

## **Virtual Mentor**

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**Obstetrics and Gynecology**

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## *Virtual Mentor*

American Medical Association Journal of Ethics  
May 2003, Volume 5, Number 5: 153-154.

### **FROM THE EDITOR**

#### **A Compound Specialty**

Faith Lagay, PhD

The revised, theme-centered *Virtual Mentor* takes one medical specialty as its focus in each calendar quarter. As we do so, we discover that, while medicine has core values expressed in its principles and reflected in the opinions of *the Code of Medical Ethics*, each specialty has distinct issues that arise from the particulars of its own practice and patient base. In the emergency medicine theme issue last February, the absence of a patient-physician relationship, the pressure of life-and-death decision making, and the external regulation that mandates emergency care for all patients were seen to pose ethical questions particular to emergency medicine. This month's specialty, obstetrics and gynecology, presents the unique (an accurate use of that word) circumstance of what we have chosen to call the "compound" patient. In August's theme specialty, pediatrics, physicians manage the ethical challenge of depending in large part upon patient surrogates, ie, parents, as partners in making treatment decisions.

Professionalism concerns long associated with the practice of obstetrics include conflicts in maternal-fetal interests and the liability physicians can face when problems during labor and delivery are implicated in injury to mother or newborn. Today's obstetricians confront a range of new ethical issues related to assisted reproductive technologies, confidentiality of genetic information, and the possibility of selecting traits for our children. The combined OB/GYN specialty addresses the health of all women and adolescent girls, not only those who are child-bearing. Hence the wide array of learning objectives for this issue:

- Understand the ethics and professionalism issues arising from 2, possibly different, sets of interests—those of the mother and those of the fetus.
- Understand the possible conflicts between confidential patient information and duty to inform others of test results.
- Recognize the risk of viewing children as "commodities" or as "means" only when using such technologies as pre-implantation genetic diagnosis.
- Recognize special privacy and confidentiality interests of adolescents in matters relating to sexuality and reproduction.
- Identify how much information patients must have about controversial treatments to give "informed" consent.

The decision to feature obstetrics and gynecology in May was partly in recognition of this month's dedication to honoring mothers. I invite VM readers to broaden the

conventional notion of mothering and take this month's theme as a cue to reflect on women who have nurtured you physically, intellectually, emotionally, or spiritually and, if possible, to thank them.

Faith Lagay, PhD is managing editor of *Virtual Mentor*.

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## ***Virtual Mentor***

American Medical Association Journal of Ethics  
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### **CASE AND COMMENTARY**

#### **Gynecological Care for Adolescents**

Commentary by Melanie A. Gold, DO

#### **Case**

Mrs. Johnson brought her daughter, Mandy, to see Dr. Jones for her first gynecological visit when Mandy was 13 ½ years old and had just begun to menstruate. Dr. Jones performed a regular physical, but not a vaginal exam, and talked to Mandy about the changes that were leading her to sexual maturity.

Dr. Jones did not see Mandy again until 15 or 16 months later when Mandy made an appointment and showed up on her own worried about vaginal irritation and itchiness. Dr. Jones examined Mandy and, by microscope confirmed his suspicion that Mandy had contracted trichomoniasis. He told Mandy what the infection was and that the person from whom she got it needed to be told so that he could get treatment. Mandy was vague and non-communicative about the topic. Dr. Jones could understand her embarrassment, but Mandy was not able to agree that she would tell her partner. Her main concern was whether Dr. Jones was going to tell her mother.

Mandy was in otherwise good health, upon general examination. Dr. Jones prescribed metronidazol and, because he wanted to talk to her again, asked to see her in 3 weeks. He spoke to her about safe sex and the possible long-term consequences of certain STDs. He assured her that he would not call her mother, but said that the diagnosis would go into Mandy's own personal and private medical record. Mandy kept the appointment 3 weeks later and was clear of infection.

Four months later, however, Mandy was back, again with symptoms of an STD. Dr. Jones is concerned, not only about Mandy's recurrent infection, but also about what appears to be casual sexual activity; she's not yet 16 years old.

#### **Commentary**

Caring for adolescents who appear to be engaging in unhealthy behaviors is challenging. It is tempting to warn them about the numerous negative outcomes of their behaviors in an attempt to dissuade them from continuing their "risk-taking." Although there is a role for educating, providing information and advice without first determining the patient's readiness to accept it or to change behavior often results in resistance. Education is, by itself, insufficient to facilitate behavior change. Strategies that facilitate behavior change include assuring confidentiality, eliciting information from the patient about the behavior and alternatives, assessing

readiness to change, asking permission before providing information or advice and then checking reactions to it, emphasizing autonomy and control, and offering a menu of options to choose from.

At her first visit, there are 3 things that might have made Mandy more comfortable talking about her sexual health. First, Dr. Jones could have talked with Mandy privately explaining to Mandy and her mother that he always sees teens alone for part of each visit. Second, Dr. Jones could have explicitly discussed with both Mandy and her mother his obligation to keep his patient's medical information confidential, re-emphasizing the confidentiality of the visit when speaking with Mandy alone. It should be explained to Mandy that discussions about sexuality, depression, and substance use will be kept private but reports of homicidal or suicidal ideation or physical or sexual abuse must be shared with the appropriate authorities. Third, Dr. Jones could have obtained a more thorough sexual history including assessing Mandy's feelings of sexual attraction and whether she had begun to engage in any specific sexual behaviors or was considering doing so soon.

To initiate these discussions, one could ask Mandy's permission to talk about her sexual health and elicit from her what she knows about puberty. Asking permission demonstrates respect and facilitates willingness to collaborate in discussion. Eliciting from Mandy her own knowledge about puberty acknowledges that she already knows a lot and allows the health care professional to identify misinformation. One could have also assessed Mandy's readiness to engage in sexual behaviors by asking open-ended questions such as "How soon do you plan to have sex? Why then instead of now?" If Mandy was not planning to have sex soon, Dr. Jones could have reaffirmed her decision to stay abstinent by reporting that her exam was normal and healthy, that she was doing a good job of keeping it that way, and confirming the safety of her decision. He could have concluded the visit by thanking Mandy for speaking with him about herself and inviting her to return when she was considering having sex to learn more about ways to stay healthy.

If Mandy said she was thinking about having sex soon, Dr. Jones could have assessed her reasons for initiating sexual activity by asking "What are the good things for you right now about having sex? What else? What else?" (until she could not come up with any more "good things") then asked "What are the 'not so good' things about having sex?" Asking about "good" and "not so good" things related to behavior change is preferable to asking about the "good" and "bad" things. Labeling the other perspective as "bad" may elicit resistance by forcing the adolescent to feel like she is being manipulated into admitting what she is doing is "bad" and to seeing things your way as the "right" way. The same strategy could be used to assess Mandy's readiness to use different forms of contraception.

At the second visit Dr. Jones spoke with Mandy about "safe sex" and the "possible long-term consequences of certain STDs" after diagnosing her with *Trichomonas*. A different approach might have facilitated more active participation on Mandy's part and enhanced her willingness to discuss treatment with her partner. Dr. Jones could

have told Mandy that her test showed she had Trichomonas and asked her what she knew about it. If Mandy was familiar with Trichomonas but had misinformation about it, he could have asked permission to give her more correct information and, after providing that information, could have checked her reaction to it. If Mandy did not know anything about Trichomonas, he could have asked permission to give her that information and with her permission explained what Trichomonas is, how it is transmitted and treated, and the importance of treating her partner so she will not get re-infected. After the discussion, Dr. Jones could have checked Mandy's reaction to the information by inquiring, "What do you make of this? How does that help or change things for you now?" and asked her what she planned to do.

At the third visit the physician should not assume that Mandy is having "casual sex" because she returned with symptoms of an infection; it is more likely that her symptoms are the result of re-infection with Trichomonas from her untreated partner. Feedback about the infection should be presented in a way that is nonjudgmental and objective. Another way to facilitate behavior change, especially when a patient does not appear ready to change is to offer a statement that emphasizes personal autonomy and control. An example of this would be: "As your doctor I'd like to give you advice about what to do, but I can't make you do anything that you do not want to do. It is up to you to decide whether or not you want to make any changes in what you are doing and if so, what changes you want to make." Such a statement may decrease resistance. It is critical that health care professionals say this genuinely and avoid a condescending or facetious tone.

