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At the Bedside

How Should Careproviders Respond When the Medical System Leaves a Patient Short?

Edmund G. Howe

This issue of *The Journal of Clinical Ethics* offers a new feature: a public forum on bioethics conducted at Harvard Medical School. The first of these transcripts involves a new law in Massachusetts that provides more-universal medical insurance to residents of that state.[1] But, despite this new law, patients may still be left short. Marcia Angell, MD, one of the presenters in the forum, comments that trying to meet the needs of all Massachusetts residents may be like trying to squeeze blood out of a turnip. *What about inflation?* she asks. In every context, some patients will need more medical resources than they can get, raising difficult questions for careproviders:

- When — if ever — should careproviders limit the medical resources they give to some patients, so that these resources can be given to other patients?
- When — if ever — should careproviders game the system for a patient?
- When — if ever — should careproviders sacrifice their own needs to benefit a patient?

In my introduction to this issue of *JCE,* I will discuss what careproviders might best say to patients in each of these three circumstances.

TRIAGE

Two or more patients may sometimes need the same medical resource, such as an ICU bed, and when this happens, someone must decide who will get the resource. When two or more patients who need the same scarce resource have the same careprovider, the careprovider may have to decide who will get the resource, or may refer the decision to someone else. The example of the scarce ICU bed is, in fact, the most frequent kind of triage problem that careproviders face.[2]

When making a decision about which patient will be admitted to the ICU, careproviders will accord the most weight to medical considerations, but such decisions are always, to some

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extent, inherently ethical. Thus, perhaps the greater society should make the decision about who should be admitted to the ICU — and so perhaps who has the greater likelihood of living or dying. Often, however, for numerous reasons, society hasn't spoken,[3] and careproviders make these triage decisions by default. It may be ethically preferable for careproviders to try to find an available ICU bed elsewhere, but what they should *do* isn't the question I will discuss. Rather, I will discuss what they should *say*.

In these circumstances, careproviders can choose to make a decision themselves, or they can let someone else make the decision. Referring the decision to another may be much easier, because they will be able to wholly ally themselves with their patients' interests. If they opt to make triage decisions themselves, however, it may be much more painful: they will have to tell their patient that they will make a decision that may compromise the patient's best interests, due to limited resources.[4] Should careproviders divulge this, and, if yes, what is the best way to do this?

Before considering these questions, however, I would like to clarify that this ICU example is only one of many possible examples; careproviders constantly face situations like this. Researchers who have studied triage in the ICU report, for example, "this overarching priority [dilemma] trickles down to everyday priority setting decisions. This trickle-down effect causes everyday decision-making to become a series of moral stress tests for clinicians."[5]

HOW MUCH SHOULD CAREPROVIDERS TELL PATIENTS?

When a triage decision must be made, what should careproviders tell a patient? If careproviders say that they — or the hospital — must make a decision that will compromise the patient's best interests, the patient may strongly react; the patient may leave the hospital or bring forth an appeal. It may be easier for careproviders to refer making these triage decisions to others, but it still may be difficult for careproviders to continue to fulfil their commitment to the patients's best interests. For example, it takes substantial amounts of time to argue that one's patient should be admitted to the ICU. Also, most patients aren't aware that triage decisions are routinely made, and those making the decisions may become irate when they learn that patients are being informed. Given these difficulties, when the need for a patient to be admitted to the ICU is marginal, and it would be within the standard of care to admit the patient to the general ward, careproviders may prefer to make a decision to admit the patient to a general ward, not the ICU, rather than refer the decision to another — and not tell the patient that they did this.

If careproviders choose to make the triage decision themselves, they compromise, to some extent, their total and exclusive commitment to the patient. Should they tell the patient that they have made a triage decision? Doing this may completely impair the patient/careprovider relationship.[6] Yet if they don't, they may add lying by omission to compromising their patient's best interest. Of course, this may be, like using therapeutic privilege, for the patient's own good.

Whether careproviders should make a triage decision is open to question, but, if they do, it may be that they should be fully honest about it. It may establish the kind of patient/careprovider relationship, based on trust, that can allow patients to transcend the negative response to the withholding of resources that they otherwise might have.

HOW SHOULD CAREPROVIDERS DIVULGE THIS INFORMATION?

What might be the best way to inform patients? Whether careproviders have chosen to make a triage decision or not, they can say how sorry they are that, due to limited resources, the patient may receive less than optimal care.[7] This simple statement is all-too-often omitted.[8] When careproviders choose to make a triage decision, they can tell the patient why, for example, they and they alone can best decide what will benefit their pati-

ents, considered together, because they best know all of their patients' medical needs. Patients who are given this explanation may accept it.

Careproviders may then talk about the pain this causes them. They could say, for example, *My having to do this is killing me. I know your pain is much, much worse than mine, especially at hearing that the resources you need are limited. But this kills me anyway!*

To the degree that careproviders can feel pain and openly acknowledge it when they have to fill this decision-making role, they may acknowledge that patients and careproviders share this state of helplessness: the need to triage is outside the control of both. To acknowledge this may help some patients feel equal. Other patients may have a shift in how they feel: prior to this they may have felt they were sitting, as it were, opposite their careprovider, but now they may feel as though they are sitting side by side, two comrades united against a common enemy, namely the limited resources available.

The possible effect of this may be transforming, and it may enable patients to transcend the sense of loss, or even outrage, they might otherwise have felt for the rest of their lives, in response to being triaged. This possibility was expressed well by Hans Georg Gadamer, who said, in a more general context, "this whole process is only valid if it is reciprocal. Think of the humiliation when a greeting is not returned,"[9] and "what we have here is something truly universal in which you and I are the same."[10]

WHEN SHOULD CAREPROVIDERS DIVULGE THIS INFORMATION?

Careproviders make these kinds of decisions every day, for example, whenever they choose to spend less time with one patient than they could, knowing that, as a result, they will be able to spend more time with another. These kinds of decisions are made so frequently that it is difficult to know when to disclose them to patients. I have two principal criteria that I suggest.

The first criteria for careproviders is, *Do you think the patient will see your making a triage decision as compromising his or her best interests?* One rationale underlying this criterion is that careproviders should not withhold information from patients.

The second criteria is, *Do you feel any anxiety in response to withholding information from a patient?* One rationale underlying this criterion is that what careproviders *feel* may, in some cases, be a better guide to what they should do than what they *think.* This is likely to be the case when a patient's feelings and his or her relationship with the careprovider are at stake.

On the other hand, careproviders may (like anyone else) rationalize how they would like events to turn out. As I mentioned above, it may be painful for careproviders to disclose to a patient that a triage decision has been made, whether the decision was made by the careprovider or not. Realizing this, careproviders may rationalize that it is appropriate to keep a triage decision secret.

But careproviders can also take into account whether — or to what degree — the triage decision makes a significant clinical difference. When the patient is placed at little risk by a triage decision, it may not be as important to divulge that such a decision was made — although the effect on careproviders of keeping any secret from patients — important or less important — is the same, oddly enough. It may be that, in making triage decisions, it is as theologian Paul Ramsey said: "*absolutely everything* is commanded which love requires, absolutely everything without the slightest exception or softening."[11]

There is, finally, one more problem. Researchers report that, on a neurobiological level, manifested through neuroimaging, some of us respond more empathically to pain than others.[12] Similar to the rest of the population, some careproviders are probably more empathic than others. Careproviders who are interested in using the two criteria above may first try to imagine where, on a hypothetical scale for being empathic, they may be. Careproviders who rate themselves lower on the

scale shouldn't feel discouraged, as they may be more effective in innumberable contexts when they are more objective than empathic. Many patients, if they had to choose, would prefer to have a careprovider who is optimally knowledgable, rather than one who is less knowledgable and more empathic.

But careproviders who see themselves as less empathic on this scale may be at a disadvantage using only the second criteria (how they themselves would feel about keeping a secret from a patient). These careproviders may try, systematically, to use the first approach more (whether patients could see making a triage decision as compromising their best interests). This approach requires careproviders to use their imaginations more than their emotions; careproviders might systematically place themselves, in their imagination, in the shoes of every patient they see who could be affected by limited resources. This exercise may enable them to compensate for the empathic capacity they may feel they lack, relative to other careproviders.

GAMING THE SYSTEM

Studies report that it is not uncommon for careproviders to game the system to help their patients. In one study, for example, 28 percent of the careproviders interviewed reported that they exaggerated the severity of a patient's symptoms; 24 percent said they had changed a patient's diagnoses; 10 percent said they had recorded nonexistent signs and symptoms to help a patient.[13] Many careproviders say they do this because their professional obligations require it.[14] Careproviders may do these things more often in managed-care settings.[15] Gaming may or may not be ethically justifiable in any context, but if gaming is ever justifiable, the argument in its favor is stronger, obviously, in some cases than in others.

Such an instance may be, in general, when a new medical policy has just been adopted, and at the present its relative benefits and burdens are not entirely clear. For example, some years ago a policy was adopted to discharge newborn infants and their mothers more rapidly after delivery.[16] Some careproviders who feared that some of these newborns could be unduly harmed by the new policy tried to game the system, and found reasons to keep the new mothers — and so their infants — in the hospital longer.[17]

In general, it is the majority ethical consensus, by far, that careproviders should not game the system.[18] A primary concern is that if careproviders game the system it may seriously and fundamentally undermine the medical system itself. Instead, the majority consensus is that careproviders should try to change the system if they feel it does undue harm or is unjust.

I have heard from several careproviders who want to help patients who need home oxygen but can't afford it. When patients' oxygen levels are low enough, they may be able to qualify for assistance. The careproviders tell me that they advise their patients to exercise before their blood is drawn, to lower the level of oxygen in their blood. (There is now some evidence, however, that oxygen may not be as helpful as careproviders once believed.)[19]

In circumstances like this, the first choice careproviders make is whether to game the system. Their second choice is deciding what to tell a patient if they decide they won't game. A third choice may be whether to give a patient the name of a careprovider who *will* game the system (if known). This is legally safe. Many careproviders who admit that they game the system say they fear being caught; in one study, 57 percent of the careproviders who admitted that they gamed the system to aid patients said that they feared being prosecuted for fraud.[20]

It may be easier for patients to accept that their careprovider refuses to game the system than it is to accept that their careprovider is willing to make a triage decision that may affect the patient's best interests. Careproviders who refuse to game can tell patients quite credibly that they won't do it because it is immoral. Even though patients won't benefit, they may respect their careproviders more. Still, care-

providers who won't game may be obligated to tell patients even when patients don't know to ask. Part of their ethical obligation — if not their professional obligation — is an implicit promise to help patients as much as they can. Since careproviders have more knowledge about gaming, perhaps they are obligated to tell patients that they will not game, but there are careproviders who will — and perhaps help patients who are interested find them.

Careproviders who educate patients about gaming the system may decrease the amount of injustice in the system, because patients who know that the system can be gamed will no longer have an advantage over patients who don't. (The same arguments apply, to an extent, to informing patients about triage decisions.) Patients may react strongly upon learning that the system can be gamed, but that their careprovider won't do this because it is wrong — they may try to find a careprovider who will game the system.

Beyond this, it may be morally inconsistent for a careprovider to tell patients that he or she could game the system but won't because it is wrong: by telling patients that the system can be gamed, the careprovider may in fact further the values that he or she opposes. This is the case to an even greater extent if a careprovider gives patients the name of a careprovider who will game.

Beyond ethical concerns, careproviders who game the system may, as I mentioned above, be emotionally harmed by a fear of legal liability. Even when careproviders won't game, they may be vulnerable to feeling emotional pain: they may feel guilty that they did not help a patient, whether or not this is irrational. But there may be an optimal way for careproviders to tell patients that they won't game the system, that will lessen these hurtful feelings, for both parties.

As discussed in regard to triage, careproviders can begin by expressing regrets, and then explain why they believe that they can't game. Should they decide to do this, the challenge is to be fully honest. Careproviders may want to say they will not game because it is a matter of moral conscience, when in reality part of their concern is fear of being prosecuted (even when the possibility that this might happen is extremely remote). It is morally acceptable in almost every case for careproviders to choose not to do things for a patient that causes them fear — among other reasons, if they do something that causes them fear, they may come to resent the patient, and this may destroy their relationship altogether. In this situation, a fully honest disclosure might be: *I don't want to game the system — partly due to personal moral scruples, partly because I don't want to be caught breaking the law — and, really, it might be hard to say which is stronger!* Sharing this openly and honestly may preserve the sometimes profound positive outcomes that a trusting patient/careprovider relationship can achieve.[21]

SACRIFICING PERSONAL INTERESTS

A third way that careproviders may respond when medical resources are deficient is to sacrifice their own personal interests to better meet the needs of their patients. A classic example is when careproviders risk death to care for patients during an epidemic.[22] In the early years of the HIV epidemic, careproviders feared caring for patients with HIV. If a pandemic were to occur, to what extent would careproviders be willing to sacrifice their own interests — and those of their families? Mitigation plans for these kinds of catastrophes commonly include how best to distribute the services of careproviders who are available0.

Yet careproviders could, in these conditions, refuse to assist. They would know that their loved ones could become infected, and, in these extreme conditions, they might choose to stay with their family members to protect or care for them, rather than attend patients. Such potential conflicts between meeting patients' needs optimally or meeting our own needs, also arise daily in clinical situations due to limited medical resources. Conflicts may involve such small acts as a careprovider deciding whether to call a patient

after work, at the end of the day, to inquire how the patient has fared on a new medication.

