incurred today. With an annual interest rate of 10% today, we can afford to spend approximately \$1,000 a year on compliance assistance for the rest of the patient's expected life, if we do not have to incur the hospitalization cost of \$10,000 today. Of course, we must determine whether this optimistic scenario is more appropriate than the fatalistic scenario.

In summary, the accounting analysis is straightforward. The costs were about \$10,000. The economic analysis based on a health-production function suggests that compliance problems were a result of increased patient costs. Further, it suggests that bolstering our existing health care delivery system with people who could compen-

(continues)

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Drug Abuse and Dependence: Withdrawal symptoms similar to those noted with barbiturates and alcohol have occurred following abrupt discontinuance of chlordiazepoxide; more severe seen after excessive doses over extended periods; milder after taking continuously at therapeutic levels for several months. After extended therapy, avoid abrupt discontinuation and taper dosage. Carefully supervise addiction-prone individuals because of predisposition to habituation and dependence.

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HEART (continued)

sate for such increase in compliance costs may well be worth it.

Dr. Bosomworth:

Dr. Susan Abbott [Associate Professor, Department of Anthropology and Psychiatry] is going to join our discussion.

Dr. Abbott:

Two major points seem to arise over and over again. The first one is the general problem of teenage pregnancy in our society. The second is the problem of management of chronic, life-threatening disease in adolescence.

With regard to the first point, the table gives an idea of where the United States stands in comparison with the rest of the world on strategies for dealing with emerging sexual maturity among young women. The United States, with a delay of about 7.8 years between menarche and marriage, is in midrange for the period of risk for unwed pregnancy. Japan has the longest period of delay, 11.8 years. India has the shortest, 2.4 years. In some countries customs dictate that young girls be married before, right at, or soon after menarche, so there is minimal risk of unwed pregnancy.

The strategies for guiding conduct during the years of delay until marriage range from cultures that absolutely prohibit premarital sex while placing a high value on virginity to those that encourage sexual experience before marriage. Societies like ours prefer to delay marriage until the 20s and pressure adolescents to refrain from sexual activity. When teenagers and single women become sexually active, they are to do so responsibly—that is, they are to use contraceptives. Thus, we could fall into either a restrictive or a permissive category. Over the past century in the United States, statistics show a trend toward earlier menarche and a concurrent increase in the age that we think appropriate for marriage. Because of the demands of education in a technological society, it is desirable that women not become pregnant for a long time. We need to keep this cultural context in mind.

Teenage pregnancy is a major public health issue, not only because of the health and social cost to the mothers but also because of the cost to their infants. A disproportionate number of premature and underweight births occur in the age group. This health problem raises some im-

(continues)

portant issues with regard to public health priorities. Funding, research, social service programs, and educational programs that now focus on the population at risk are clearly inadequate. In terms of the long-term public health benefits for the largest number, it is vastly more important to teach birth control techniques and provide other social outlets for young people than to concentrate our resources on the development of the artificial heart and dramatic organ transplants. Clearly, a value judgment in our public health policies is in order.

The second problem is that of management of chronic, life-threatening disease in adolescence. First, let's take a look at normal adolescents: They are perplexing and noncompliant, they start questioning authority, and they are hard to handle. In the comments by panel members we notice a dichotomy of views—Dr. Noonan likes to think of this patient as a child because physically she looked like a child, while our economist refers to her as a young woman.

We are dealing with a cognitive developmental issue. Adolescents simply are not yet mature; they are much more emotional, their feelings are too big, and their sense of self is not yet well developed. At about the age of 12, the adolescent starts to integrate his or her personality into an adult form. This process takes a number of years. The acting-out behaviors during this time of experimentation are absolutely essential to the process, so they shouldn't always be seen in a negative light. The teenagers have to test the limits. They have to ask: "Who says I have to do that?" "Who says I have to take my heparin?" "Who says I can't eat all the candy bars I want?" "Who says I have to eat my meals at regular intervals?" This rebellion is normal, not pathologic, and it is self-limiting. Unfortunately, for some youngsters—as in the case we are discussing—this normal acting-out behavior carries the risk of death. It could have been severe diabetes, hemophilia, or some other life-threatening condition.

The other issues in this case are psychologic. The mother used her child's illness to gain various advantages. Because the disease was so central to the dynamics of the family, it was difficult, if not impossible, for the patient to cope in a more mature way with her problem.