After asking and receiving permission, health care professional can express concern for a patient's health and give advice that is clear and concise. Mandy could have been asked, "Would it be OK if I shared with you my concerns and some ideas I have about what you could do to keep yourself healthy and not get any further infections?" One could then ask Mandy for a menu of options or list of alternative behaviors. It is more effective if Mandy generates these options. However, adolescents are often unable to generate several options. Health care professionals, with permission, can offer options from which a patient can choose. It is important to offer at least 3 or 4 options at one time. If fewer than 3 options are offered or if each option is offered individually, patients may argue why each one will not work rather than picking the most acceptable choice from several possible alternatives.

Melanie A. Gold, DO is an associate professor in Pediatrics with subspecialty certification in Adolescent Medicine at the University of Pittsburgh School of Medicine. She is the director of Family Planning Services at the Children's Hospital of Pittsburgh and a Motivational Interviewing Network Trainer.

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## ***Virtual Mentor***

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### **CASE AND COMMENTARY**

#### **Responding to a Request for Early Delivery, Commentary 1**

Commentary by Wendy Savage, MD

##### **Case**

Maggie Olsen is 6-months pregnant with her third child and first son when she and her husband, Dave, receive news that his unit is being sent overseas. Dave, a Marine pilot, is not sure how long he will have to stay or how dangerous this mission will be. Maggie understands that the separation is part of being married to a military man but worries about her husband and the possibility of his getting hurt or even killed. Maggie and Dave have planned to name the little boy after his father, and the couple would really like Dave to be able hold his first son before he leaves.

At her next appointment with her obstetrician, Maggie brings all of this up with her doctor, Dr. Anita Beal. With her first daughter, Stephanie, Maggie had difficult and long labor and, when Stephanie's heart rate started to fall, Dr. Beal decided on a cesarean. Stephanie was a healthy baby and has been a healthy child, but she weighed just 5 lbs 10 oz at birth. Maggie had her second daughter, Christine, by cesarean as well; the baby weighed 6 lbs 3 oz. Maggie is scheduled to have this baby by cesarean on June 12, which puts her right at 39 weeks. Maggie asks Dr. Beal if it would be okay to reschedule the surgery for May 30 since her husband has to report on June 1.

Although Dr. Beal understands Maggie's desire for her husband to meet his son she worries about the possibility of complications if the baby is born too soon. Dr. Beal notes that Maggie's two daughters were on the light side and thinks this baby might really need those last two weeks in utero for weight gain. Dr. Beal explains the risks of moving back the delivery date to Maggie and her husband. The couple talks about it and decides they would still like to have the baby before the first of June.

##### **Commentary 1**

My first piece of advice to this couple would be for Dave to approach his commanding officer and ask if he could have some compassionate leave so he could be with his wife for the birth at term. Usually units do not travel to their destination by the swiftest route and it might be possible for him to go later by a scheduled airline and still be available when he is needed. I would be happy to write a letter to support him being present at the birth since this is a special time during which couples cement their relationship--and service personnel are known to have a higher than average rate of marriage breakdown.

Although Maggie's first child was small and required a cesarean section (CS) presumably for fetal distress after a long labor, the size would be due to some degree of intra-uterine growth retardation (now sometimes called intra-uterine growth restriction-IUGR). Maggie's second daughter was also on the small side but the case offers nothing to suggest that the CS was necessary. Since all seems to be going well in this pregnancy I would argue that Maggie should be offered a trial of labor to see if she could deliver normally this time around. The chances of this being successful are good, 60 to 80 percent in most studies.

Since Maggie is now only 6 months pregnant, one could do an ultrasound at about 32 weeks to see if the baby's growth is normal and, if so, then investigate with ultrasound at 36 weeks or earlier if clinically indicated. If there was any evidence that growth was beginning to tail off I would offer induction of labor at 37 weeks. Leaving a growth retarded baby in utero so it can gain some weight is not a sensible thing to do because the baby will use up its reserves of glycogen and possibly switch the blood supply to the upper body thus reducing the renal output and the liquor volume. I would explain that, whilst there was not an absolute guarantee that Maggie would deliver vaginally, this was the most likely outcome, and I would hope that the baby would have enough reserves to get through labor without becoming distressed.

I would explain to Dave and Maggie that going through labor offers the baby some health benefits such as the effect it has on the baby's ability to breathe spontaneously and prepare for the extra-uterine environment. Babies born by elective CS may have transient breathing difficulties and require admission to the special care baby unit, and those born too early may even develop respiratory distress syndrome (RDS) which occasionally can be fatal. It is hard to put a figure on this because most of these data are old, but at 37 weeks it may be as high as 1 in 1000.

As the doctor for both the woman and the baby at this time, I must decide whether my role is purely an advisory one in informing the couple about the increased risk to the baby if delivered at 37 rather than 39 weeks.

Do I then leave the decision to them?

Epidemiologically the risk of stillbirth is lowest at 40 weeks and the overall perinatal mortality falls to its lowest at 40 weeks. Even if the risk of a baby dying at 37 weeks is only 1 in 1000, is it the doctor's role to prevent the couple from taking this risk after having put it to them? Or is it up to the couple to decide for themselves? Who is the advocate for the baby?

It seems presumptuous to say that the doctor cares more about the baby than the couple does. But clearly in a highly emotionally charged situation such as this, the doctor has the ability, and I would contend the duty, to act rationally since she is not as emotionally involved as the parents are. Experience has shown me that if

something goes wrong during a birth, couples often cannot cope with their own guilt. They blame themselves excessively and sometimes their doctor or midwife, and the grieving process is prolonged and may be unresolved after years.

Whilst it would be ideal for Dave to be present at the birth of his son, and I do not underestimate the emotional bond that this could create, his absence would not damage his son or his wife in any serious or lasting way. If the child were to die of RDS, it would be hard for Dave or Maggie not to blame themselves, and this could lead to lasting regret and damage to their marriage. One of the most important lessons for a physician is to learn is "*primum non nocere*." first do no harm. I would try to explain my viewpoint to the couple, that as an autonomous professional I cannot ethically do what I do not think is in the best interests of the child, the mother, and the whole family. However, if they do not wish to accept my advice, they have a right to seek a second opinion about the timing of the birth. Naturally I would be sad to see this happen, having looked after Maggie during her first two pregnancies, but would quite understand should they wish to do this.

Wendy Savage, MD is a retired obstetrician and gynecologist, honorary professor at Middlesex University and honorary senior lecturer at the Medical School of St Bartholomew's and the Royal London Hospitals at Queen Mary College, University of London.

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## ***Virtual Mentor***

American Medical Association Journal of Ethics  
May 2003, Volume 5, Number 5: 162-164.

### **CASE AND COMMENTARY**

#### **Responding to a Request for Early Delivery, Commentary 2**

Commentary by Mary Briody Mahowald, PhD

#### **Case**

Maggie Olsen is 6-months pregnant with her third child and first son when she and her husband, Dave, receive news that his unit is being sent overseas. Dave, a Marine pilot, is not sure how long he will have to stay or how dangerous this mission will be. Maggie understands that the separation is part of being married to a military man but worries about her husband and the possibility of his getting hurt or even killed. Maggie and Dave have planned to name the little boy after his father, and the couple would really like Dave to be able hold his first son before he leaves.

At her next appointment with her obstetrician, Maggie brings all of this up with her doctor, Dr. Anita Beal. With her first daughter, Stephanie, Maggie had difficult and long labor and, when Stephanie's heart rate started to fall, Dr. Beal decided on a cesarean. Stephanie was a healthy baby and has been a healthy child, but she weighed just 5 lbs 10 oz at birth. Maggie had her second daughter, Christine, by cesarean as well; the baby weighed 6 lbs 3 oz. Maggie is scheduled to have this baby by cesarean on June 12, which puts her right at 39 weeks. Maggie asks Dr. Beal if it would be okay to reschedule the surgery for May 30 since her husband has to report on June 1.

Although Dr. Beal understands Maggie's desire for her husband to meet his son she worries about the possibility of complications if the baby is born too soon. Dr. Beal notes that Maggie's two daughters were on the light side and thinks this baby might really need those last two weeks in utero for weight gain. Dr. Beal explains the risks of moving back the delivery date to Maggie and her husband. The couple talks about it and decides they would still like to have the baby before the first of June.