Careproviders who make phone calls for this and other reasons may benefit patients far more than might be imagined. They may significantly motivate patients to better manage any number of chronic illnesses such as diabetes that may cause very serious additional medical problems such as blindness and death.[23] Careproviders' phone calls have even been reported to help patients who have problems involving substance abuse and adolescents who are suicidal,[24] both of whom are among the most difficult patients to treat. The most common conflict, however, is when a patient requests an intervention that a careprovider, due to conflicting personal feelings, doesn't want to provide.

For example, patients may ask careproviders to give them exceptional medications, diagnostic tests, or referrals to specialists.[25] These exceptional measures will probably provide greater benefit, but are more costly than routine measures. Careproviders may want to avoid them, in part to hold down costs, but also because they fear that others who have greater responsibility for minimizing costs will criticize them for "caving in to patients' demands." In many cases careproviders could agree to patients' requests for medical reasons, but, in fact, careproviders often agree for personal reasons.[26] Patients may exert extreme emotional pressure on careproviders to comply with their wishes, over time. As one cardiac surgeon stated, "I think what's more of an urgency rating score is the guy who stamps his feet."[27] At a certain point — and this is different for every careprovider — we may choose to grant patients' requests over and against our own personal wishes to avoid discomfort.

When situations arise in which careproviders can benefit patients by making self-sacrifices, and they are aware that this is the conflict they face, they should answer the same questions discussed above:

- Should careproviders ever self-sacrifice? If yes, when?
- If careproviders can help a patient by self-sacrificing, but choose not to, for whatever reason, should they tell the patient?

The second question can be extended. Suppose a careprovider decides to tell a patient that she or he *could* self-sacrifice — but *won't.* Should the careprovider go further? Should the careprovider tell the patient that he or she would make the same self-sacrifice if the patient was a family member? It may sound absurd to even ask this last question, because no matter how nicely it is stated, it sounds contemptuous, but it is very often the truth. For example, it is not all that unusual for a careprovider to bypass usual channels to reach another careprovider when a family member has an urgent medical need. As I will discuss below, some patient populations will only do well when their careprovider is absolutely honest with them, and tells the truth to this degree.

Further, as I stated above, when careproviders disclose information to patients, they help to decrease the advantage that informed patients have over uninformed patients. Or, careproviders could decide that they will disclose this kind of information to patients only when patients ask about it; for example, a patient may say, "I bet you would do this for me if I were a member of your own family. You would do this for your family, wouldn't you?"

As in the discussion about triage decisions above, careproviders may be able to use how they feel in a situation to understand what they should do. If they can identify a painful feeling because they did not do something for a patient that they could have, they can use this feeling to infer the possibility that they have not meet the patient's needs to the greatest extent possible, because it conflicted with meeting a need of their own.

As an example, I recall a time that I chose not to self-sacrifice for a patient, which I regret even now. A patient had a problem involving drug abuse and missed his appointment with me. I considered calling him immediately, but didn't. Even though I didn't call, I continued to feel anxious that I hadn't.

At the time, the patient was experiencing cravings, and there is data suggesting that my calling him may have made a difference in his outcome. In fact, the patient did relapse, but now is doing better.

My point is not that I should have called (whether I should have is now clinically a very controversial debate).[28] My point is that the painful feeling I experienced when I decided not to call could have alerted me that the call might have met my *own* needs. I was fully aware that, to succeed with the patient, I should begin wherever the patient was at that time.[29] But I rationalized and told myself that the patient should take responsibility for his own problem. While this was true in one sense, it was not true in that the patient lacked the skills he needed to do this on his own, at that time.

In any case, there are a number problems with self-sacrificing; for example, even when the degree of self-sacrifice is small, careproviders may feel resentment toward a patient afterward, and this resentment may deprive them of the capacity to relate well with the patient. One careprovider stated, for example, "[I am] not the sort of moral saint who could carry out a self-sacrificial life without exhibiting bitterness and resentment."[30]

Given that some careproviders know that they could self-sacrifice and will not, why even consider disclosing this to a patient? Why take truth-telling to this degree? The overriding answer is: *It is the truth.*

Careproviders may be able to be honest about who they are, as fellow humans, with patients. This may be particularly important to patients, should they end up without medical resources they need. When careproviders tell patients they won't self-sacrifice, the effect on patients may not be as bad as might be imagined; in fact, the effect might be just the opposite. For example, I have shared this kind of painful truth with patients on more than one occasion, usually involving my challenging another careprovider who has made a determination regarding the patient. In these instances, the patient might have benefited if I was successful in challenging the determination — for example, the patient might have received increased monetary gain for her or his illness. I should add that, in all of these instances, it would have been most unlikely that I would have been able to change the determination, as sole dissenter — the majority view would almost surely have prevailed.

I have sometimes said to a patient in these situations: *I could challenge this determination, but I can vividly imagine the exceptional stress I will feel if I do. Thinking about it, I really don't want to do this. I'm sorry.* Surprisingly, the patients have not become angry, walked out, or sought another careprovider. It is as if they appreciated and perhaps even were moved by my candor. In one way or other, they offered me their support! One patient, for example, reversed roles and gave me counseling: he said, "People have to make decisions whether they are right or wrong. If they are wrong, that's just how it goes."

As I mentioned above, it may not be a net good for careproviders to consider making such sacrifices because they end up resenting the patient, which will harm the relationship with the patient, and harm the patient. This resentment may be outside the careprovider's conscious awareness, and be insidious. In my very limited experience, the most important benefit in disclosure has been the gain in the quality of the relationship that patients and careproviders experience. Such improved emotional engagement may be exemplified by the response of the patient I described above, who decided to offer me some counseling. The increased engagement may occur in response to self-disclosure; perhaps the disclosure has a leveling effect, as I previously said.

On the other hand, some careproviders might want to disclose to a patient that they could help, but won't, as a way to relieve their own guilt feelings — almost as an unfaithful spouse might, confessing to a marital partner after an affair. Given these complexities, what should a careprovider say to a patient who says, "You would do this for me if I were a member of your family!"?

I have had this experience, as have many others; for example, when a patient is a per-

son who feels exceptional agony when alone, and wants the careprovider to be available night and day. When a patient who felt this way said to me, "You would do this for me if I were a member of your family!" I said, *Yes, you're right. I would be available to a family member as you want me to be available to you, just as you say.* Whenever this occurs, responding honestly to the patient is critically important to the survival of the relationship and its subsequent thriving.

This is where I have chosen to draw the line in my own practice: I do not tell patients that in some instances I will not self-sacrifice unless they ask me. In this way I may be treating my patients less than equally, as my patients who don't ask me about this won't know.

Some patients will not feel resentment even when careproviders do share this kind of information with them, for example, patients who are homeless or those who are presently incarcerated. I have had the extreme good fortune to talk with some careproviders who are exceptionally effective in enabling these patients to transform and find new meaning in their lives. The careproviders are able to reach the patients, form relationships with them, and, based on the relationships, enable the homeless and incarcerated to find unprecedented meaning in their lives. The careproviders say they have been able to do this by being absolutely authentic, or honest, with these patients. The careproviders say that their success includes telling patients, when they ask, the truth about what they and others feel about the patients.

It is possible that the patients who ask, "Would you sacrifice more for your family than you would for me?" want, more than anything else, to know if their careprovider will tell them the truth. Patients who don't ask may not want to know; they may prefer to avoid the ugly human truths that can be made explicit with total candor.

It is possible that the absolute candor that persons who are homeless or imprisoned may require in a relationship with a careprovider exists in all of us, wholly out of our consciousness. Here is an account that suggests this.

I was seeing a teenager who, in a fit of anger, smashed out all of the windows in his father's car with a sledgehammer. He said his family had told him that they thought his doing this was both crazy and wrong, and he asked me if I agreed with them. Perhaps unwisely, I said "Yes." He became very angry and stormed out. He refused to see me again. After some time had passed, though, he called, saying he wanted more than anything to take his own life, so didn't know why he was calling me. He agreed to resume treatment. He didn't take his life and is now doing well. Why did he call? Perhaps it was because of my previous honesty.

Some final points. In the situations described above — triage, gaming, and self-sacrifice — rather than making decisions about disclosure, careproviders could ask patients what they want. They might say,

- *Due to limited resources, other patients' competing medical needs may have to be considered against yours. Would you want me to tell you more about this, if this was going on now?* or
- *Sometimes careproviders game the system for patients, or they may be willing to stretch — or even distort — medical findings to benefit patients. Would you want me to tell you if this was possible, even if I, myself, was not willing to game the system?* or
- *In some instances, careproviders can go beyond the present standard of care, and that may possibly benefit a patient. Would you want me to tell you when this is a possibility, even when it isn't something I myself would offer?*

The downside to asking is that patients may well say, "No, I don't want this information." They may say this not because it is the truth, but because they sense that saying "Yes" would be painful for the careprovider or for themselves. They may want to protect their careprovider, as I mentioned previously.

Finally, what happens if a careprovider takes one of the initiatives I've described and it *bombs?* What if a careprovider says one of

the things I've suggested, and the patient objects? There are ways that a careprovider can help. First, express regret: *I'm sorry that I am only able to offer you somewhat less than full treatment,* or, *I'm sorry that I'm not willing to game the system,* or, *I'm sorry I wont be available for you as much as you'd want me to, when other careproviders might.*[31] When apologizing, a careprovider should be particularly careful not — even implicitly — to give a patient some (false) excuse. It may be overwhelmingly tempting to make an excuse in this situation, but doing this may undo all the careprovider has gained from telling the whole truth.

Second, careproviders should validate the patient's responses. *Of course you feel hurt and angry. I would feel this way if I were you, too.* Third, a careprovider should ask, *Is there a way — anyway that you can think of — that I could still possibly make amends? Perhaps even something I could do differently when I see someone else?*

It may be that what the patient asks for is not be possible. Still, the careprovider asked, and what the patient suggests may be possible.

I end this section with another example. Several years ago, I failed to free myself up to go to a patient's funeral. The patient's husband, whom I'd treated with her, told me when the funeral was, and then said, "I know you're busy, please don't come." I didn't, and it turned out that the husband was crushed. I called him later and acknowledged how bad I felt for not attending the funeral. I also said that this would not happen in the future; I would make it my priority to go to the funerals of patients. This was how I made amends. Saying all this, particularly making and expressing this amends, I believe, enabled us to get back to where we had been.

CONCLUSION

Political innovations, such as those now taking place in Massachusetts, will result in more patients receiving the care they most need. Still, careproviders will most likely continue to face many difficult ethical choices when resources are limited.

Careproviders may want to tell patients more in these situations than they customarily have said in the past; in regard to self-sacrifice, I have suggested that when careproviders share that they *could* help, but *won't,* the results may be paradoxical: some patients may respond by wanting to reassure their careprovider that if they are human in this way, it is okay with them.

Albert Camus wrote in *The Plague* about a physician, Dr. Bernard Rieux, and his anguish under the conditions of a plague. Camus wrote, "What's true of all the evils in the world is true of plague as well. It helps men to rise above themselves."[32] This may be so; when resources are limited, as they are during a plague, it may also bring out the very worst in people. But in the more everyday circumstances of scarce resources, careproviders may have a unique opportunity to relate to their patients without the usual barriers. Careproviders may be able to openly acknowledge their shared helplessness and even vulnerability. By acknowledging more openly the stark realities that confront them, careproviders may be able to establish a connection with patients that they, or their patients, have not had before.[33]

NOTES

1. This public discussion perhaps exemplifies Alvin Gouldner's claim that, in general, as persons become more educated they become increasingly committed to the collectivity as a whole. A.W. Gouldner, *The Future of Intellectuals and the Rise of the New Class* (New York: Continuum, 1979), 65. To the degree that this commitment has occurred or will occur, most persons in ethics would not only celebrate this vision, but consider its emergence long overdue.

2. The most common in-patient triage decisions in U.S. hospitals involve access to intensive care. J.C. Moskop and K.V. Iserson, "Triage in Medicine, Part II: Underlying Val-

ues and Principles," *Annals of Emergency Medicine* 49, no. 3 (March 2007): 282-7, p. 282.

3. Physicians' decisions affect almost 80 percent of what care patients get. M.K. Wynia, D.S. Cummins, and J.B. Van Geest, "Physician Manipulation of Reimbursement Rules for Patients," *Journal of the American Medical Association* 283, no. 14 (12 April 2000): 1858-65, p. 1858.

4. There are obviously problems when any persons make potentially life-and-death decisions for others. See, e.g., R.M. Veatch, "Who Should Manage Care? The Case for Patients," *Kennedy Institute of Ethics Journal* 7, no. 4 (December 1997): 391-401.

5. N.A. Walton et al., "Priority Setting and Cardiac Surgery: A Qualitative Case Study," *Health Policy* 80, no. 3 (March 2007): 444-58, p. 454.

6. R.M. Veatch and C.M. Spicer, "Futile Care: Physicians Should Not be Allowed to Refuse to Treat," *Health Progress* 74, no. 10 (December 1993): 22-7, p. 23.

7. For a discussion of this see A. Fiester, "Viewpoint: Why the Clinical Ethics We Teach Fails Patients," *Academic Medicine* 82, no. 7 (July 2007): 684-9.

8. Ibid.

9. H.G. Gadamer, *Hegel's Dialectic*, trans. P.C. Smith (New Haven, Conn.: Yale University Press, 1976), 64.

10. Ibid., 72.

11. Emphasis Ramsey's. D.H. Smith, "On Paul Ramsey: A Covenant-Centered Ethic for Medicine," *Second Opinion* 6 (November 1987): 107-27, p. 89, citing P. Ramsey, *Basic Christian Ethics* (New York: Charles Scribner's Sons, 1950), 89. Ramsey argues, according to Smith, that "Jesus's commandment to love shows me how I ought to be related to each and every one of the many other persons with whom I come in contact," p. 109.