A second point is the patient's low self-esteem. She had lost her father; she lost her first boyfriend; her physical appearance (small stature, unkempt appearance) would give her low status

Comparison of Risk Periods for Unwed Pregnancy in Different Countries

Country	Mean Age of Menarche	Mean Age of Marriage	Risk Period
Japan	12.9	24.7	11.8
Switzerland	13.1	23.8	10.7
Sweden	13.1	23.2	10.1
Netherlands	13.4	23.2	9.8
Finland	13.2	22.8	9.6
Hong Kong (Chinese)	12.8	22.3	9.5
France	13.2	22.5	9.3
Belgium	13.1	22.3	9.2
Norway	13.2	22.2	9.0
Denmark	13.2	22.2	9.0
England and Wales	13.0	21.8	8.8
New Zealand	13.0	21.7	8.7
Canada	13.1	21.7	8.6
Australia	13.2	21.7	8.5
Israel	13.2	21.4	8.2
Singapore	12.7	20.5	7.8
United States	12.8	20.6	7.8
Hungary	13.4	20.7	7.3
Czechoslovakia	14.2	21.1	6.9
Malaysia (Chinese)	14.2	20.7	6.5
Iraq	14.0	20.1	6.1
Turkey	13.2	19.2	6.0
Iran	13.3	19.1	5.8
Tunisia	14.0	19.2	5.2
Pakistan	13.9	17.7	3.8
Bangladesh (Hindu)	15.9	18.6	2.7
India	14.4	16.8	2.4
Bangladesh (Muslim)	15.6	17.4	1.8

Whiting J, Burbank V, Ratner M: Paper prepared for SSRC Conference on School Age Pregnancy, 1983

with her peers; she began to fail in school, whereas before she had performed well academically; there had been a loss of socioeconomic status with the divorce of her parents. A whole series of losses contributed to her low self-esteem. Apparently, this led her to gravitate to a low-

status peer group, whose members may have been sexually active and less concerned about possible pregnancy. Adolescents are just not as rational as adults like to think they are; they don't pause to think of the consequences of their acts. A final point is that teenage pregnancy often does have to do with underinvolvement with one or the other parent, and sexual activity may be a substitute for the loss of a significant other in one's life.

I have some final questions. Given the facts of normal adolescent development, how should we approach the management of an adolescent at high risk because of a life-threatening, chronic illness? This is a problem for all adolescents, even those from the most ideal home environment. Second, if we know that there are significant psychologic issues, as in this case, does that additional burden fall to the health care team? Finally, given the significance of teenage pregnancy as a public health problem, why doesn't it have a more important place in our funding priorities?

Dr. Bosomworth:

Do you think that the disease itself contributes to the adolescent's low self-esteem?

Dr. Abbott:

Yes, because a teenager may feel that he or she is, somehow, not a whole person.

Dr. Bosomworth:

Rejection of the disease is rejection of self in a way. The adolescent may extend his or her risk-taking behavior to include noncompliance with prescribed treatment. An adolescent boy may, for example, decide he doesn't have a particular disease and therefore doesn't have to take prescribed insulin or heparin, or an adolescent girl may refuse to be careful and then become pregnant. This attitude is common, regardless of economic status.

Question:

Since the mother's adverse treatment of the child was known to many people, why were no efforts made to have this young girl placed in a foster home or with her grandmother, who might have taken better care of her?

Dr. Noonan:

We recognized the emotional neglect. However, the perception that a mother is inadequate, that she is coping poorly with a child's illness, is not sufficient reason to have a child removed from

the home. The child came for her appointments, and she had surgery when it was necessary. Apparently, the school authorities made a number of complaints and were going to have the mother arrested because she didn't send her child to school, but parents are rarely arrested for this legal inaction. A child cannot be placed in a foster home simply because the parents do not provide a loving environment. Only when this lack of love develops into outright physical abuse can the law intervene. This child wanted her mother to love her, and she did everything she could to win her mother's love. I don't know whether she would have been happy if she had been taken away from her mother.

This girl's grandmother was very nice, and she brought her to the clinic quite often. I suspect, however, that a problem developed with that relationship when our patient became a teenager. Her behavior probably alienated the nicest person in her life.

Comment:

One of the observations we could make about the recent Commonwealth of Kentucky legislative session is that for the most part, people with health problems that do not require hospitalization have no constituency. A bill that included home health care was defeated.

Question:

Was the patient ever referred to psychotherapy for emotional problems?

Dr. Noonan:

Yes, she was referred for counseling. She kept only one of her appointments. The sad part of this case is that all the resources this girl needed were available here at the medical center. Unfortunately, she would not cooperate with us, and she had no support from her mother. The patient came to the heart clinic periodically for follow-up and to get her warfarin level checked, but we were not able to counsel in depth. She probably spent more time with us than with any of the other health care personnel. □

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