#### **Commentary 2**

Any doctor who assists a woman in delivering her baby is morally, legally, and professionally bound to weigh the expected harms and benefits of the timing and choice of alternative modes of delivery to both the woman and her expected child. Respect for her and her partner's wishes are also relevant to the doctor's calculation. However, when a patient asks for treatment that involves a health risk to her or to another, without countervailing medical benefit to either, no doctor is bound to give priority to her request. Respect for patient autonomy does not impose the obligation of conformity to a patient's request for treatment that is not medically indicated.

Two distinctions are particularly relevant to this case. The first is between treatment for health reasons and treatment for other-than-health reasons. Operative procedures such as cosmetic surgery are routinely performed for nonmedical reasons that may be frivolous in comparison with those that motivate Maggie and Dave, but only when the health risks associated with the intervention are relatively minimal. In the hands of an experienced practitioner, cesarean section at 37+ weeks gestation involves minimal risk to Maggie and her potential child. An infant born at this gestation falls within the threshold of a term pregnancy, and therefore, if the gestational age is correct, does not face the risks of prematurity. However, to insure that the risk is minimal, fetal lung maturity should be tested and fetal weight should be estimated, and both should be judged adequate to healthy survival after delivery on May 30. As long as the risks are small, and Maggie is fully aware of them, Dr. Beal may, but is not obliged, to perform the surgery on that date. Dave's wishes are morally relevant, but Maggie's consent is ethically indispensable because she, not he, will undergo the risks of surgical delivery.

The second important distinction is between the right to refuse treatment, regardless of whether it is medically recommended, and the right to obtain treatment that is not medically recommended. The latter is never as compelling as the former because practitioners may not justifiably be coerced to perform procedures that are professionally inappropriate or morally unacceptable to them. If Maggie were to refuse rather than request surgical delivery, even if cesarean section were considered necessary to preserve her life or that of her fetus, going ahead with it would legally be considered assault. Although some would argue that her refusal is overridable if the surgery is necessary to save or reduce disability in her potential child, this rationale is not generally supported by legal statutes or by medical organizations. However, Maggie is requesting rather than refusing treatment, and the treatment is not only medically unnecessary but entails some risk to her and to her fetus. If the treatment were medically beneficial to either, the physician would be legally, professionally, and morally bound to provide it with Maggie's consent. As it is not medically beneficial to either, Dr. Beal may refuse to perform the cesarean section on May 30. If she cannot in good conscience do so, she should transfer Maggie's care to a colleague for whom the early delivery does not pose a moral problem. Maggie and Dave should not object to this because the ethical principle of respect for autonomy applies to practitioners as well as patients and family members.

If Dr. Beal chooses to perform the surgery, her rationale should be based not only on respect for the couple's autonomy but also on the calculation that nonmedical benefits to them outweigh the health risks to Maggie and her soon-to-be-born son. Presumably, the principal nonmedical benefit to her and Dave is the comfort and joy of both being present to welcome their son into the world on his first day of life. The fact that this is a son rather than a daughter is, or ought to be, irrelevant to the calculation of benefit.

Mary Briody Mahowald, PhD is Professor Emerita in the Department of Obstetrics and Gynecology and the MacLean Center for Clinical Medical Ethics at the University of Chicago, and currently Visiting Professor Emerita at Stanford University Center for Biomedical Ethics. Her recent books include *Women and Children in Health Care: An Unequal Majority* and *Genes, Women, Equality* both published by Oxford University Press.

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## *Virtual Mentor*

American Medical Association Journal of Ethics  
May 2003, Volume 5, Number 5: 165-167.

### **CASE AND COMMENTARY**

#### **Just Don't Tell My Husband, Commentary 1**

Commentary by Carol Tauer, PhD

#### **Case**

Dr. Joe Wilkins delivered Carol Mason's first daughter 3 years ago, and her second daughter is due in 6 weeks. Mrs. Mason's pregnancy has been uncomplicated so far. At her last regular check-up a month ago, Mrs. Mason, who is now 33, asked whether Dr. Wilkins would "tie her tubes" at the time of the delivery. Dr. Wilkins agreed to do so.

At this visit, Mrs. Mason brings up the topic again and requests that Dr. Wilkins not tell her husband, John, about the tubal ligation. "I know he would like to have more children, and really wants a son," she explained.

"You're my patient, and there is no reason for me to tell your husband," Dr. Wilkins replies, "but you should think about the consequences of not telling him. He'll expect you to become pregnant again and wonder why you're not."

"I know, but I don't want any more children. I'm establishing a career that's important to me. John and I have had this conversation a dozen times, and it goes nowhere. The bottom line is, it's my body and I don't want any more children. But I just wanted to warn you that as soon as John sees you in delivery, he's going to ask how it went and whether it looks as though everything's all right for me to have more babies."

#### **Commentary 1**

Carol Mason seems to be placing Dr. Wilkins in an untenable position. She wants him to perform a tubal ligation, conceal this procedure from her husband, and yet be prepared to respond to her husband's anticipated question: Is everything all right for my wife to have more babies?

Dr. Wilkins' first option is to refuse to perform the procedure. Two possible reasons would clearly justify such a refusal: if Dr. Wilkins had a moral objection to permanent sterilization, he would have every right to inform Mrs. Mason of that fact and refer her to another physician. Second, if the woman requesting the procedure were unable to give a true informed consent, either because she did not understand the nature of sterilization or because she was being coerced into having it, then Dr. Wilkins would not only be justified in refusing her, but he would be obligated to do so. There may be other situations in which a refusal would be

legitimate, for example, a request for sterilization from a 19-year-old woman who has not had any children, but such cases are more debatable and require individual analysis.

At any rate, none of these possible justifications applies in the case of Mrs. Mason. Dr. Wilkins has already agreed to perform the procedure, and Mrs. Mason is simply making an additional request of him. How should he respond to her request?

It is clear that Dr. Wilkins' patient in this case is Carol Mason, and that he owes her confidentiality with respect to her medical treatment. All medical codes of ethics stress the importance of confidentiality, and the HIPAA regulations that took effect on April 14 (2003) protect patient information under federal law. There is no spousal exception to the duty of confidentiality.

However, Dr. Wilkins needs to help Mrs. Mason consider the consequences of pursuing her plan to conceal her tubal ligation. She, as well as Dr. Wilkins, would likely be faced with years of questioning from her husband as to why she isn't getting pregnant and whether they should pursue medical services to help her conceive. Is she willing to undergo infertility testing and perhaps even pursue infertility services? To what extent is she willing to engage in an extended charade in order to conceal her medically induced sterilization?

Dr. Wilkins could support Mrs. Mason's wish not to become pregnant by suggesting effective alternatives to sterilization. Her husband might be agreeable to using of contraceptives, even a long-term contraceptive, since this would not permanently foreclose the possibility of another child. Dr. Wilkins could reflect on experiences with other pregnant women who had decided this was to be the last child but who changed their minds later. He could also encourage Mrs. Mason and her husband to seek out a counselor to help them work through their disagreement. Since their numerous one-to-one conversations on the topic "went nowhere," perhaps they need the assistance of a skilled counselor.

If it were clear that Dr. Wilkins was faced with the choice of either breaking confidentiality or outright lying (for example, if Mrs. Mason insisted that he record a false code on the insurance claim because her husband might see it), Dr. Wilkins would be justified in refusing to perform the procedure under those conditions. Otherwise, he should go ahead with the sterilization he previously agreed to perform but should carefully prepare his responses to Mr. Mason's anticipated questions. In addition, he should inform Mrs. Mason what those responses would be.

It is possible for Dr. Wilkins to respond in a way that protects patient confidentiality but is not deceptive. A possible scenario:

**Mr. Mason:** *Did everything go OK?*

**Dr. Wilkins:** *Yes, fine. Mom and baby are doing great.*



**Mr. Mason:** *Is everything all right for Carol to have more babies?*

**Dr. Wilkins:** *She's in excellent health. But with the new federal laws on privacy, I need to be sure I have Carol's consent before I discuss specific medical information with anyone. As her husband, you're certainly in a special position here. I'd suggest that you discuss with her whether the two of you might want to make an appointment to come to my office together in the next few weeks.*

When Mrs. Mason realizes that it is she, not Dr. Wilkins, who will have to answer her husband's questions, she may decide to pursue a different plan. It is she, not Dr. Wilkins, who will have to live with the consequences of her decision for her marriage and her family. The responsibility for these consequences rests on her, not on Dr. Wilkins.