12. M.J. Banissy and J. War, "Mirror-Touch Synesthesia is Linked with Empathy," *Nature Neuroscience* 10, no. 7 (July 2007): 815-6.

13. Wynia, Cummins, and Van Geest, see note 3 above, p. 1861. See also R.M. Werner, G.C. Alexander, and A. Fagerlin, "Lying to Insurance Companies: the Desire to Deceive among Physicians and the Public," *American Journal of Bioethics* 4, no. 4 (2004): 53-9.

14. Wynia, Cummins, and Van Geest, see note 3 above, p. 1859.

15. Ibid.

16. M.J. Maisels and T.B. Newman, "Jaundice in Full-Term and Near-Term Babies Who Leave the Hospital within 36 Hours: The Pediatrician's Nemesis," *Clinical Perinatology* 25, no. 2 (June 1998): 295-302.

17. For a contemporary view, see L. Goulet, A. Fall, and D. D'Amour, "Preparation for Discharge, Maternal Satisfaction, and Newborn Readmission for Jaundice: Comparing Postpartum Models of Care," *Birth* 34, no. 2 (June 2007): 131-9.

18. See, i.e., E.H. Morreim, "Gaming the System: Dodging the Rules, Ruling the Dodgers," *Archives of Internal Medicine* 151, no. 3 (March 1991): 443-7.

19. M.L. Nonoyama et al., "Effect of Oxygen on Health Quality of Life in Patients with Chronic Obstructive Pulmonary Disease with Transient Exertional Hypoxemia," *American Journal of Respiratory and Critical Care Medicine* 176 (2007): 343-9.

20. Wynia, Cummins, and Van Geest, see note 3 above, p. 1862.

21. See, as an example of the meaning that a relationship with a careprovider can create, L. King, "On Being a Doctor: The Veil," *Annals of Internal Medicine* 145 (2006): 932: "His hand grabs mine and closes on it with surprising strength. 'No. Don't leave.' . . . He is not alone after all. At least not while I am with him."

22. O.P. Grell, "Conflicting Duties: Plague and the Obligations of Early Modern Physicians Towards Patients and Commonwealth in England and the Netherlands," *Clio Medico* 24 (1993): 131-52; J.D. Arras, "The Fragile Web of Responsibility: AIDS and the Duty to Treat," *Hastings Center Report* 18, no. 2 (April-May 1988): S10-20.

23. S.M. Donahoe et al., "Diabetes and

Mortality Following Acute Coronary Syndromes," *Journal of the American Medical Association* 298 (2007): 765-75.

24. J.A. Burleson and Y. Kaminer, "Aftercare for Adolescent Alcohol Use Disorder: Feasibility and Acceptability of a Phone Intervention," *American Journal of Addiction* 16, no. 3 (May-June 2007): 202-5; G. Vaiva et al., "Effect of Telephone Contact on Further Suicide Attempts in Patients Discharged from an Emergency Department: Randomized Controlled Study," *British Medical Journal* 332, no. 7552 (27 May 2006): 1241-5.

25. R.A. Bell et al., "Unmet Expectations for Care and the Patient-Physician Relationship," *Journal of General Internal Medicine* 17, no. 11 (November 2002): 817-24.

26. S.A. Keitz et al., "Behind Closed Doors: Management of Patient Expectations in Primary Care Practices," *Archives of Internal Medicine* 167, no. 5 (12 March 2007): 445-52; R.L. Kravitz et al., "Direct Observation of Requests for Clinical Services in Office Practice: What Do Patients Want and Do They Get It?" *Archives of Internal Medicine* 163, no. 14 (28 July 2003): 1673-81.

27. Walton et al., see note 5 above, p. 451.

28. "This model . . . is in contrast to the abstinence model that has long dominated the substance abuse field. . . ." D. Fisk, D. Sells, and M. Rowe, "Sober Housing and Motivational Interviewing," *Journal of Primary Prevention* 28 (2007): 281-93, p. 290. See, in this regard, C. Strong, "The Neurobiology of Free will and Drug Addiction," *NeuroPsychiatry* 8, no. 7 (July 2007): 1ff.

29. D. Fisk, J. Rakfeldt, and K. Hefferman, "Outreach Workers Experience in a Homeless Outreach Project: Issues of Boundaries, Ethics and Staff Safety," *Psychiatric Quarterly* 70, no. 3 (Fall 1999): 231-46, p. 239.

30. J. Stuart, "A Virtue-Ethical Approach to Moral Conflicts Involving the Possibility of Self-sacrifice," *Journal of Social Philosophy* 35, no. 1 (Spring 2004): 21-33, p. 24.

31. Fiester suggests that if this relationship can't be established, careproviders should refer the patient to another. See Fiester, note 7 above, p. 688.

32. A. Camus, *The Plague*, trans. S. Gilbert (New York: Random House, 1991), 125.

33. Fiester states, "Because the patient has no other support people with him . . . , the only individuals with whom he has a relationship are the members of the treatment team, and they must assume this role." Fiester, see note 7 above, p. 687. See also King, note 21 above.

Features

Autonomy and the Family as (In)Appropriate Surrogates for DNR Decisions: A Qualitative Analysis of Dying Cancer Patients' Talk

Jaklin Eliott and Ian Olver

INTRODUCTION

A fundamental premise of Western medical discourse and practice is that of patients' autonomy, holding that patients have a right to make decisions about their healthcare, including treatment at the end of life.[1] One such decision is to refrain from initiating cardiopulmonary resuscitation (CPR) following cardiac arrest in a terminally ill patient: a *do-not-resuscitate* (DNR) decision. The ascendance of patients' autonomy has led to increased promotion of advance directives, wherein patients state their preferences for their future treatment, including decisions about DNR.[2] Despite this, many if not most patients do not make such decisions in advance, and, as decisions about CPR are typically required when a patient is incompetent,[3] decisional authority passes to another, to a surrogate decision maker. Debate continues, however, regarding standards of surrogate judgment, the criteria for the nomination of surrogates, the existence of competing models of autonomy, as well as dispute over the nature of decisions about DNR. Some identify these decisions as not simply a matter of personal choice, but as constrained by medical, social, legal, and economic concerns.[4]

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AUTONOMY AND SURROGACY

Surrogacy is premised upon a presumption that the autonomy of patients is the dominant standard for decision making. When making decisions, a surrogate is presumed to apply particular standards. The dominant, legally accepted standards are *substituted judgment* and *best interest*.[5] Substituted judgment is generally preferred, with the justifi-

cation that it encodes and reflects patients' wishes, and thus best serves patients' autonomy.[6] Family members are sometimes deemed to have a *prima facie* claim to surrogacy[7] because they are likely to know about the patient's wishes due to their mutual long-standing intimate engagement, are most likely to care about the patient and the realization of her or his wishes,[8] and to shape and share the values underpinning the patient's decisions.[9] Finally, family members are patients' preferred and most-often named surrogates,[10] despite consistently reported discrepancies between a competent patient's preferences for treatment and a family member's assessment as a surrogate.[11] Differences between a surrogate's and a patient's judgments may be moot in many cases, as, when judgments differ, significant numbers of patients identify some deviation from their wishes as acceptable.[12]

The best-interest standard requires that surrogates consider only the patient's current state to make a decision in the patient's best interest.[13] This standard is recommended as avoiding the emotional turmoil and conflict of interests that may be inherent in the more subjective standard of substituted judgment.[14] Some have argued that emotional attachments between family members may interfere with a family member's ability to make a rational decision about a patient's preferences, and displays of emotion have been seen as potentially constituting grounds for disqualifying the judgment of family members,[15] thus excusing them from the responsibilities of surrogacy, with the physician identified as a preferred, dispassionate decision maker.[16] Such arguments draw upon a model of autonomy that values a process wherein an individual rationally and independently weighs up objective facts before arriving at a reproducible decision. Some claim, however, that this model is theoretically and empirically flawed, and recommend, rather, *relational autonomy,*[17] which defines and locates an individual within a network of social relationships and moral obligations, and emphasizes the presence and effect of emotions in decision making.

Most debate about DNR and surrogacy cites practices and policies within the United States, with relatively little discussion or research within Australia.[18] As in the U.S., however, when there is no documented decision regarding DNR, CPR is the default option for patients who experience a cardiac arrest within an Australian medical institution.[19] Additionally, Australian legislation covering advance directives (which allow for naming a surrogate and encompass patients' preferences regarding DNR) has followed U.S. models.[20] Australian law and ethical debate pertaining to DNR decision making has confirmed patients' autonomy as paramount.[21] Despite this, advance directives are rarely used,[22] patients do not always discuss CPR with their doctor,[23] and some do not wish to do so.[24] Thus, doctors often make these decisions, deeming them to be medical decisions,[25] although some report that family members are typically enjoined or expected to make decisions on the patient's behalf.[26]

The majority of medical discussion regarding DNR, decision making, and surrogacy reflects a professional perspective, and patients' perspectives about end-of-life decision making are correspondingly sparse.[27] Some qualitative studies have questioned medical professionals,[28] patients' families,[29] non-patients,[30] or cancer patients who are not approaching death,[31] but the views of dying patients have been absent. One study featured interviews with terminally ill patients regarding their currently established DNR orders, but this was limited to discussions about their relevance during a perioperative period.[32]

There has been less examination of patients' talk about surrogacy. Determining how patients justify their preferences regarding surrogate decision making would enable investigation or verification of the relevance of theoretical assumptions, recommended guidelines, or hospital policies.[33] In one qualitative study examining cancer patients' perspectives

on DNR decision making, participants typically asserted that patients should state their preferences for future treatment, and named family members as appropriate surrogate decision makers.[34] Yet few had recorded their views or had named an appropriate surrogate. Furthermore, family members were identified as potentially or actually constraining patients' autonomy, or as unwilling or unable to undertake surrogate decision making. These patients were not currently dying, however, and many implied that these issues were relevant only for dying patients. This article focuses upon such patients, and is part of a larger study on issues surrounding dying patients' perceptions of DNR orders, some of which have been reported elsewhere.[35] Here we examine participants' responses to questions regarding surrogacy, particularly focusing on how family members featured in surrogacy.

METHOD

This study was conducted at the Royal Adelaide Hospital and was approved by the hospital ethics committee. Patients attending the oncology clinic who met inclusion criteria received an information sheet detailing the project, and were asked by their primary caregivers (including oncologists and palliative care physicians) if they would be willing to participate in an interview. Inclusion criteria were that patients were older than 18 years with English as their first language, and had been assessed by their long-term attending medical oncologist as being capable of coherent discussion and as being emotionally stable. Of these patients, 28 participated (13 female, 15 male, average age 61), and all but four were in-patients. Patients' primary cancer sites varied, but all were currently in the final phase of their illness, assessed by their medical oncologist as likely to die within three months, and — critically — aware of their prognosis; most (23 of 28) died within three months of interview. Half of the subjects chose to have others (usually family members) present, who sometimes spoke during interview. These interjections provided valuable data, specifically demonstrating familial interaction around DNR decisions.

Recruitment ceased when subsequent interviews revealed no additional information. Signed consent was obtained prior to commencement of the interviews (25 to 75 minutes long); these were conducted by the first author, who was not part of the clinical team. To ensure anonymity, pseudonyms have been adopted. We asked open-ended questions to elicit patients' speech about the issues surrounding DNR decision making, but encouraged participants to discuss anything they considered relevant. Interviews were taped, then transcribed using standard grammatical convention to enhance readability and clarity.[36] Transcribed data were entered into the software package N6,[37] and, following the principles of discourse analysis (DA), coded into categories representing particular ways of talking about DNR orders, associated people, and events.

Discourse analysts argue that, in using language, individual speakers draw upon pre-existing ways of talking about things, using patterns of meanings that are culturally and historically specific. In so doing, speakers re-produce and collectively re-construct (rather than merely describe) their social world. Further, proponents of DA propose that talk is action-oriented — that people use language to different effect, to achieve different things. Thus an individual's account of a phenomenon — or different individuals' accounts of the same phenomenon — will exhibit variation according to the specific context within which the account is produced.[38]

Two distinct strands of DA have been defined: *conversational analysis* examines sequential turns of talk in the immediate interactional context, determining what talk is doing at each moment. *Foucauldian* or *post-structuralist analysis* situates language within a wider societal context, noting that patterns of meaning (sometimes called *discourses*) carry with them particular power relations

that enable and constrain what can be said and done.[39] One relevant concept within this approach proposes that individuals are allocated a position (are positioned) within a discourse, one that carries with it a set of rights and responsibilities that acts to delimit what they can do and say.[40]

Some have recommended integrating these two strands, noting that while talk functions to achieve some specific action *in situ,* it must engage the social, cultural, and historical context in which the talk is produced, either reproducing or challenging available discourses.[41] We used this "synthetic" approach[42] to explore how participants drew upon commonly available discourses to support different conclusions about family members as surrogate decision makers, and to investigate the interactional implications of their talk, including how patients and family members were variously positioned, as well as how speakers discursively negotiated issues that may have been problematic. This was specifically relevant when family members were either the producers or referents of speech.

In the following, we describe how different aspects of autonomy were invoked to render family members as both appropriate and inappropriate surrogate decision makers. We then consider how, in interactive dialogue, patients and family members can re-present opposing positions, noting some implications of such conflict. We present results and discussion (data and analysis) together to facilitate readers' assessment of the credibility of our conclusions.[43]

RESULTS AND DISCUSSION

FAMILY ARE APPROPRIATE SURROGATES

Participants' accounts of their own decision making lend support to models of decision making that presume autonomy to have a relational or social component.[44] Most participants held that DNR decisions were theirs to make, but the involvement of some family members appeared to be taken for granted, although the nature and extent of this assumption varied.

Family Members Who Support the Patient

Most participants reported discussing the issue with various family members, suggesting that family members knew their wishes, and would support or agree with their decision.

> Ross's wife Margie: I can understand the illness, and we've [she and Ross] already talked about it, and so the decision could be [up to] me. . . .
> Ross: I've made the decision on the path that I'd like them to follow.
>
> Uri: I've made my decision and my wife and I have talked about it, and we've just made the decision that if it comes to that point, that I've instructed her not to go ahead with it, and, so that's how we've made that thing go. . . . And that's my decision, that's how I feel anyhow.

These participants re-presented the conventional version of family members as literally and figuratively "there" for the patient, thereby best qualified to know and convey his or her wishes.[45] The involvement of family members in the decision-making process was taken as normal and appropriate, particularly in the role of providing support through participation in discussions.[46]

Patients were nonetheless constituted as primary. Patients make the decisions, then speak to their family members, who then "follow" or are "instructed" accordingly. There is, however, a reciprocal implied obligation that the patient should actually make the decisions, most clearly articulated by Vera and her husband Ben.

> Vera: But basically I guess I decided all myself. Didn't I, because you wanted me to do=
> Husband Ben: =Well it was your decision=
> Vera: =what I wanted to do.
> Ben: That was my thinking on it. . . . That you had to make that decision, and then

> I'd support you and go along with it. But I think that that had to come from you. . . . I think the whole family sort of thought like that.

Thus, although the family might support Vera, she "had to make that decision. . . ." To assign the roles of decider and supporter is relatively uncomplicated in (most) cases, wherein the patient accepts responsibility for making the decision; but it is problematic if the patient does not accept the responsibility (see the sections "When Family Members Are Inappropriate Surrogates" and "When Family Members and Patients Are in Conflict," below). Participants also suggested, however, that familial discussion might fulfil other functions than establishing patients' decisions and family support.

> Uri: To a point, you must discuss it first because, you know [your family] have got to have some point of intake too that you, that they can point out things that you might have overlooked on the way. . . .

Uri depicted family input as useful in aiding the patient to consider all relevant information, a further aspect of the support role,[47] simultaneously implying that the family's "point of intake" constituted relevant information for the patient. However, Uri, as did Scott and Tom below, presented such familial discussions as mandatory, using imperatives such as "must" and "should." This establishes inclusion of the family in the process as an obligation placed upon the patient, highlighting the decision as being both moral and social.

> Scott: I discussed it with . . . me whole family. . . . If you don't [discuss with them], my opinion . . . they'll tend to think "Well he never discussed it with us, and he's left us out in the lurch" or whatever. And I think it's vital that they do talk it over with the family. Because . . . the final decision is up to you what you do. But the family will then have a good idea what you're doing. . . . Yeah, keep them in the know, yeah.

> Tom: I can't see why anyone wouldn't wanna discuss it [with their family], I mean, if they didn't wanna discuss this, I think they'd be a pretty cold attitude of looking at the situation. . . . I think the more open it is, about the situation, the better. But when the time comes it's still a blow, but perhaps lightened, lightened the way by sort of talking. . . .

Here, failure to discuss DNR decisions with family members was negatively presented as insensitive and, conversely, keeping family members informed was positively presented as benefiting the family. Although others have noted that patients consider the consequences of their decisions upon family members,[48] this analysis suggests that participants also considered the consequences of including (or not) the family in the decision-making process. What featured as important were the consequences upon the family's emotional status, and discussing the issue with family further rendered both normative and a moral necessity for the patient.

Notwithstanding family member's entitlement to inclusion or consideration in the decision-making process, many asserted that ultimately the patient's "opinion" should hold sway, even in the face of potential disapproval or disagreement from family. The language used below, moreover, suggests that there may be some obligation laid upon family members to work to effect the patient's wishes.

> Yves: I said to [my wife] before, "It's probably me being selfish in my views, but they're my views and that's what I want to happen. . . . I'd appreciate those things . . . being observed."

> Opal: I suppose if I'd made the decision not to go along with [resuscitation] . . . that should apply. But I suppose the family also should have a right to say whether you can

> or not, I guess it'd be up to them as well. I don't know. No, the only thing I would feel is that if I told them definitely that I didn't want to be put on life-support then they wouldn't do it. They'd go along with what I wanted.

Family is here construed as appropriate surrogate decision makers on the grounds that they represent the patient's wishes and enact the patient's autonomy,[49] regardless of their own positions on the matter. Although John Hardwig has argued that patients' autonomy should not include a right to assert their values over those of their family,[50] this representation by the participants in our study mirrors claims that patients' consideration of their family members' dissent or disapproval constitutes another factor that patients might legitimately take on board while arriving at their own decision.[51]

Family Who Have a Stake in the Outcome

Participants most often nominated family members (or a specific family member) as surrogate decision makers when considering a situation when the patient's decision was not available at the time that a decision was needed (for example, at the moment of crisis), a point that has been noted by others.[52] The common-law assumption that family members have "a presumptive right"[53] to be consulted in such circumstances, with appropriate explanation and justification required if they are not,[54] is evident in the following excerpts.

> Wendy's husband Dennis: But doesn't it . . . come back to the next family member? . . . If you ask "Well do you want to resuscitate?" isn't it the mother, the son would be asked. I know that if she's too far gone to make a decision, they'd ask the next-of-kin surely, to make that decision for them, is what they'd do?

> Yves: I mean it's different if a person is in a kind of comatose or vegetive [*sic*] state. It revolves [*sic*] to the next-of-kin then I should say. . . . If they won't make the decision, I think it's best off for the next-of-kin to make the decision that's best off for them.

We note that the terms *family* and *next-of-kin* may be problematic. Their use obscures the fact that the entity to which they refer is composed of individual members in different relationships to the patient (who is also part of that family), who have different sets of values, experiences, and needs. In nominating family members as surrogate decision makers, participants reproduce the construction of the family as a homogenous "superpersonality" that thinks and acts as one,[55] despite evidence to the contrary,[56] including within this research (see the sections "When Family Members Are Inappropriate Surrogates" and "When Family Members and Patients Are in Conflict," below).

The positioning of the patient and his or her family with respect to DNR decisions (including process and outcome) might usefully be characterized as points along a continuum. At one extreme — that emphasizes the personal, individualistic aspects of autonomy and of DNR decisions — patients may justifiably assert their views over that of their family members. At the other extreme — that emphasizes the social, relational aspects — family might be deemed as entitled to claim (or to be assigned) greater involvement in or responsibility for making decisions, even obliged to make decisions. Within this study, discussions with patients and family members are not depicted as a one-way street, wherein a patient considers her or his family members' views and then his or her decision. For example, in discussing one decision, Sally spoke of obtaining her family's views, then basing her decision upon their expectations of her.

> Sally: [My family and I] all got together . . . and I said "This is it, it's up to us now what to do." And they all gave their opinions, I said I wasn't going to give my opinion at first. And they all gave their opinions on it. And they were all heartily agree-

> able that I should fight on. Do take the necessary precautions, the treatment that was being offered to me, and that. That they were behind me. And they spoke so nicely about it that I didn't answer them straight away, but I thought about it, and I thought "I cannot refuse them that, try, try it."

This excerpt conveys how Sally established and balanced her obligations to (1) take responsibility for a decision that is ultimately about her treatment and (2) consider others. She began by identifying the decision, not as hers, but as her family's ("it's up to us"). Nevertheless, her family's acquiescence that she not voice her views initially suggests some tacit acceptance of her authority to control the decision-making process. In addition (by her account), they construed the issue and potential future actions under review as hers (she "should fight on" et cetera), with themselves in a supportive role ("they were behind me"), further confirming her in the primary role.

Sally's description might be understood simply as reflecting a process of rational decision making, but her description also indicates the complexity of her situation and the decision she faces. It was not information conveyed by the family that Sally identified as the relevant factor in accounting for her decision, but the "nice" way that they presented it. "Nice" carries an evaluative and emotional connotation, which works to stress the emotional as an important element in this process.[57] Furthermore, Sally's presentation of herself as obliged to responding positively to a family request ("I cannot refuse them") indicates that her decision has social and moral import.

Nonetheless, Sally's authority to make the decision is implicit in her statement that she "didn't answer them straight away, but I thought about it." This represents her as weighing up her family's requests, with an implied ultimate right to accept or decline their preferences. Thus, decisions about an individual were re-established as fundamentally personal.

Although this leaves unanswered the question of whether Sally's actions might represent some degree of coercion by her family members, or simply Sally's autonomous decision to engage and accept her family members' viewpoints, or even some amalgamation of the two, it reveals that although it may be difficult to separate the interests of family members and patients, patients can manage to value both while maintaining the supremacy of the patient's choice.

WHEN FAMILY MEMBERS ARE INAPPROPRIATE SURROGATES

There were instances wherein participants identified family members as inappropriate surrogate decision makers, most often in descriptions of their experiences as the patient approached death.[58] For example, some participants indicated that the inevitability and imminence of a patient's death were difficult for some family members, manifested in some form of denial.

> Pete: I guess it [responsibility for DNR decision] depends where there's acceptance of where they're going, you know, (. . .) the family stuff. I know with my neighbor, she stood by her husband's bed day and night saying all the time "Don't you dare leave me, don't you dare leave me." And (. . .) how could he die? . . . she never wanted to talk about it.

> Opal: Although he [Opal's husband] knows it's inevitable, he's a bit of an ostrich too, he doesn't sort of want to think about it yet. . . . I said to Beckie [her oldest daughter] "Further down the road you've got to see to this, see to that," and she seems to be accepting of it all, she's not quite, buries her head like her dad. . . .

Here, a spouse was characterized as avoiding thinking about or discussing "it," that is, the patient's imminent death. The behavior

of each spouse can be readily understood as emotionally derived, and failing to meet the standards required for rational decision making. This potentially justified excusing them from the responsibility of the decision, rendering them inappropriate surrogate decision makers.[59] Certainly, insisting that such individuals actively deal with and make such decisions can be deemed to violate their autonomy, and thus would be of questionable ethical status.[60]

If family members and patients can justifiably avoid these discussions as liable to have a negative effect on their (emotional) well-being, the extent to which family members can know and represent the patient's wishes will be compromised. Indeed, discussions of death by family members and patients are often limited.[61] What is of critical importance here is that family members' participation in good familial relationships (and this includes the participation of the patient) may compromise the extent to which they can know and represent the patient's wishes. Similarly, Una specifically rejected her family members as appropriate surrogate decision makers, on the grounds that they would be too emotional and involved, implying that the "head medical person" was a preferable surrogate precisely because she or he would not be so involved.

> Una: If the patient is not of mental capacity to make that decision, I think it's up to a medical doctor. Not the family because they get, there's too much emotional and other involvement.

Emotional involvement or closeness is typically used to justify naming a family member as a surrogate (see "Family Members Who Support the Patient," above), and such emotional involvement is part of normative notions of family.[62] However, as the display of emotion in decision making can be deemed to interfere with the desired rational process, the very conditions that constitute family members as appropriate decision makers can function to identify them as inappropriate surrogate decision makers.

WHEN FAMILY MEMBERS AND PATIENTS ARE IN CONFLICT

Precisely because the concepts of family and autonomy can be differentially invoked to justify prioritizing the wishes of either the patient or the family, conflict is possible, as demonstrated in an interchange between Sean and his wife Vicky. The conflict followed Sean's justification of his deference to his family and his positioning of Vicky as integral to his decision making.

> Sean: [I've] never even thought about anything like [making a decision about DNR]. But I think, yeah, I think my answer would have to be, well, . . . I'd be happy that the family, whoever were around at the time, would do just what they wanted to do. . . . I want to be so independent. And I don't want [Vicky] cracking herself up because of me. . . . Especially because we've [Sean and Vicky] worked so much together, that I don't like to work independently.

Here, Sean asserted his willingness to defer to his family members, notwithstanding a desire to be independent and ensure Vicky's well-being. The importance of "independence" is often associated with the patient assuming responsibility for the decision in order to relieve others.[63] Thus independence is valued because of the effects manifested within an interpersonal relationship: independence does not imply separation from others, but attachment to them. Sean presented interdependence as the habitual practice between he and his wife, providing further support for his deference to her (as a specific member of his family). Drawing upon a relational version of autonomy and identification of the decisions about DNR as social, Sean justified his position of not accepting responsibility for it.

His wife Vicky, however, invoked the primacy of a patient-based decision to justify her insistence that Sean decide and she function merely to carry out his expressed wishes.

> Vicky: I don't want to get involved. I want to get his opinion, not mine. I just want

him to say what he wants. . . . Well, I think my decision really, should rest with the patient, so that his wishes are strictly carried out, and that is my opinion. That is strictly my opinion. Whether it is his opinion is totally different. . . . I won't say too much, because I don't want to sway him, but I really want him to have his say in what he feels, and what he wants.
Sean: Well, I feel I want you to say. I have said what I wanted to say. And I haven't asked you many questions. I haven't asked you for many questions.
Vicky: No, but I came in here to listen
Sean: Yeah, I know. . . .
Vicky: You can see that different people do have different views which is why I've kept quiet, I just wanted to get his.