Carol Tauer, PhD is a bioethicist, Professor Emeritus at the College of St Catherine in St Paul, currently Visiting Faculty at the Center for Bioethics of the University of Minnesota, and a member of the Committee on Ethics of the American College of Obstetricians and Gynecologists.

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## ***Virtual Mentor***

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May 2003, Volume 5, Number 5: 168-169.

### **CASE AND COMMENTARY**

#### **Just Don't Tell My Husband, Commentary 2**

Commentary by Cynthia R. Daniels, PhD

#### **Case**

Dr. Joe Wilkins delivered Carol Mason's first daughter 3 years ago, and her second daughter is due in 6 weeks. Mrs. Mason's pregnancy has been uncomplicated so far. At her last regular check-up a month ago, Mrs. Mason, who is now 33, asked whether Dr. Wilkins would "tie her tubes" at the time of the delivery. Dr. Wilkins agreed to do so.

At this visit, Mrs. Mason brings up the topic again and requests that Dr. Wilkins not tell her husband, John, about the tubal ligation. "I know he would like to have more children, and really wants a son," she explained.

"You're my patient, and there is no reason for me to tell your husband," Dr. Wilkins replies, "but you should think about the consequences of not telling him. He'll expect you to become pregnant again and wonder why you're not."

"I know, but I don't want any more children. I'm establishing a career that's important to me. John and I have had this conversation a dozen times, and it goes nowhere. The bottom line is, it's my body and I don't want any more children. But I just wanted to warn you that as soon as John sees you in delivery, he's going to ask how it went and whether it looks as though everything's all right for me to have more babies."

#### **Commentary 2**

Mrs. Mason's physician is correct to maintain patient-doctor confidentiality—it is indeed Mrs. Mason's body, and she has the right to make her own reproductive decisions. For instance, the courts have consistently struck down "husband notification" requirements in state abortion laws, and the same legal principle applies in this case. There is no legal obligation to inform the husband (or father, if the husband is not the biological parent).

Nevertheless, Mrs. Mason's request for a tubal ligation, without her husband's knowledge, is troubling and should send up red flags for the physician. Dr. Wilkins would be wise to further explore the reasons for the requested deception. Are there any outward signs that Mrs. Mason's husband is physically abusive? Is Mrs. Mason in danger of triggering a round of abuse if she reveals her planned action to her husband? Husbands who are abusive often try to isolate their partners. Mr. Mason's

preference that his wife have more children rather than pursue her career may be indicative of this pattern. She is also asking Dr. Wilkins to act as a "barrier" between herself and her husband—another sign that there is fear in her relationship. Dr. Wilkins should be prepared to refer Mrs. Mason to domestic violence service if this is the case. If it is an abusive relationship that Mrs. Mason decides to end, she may have sacrificed her ability to have children with a different future partner—a decision she may later regret.

If this is not an abusive relationship, it is a troubled one. Mrs. Mason's actions are morally questionable. If indeed her husband is a caring father and partner, she may be seriously restricting her husband's future reproductive options by taking this action without his knowledge. Dr. Wilkins is right to encourage Mrs. Mason to be truthful and open. Her husband will no doubt learn of both the tubal ligation, as well as the deception, sooner or later. If she has post-operative complications and her husband is responsible for her care, he will learn of it sooner. Mrs. Mason may then well end up divorced and a single mother, or worse, in a contested divorce where her actions may be used against her in a custody battle. The physician has a responsibility to forewarn her not only of the medical but of the social consequences of her deception.

If confronted in the operating room, or elsewhere, by Mr. Mason about the possibility of future children, Dr. Wilkins should encourage Mr. Mason to treasure the two children his wife has already given him and, together with his wife, discuss their reproductive future.

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## *Virtual Mentor*

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### IN THE LITERATURE

#### **Does Medical Uncertainty Justify Medical Paternalism?**

Jeremy Spevick

Though there is no shortage of studies designed to determine the efficacy of mammography, debate continues in the profession about the effectiveness of routine mammography in reducing mortality from breast cancer.<sup>1</sup> Research over the past 10 years, involving more than 500,000 women worldwide, has drawn vastly disparate conclusions. A meta-analysis of 5 Swedish studies found that mammography screening lowered breast cancer mortality by 29 percent. However, an epidemiological study, also from Sweden, found no decrease in mortality for women who were screened.<sup>2</sup>

The argument for screening is that mammograms can detect smaller tumors with less likelihood of lymph node metastases. There is a cure rate of approximately 90 percent for small tumors (less than 10 mm) without lymph node involvement, and proponents of mammography think that screening will detect many tumors in this size range.<sup>3</sup> Critics contend that mammograms can miss up to 20 percent of potential tumors, thus leaving a significant percentage of tested women who believe, falsely, they are tumor-free for at least another year or until they are tested again. Coupled with the risk of anxiety-provoking false positives, this makes screening less effective than is often believed. The result seems to be that research on the efficacy of mammography has generated, "more heat than light for the public."<sup>3</sup>

The disputed effectiveness of mammography is only one example of a disagreement in the field of obstetrics and gynecology. Research is still inconclusive on the association between oral contraceptives and cervical cancer.<sup>4</sup> And, while physicians agree that tests for the BRCA 1 and 2 genes can identify individuals who have increased risk, they are divided about appropriate use of the test. The BRCA 1 and 2 mutations account for only 5 to 10 percent of breast and ovarian cancer, so negative test results do not mean a woman will not get the disease. On the other side of the argument, for women found to have the mutation, the only known prophylaxis at present is bilateral mastectomy and oophorectomy<sup>5</sup>. Because many women are unwilling to undergo these life-changing surgeries, the value of positive test results is debated.

On issues such as these where there is no professional consensus, physicians face the challenge of how best to inform and advise patients about diagnostic procedures and treatment. When the profession's absence of consensus reaches the mass media,

physicians must decide whether it is ethical to share just their own bias about the disputed treatment and, if not, how much information should be shared with patients; when does information confuse more than clarify?

There is a full range of possible patient-physician combinations in decision making, but 3 are obvious. A physician can use his or her medical knowledge and judgment to arrive at a conclusion and present only that recommendation to the patient. Secondly, the physician may choose to tell the patient that a controversy exists, offer his or her medical opinion, and work with the patient in assessing the risks and benefits associated with different decisions. Lastly, a doctor who is treating a highly informed patient may choose to allow the patient to make a decision after the patient has reviewed the relevant literature.

These 3 scenarios present a spectrum of patient decision-making autonomy. In the minds of many, when either patient autonomy or physician paternalism assumes a dominant role in the patient's decision making the other must be a subordinate influence. Prior to the 1970's, most medical decisions were left to physicians; patients and their families were "spared" the difficult choices encountered in medical treatment. The paradigm shift of the last 30 years has created a patient-centered approach to decision making as the profession recognized the shortcomings of the paternalistic approach: the difficulty of determining a patient's best interest, the risk of stereotyping patients based on race or sex, and the lack of an opportunity for patients to consider treatment options in the context of their particular situation.<sup>6</sup> Today, physicians present medical options, along with risks and benefits, but often leave the final choices up to patients. Some physicians will go to great lengths to not reveal their preference for a particular treatment option.<sup>6</sup>

Writing in the *Annals of Internal Medicine* in 1996, Timothy Quill and Howard Brody suggested ways for physicians to balance physician power with patient choice.<sup>6</sup> As a middle ground for patient involvement, Quill and Brody put forth a model they call "enhanced autonomy." The key element of this model is open dialogue between the patient and physician that explores the patient's values and experiences. The authors argue that it is better for a physician to openly admit biases rather than remain artificially neutral. When facing difficult health care decisions, patients will often be emotionally overwhelmed and seek guidance from their physicians. At the same time, patients are more likely to report greater satisfaction with their medical care when they actively participate in decision making.<sup>6</sup>

Raisa Deber et al took on the task of explaining the patient paradox of need for guidance yet desire to make decisions. In a study reported in *Archives of Internal Medicine* in 1996, the authors asked more than 400 patients how much physician involvement they would like to have in a variety of medical decisions.<sup>7</sup> Looking at the patterns in their results, the authors realized that patients separate medical encounter activities into 2 categories, which the authors called "problem-solving" (PS) and "decision-making" (DM). PS activities are those that require specific

expertise and have a single correct solution. Examples of PS activities include making diagnoses and presenting treatment options with the associated risks and benefits. DM activities are those in which patients must choose the acceptability of risks and benefits for their particular situations and make informed treatment decisions.<sup>7</sup>

Given a series of vignettes, the respondents rated the level of involvement they would wish to have on a 5 point scale, where 1 was the doctor acting alone, and 5 was the patient acting alone. The results confirmed the authors' hypothesis that patients are more willing to have physician control in PS activities than in DM activities.<sup>8</sup>

Although it would be convenient if doctors could classify all decisions into PS or DM, with the knowledge that patients prefer to be involved in DM choices, most medical decisions have elements of both activities. For example, a physician may wish to order a test for the BRCA 1 and 2 genes, the result of which significantly changes a patient's likelihood of developing breast cancer. Formulating patient risks and benefits are PS skills that are usually performed by physicians. However, the decision of whether or not to perform these genetic tests may fall in the DM category, since each patient must determine whether the potential information gain outweighs the possible anxiety and worry that knowledge of the genetic mutation may bring.