Although Vicky was ostensibly prioritizing Sean's "wants," his wants were repeatedly framed in the context of what she wanted, thus asserting the weight of her wants. In doing this, Vicky (1) effectively invalidated Sean's position of wanting not to actively articulate (or make) a decision, and of wanting to know her position; (2) countered Sean's wants with her wants; and (3) placed some moral obligation upon Sean to respond positively to her desire to know his wants. Indeed, the conversation emerged as the clash of "wants." Both Sean and Vicky, however, could justify their own silence on the matter (and their deferral to the other) by invoking a particular aspect of autonomy, with associated representations of DNR decisions. Sean did this through an appeal to relational autonomy, and by construing DNR decisions as social decisions. Vicky did this through an appeal to individual autonomy, and by construing decisions about DNR as essentially personal decisions.

Nonetheless (perhaps unfortunately for Sean), his account and Vicky's account identified a patient's avoidance of making decisions as problematic; that is, if Sean continues to maintain his silence, he risks disappointing Vicky and demonstrating that he has dismissed her views, which he earlier identified as important to him. Conversely, Vicky's repeatedly stated preference — that Sean decide — undermines the validity of what might arguably represent an autonomous decision on Sean's part: to not make a decision regarding DNR. Finally, to the extent that Sean's equivocation can be seen as failing to meet his obligations to Vicky, or as failing to make an autonomous, adult decision about his own healthcare, Sean could be subject to moral censure. Thus, in contrast to normative assumptions regarding autonomy, individuals might be constrained to disregard their own preferences in situations such as these.

CONCLUSION

We acknowledge that only dying patients with cancer were interviewed, and patients dying from other illnesses may draw upon different discourses when making decisions at the end of life. However, as participants represented prevalent discourses surrounding autonomy, decision making, the patient, and the family, our analysis may be relevant to patients with other diagnoses. Participants were exclusively White and predominantly Christian, limiting the extent to which these findings may apply elsewhere; a future research program is planned to interview similar patients with a different language, religion, and culture. Even within a homogenous group, however, the positions of patients and family members regarding DNR decision making and surrogacy can be contested, indicating the complexity of these issues, and need for sensitivity and flexibility on the part of clinicians interacting with patients in and with their families.

We found that participants drew upon normative characteristics constituting family — namely, emotional closeness between a patient and his or her family members — to sanction and veto familial involvement in decision making. Practically, families who were emotionally close (perhaps providing the support valued by participants) are more likely to find objective decision making diffi-

cult. When objective decision making is sought, family may be seen as less than ideal surrogate decision makers, and professional detachment is seen as an endorsement of a physician as the surrogate. Alternatively in such situation, an independent entity (for example, a Guardianship Board) may be appropriately enjoined.

We found that family members' preferences were deemed to be central, but not equivalent to, those of the patient, indicating how family members' and patients' sets of preferences can invoke different construals of autonomy (individualistic versus relational), decision making (personal versus social), and the patient with and in the family, to justify avoidance or rejection of responsibilities for making DNR decisions — despite the force of arguments that would otherwise assign said responsibilities to family members. Practically, this may prove problematic for clinicians and policy makers when they address DNR decisions (individually or through policy), intending to ensure that patients' autonomy is appropriately incorporated and that patients and family are included equitably and compassionately in these decisions.

Most patients (especially those who face important decisions) will identify themselves as individuals and as part of a social structure, the family. Each patient, each family, will have its own history and habitual mode of addressing decisions that, though dealing with one family member, will affect all. When important decisions loom large, it would be advisable for clinicians to ascertain the habitual mode of decision making within a family. Family members will sometimes, but not always, be identified, or identify themselves (officially or otherwise), as appropriate surrogate decision makers. Familial involvement in decision making can be tailored to best meet the expectations of patients and their family members. Regardless, the opinions and needs of patients and their family members, although interconnected, will likely differ somewhat, and this may render family members as inappropriate surrogate decision makers, although they may continue to have a role to play in the decision-making process. Additionally, because normative familial behavior dictates that patients elicit and attend to the opinions of their family members (even opposing opinions), patients' and family members' decisions are unlikely to be made based upon biological or medical parameters. When differences exist, patients and family members may experience increased distress, particularly when differences center on a patient's desire to assign responsibility for making decisions to another person. Although this may be interpreted negatively as a patient's denial, we argue that respect for the autonomy of the patient dictates that the patient not be coerced to voice a direct preference, but rather that a patient's autonomous choice not to make a decision should be heard and accommodated. This may require increased familial discussion with clinical staff and assurance that appropriate decisions will be made in the best interest of the patient.

Medical policies that routinely assume that patients will make decisions about DNR, or that assign or deny surrogate roles to family members, or that assume that all patients will do likewise, will not meet the expectations of all patients and families, increasing the potential for distress and conflict. Such distress and conflict will be exacerbated if patients and families are confronted with making decisions at a time when they are not prepared to face them — at a time that is instead dictated by medical practice or protocol. A patient's or family's avoidance of decision making, or denial that a decision is required, is problematic only if patients' autonomy is deemed to be mandatory, or if the only acceptable model of decision making excludes a decision to remain silent or to defer decision making to another time or another person. When medical facts are known, denial need not be deemed as negative, but can instead be seen as a positive and often temporary psychological coping mechanism by patients and their families. Attempts to break down this response at a particular time to meet

particular policy demands regarding DNR orders may be harmful to patients and their families. As such, the ethics of "one-size-fits-all" policies, which leave little room for sensitivity to patients' and families' circumstances, might be called into question. Conversely, policies that permit — but do not require — the participation of patients and families in determining the provision (or not) of CPR to a patient are more likely to adequately account for, and respect, the range of patients' and families' preferences and behaviors at the end of life.

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What Families Say about Surrogacy: A Response to "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions"

James L. Nelson and Hilde Lindemann

The authors of "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions" (hereafter "Autonomy and the Family") have conducted a small qualitative study of terminally ill patients to arrive at what would seem to be common-sense results: different patients and members of their families have different understandings of the nature, scope, and justification of families' roles in the decision to perform cardiopulmonary resuscitation (CPR) in the event of an in-hospital cardiac arrest. The differences that emerge, however, say the authors of the study, tend to draw on similar normative notions about familial responsibilities, familial strengths, and familial weaknesses.

These results are taken to support a policy of diversity in approaches to medical decision making. Different patients and different families should be allowed to play different roles in decision making, patients should not be forced to make decisions they do not wish to make, and family members should not be forced to participate in making decisions for their ill relatives if they don't want to. The authors view these results as a challenge to clinicians and policy makers, although why they're a challenge isn't clear. Is the idea that research results of any kind constitute a challenge as long as they support a change from current practice or policy? Or is the particular change advocated here supposed to be especially difficult to bring about in some respect(s)? If so, the cause of the difficulty might be confusions about autonomy that are so tenacious they even influence the conduct and interpretation of this study.

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A strength of "Autonomy and the Family" is that it allows us to hear the voices of some patients and family members discussing very difficult issues among themselves. The article conveys an immediate sense of how bioethicists' abstractly characterized norms and procedures (autonomy, proxy decision making, decision-making standards) appear to, and are thought about by, those whom they most directly affect. It seems to us that the article's conclusions ought to be endorsed, as far as they go. If they were absorbed into Australian medical practice, that would constitute progress — at least, to the extent to which current routine inflexibly assigns DNR decisions to competent patients or to families of incompetent patients, regardless of what the parties themselves want.

We believe, however, that the road to these unsurprising results and the ensuing reasonable recommendations is bumpier than it needs to be, and that the authors miss the chance to address some of the most interesting ethical issues lurking within the subject matter of the article — issues surrounding families, decision making, and end-of-life care that, if better understood, could improve how we die in hospitals. We'll argue that the question the authors use to locate their examination of the role of the family in end-of-life decision making, while very much taken for granted by healthcare professionals and bioethicists alike, is seriously misplaced. We'll then explore some of the distortions and misinterpretations that arise from too single-minded a focus on autonomy at this location. And finally, we'll reflect on the oddity of regarding families as though their primary role in the care of the dying is to make treatment decisions — let alone decisions that conform to professional caregivers' code of ethics.

THE DNR QUESTION

We begin with our concerns about the conceptual site of the interviews. The patients, all suffering from cancer and none with a life expectancy of more than three months, are asked something (it isn't clear exactly what) about the degree to which their families either do or should (this isn't clear either) participate in the decision not to receive CPR if they suffer a cardiac arrest. The authors explain that, just as in the U.S., "CPR is the default option for patients who experience a cardiac arrest within an Australian medical institution."

But *why* is it the default option? A number of retrospective studies report that patients receiving CPR after in-hospital arrest seldom survive to hospital discharge, and this is particularly true if they suffer from cancer, vascular disease, chronic liver disease, end-stage renal disease, or other serious long-term conditions.[1] In one study, a mere one out of 29 resuscitated patients whose underlying disease was malignancy survived, only to die within one year (the study is silent regarding whether this patient was in the final stages of cancer at the time of the resuscitation).[2] Given these grim statistics, why are cancer patients with fewer than three months to live being presented with a DNR decision at all? And *how* is it presented to them? A Medline search and review of the literature conducted in 2004 indicates that conventional CPR in adults produces an incidence of rib fractures ranging from 13 to 97 percent and sternal fractures from 1 up to 43 percent, depending on the age and general condition of the patient.[3] Were the patients in the current study made aware of these data?

They should have been, if the public's general ignorance is anything to go by. A 2006 survey of 100 patients aged 70 years or older, randomly selected from the general medical, internal medicine, and emergency departments at an urban medical center in the U.S., revealed that 81 percent of the respondents "believed that their chance of surviving inpatient CPR and leaving the hospital was 50 percent or better"; 23 percent of the respondents thought it was 90 percent or better.[4] If, as is likely, the cancer patients labored under a similar misconception, did anyone explain to them how slim the chances really are and how

physically traumatic the procedure? This is not the impression received from the interviews.

Let's suppose, though, that the study subjects had been carefully informed that for end-stage cancer patients, CPR is a punishing ritual with virtually zero odds of meaningful success — that there is almost no chance that resuscitation could prolong their lives past the three-month mark of their current prognosis. Because almost no chance is not the same as no chance at all, some patients might nevertheless consider the resuscitation option to be a reasonable object of deliberation. But then the question arises as to whether they would reason about a similar option in similar ways if they were at home. How much burden would they accept outside the hospital context for an equally tiny chance of extending their lives by at most a few weeks? Would they, for example, take seriously the possibility of not traveling by car for a month for an infinitesimal reduction in their odds of dying? Maybe some of them would. But the point we want to press here is that, as peculiar as it would be for families to sit around the dinner table helping Dad decide whether to undergo a Ford-free February, it's no more peculiar, if one stops to think about it, than sitting around the hospital bed helping Mom in the end stages of cancer decide about CPR.

AUTONOMY: GOOD SERVANT, BAD MASTER

The authors of "Autonomy and the Family" vaguely characterize patients' autonomy in two ways: as "holding that patients have a right to make decisions about their healthcare" and as "relational," locating individuals "within a network of social relationships and moral obligations" and emphasizing "the presence and effect of emotions in decision making." More precisely, autonomy as properly understood in healthcare contexts is the source of the right to exercise an effective veto over unwanted treatment, expressed in practice by informed consent policies. The individuals who consent to or decline treatment are certainly nested within a network of social relationships (more about this later) and may or may not include emotions in their deliberations, but these matters, we think, are better understood if they are not subsumed under the concept of autonomy.

While respect for autonomy is surely an important value in any healthcare context, a single-minded focus on it is apt to produce moral astigmatisms, creating blind spots or visual distortions where clarity of sight is particularly needed. So, for example, as we've just suggested, a fixation on autonomy can distract attention away from the context in which it's exercised, allowing a DNR decision for end-stage cancer patients to be passed over as unproblematic. Equally, this fixation allows other moral values to be absorbed under the respect-for-autonomy rubric even though they are conceptually quite distinct: in "Autonomy and the Family," the best-interests standard for proxy decision making is mistakenly characterized as an autonomy-motivated standard, although it's actually a beneficence-based standard to be used when a patient's values and desires are unknown (or determined not to be authoritative, as with children or the mentally ill). Best interests is a generic standard, in which the interests in question are determined from the perspective of a "reasonable person."[5] It's invoked in precisely those cases when no autonomy exists.

Focusing solely on autonomy also produces the hammer-and-nail problem. If to a hammer everything looks like a nail, so to researchers fixated on patient self-determination all study data look like exercises of, infringements on, or threats to autonomy. For instance, here is what one study participant, Sally, says about her family:

> I said I wasn't going to give my opinion at first. And they all gave their opinions on it. And they were all heartily agreeable that I should fight on. Do take the necessary precautions, the treatment that was being offered to me, and that. That they were behind me. And they spoke so nicely about

> it that I didn't answer them straight away, but I thought about it, and I thought, "I cannot refuse them that, try, try it."

The researchers interpret these data as Sally's expressing "an implied ultimate right to accept or decline [her family's] preferences," although they worry "whether Sally's actions might represent some degree of family coercion or simply Sally's autonomous decision to engage and accept family viewpoints." But to look at it this way is to miss a more plausible interpretation of what Sally is actually saying, which is that she wants to continue treatment because her family will go through it with her. She's not standing on her rights or concerned about being browbeaten: she's undertaking a venture that requires family participation. To pit Sally against the family is to miss that Sally is a *part* of the family. There is an "us" here that has deliberated together and come to a decision about the best thing to do, against the backdrop of a shared understanding that (a) Sally is a necessary part of "us" and (b) the rest of "us" will take care of her.

Of the number of interesting issues raised by Sally's comment, patient self-determination is pretty far down the list. We see what she describes as having much less to do with autonomy than with agency, and in particular, with shared agency. To judge by how they are acting, Sally and her family may well constitute what Carol Rovane calls a "group person" — a person composed of many single human beings who share a "single rational point of view" from which they can engage in distinctively interpersonal relations.[6] Michael Bratman calls this kind of collective action "shared cooperative activity," and argues that it is characterized by mutual responsiveness, commitment to the joint activity, and commitment to mutual support — all of which are clearly visible in the interchange that Sally reports to the interviewers.[7] Margaret Gilbert too has argued that groups have a capacity for collective agency that can't be reduced to that of the individuals of which they are composed: the "we" that is made up of Sally and her family, Gilbert might say, has its own beliefs and reasons and is capable of intentional action.[8] On such a reading, when Sally says, "I cannot refuse them that," she's not exercising her final and ultimate authority to choose. She is rather finding out what her commitment to sharing her life with her family requires of her.

The focus on autonomy makes mischief elsewhere in the study as well. As the authors see it, the problem with Sean isn't so much that family members might be constricting his autonomy as that he himself won't exercise it. "[I've] never even thought about anything like [making a decision about DNR]," Sean says. "But I think, yeah, I think my answer would have to be, well, . . . I'd be happy that the family, whoever were around at the time, would do just what they wanted to do." To the authors of the study, this is evidence that Sean is neglecting his own autonomy, abdicating responsibility for decisions that are properly his to make. And they write as though they disapprove: despite their general view that patients should not be forced to make decisions they don't want to make, they regard his "failing to make an autonomous, adult decision about his own healthcare" as leaving him "subject to moral censure."

Here again, we think, the autonomy-driven analysis has produced a distorted understanding of what the subject of the interview is doing. To clear an obvious point out of the way first, we note that refusing to exercise one's right to self-determination is, contrary to what the authors imply, no sin. That patients have a *right* to reflect critically on the recommendations of their caregivers does not mean that they have a *duty* to do so; as the authors elsewhere acknowledge, rights, typically, can be waived. We suspect, though, that Sean is doing something more interesting than waiving a right. Instead he may well be asking his family to engage in an instance of *substituted agency* (as contrasted to substituted judgment). He wants them to act, not only in his interests, but *in his stead.* If that's correct, then Sean doesn't care as much about the outcome

of the decision as he does about who makes it.

Let's suppose the contrary — that what matters most to Sean is the outcome. In that case, he might make the decision himself. He could exercise his autonomy by trying to determine how far his cancer is likely to have progressed by the time he suffers a cardiac arrest, figure out what quality of life, if any, CPR under those circumstances might buy him, and decide accordingly. Or he might think that he doesn't know enough to make the decision himself. He could then exercise his autonomy by asking his doctor to draw on her expert knowledge to make the decision for him. In fact, in the not too distant future, we could even imagine him programming all the relevant information about his physical condition and his personal values into a computer that could predict with 99 percent accuracy what he would choose when he got to that point.

But Sean does none of these things. Instead he says he wants whoever in his family is around when the time comes to do what they want. This suggests that while the outcome doesn't seem to matter to him (or that he doesn't think he's in a position to predict what considerations will be relevant when the time comes), he does care that the outcome be effected by the agency of those he loves. He doesn't turn to his doctor, and we suspect he wouldn't turn to the hypothetical computer, either. He turns to his family, not because they can be counted on to make the decision as he would have made it (substituted judgment) but because whatever the decision is, he wants it to be *their* decision (substituted agency). Sean's preference isn't for everybody, but given the alternatives of guessing when one has only a hazy grasp of what the situation will be when a decision about CPR must be made, or having a stranger (whether physician or machine) make the decision for you, we imagine that others beside Sean would want to leave these matters to be decided by those with whom, as we sometimes say, they identify.

In their discussion of what Sean says, the authors, perhaps against their own better judgment, treat autonomy as if it were a substantive moral or medical goal: a good to be pursued for its own sake. At least as understood in bioethics and sound clinical practice, however, autonomy is not the highest human good, but a procedural value: it's a side-constraint on how goods are pursued. That it's disrespectful for medical professionals to treat competent adults as though they were children goes without saying (or should, although it's still sometimes necessary to say it), but it's not the business of healthcare professionals to promote certain character types — planners and organizers, informed consumers, take-charge guys — among their patients. Claims about the roles and responsibilities of patients are best established on philosophical rather than empirical grounds. At most, empirical studies could only show that some people want to take up executive roles regarding their medical care, not that they have the responsibility to do so. Nothing about the concept of autonomy as a consensus value in healthcare entails that taking such roles is a general moral requirement.

WHAT FAMILIES ARE FOR

> The authors note that
> the terms *family* and *next-of-kin* may be problematic. Their use obscures the fact that the entity to which they refer is composed of individual members in different relationships to the patient (who is also part of that family), who have different sets of values, experiences, and needs. In nominating family members as surrogate decision makers, participants reproduce the construction of the family as a homogenous "superpersonality" that thinks and acts as one, despite evidence to the contrary. . . .

Two things in particular strike us about this observation. The first, as we've already suggested, is that families are often more than the

sum of the individuals they comprise, so worrying that the designation "obscures" the fact of differences among those individuals is a bit like worrying that the term 'orchestra' takes away from the violinists, bassoonists, and clarinetists who are playing the music. The other thing that's striking, though, is how often the term 'family' is lamented as problematically homogenous, when we so seldom hear similar worries about 'doctor,' 'nurse,' or 'treatment team' — as if the concord or discord among individuals in these groups were of little importance to their involvement with patients.

We concur with the authors' view that it's a mistake to idealize families as decision makers, as individual family members can be selfish, overcome by emotion, over involved in the care of the patient, sexist, withdrawn, or just plain mean. But the same holds true for *all* potential decision makers, whether doctors, ethics committees, or the patient herself. And while it's a mistake to idealize any of these players, it's just as much of a mistake to idealize the decision. The best end-of-life decision making doesn't necessarily replicate as precisely as possible what the patient would have chosen; if it did, to hearken back to our reflections on substituted agency, the patient would be obligated to find the best possible decision maker (or computer program) to make the decision for her.[9] Instead, the goal is to attend to the needs and values of the dying person, which may be better served by taking pains over who decides, rather than what is decided.

The responsibilities of a terminally ill patient's family members are hardly exhausted by making treatment decisions when the patient can't. They have a wide array of other tasks to perform. Families (a) provide hands-on care, in increasing amounts and of increasing complexity; (b) provide financial support; (c) monitor the quality of the patient's professional care; (d) fill out insurance forms and do battle with insurers; (e) drive the patient to doctors' offices and therapy sessions; (f) monitor the patient's medications; (g) sleep at the patient's house so someone will be there in the middle of the night; (h) sit with the patient; and (i) much, much more.

In the course of all this activity, we argue, they are also doing something of enormous moral importance: they are holding the patient in her identity. By this we mean that they are mitigating the force of the illness's assault on the patient's sense of who she is. The physical, mental, and spiritual changes that terminal illness inflicts on its victims cannot, of course, be staved off altogether, but by interacting with the patient in familiar ways, being with her as she enters unfamiliar territory, and keeping her nested within the web of intimate relationships that sustain her, family members remind the patient of who she has been and help her to continue to be it.

Terminal illness can and frequently does play havoc with one's identity. To be even seriously ill for more than a few days is to lose control over one's physical and mental processes. It puts a stop to one's usual activities and interferes with one's memories, hopes, plans for the future, and ongoing projects. It usually involves hospitalization, which means that one is uprooted from one's customary surroundings and thrust into a milieu governed by insider understandings to which one isn't privy. All of this contributes to a disintegration of one's sense of self. The physician Eric Cassell conceptualizes this disintegration as *suffering:* to suffer is to feel oneself coming undone. Suffering persists, writes Cassell, until the threat to the identity has passed or until the integrity of the identity can be reestablished in some manner.[10]

It's when a patient suffers in Cassell's sense of the word that she most needs the help of others to hold her in her identity. Torn out of the contexts and conditions in which she can maintain her own sense of herself, the patient runs the risk of losing sight of who she is — at least temporarily — unless someone else can lend a hand. Because family members are typically the people with whom the patient's life has been longest and most closely intertwined, they are the ones who, not only by their ac-

tions but also just by their presence can make the patient feel more like herself.

The changes in the patient are terrible and real: she is no longer, nor ever can be again, exactly the same person she was before she became ill. But there can be greater or lesser degrees of continuity between the self she was then and the self she is now — selves are not, to use Charles Taylor's language, temporally punctual.[11] Because some important things about us stay the same even as other important things change, the disconnect between past and present selves is never complete. That we are someone's wife, sister, or mother endures, which is what makes it possible for the people with whom we are in those relationships to hold on to us as we navigate the changes that assault our self-conception.

Family members also often need to hold each other when one of their own faces death. The loss of a parent, a spouse, or (especially) a child can inflict profound changes in who we are, and it's particularly then that we need others to anchor us lest we lose ourselves altogether. In the study, Pete says, "I know with my neighbor, she stood by her husband's bed day and night saying all the time 'Don't you dare leave me, don't you dare leave me.' " Pete's point is that his neighbor couldn't make good treatment decisions for her husband; our point is that she herself needs care, of the kind that those closest to her are often in the best position to provide. If she were to receive it, she might be an excellent proxy for her husband, although clearly that is not her primary claim to care.

The various manifestations of holding we describe here can be done well or badly. Pete's neighbor holds on to her husband frantically and desperately; other families can't let the patient go when it's time. Family caregivers become overwhelmed and take out their frustration on the patient. Others in the family refuse to do their share, or don't see why the primary caregiver needs a respite. These considerations don't, however, detract from the moral value of holding people in their identities when it's done well, any more than foolish treatment decisions lessen the importance of respecting patients' autonomy.

We would like to see discussions of shared and proxy decision making situated within the full range of responsibilities family members assume when one of their own is terminally ill. If this were done more often, bioethicists might better understand the practical and moral context in which families operate, the values that guide their thinking, and the roles and relationships that are likely to characterize them. As we've argued elsewhere, the failure to appreciate the distinctive features of families causes confusion and frustration in healthcare settings, distorts the way families interact with members who are ill, and puts pressure on families' precarious understanding of themselves.[12] What has happened, we think, is that healthcare treatment decision making has come to be seen as a 'carve-out', a detachable function that can be unplugged from the rest of family life and plugged into the healthcare context, where it is assessed according to the moral standards that govern the behavior of healthcare professionals. But because the delivery of healthcare is only one of many familial functions, and because families don't exist merely to serve others' ends, they are too different from healthcare institutions to share the same code of values. Treating them as if they did is disrespectful at best, and sometimes causes genuine harm.

We close with a caution against evaluative imperialism. It's true that the ethics of families has received little scholarly attention, possibly because families have been relegated to the private sphere by moral philosophers who are far more interested in the moral relations that hold in the marketplace than those that hold at home. For that reason and probably others, it's not hard to see why bioethicists and healthcare professionals alike might fail to notice that the differences between families and healthcare institutions give rise to different sets of norms and values. That said, however, when professional caregivers regard family members as extensions of the healthcare system, valuable only instrumen-

tally — for the information they can provide about an incapacitated patient's former values or as a source of cheap semi-skilled labor — they are open to the charge of arrogance, whether they intended it or not. A closer look at what families are actually up to, unbiased by the assumption that medical ethics should govern everything to do with the care of patients, reveals all kinds of interesting things that would otherwise escape our notice. Here, as in so many other arenas of life, a little humility takes us a long way.

NOTES

1. G.E. Taffet, T.A. Teasdale, and R.J. Luchi, "In-Hospital Cardiopulmonary Resuscitation," *Journal of the American Medical Association* 260 (1988): 2069-72; F.J. Landry, J.M. Parker, and Y.Y. Phillips, "Outcome of Cardiopulmonary Resuscitation in the Intensive Care Setting," *Archives of Internal Medicine* 152 (1992): 2305-8; M. Karetzky, M. Zubair, and J. Parikh, "Cardiopulmonary Resuscitation in Intensive Care Unit and Non-Intensive Care Unit Patients: Immediate and Long-Term Survival," *Archives of Internal Medicine* 155 (1995): 1277-80; L. Bialecki and R.S. Woodward, "Predicting Death after CPR: Experience at a Nonteaching Community Hospital with a Full-Time Critical Care Staff," *Chest* 108 (1995): 1009-17.

2. Landry, Parker, and Phillips, see note 1 above.

3. R.S. Hoke and D. Chamberlain, "Skeletal Chest Injuries Secondary to Cardiopulmonary Resuscitation," *Resuscitation* 63, no. 3 (2004): 327-38.

4. D.H. Adams and D.P. Snedden, "How Misconceptions Among Elderly Patients Regarding Survival Outcomes of Inpatient Cardiopulmonary Resuscitation Affect Do-Not-Resuscitate Orders," *Journal of the American Osteopathic Association* 106 (July 2006): 402-4.

5. The standard discussion of this is A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1989), pp. 122-33.

6. C. Rovane, *The Bounds of Agency: An Essay in Revisionary Metaphysics* (Princeton: Princeton University Press, 1998), p. 127.