In cases such as mammography, where the profession is not in agreement, the question is: does uncertainty justify less patient involvement in decision making, ie, greater physician paternalism? No simple formula or equation tells a physician when to use his or her own judgment exclusively, when to tell patients about professional disagreement, or how much information to provide. Doctors must make that decision for each patient. Some patients will want to know the details of the medical community's disagreement in making an informed choice. Others may state clearly that they wish to follow the physician's recommendations. It may help physicians to be aware of the PS and DM elements of medical decisions in order to allow patients to participate at appropriate times. As expressed by Quill and Brody, this will require a constant balance between patient autonomy and paternalism.

### **Questions for Discussion**

1. How should physicians decide when to tell patients about treatment controversies within the profession? Can you think of circumstances where they would be justified in not informing patients?
2. How can physicians decide how much patient involvement to invite without resorting to patient stereotypes based on culture, age, ethnicity, religious beliefs, or educational level?
3. As a patient, do you agree with Deber's conclusion that patients prefer to be involved in decision-making but not problem-solving activities?
4. Does medical uncertainty justify greater physician paternalism?

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### IN THE LITERATURE

#### **HIV Policy: Does Most Effective Equal Best?**

Susanna Smith

When AIDS was first diagnosed in this country the diagnosis was a death sentence. For women, the diagnosis came with recommendations from the Centers for Disease Control and Prevention (CDC) and the American College of Obstetrics and Gynecology (ACOG) to avoid spreading HIV to an unborn child by not getting pregnant.<sup>1</sup>

The 1994 finding that the antiretroviral drug zidovudine could reduce by 2/3 the likelihood that a woman with HIV would pass on the virus to an unborn child promised to expand reproductive options for women with HIV and change the face of pediatric AIDS cases.<sup>2</sup> (Without intervention approximately 1 in 4 women who are HIV-positive will pass on the deadly virus to their infant either in utero or during labor and delivery.)<sup>3</sup>

The Public Health Service (PHS) then created practice guidelines calling for clinicians and other prenatal caregivers to counsel all pregnant women about the benefits of HIV testing and to offer voluntary HIV testing. These guidelines were quickly endorsed by ACOG as well as the American Academy of Pediatrics (AAP) and other organizations.<sup>4</sup>

Later discoveries of combination antiretroviral therapies reduced HIV vertical transmission rates to as low as 1.5 percent<sup>5-7</sup> and even as low as 1 percent when cesarean delivery was coupled with zidovudine therapy.<sup>8,9</sup> Changes in standard clinical practice have resulted in a sharp decline in the number pediatric AIDS cases attributable to perinatal HIV transmission from its peak at 954 cases in 1992 to just 101 cases in 2001.<sup>10</sup> The CDC currently estimates that about 300 babies contract HIV from their mothers every year.<sup>11</sup>

As of 2000, 35 states (including Puerto Rico and the District of Columbia) offered voluntary HIV testing but had no specific laws governing the testing during pregnancy; 11 states required health care professionals to offer an HIV test to pregnant women; 4 states required caregivers to test the woman for HIV unless she refused testing. In 2 states (New York and Connecticut) it is mandated that a newborn be tested for HIV when its mother's HIV status is not known.<sup>12</sup>

In 1997 Amy E. Lovvorn, Sandra C. Quinn, and David H. Jolly analyzed various strategies for preventing perinatal HIV transmission that they found in range of



policies, from those that did not specify advice during pregnancy to those that proposed mandatory testing of all pregnant women. The Lovvorn et al analysis was based on 4 criteria: avoidance of stigma, right to privacy, effectiveness, feasibility, and 2 that the authors called vertical equity and horizontal equity. They defined vertical equity as treating people in different circumstances differently, usually in an attempt to improve their circumstances, eg, affirmative action or providing special HIV education for groups at high risk for contracting the virus. Horizontal equity was seen as the equal treatment of individuals in similar circumstances, eg, the equal treatment of all pregnant women.<sup>13</sup>

Based on these criteria the authors believed the most acceptable policy was counseling all pregnant women about risks of perinatal HIV transmission and the importance of HIV testing. The only criterion this policy failed to satisfy, in the minds of the authors, was vertical equity because those at higher risk received no special attention. But because all pregnant women would be counseled, Lovvorn et al suggested that this policy would be an effective means of thwarting perinatal HIV transmission.

In April 2003 the CDC released new HIV prevention recommendations, which call for HIV testing to become a routine part of medical care for all individuals including the prenatal care of pregnant women. In instances where the woman's HIV status is unknown at delivery, the CDC recommends HIV testing of the newborn.<sup>10</sup>

The policy analyzed by Lovvorn et al that most closely resembles the policy now being recommended by the CDC was labeled "test pregnant women unless" meaning all pregnant women would be tested for HIV unless they refused. Lovvorn found that this type of policy would satisfy horizontal equity in that it would treat all pregnant women the same, and it would be both feasible and effective. Lovvorn et al objected to this policy, and would presumably object to the current recommendations of the CDC, because it puts the burden of refusing HIV testing on the woman, a move the authors see as a mild form of coercion. They posit that this coercion might compromise the patient-physician relationship and trust. The authors further objected to this type of policy because they think it stigmatizes pregnant women and does not guarantee their rights to privacy. It would seem that the CDC's current recommendations address the stigmatization criticism by calling for routine HIV testing of all people, not just pregnant women.

Although society does have an interest in the health of the unborn and in preventing the spread of the virus, as Lovvorn et al point out, state policies must recognize not only women's rights to privacy and confidentiality but also their parental interest in protecting their infants' well-being. Laws that mandate HIV testing during pregnancy deny women the right to privacy and deny them the opportunity to assert, voluntarily, their parental role as the health care decision-maker for their unborn child.

There is concern that if laws mandate HIV testing, be it for the population at large, among pregnant women, or for all newborns, some patients may not seek needed medical care so that they can avoid being tested for HIV. Lovvorn, Quinn, and Jolly rightly point out that the policy that best identifies HIV-infected women and reduces the number of perinatally transmitted HIV infections may not be the most acceptable policy overall.

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### **HEALTH LAW**

#### **Can the Court Protect a Fetus from Maternal Harm?**

June M. McKoy, MD, MPH, JD

*The primacy of the person is central to the concept of autonomy. Our constitution supports the notion that each person is free to make personal decisions based upon his or her value systems and their beliefs.*

Helen Kasey was addicted to drugs and alcohol. When she became pregnant, her obstetrician told her that cocaine and alcohol could cause harm to her baby and referred her to programs that could help her discontinue their use. Helen did not follow up on these recommendations. After delivery, the hospital tested the baby's blood and found high levels of cocaine and alcohol. The baby girl was later diagnosed with severe cerebral palsy. A court subsequently appointed the child's adult sister as her sole conservator, and the conservator later brought suit against Helen, arguing that Helen's use of cocaine was the proximate cause of her daughter's severe and permanent neurological injuries. The conservator sought damages for past and future medical care, loss of earning capacity, special education, physical and occupational therapy, disfigurement, physical impairments, and past and future pain and suffering. She further sought punitive damages.