7. M. Bratman, *Faces of Intention: Selected Articles on Intention and Agency* (New York: Cambridge University Press, 1999).

8. M. Gilbert, *On Social Facts* (Princeton, N.J.: Princeton University Press, 1992).

9. This leads to the interesting question whether the patient is the best person to decide who the decision maker should be. And, of course, who the best person is to make that decision.

10. E. Cassell, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306, no. 11 (1982): 639-45.

11. C. Taylor, *Sources of the Self: The Making of the Modern Identity* (Cambridge: Harvard University Press, 1989).

12. H.L. Nelson and J.L. Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (New York: Routledge, 1995).

The Armchair Ethicist: It's All about Location

Douglas S. Diekema

Where one sits in relation to an ethical issue matters. It changes the way things look, it changes the nature of the problem one faces, and it may require different tools of analysis than the same ethical issue faced by someone sitting in a different place with regard to that issue. Why is this important? Quite simply because the ethics consultant involved in a clinical case or the academic ethicist writing a paper or assisting in developing policy will almost always confront an issue differently and ask different questions than a person who is more personally immersed in the problem. It should thus come as no surprise that family decision making in the medical context sometimes fails to correspond to our notions of surrogate decision making, autonomy, or informed consent. The ethics consultant in a clinical case must remain mindful that the ethical question faced by a patient or family may be quite different than the one they are being asked to address as ethics consultant, and that the tools of analysis must fit the question if the result of the consult is to be meaningful.

We can confront ethical issues at a number of levels, and figure 1 illustrates at least four of those. I have labeled these levels as primary through quaternary because, as one moves through those levels, one's proximity to the primary level and what is personally at stake both decrease. The level at which one engages an ethical issue will determine the nature of the question being asked and the appropriate tools of analysis. While different people may interact over the same ethical concern, they often engage the ethical issue at different levels because their relationship to the issue differs. A lack of awareness of that fact can lead to a lack of clarity about the nature of the problem and the appropriate means to solve it.

LEVELS OF ENGAGEMENT

An ethical concern is engaged at a primary level when it directly confronts the primary

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moral agent. It is *your* problem, and *you* must decide what to do. The primary ethical question here is, "Given who I am and what I see, what should I do?" The question is not simply "What is the right thing to do?" but "What is the right thing *for me to do given my responsibilities in this situation*?" Someone confronting an issue at this level is the central moral agent in a drama. This is the woman who is perhaps reluctantly or unwillingly pregnant who must decide whether or not to have an abortion, the physician who must decide whether or not to meet with a pharmaceutical representative in her office, and the parent who must decide whether to immunize a child. It is the terminally ill patient who must decide whether to ask a physician for active assistance-in-dying.

To engage an issue at the secondary level is to be one step removed from the person directly confronted by the primary choice. While the moral concern confronts the other person more directly, you are being asked to participate in some way, perhaps by giving advice, perhaps to pass judgment, and perhaps to enable, support, or cooperate with the primary moral agent as he or she embarks on a chosen path. This is the level at which a family member, a clinician, or an ethics consultant may confront an ethical issue related to a specific patient. The secondary ethical question is likely to take the form, "Will I help this person in what they have chosen? Will I cooperate with him or her and provide what he or she has asked?" This is the friend or relative of the reluctantly pregnant woman who is asked for advice or asked for help and support when the woman has made a decision to proceed with abortion, or the gynecologist asked to perform the abortion who may or may not choose to cooperate with the woman's request. It is the colleague or ethics consultant or teacher who provides guidance about the moral issues related to a physician's meeting with pharmaceutical representatives, the physician who is confronted with a family who has chosen not to immunize their child, and the physician who must decide whether she can in good conscience write a prescription at the request of a patient seeking assistance-in-dying. These individuals all confront an ethical issue, and in some cases what is being asked of them may be as difficult and integrity challenging as it is for the primary moral agent. But the question being asked of them is not the same as that being asked of the primary moral agent.

Engagement of an ethical issue at the third level represents a different relationship to the ethical concern than either of the two previous levels and poses a different sort of question. Rather than asking "What should I do?" or "What do I think is the right thing for him or her to do?" or "Am I going to assist or cooperate with this person?" the question here is "Am I going to *tolerate* the decision that someone else has made in relation to the ethical issue at stake?" A person confronting an ethical issue at this level acts as judge of the other's actions, and the central concern goes one step beyond deciding whether someone's proposed course of action is right or wrong, to whether it constitutes the sort of decision that ought to be disallowed. This is the person who decides to actively interfere with a woman who has chosen to have an abortion, the colleague who questions whether to do something about a physician who appears to

Figure 1. Levels of Engagement in Ethical Analysis

Level	Question	Role	Tools/Considerations
1st	What should I do?	Agent/actor	Personal ethics
2nd	What should she or he do? Will I assist or cooperate?	Counselor/educator	Ethics consultation
3rd	Will I tolerate her or his decision?	Judge	Criminal law
4th	Should we make a rule?	Citizen/legislator	Public policy

be behaving unethically with regard to his relationships with pharmaceutical representatives, and the physician who must decide whether a family who refuses to immunize their child should be reported to child protective services for medical neglect. The third level is the level at which many ethics consultants and ethics committees engage ethical issues arising from conflict between a patient or family and the medical team. While a consultant or members of a committee engaging an issue at this third level might address what they believe to be the right course of action, they are generally being asked a different question: "Are there grounds to interfere with the decision that the family is trying to make?"

On occasion, ethical issues are engaged at a fourth level. This is the level of public policy. The question here goes beyond whether to interfere with someone's choice *this time,* and moves to whether the sort of action or decision should be outlawed *for everyone* under certain circumstances. This is the activist who seeks to change the laws regarding abortion, the institution or legislator or licensing agency that seeks to establish rules about physicians' interactions with industry, or public health authorities who make decisions about whether vaccination should be required for all children and whether there should be any exceptions to that rule. At this level, public concerns become much more prominent, and, rather than focusing solely on the personal aspects of the ethical concern, those engaging an issue at the fourth level focus on whether it is justifiable to systematically interfere with individual freedom and autonomy for the sake of some compelling public good or competing interest. Considerations of justice and politics are more likely to be introduced at this level of engagement.

LEVELS OF ENGAGEMENT AND THE ETHICAL QUESTION

As illustrated above, the ethical question faced by a person will change depending on which level the moral concern is engaged. "What kind of a decision is right for me with regard to end-of-life care and who do I want to make those decisions if I cannot?" (1st level) differs from "Am I willing to make decisions for my husband should he become incapacitated and unable to do so?" (second level) and "How will I determine whether the decisions made by the patient's surrogate decision maker are consistent with the patient's desires, in his best interest, or sufficiently harmful to him that I will seek to have the surrogate's decisions overturned?" (third level) and "Should we have a law that establishes who will serve as a medical surrogate for an incapacitated patient and dictates the parameters within which that person must act?" (fourth level). Different people involved with the same situation or "case" might face very different questions.

This has implications for how we view the kinds of discussions that occur between family members around end-of-life issues. While these families struggle to weigh the value of possible medical interventions against the burdens those interventions might impose, decide how to make those decisions, and determine whether they can assume the responsibility and burden of surrogate decision maker should the patient become incapacitated, a consultant may focus on whether surrogacy is legitimate, what standards we should use to judge the adequacy of surrogate decision making, on what basis those decisions can be justifiably overturned or ignored, and what process should be in place to assure that the decision is made defensibly and not arbitrarily (all issues that the patient and the family do not address).

LEVELS OF ENGAGEMENT AND THE TOOLS OF ANALYSIS

Moral agency exists at each level of engagement, but the manifestation of that agency will differ. Academic bioethicists are skilled at applying a set of analytic tools to an ethical issue. They may try to bring those tools to the

bedside, and find that the tools that served them well in an academic analysis of an ethical issue don't always fit well when consulting on a case, or that the appropriate tools may differ depending on the reason they were asked to consult. Likewise, those tools may bear little resemblance to the way in which the patient or family or clinicians approach the issue. For example, in this issue of *The Journal of Clinical Ethics*, Eliott and Olver present their findings from interviews with dying cancer patients and their families. These interviews are viewed through a frame of autonomy, and the authors conclude that "different aspects of autonomy were invoked to render family members as both appropriate and inappropriate surrogate decision makers." These interviews provide important insights into the world of dying cancer patients, their families, and the different ways in which they make decisions. The frame of autonomy may not be the best way to understand these discussions, however. It represents an attempt to make sense of ethical deliberation at the primary level, using tools of analysis that are better suited in this case for someone at the tertiary or quaternary level. How so?

The patients described in these interviews face death in the near future. They must struggle with how to make sense of that death, how to make the process of dying fit their vision of a "good" death, or at least one that is "better" or "tolerable" or "reasonable" for themselves and those they care about. These decisions clearly have moral dimensions, because the choices they make will affect others around them. A patient may choose to include family members in these decisions, trying to craft the kind of death they envision as best, but also one that is tolerable for their family. For someone in this position, autonomy is not a particularly useful construct. These patients can certainly be described as exercising autonomy, but the principle of *respect for autonomy* is one of respecting autonomy, not exercising it. For the person in the position of facing his or her own death, the principle of respect for autonomy provides little guidance in making decisions, since a dying patient struggling with end-of-life issues rarely focuses on the question of how to respect the autonomy of others. The ways in which a patient struggles with end-of-life decisions are better understood in terms of virtue ethics or narrative ethics, since these patients are trying to answer questions like "How do I want my story to end?" and "What do I want my death to say about the kind of person I was?"

My wife's cousin recently died of cancer, and spent his last weeks and months planning for his death and what would follow. He planned his own funeral, wrote his own obituary, and continued to make decisions until the end. His final days, his death, and his funeral were orchestrated in a way that "fit" his life. They were just so "like Dale." The principle of respect for autonomy just doesn't help much in capturing the ethical nature of his decisions, at least not without the help of a crowbar. The principle of beneficence works better, since one of the questions he asked is "How can I make my dying less burdensome to others?" Like the patients in the interviews cited by Eliott and Olver, he had conversations with his wife and respected her autonomy by including her desires in those decisions, but, in doing so, he was most concerned about her welfare (beneficence) than a desire to respect her autonomy.

The family members whose voices are heard in these interviews speak from a somewhat different place than the cancer patients. They face these end-of-life issues at a secondary level. They are not being asked to decide how they themselves wish to die and what obligations they have to others in making those decisions, but they are being asked whether they can cooperate in some way with the dying person, perhaps by providing advice, assisting in decision making, or serving as a surrogate decision maker or guardian of the patient's decisions should the patient become incapacitated. The principle of respect for autonomy makes more sense in this context, since the family members are trying to balance their own interests (and perhaps per-

ceived limits) with the principle of beneficence ("I want what is best for my dying family member") and respect for autonomy ("I should make sure my decisions reflect the wishes of the dying person"). Perhaps the most important question these family members face is whether they are willing to assume the role of surrogate, and, if they do so, whether they will respect the wishes of the dying patient in exercising that role.

Were an ethics consultant to be involved in these cases, perhaps because there was some disagreement about what the now-incapacitated patient would have wanted, the tools for analyzing the situation may differ from those used by either the patient or the family. While the ethics consultant would no doubt describe the principle of respect for autonomy as guiding his or her thinking about the case and explore whether any objective evidence of the patient's wishes exists, in many cases that objective evidence will be lacking, and the true questions that must be settled include "Whose choice is this?" "Who gets to decide what the patient would have wanted?" and "Are there any constraints on what kind of decision a surrogate can make?" The principle of respect for autonomy is only helpful here insofar as our ability to determine what the patient's wishes might be. Without any objective guidance from the patient, the standard fall-back has been the best-interest standard, a standard that provides little guidance in these cases, precisely because the disagreements that lead to the request for an ethics consult are frequently disagreements about what constitutes the best interest of the patient. The background question being asked of the consultant is not whether the surrogate is making a decision that is in the best interest of the patient, but, rather, whether the institution should seek legal action to prevent the surrogate decision maker from making certain kinds of decisions. This engages the issue at the tertiary level of ethical engagement, and the question here is really about whether to tolerate someone else's decision, and the tool of analysis — as I have argued previously — should be the *Harm Principle:* the consultant must ultimately decide whether the surrogate is making a decision that places the patient at significant risk of serious harm, as compared to any alternative decision.[1]

THE ETHICIST IN THIS FRAMEWORK

The ethics consultant nearly always sits in a different place in relation to an ethical issue than the patient or family member sitting at the center of a request for consult. Likewise, the bioethicist writing an academic paper will frequently address a different set of questions and use a different set of analytic tools than a patient or physician facing the issue discussed in that paper. Discussions of physician aid-in-dying, for example, frequently rely on arguments about the social context within which that practice occurs, the potential for abuse, concerns about the slippery slope, and perhaps claims about the identity of the physician. These arguments address whether the practice of physician aid-in-dying should be allowed, and the arguments relate more to societal concerns than to whether the practice would be right or wrong in an individual case. Slippery slopes, claims about physicians' identity, and potential for abuse have little relevance to a thoughtful, fully competent individual who is trying to decide whether it would be ethical to make this request for him- or herself (at the first level of engagement). Because the nature of the arguments differ, it may also be the case that one's conclusion at one level of engagement (that is, whether a patient is morally wrong to seek aid-in-dying) does not necessarily correspond to one's conclusion at another level (that is, whether physician aid-in-dying ought to be outlawed). Presumably, if the patient were to ask for guidance from an ethics consultant in order to help arrive at a decision for herself, the conversation and the issues discussed would be different than those faced by the same ethicist writing a paper about the permissibility of physician aid-in-dying or pro-

viding guidance to legislators concerning whether a law is needed to prohibit or limit the practice.