The conservator introduced into evidence the child's medical records, which included the physician's notes. It was clear from the notes that the physician knew that Mrs. Kasey was drinking alcohol and using cocaine, and had warned her at every visit to discontinue these substances because they could harm her unborn child. Helen Casey's baby died at the age of 5 years and 7 months.

#### **Legal Analysis**

The above facts are adapted from *Chenault v. Huie*. The plaintiff in this case was the minor child's adult sister, Melissa Chenault, whom a court had appointed as sole managing conservator of the child after the child was diagnosed with severe cerebral palsy. The plaintiff sued the child's mother charging that her consistent use of illegal drugs and alcohol was the proximate cause of the severe neurological damage that left her daughter, now Melissa Chenault's ward, unable to walk, talk, or live independently. The case was dismissed in district court but appealed by the plaintiff. On appeal, the plaintiff's lawyer asked the court to decide whose rights it supported; those of "a selfish crack-addicted mother or her defenseless unborn child?"

The central issue before the Court of Appeals of Texas, Fifth District, was whether a legal duty existed between a pregnant mother and her unborn child. The court reasoned that it was unconstitutional to curtail the rights of the mother. It held that no cause of action exists under tort law (ie, laws governing wrongful acts for which relief may be obtained in the form of damages or an injunction) against a mother for injuries to her child caused by the mother's negligent or grossly negligent conduct during pregnancy. In making its decision, the court posited that the legislature did not intend this type of tort claim to be litigated. The court refused to judicially create a legal duty that would ultimately dictate how a pregnant woman behaved toward her unborn fetus.

The law of torts has very limited role in the regulation of family life, and it is well settled that parents do not owe legally enforceable duties to their unborn children. While the court in *Roe v. Wade* held that the state has an interest in protecting the life of a viable fetus, it recognized the woman's privacy rights. It therefore established a trimester framework to balance state interests against those of the privacy rights of women. It held that states could only prevent abortions where the fetus is deemed to be viable, and, even when the fetus is viable, cannot prevent abortion if it is necessary to protect the life of the mother.

Some have argued that the legislature is the best realm for a discussion and determination of the utility of forced medical and psychological treatment of pregnant women who are engaging in practices that endanger their fetuses. They believe that when a woman chooses to carry a fetus to term, she must accept responsibility for the well being of the fetus. Under the rubric of *parens patriae* [the parents' role], the state could extend protection to the unborn fetus. Others strongly believe that forcing a pregnant woman into unwanted medical treatment, such as treatment for substance abuse, supports beneficence at the expense of autonomy, and is a gross violation of constitutional mandates.

It has been argued that since a fetus is a non-person under federal law, then no person is being harmed when a mother abuses her body, other than the mother. It therefore stands that to interfere with a woman's pregnancy against her will, even when she engages in detrimental health behavior that indirectly or directly threatens her fetus, violates that woman's fundamental rights.

Traditionally, guardians ad litem (GAL) are appointed to represent the interests of individuals who are deemed incompetent to represent their interests in legal proceedings, and in situations where a potential conflict exists between the incompetent person and another decision maker, such as an adult child. Guardians ad litem have been appointed in abortion cases, cases involving maternal substance abuse during pregnancy, and in situations where forced medical treatment is deemed necessary to protect the health of the fetus. In cases where persons have petitioned the courts to appoint a GAL for a fetus to prevent a woman from aborting the fetus, the courts have consistently denied the appointment on the grounds that the represented party, ie, the fetus, has no status or standing under the Fourteenth

Amendment. Courts have split on the issue of appointment of a guardian for pregnant women who abuse drugs. In these cases the courts' judgment rested on whether the fetus was considered to be a child for purposes of the child welfare or child abuse act. *In re D.K.* the court held that prior to viability, the appointment of a guardian ad litem for the fetus was improper. Here the woman was in her first trimester when the guardian was appointed. The court reasoned that the appointment of a guardian in the first trimester was improper since it permitted a third party to exert control over the fetus in ways that contravened *Roe v. Wade*. However, in *In re Smith* the court determined that an unborn child is a person entitled to protection under the state's family court act. Finally, in cases involving forced medical treatment, courts have routinely appointed representatives without comment, and the rulings have been varied. In *Raleigh Fitken-Paul Memorial Hospital v. Anderson*, the court appointed a guardian for an infant when a pregnant woman refused blood transfusion deemed necessary to save her fetus. However, in *Taft v. Taft* the Supreme Court of Massachusetts overturned a lower court's appointment of a guardian to compel a woman to have a cerclage to prevent her from having a miscarriage, reasoning that the state's interest was not sufficiently compelling to justify "curtailing the woman's constitutional rights."

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### STATE OF THE ART AND SCIENCE

#### Treating Uterine Fibroids

Audiey Kao, MD, PhD

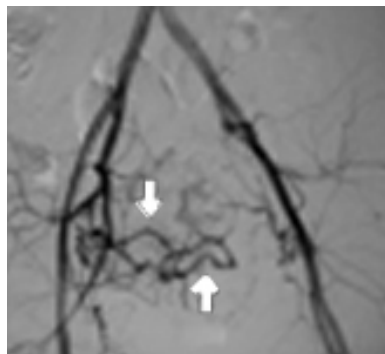
Uterine leiomyomas or fibroids are benign tumors of the uterus that develop in up to 25 percent of women.<sup>1</sup> Significant morbidity from uterine fibroids include prolonged or heavy menstrual bleeding, pelvic pressure or pain, and, in rare cases, reproductive dysfunction.<sup>2</sup>

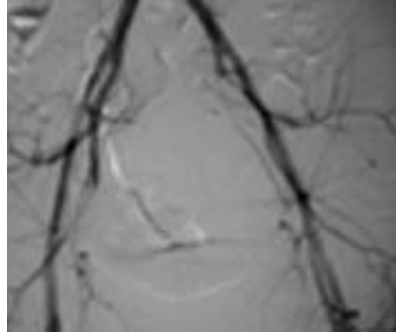
Surgery has been the mainstay of fibroid treatment, and in fact, uterine fibroids are the most common indication for hysterectomies. Treatment with gonadotropin-releasing hormone agonists, alone or in combination with more conservative surgical treatments, such as myomectomy or myolysis, are also used.

More recently, patients have a less invasive option than hysterectomy—uterine artery embolization (UAE). Studies have found that UAE is safe, effective for the treatment of fibroids and less costly than a hysterectomy.<sup>3,4,5,6,7</sup> Some patients, however, may not be good candidates for UAE such as patients who:

- Have extremely large fibroids (fibroid volume is generally reduced by no more than 50 percent),
- Have fibroids that compress the bladder (uterine arterial embolization in these cases may not provide sufficient symptomatic relief),
- Wish to bear children in the future.

UAE interrupts the uterine blood supply by injecting agents such as polyvinyl alcohol articles. As seen in Figure 1, the pre-embolization angiogram shows the uterine arterial blood flow (arrows designate the uterine arteries), while in Figure 2, the post-embolization angiogram reveals no further blood flow through the right or left uterine arteries.





Side effects and complications of UAE include:

- Infection (in approximately 2 percent of cases),
- Irregular menses or amenorrhea (in approximately 10 percent of cases),
- Partial bowel obstruction (rare).

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### **STATE OF THE ART AND SCIENCE**

#### **Reducing HIV Transmission from Mother to Infant**

Audiey Kao, MD, PhD

#### **Epidemiology**

Perinatal HIV transmission is the most common cause of HIV infection in infants in the US, responsible for more than 90 percent of pediatric cases. It is estimated that about two-thirds of mother-to-child transmission occur at delivery and the rest in utero. The epidemiological pattern differs in many parts of the world, where it is estimated that breast feeding can account for up to 50 percent of HIV transmission from mother to infant.<sup>1</sup>

#### **Initiation of Treatment**

In the nonpregnant HIV- infected individual treatment is initiated when:

- CD<sub>4</sub> count falls below 350 mm<sup>3</sup> or,
- Plasma HIV RNA levels exceed 30,000 copies/mL (by b-deoxyribonucleic acid assay) or,
- Plasma HIV RNA levels exceeds 55,000 copies/mL (by reverse transcription polymerase chain reaction assay).

However, for pregnant women who are HIV positive, treatment including cesarean delivery is recommended for women when:

- Viral loads exceed 1,000 copies/mL (by reverse transcription polymerase chain reaction assay).<sup>2</sup>

Factors other than viral load that are associated with increased mother-to-child transmission include:

- Prolonged rupture of membranes,
- Vaginal delivery,
- Premature births,
- Maternal illicit drug use.

#### **Treatment and Prognosis**

Many studies have shown reduction of perinatal HIV transmission among women who received active anti-retroviral therapy (when viral loads were greater than 1000) and elective cesarean delivery.<sup>3,4</sup> With such treatment, transmission rates can be reduced to approximately 1 percent. There has been more experience with zidovudine than with any other anti-retroviral therapy, and the current standard dose is 200mg three times a day or 300mg twice daily.

Women who are first identified as HIV-infected during labor (with no prior treatment) and the babies they deliver should be treated with any of the following regimens:<sup>5</sup>

<b>Treatment</b>	<b>Woman</b>	<b>Neonate</b>
<b>Zidovudine</b>	2mg/kg IV bolus, followed by continuous infusion of 1mg/kg/hr until delivery.	2mg/kg orally every 6 hours for 6 weeks.
<b>Nevaripine</b>	600mg orally at onset of labor, followed by 300mg orally every 3 hours until delivery.	A single dose (2mg/kg) at age 48 to 72 hours.
<b>Zidovudine and lamivudine</b>	Zidovudine-600mg orally at onset of labor, followed by 300mg orally every 3 hours until delivery and,  Lamivudine-150 mg orally at onset of labor, followed by 150mg orally every 12 hours until delivery.	1 week of zidovudine 4mg/kg orally every 12 hours and lamivudine 2mg/kg orally every 12 hours.
<b>Both nevaripine and zidovudine</b>	Both nevaripine as above and the zidovudine regimen as above.	Both nevaripine as above and the zidovudine regimen as above.

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### **POLICY FORUM**

#### **The Virtue of Drawing Lines in Genetic Testing**

Rosemarie Tong, PhD

At present it is possible to test for a wide variety of genetic diseases (both single gene disorders and chromosomal abnormalities) at the preimplantation state (through pre-embryo biopsy) or sometimes during the course of gestation (through maternal serum screening, ultrasound, chorionic villus sampling, and amniocentesis). Such tests are usually offered only for serious genetic diseases such as cystic fibrosis, Duchenne muscular dystrophy, Tay-Sachs disease, hemophilia A and B, Betathalassemia, sickle-cell disease, a -1-antitrypsin deficiency, fragile X syndrome, Lesch-Nyhan syndrome, Down syndrome, and neural tube defects. Moreover, they are usually offered to prospective parents only for established medical reasons. For example, preimplantation genetic diagnosis (PGD), is indicated when a couple has been "psychologically traumatized by repeated pregnancy loss due to genetic disorders"<sup>1</sup> or has had a child with a serious genetic disease previously and is at high risk for having another. Similarly, prenatal genetic testing is indicated when 1 or more of the following conditions is met: (1) advanced maternal age (age 35 and upwards), (2) a family history of genetic abnormalities, (3) membership in an ethnic group that is at risk for a specific condition (eg, Tay Sachs in Ashkenazi Jews, sickle-cell anemia in African-Americans, and cystic fibrosis in Caucasians), (4) a family history of infants with birth defects, and (5) multiple miscarriages.

The present state of affairs is unlikely to remain the same for much longer, however. As genetic tests become available for mild genetic diseases and susceptibilities to genetic disease as well as for a greater number of serious genetic diseases, and as the public becomes increasingly aware of the existence and availability of such tests, prospective parents may demand as much in the way of tests for their future children as their wallets can afford. Some of these prospective parents will want the information to prepare for life with a child that may be born with significant physical and mental disabilities. But others will want the information for the purposes of discarding their pre-embryos or aborting their embryos. Indeed, there is considerable evidence that a high percentage of prospective parents already choose to eliminate embryos with Down syndrome, for example.<sup>2</sup> There is also increasing evidence that a significant percentage of prospective parents would consider aborting their embryos if they had only a slight genetic disease, a susceptibility to genetic disease, or a characteristic that did not mesh with one of their preferences (for example, a preference for a boy as opposed to a girl). In one study, researchers surveyed a sample of prospective parents about

what type of genetic risks would lead them to terminate a pregnancy. They discovered that 1 percent of the surveyed couples would terminate a pregnancy if the fetus was not the sex they wanted; 6 percent would abort a fetus susceptible to Alzheimer's disease; and 11 percent would abort a fetus susceptible to obesity.<sup>3</sup>

Studies such as the one above have triggered heated debates about procreating "less-than-normal" children. Advocates of procreating only "normal" children claim that it is emotionally and economically draining to bring children with disabilities into the world, especially if they have serious genetic diseases or disorders. Furthermore, they argue that it is not in the best interests of such children themselves to be forced to live difficult lives that could have been avoided if only their parents had acted responsibly.

Critics of the "normal" children only argument claim that it reinforces the view of those who long for a society in which only perfect or nearly perfect people are tolerated. They point out, as does lawyer Lori B. Andrews, that the concept of "normality" is a moving target. She claims that as genetic testing becomes available for a greater number of genetic characteristics (most of them non-medical), our understanding of what is normal and what counts as a life worth living will be continually "upgraded."<sup>4</sup> She cites approvingly the views of Michael S. Lagan, a vice president of the National Organization for Rare Disorders, who has commented that "Eventually there will be discrimination against those who look 'different' because their genes were not altered. The absence of ethical restraints means crooked noses and teeth, acne or baldness, will become the mark of Cain a century from now."<sup>5</sup> Like others who wish to slow the march towards genetic perfectionism, Andrews and Lagan are particularly concerned that prospective parents will increasingly feel they have not simply a *right* to test their embryos for genetic disorders and diseases, mild as well as serious, but a *duty* to do so with a view towards aborting embryos that prove to be less than completely "normal."

The current consensus of clinicians is that it is wrong to pressure women to abort "less than normal" embryos. As they see it, couples in general and women in particular must decide whether, in each particular case, they should or should not bring into the world a child with a *serious* genetic condition. However, clinicians are not presently of one mind with respect to advising prospective parents who wish to abort embryos affected by a *slight* genetic disease (eg, myopia), a *susceptibility* to a genetic disease (eg, cancer), or a *non-disease-related* genetic characteristic (eg, sex). Some clinicians believe that it is up to prospective parents to decide what they consider a "normal" child; but others insist that judgments about "normalcy" belong to the public as a whole.

One way to prevent prospective parents from terminating pregnancies of embryos not affected by serious genetic diseases and defects would be to withhold from prospective parents information about their fetuses' slight genetic diseases, genetic susceptibilities, and generally non-health related characteristics (eg, sex).<sup>6</sup> But the *medical* justification for this policy is not altogether clear, unless test results for

such genetic characteristics are highly inaccurate, difficult to interpret because of the way in which environmental factors influence one's genetic health, or very costly. Thus, an increasing number of clinicians who value autonomy over paternalism believe that absent such considerations, they have neither a right nor a duty to withhold from prospective parents any of the information they discover about the embryo's genetic condition. Not only do they reason, as mentioned above, that it is up to prospective parents to decide what kind of child they are ready, willing, and able to raise, they also reason that if a woman decides to exercise her right to have an abortion, it does not matter to the law whether she does so because her healthy fetus is male rather than female, because she and her husband do not have the means to rear a child, or because her fetus has tested positive for Tay-Sachs disease. Finally, some clinicians stress that if clinicians prevent prospective parents from learning everything there is to know about the genetic status of their child, prospective parents will simply turn to technicians outside of the health care realm for this information. Better, they say, for prospective parents to be properly counseled and advised by trained clinicians who can guide them to wise reproductive decisions than to leave them to the vagaries of self-administered, in-the-privacy-of-your-own-home genetic tests, the results of which are sent to a distant lab which, in turn, sends prospective parents a print-out of their fetus's complete genetic status.

Although I agree that if clinicians draw lines about the kinds of genetic tests they offer, some unscrupulous technicians may arise to take advantage of prospective parents, I still think that clinicians should continue to valiantly steer between the Scylla of patient autonomy run wild and the Charbydis of clinical paternalism grown arrogant. Medicine is not simply a set of techniques and tools that may be used, willy-nilly, to attain whatever ends people have, and clinicians are far more than mere technicians who simply have a bag of skills to sell to the highest bidder. It would be a colossal shame if, in the name of preventing prospective parents from turning to an irresponsible and amoral technician-entrepreneur class that may or may not arise, clinicians find themselves no better than their rivals. Better to continue the hard work of line drawing, and all the human disagreement and tension that entails, than to destroy the hard-won and long-sustained internal morality of medicine and with it one's own ideals.

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### **MEDICINE AND SOCIETY**

#### **Assisted Reproductive Technologies, Sex Selection, and the Commodification of Children**

Timothy F. Murphy, PhD

The idea of "husbandry" in regard to children is as old as the 4th century BCE. In the *Republic*, Plato imagined a systematic breeding scheme to produce the kind of human beings appropriate to different social strata and tasks. The wish for certain kinds of children has led societies to eugenic gambles on an enormous scale—both in ambition and in disastrous effect. Even apart from vaunting ambitions of social engineering, would-be parents harbor hopes and ideas about what kind of children they want to have. Assisted-reproductive technologies (ARTs) work at an ever-receding horizon of power: the extent to which parents and society may exert control over the traits of children cannot be fully forseen.

Working with clinicians, prospective parents can now select against children with identifiable genetic traits, and this is routinely done in the United States when there are worries about hereditary disease. Some commentators object to these practices because they find the techniques involved—in vitro fertilization, embryo transfer, embryo freezing, and selective reduction among them—objectionable in themselves. Even more commentators become concerned about the use of these techniques in selecting traits that are not related to health but that are related to the expectations of parents. This worry persists even if the traits are represented as *advantages* to children: intelligence, height, and the like. The moral worry here grows out of a number of issues, including the worry that ARTs will turn children into commodities, into products like others on the shelf of Madison Avenue whiter whites and brighter brights.

When it comes to expectations about their children's traits, many prospective parents *are* keenly interested in having a boy or a girl in any given pregnancy. There is, for example, strong interest in pre-conception methods of selecting children of a specific sex. One approach involves sperm sorting in order to avoid pregnancies with a fetus of an undesired sex. At the present time, however, pre-conception techniques are not especially successful. If techniques were to become successful, the American Society of Reproductive Medicine counsels its members that it can be ethical to offer couples techniques of sex selection to blend boys and girls in their offspring. If this use proves safe generally, this professional organization also believes it would be ethical to select for a first-born or only child for reasons related to the different meanings and companionship experiences parents expect to have with the child.<sup>1</sup> Pre-conception techniques of sex selection



are still very much in the experimental stage, but other techniques do allow for effective sex selection, embryo and fetal testing. These techniques are, however, expensive and complicated and—for those reasons—not widely available. They do ultimately, however, involve the same moral issues.

Some commentators have noted the way in which the preferential selection of males over females works to the disadvantage of females.<sup>2</sup> There is divided opinion about whether this effect would be significant in countries where cultural advantages are equitably distributed across sexes. The effect of sex selection on family dynamics is also relevant to an assessment of the morality of the techniques: in selecting the sex of children, are parents treating that child in a way that works against either the bonds between parents and children or the well-being of the children themselves? And, again, there is the worry that sex selection amounts to a kind of "shopping" that devalues the dignity of children and possibly their well-being.

There is something to the moral concern that parental control over traits can alter the way children are seen. How many tests do children have to pass in order to be wanted, loved, and respected by their parents? And what happens to family bonds and to children themselves when children fail to pass those tests?

Seen in isolation, the issue of sex selection can appear to be a stark and dehumanizing focus. However, parents do elsewhere exhibit powerful control over the nature of their children's traits. Parents profoundly influence their children in regard to language, moral values, religious views, political opinions, attitudes toward health, table manners, and so on down the line of traits that one generation bestows upon another. Seen against this backdrop, it is important to ask whether sex selection is so very different from other choices that parents make about the kinds of children they work to have. Indeed, giving some say to parents about the sex of their children can work to bond parents and children more closely. It is also worth pointing out that sex selection might have a protective function for some children, namely, for those girls or boys who would otherwise be born to parents who do not want them.

Philosopher Mary Warnock has said that "it seems to me to be a fundamental moral principle that we ought to love and cherish our children as beings separate from ourselves and with their own distinct characteristics."<sup>3</sup> It is impossible to know in advance what all the effects of ARTs will be either for a given family or for society at large. There is room for plenty of caution when it comes to extending the reach of parents over the traits of their children. However, if Warnock's counsel can be preserved as parents avail themselves of ARTs, there will be fewer reasons to worry about the selection of their gender in particular and the commodification of children in general.

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### **VIEWPOINT**

#### **Pelvic Exams Performed on Anesthetized Women**

Dena S. Davis, JD, PhD

Recent revelations in the news media about unconsented pelvic exams performed on anesthetized patients by medical students for the education of the students, not the medical benefit of the patient, highlighted a stunning chasm in communication and thought between 2 groups: medical educators and potential patients. I first found out about this issue when a member of a bioethics "chat group," hosted by the Medical College of Wisconsin, posted an article about the practice. The responses by chat group members were astounding: nonphysicians (primarily female) reacted with shock and outrage. Physicians and physician educators often responded by saying, "This is the way everyone learns to do pelvic exams. What's the problem?"

Although I am not usually a proponent of resorting to law as a way to cross communication barriers, sometimes the "teaching function of the law" can be the most effective way of opening the eyes of one group of people to the way in which the world is experienced by another group. The evolution of rape law in the US is a good example of this. Defining rape as unconsented sexual intercourse, with or without physical violence, helps people (men and women) to understand how damaging to the victims such practices as "date rape" or marital rape truly are, and says in unequivocal ways that the community has ruled such behavior to be so offensive that perpetrators will be subject to legal penalties.

In the case at hand, therefore, it is useful to point out that unconsented pelvic exams on anesthetized patients are subject to both civil and criminal penalties. First, such behavior constitutes the tort of battery. Battery is defined as harmful or offensive contact. These pelvic exams clearly constitute offensive contact. The student (or the institution) might claim that she or he could not have known that the person would regard it as offensive, but that defense will not wash. For one thing, if the medical faculty assumed that most patients would consent, they would just ask; the resistance to asking permission suggests that they know that at least some patients would refuse. (Further, even among the number of patients who would give permission if asked, there are certainly many who would be outraged to discover that they had been handled in this way without their knowledge and consent.)

In the realm of criminal law, the Ohio Criminal Code tracks many other states when it defines "sexual conduct" as "without privilege to do so, the insertion, however slight, of any part of the body or any instrument, apparatus, or other object into the vaginal or anal cavity of another" (Sec. 2907.01(A)). "Without privilege to do so,"

clearly implies the necessity of consent. The definition of rape (Sec. 2907.02) includes sexual conduct with another when...the other person's ability to resist or consent is substantially impaired because of a mental or physical condition. Sexual battery (Sec. 2907.03) includes sexual conduct when the "offender knows that the other person submits because the other person is unaware that the act is being committed."

Defining the offense as a sexual one is understandably distressing to physicians, who have gone to great lengths to define pelvic (and mammary) exams in nonsexual ways. But medical practice cannot abstract itself from the culture in which it operates; thus we have the persistent preference of many patients for female gynecologists, the practice of requiring chaperones when male doctors perform pelvic exams even on conscious patients, and other ways in which the medical establishment acknowledges the special status and concerns that attach to the reproductive parts of our bodies, parts that used to be colloquially referred to as "our privates." Our community expresses that heightened concern by surrounding offensive touching of one's reproductive parts with heightened protection and heightened penalties for infractions.

Finally, and at the risk of distracting readers and falling prey to the charge of sensationalism, I need to remind physicians of the rare but highly publicized cases of health care providers who have exploited unconscious patients by, for example, inserting a penis in the mouth of an anesthetized patient. These cases reinforce in the minds of women that they are sexually unsafe when powerless and unconscious, even in a medical setting.

It is wonderful that the objections to the practice of unconsented pelvic exams came primarily from medical students. All that training in ethics is clearly paying off! As a staff editorial in the Washington University student newspaper said, "If a student were to have performed that same procedure on an unconscious, intoxicated woman, it would certainly have been labeled sexual assault. It is horrifying that when a WU teaching doctor ordered a medical student to do the same thing to an anesthetized hospital patient, it was instead labeled a pelvic exam."

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