In his essay "Meditation in a Toolshed," C.S. Lewis relates his experience in a dark toolshed one bright sunny day. He observes a sunbeam as it comes through a small crack in the shed's ceiling. Looking at the beam provides one perspective: a striking ray of light illuminating the specks of dust that float through it. Then he moves, so that the beam falls upon his eyes. The previous image vanishes as he now looks along the beam. From this perspective he sees instead, framed in the small crack, the green leaves moving on the branches of a tree above, a butterfly flitting by, and beyond that the brilliant source of the light, the sun itself.[2]

Lewis uses this metaphor to urge those of us who consider ourselves experts to recognize the limitations of that expertise in describing the experience of those who sit in a different place. For example, he contrasts the lover's experience of being in love (looking along the beam) with the psychologist's or biologist's description of that experience (looking at the beam). The same can be said for ethical issues. They look different depending on where one is situated with regard to the issue, and the questions change as one moves into different relationships with regard to the ethical concern.

These observations will seem obvious to some readers, and I would expect others to quibble with the four levels of engagement I have suggested. Nonetheless, it has been my observation that many individuals remain conceptually unclear about the fact that ethical issues will be experienced differently by people who sit in different places with regard to those issues. As bioethicists consult, teach, and write, we need to be clear about the level at which we are engaging an ethical question and recognize that the tools of analysis that work well at one level of engagement may not be helpful at another level. At the same time, the conclusion we might draw at one level (that is, it would be wrong for her to do x) does not necessarily determine our conclusion at another level of engagement (that is, her decision to do x should not be tolerated), since the relevant question and considerations change from one level to the next.

NOTES

1. D.S. Diekema, "Parental refusals of medical treatment: the harm principle as threshold for state intervention," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 243-64.

2. C.S. Lewis, "Meditation in a Toolshed," in *God in the Dock: Essays on Theology and Ethics,* ed. W. Hooper (Grand Rapids, Mich.: Eardmans, 1978), 212-5.

Response from Eliott and Olver

Jaklin Eliott and Ian Olver

We agree with many of the points raised in Nelson and Lindemann's commentary on our article, "Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions," in this issue of *JCE.*

To address a few issues: Regardless of our or any other persons' appraisal of the merits of positing individual autonomy as the primary good in dealing with decision making at the end of life, current Australian and U.S. policy, as we state, takes individual autonomy as fundamental (illustrating ethical principles applied at the quaternary level, as described by Diekema in his commentary, "The Armchair Ethicist: It's All about Location," also in this issue of *JCE*). Patients are required to make decisions, and their family members are typically enjoined to make decisions for the incompetent patient who has not done so pre-emptively. Similarly, whether or not we or others deem it appropriate to request patients or families to make decisions regarding the provision of cardiopulmonary resuscitation (CPR) to dying patients, and whether or not they are informed of the likely outcomes of this, current policy dictates that they are so asked.

We wholeheartedly agree that instituting CPR as default is flawed as a policy and that patients typically don't realize the probable outcomes. However, we note first, this is irrelevant to our argument: We examine how patients and families negotiate the consequences of the current policy requiring that this default is rescinded, preferably by them; and second, providing information on statistical outcomes was beyond the remit of the study. Patients were not asked to make a decisions about do-not-resuscitate (DNR) orders,

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they were asked to talk about how these decisions should be made, who should be involved, and when discussions centered on these decisions should take place. Many patients spoke about their own experiences, and we demonstrate in this (and other publications)[1] that the right of the patient to decide was the dominant discourse drawn upon in these discussions. We hold that our focus on autonomy was not contingent upon our proclivities, but was prompted equally by the institutional policy and practices framing these decisions, and the accounts of the patients and families themselves. We discursively analyzed these accounts to show how family and patients were positioned, how their accounts reflected and re-presented particular versions of autonomy, and drew out some of the moral and social consequences that ensued.

At several points Nelson and Lindemann inferred our position as critical of patients' points of view, often through overlooking critical clauses in our analysis. We do not make a moral judgement regarding Sean's desire to delegate the decision to his wife Vicky. Whether or not this is appropriate is irrelevant. What is relevant is how Vicky counters his desire through asserting her desire that he make the decision. Time and again in this data set, the decision is batted back to the patient, reinstating as normative and appropriate that he or she make the decision, and thus implicitly positioning any other option as less than desirable. As we said "To this extent . . . Sean could be subject to moral censure."

Similarly, we do not pass judgement upon Sally, nor do we (as they do) offer a "plausible interpretation" of what she is saying. We examine rather what she is saying, and how she says it, arguing that she beautifully and discursively manages the paradox of autonomy in this process. She attends to family, but she is positioned (by herself and, by her account, her family) as ultimately responsible for making the decision.

Finally, we note that individual musicians do not an orchestra make: Any orchestra requires a conductor who will decide what they are to do. By contrast, a family may have no or too many potential conductors — and disharmony will ensue. Conductors are more easily established in a hierarchical medical community, and the relationship between the patient and the doctor is historically and contractually distinct from the relationship between the patient and the family. We agree, we need to attend further to the latter, and we need to do so through empirical analysis of their talk. This is a start.

NOTES

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Ethics Consultation: Continuing its Analysis

Barbara J. Russell and Deborah A. Pape

Ethics consultations in major healthcare facilities and networks are now relatively common, and consultations are performed by physicians, nurses, social workers, psychologists, philosophers, and multi-disciplinary ethics committees. In the past decade, explicitly incorporating ethics into clinical and administrative practices has been required by such powerful regulatory agencies as the United States Joint Commission on Accreditation of Healthcare Organizations and the Canadian Council on Health Services Accreditation. Although three millennia ago Meno asked Socrates whether moral virtue could be taught and by whom, controversy continues today regarding the requisite teaching and credentialing of ethicists.[1] In the 1990s, for example, discussions ensued as to the conceptual differences between and the legitimacy of an ethics consultant claiming to be an ethics expert versus having ethics expertise.[2]

This article is the result of our many discussions on what clinical staff need to know to begin doing ethics consultations, the paradigmatic activity of ethicists and ethics committees. Admittedly, informative analyses are already available.[3] Our contribution to these analyses was prompted by two events. First, while developing an introductory training module for practitioners who had been chosen by their unit or program to work on ethics consults in their respective unit or program with their hospital's formally trained bioethicist, we found that certain aspects of ethics consultation often were overlooked or inadequately emphasized. Second, our examination of the intricacies of consultations became more energized after reading this journal's re-

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cent publication of six ethicists' testimonials about consults they felt had "haunted" them, or about which they still felt very ambivalent.[4]

In this article, the epistemological work of philosopher Gilbert Ryle and the pedagogical work of mathematics professors John Mason and Mary Spence are applied to ethics consultation.[5] More specifically, Ryle's concepts of "knowing that," "knowing how," and "knowing why," and Mason-Spence's concept of "knowing-to-act-in-the-moment" are used. We then analyze the ethicists' testimonials regarding which factors made the consults especially vexing and how these factors relate to the aforementioned types of knowledge. Yet this systematic analysis does not reflect fully our discussions about the nature of consultation. We often resorted to metaphors to help capture the dynamics involved, to see the "whole," and to identify more nuances. The metaphors are included below to demonstrate the benefit of imagination to ethicists' self-reflective practices.

THE TESTIMONIALS

We commend the six ethicists for their courage and collegiality in sharing their consults that have tested, and at some points exceeded, their seasoned abilities and expertise. We, too, have done consults that have and continue to indelibly mark our own development as ethicists and therefore are indebted to these ethicists for reflecting on their personally formative consults. With this said, brief summaries of the ethicists' testimonial articles are warranted before applying the four kinds of knowledge to them.

Denise M. Dudzinski's misstep begins during discussions at team rounds about a patient's request to have her injured arm amputated.[6] Despite trying various interventions over 10 years to alleviate the disproportionately severe pain, the patient still experiences pain, hygienic problems, and bodily alienation. The clinical team, however, believes amputation will not end her psychologically based pain because phantom pain is likely. Team members are either adamantly opposed to the surgery or extremely hesitant. As the team works to resolve their quandary, Dudzinski decides to speak with the patient even though no ethics consult has been requested formally. Her candid article explains what likely caused her, an experienced ethicist, to "unnecessarily [interject] myself into the therapeutic relationship."[7]

The article by Joy D. Skeel, an ethicist, and Kristi S. Williams, a consultation-liaison psychiatrist, describes their work with an Internal Medicine team and consulting psychiatrists caring for a patient with severe borderline personality disorder (BPD).[8] The patient infuriates and exhausts the team by engaging in life-threatening self-harm behaviors, pitting team members against one another, and making erratic, often contradictory, treatment decisions. The authors detail their efforts to help the practitioners through a relentless cascade of vanishing improvements, interpersonal hostilities, and patient suffering. Yet despite Skeel and Williams' committed efforts, a palpable worry concludes their article: "was there anything more . . . we could have [done]?"[9]

Unfortunately the case described by Paul J. Ford continues to recur in acute care hospitals.[10] The patient's hospitalization for a heart attack and subsequent stroke is characterized by changing clinical teams, unpredictable prognoses, disagreement over the value of various medical interventions, and numerous team meetings with family members. The patient's hospitalization lasts several months, and, as per the title of the article, the outcome is "a messy spiral of complexity." This author admits to feelings of "dread, powerlessness, and frustration."[11] Reminiscent of Skeel and Williams, Ford worries he missed opportunities to help the family and clinical staff provide the patient end-of-life care that exemplified solidarity, compassion, and skill.

The fourth case begins with a seemingly minor question from an intensive care unit (ICU) team: can a young mother visit her baby, Angel, in the ICU?[12] Advice from the ethics service is warranted because the baby's pro-

found neurological injury may have been caused by his mother or her boyfriend shaking him. Jeffrey Spike, a professor of medical humanities, reflects on his response to the ICU team's question as well as on the seeming inadequacy of ethics consultation to address tragedy.

Richard M. Zaner's article[13] complements his earlier works that explore the experiences of and meaning for a person when he or she becomes ill or injured and, just as importantly, becomes the subject/object of contemporary healthcare.[14] In this *JCE* article, Zaner chronicles a couple's anguished efforts to decide whether to abort their fetus after diagnostic tests predict spina bifida, a condition associated with serious physical and mental disabilities. Diagnostic uncertainty increases the difficulty of the parents' decision. Urgency further compounds this difficulty: the mother's pregnancy will soon reach its twenty-fourth week, after which abortions are performed locally only if the woman's life is in danger. Demanding that ethics consultation be responsive and useful, Zaner questions whether he could ever understand what this couple experiences and faces, enough to be able to help them through another form of parental "labor," that of surrogate decision making.

KINDS OF KNOWLEDGE AND ETHICS CONSULTATION

KNOWING THAT

Ryle defines this kind of knowledge as involving facts or what is true. For instance, children demonstrate knowing the color yellow when they repeatedly choose the yellow crayon in response to "Which one is yellow?" So too for your neighbor knowing that "you live there" if he or she routinely and correctly directs delivery people who are having trouble finding your home.

In terms of ethics for healthcare settings, initiates into ethics consultation work commonly find gaining this type of knowledge the most challenging. Fuelled by the World Health Organization's expansive definition of health, health ethics involves not just terminology, concepts, and theories from moral philosophy and the health and behavioral sciences, but also from political science, the law, economics and business, and religion. When a novel issue arises, a consultant must also know the evolution of related debates and academic exegeses; for instance, to decide whether organ donation after cardiac death should be permitted ethically, the history of defining death must be understood. Or to decide whether there is no obligation ethically to provide a particular therapy to a patient, the protracted debate regarding futility must be known. Sources of ethics-related "knowledge that" are typically courses or seminars, conferences or workshops, books, and a broad range of journals in each discipline.

Problems in communication are routinely identified as the reason for many ethics consults. Yet the word "communication" may be erroneously interpreted as referring only to issues about inadequate disclosure of information, inconvenient meetings, and rudeness. However, we believe that ethics consultants must view conversations as potentially relevant "facts" in a specific situation, just as a patient's diagnosis, test results, and content of her or his advance directive are considered germane facts. Too often, clinical teams disregard past conversations with other colleagues, the patient, or his or her family, and published ethics cases lack conversational details. Yet various theorists and ethicists stress the importance of dialogue, including Jurgen Habermas, Arthur W. Frank, and Larry R. Churchill-David Schenck.[15] Conversations themselves are performative activities wherein we make promises, validate others, demonstrate various virtues (for example, honesty, sincerity), and are accountable. With respect to the ethicists' testimonials, keeping track of what was said is challenging but important. Skeel-Williams actively intervened to try to change the conversations from being antagonistic to being patient and balanced. Ford and Zaner worried when, at some point in time, well-intended meetings between the

clinical team and the family or parents became counterproductive.

Limitations to "knowing that" explain some of the frustration experienced during a consult. Uncertainty is one such complication and is clearly part of all five testimonials: Will amputating the patient's arm alleviate her pain (Dudzinski)? Will any treatment produce a lasting benefit for the bipolar patient (Skeel-Williams)? Will the patient recover neurologically (Ford)? Did the mother or her boyfriend actually shake the baby (Spike)? And does the fetus have spina bifida (Zaner)? Ambivalence, another limitation, complicates claims of "knowing that." Conflicting emotions can reduce a person's confidence in the cogency and defensibility of his or her viewpoint. Consider, for example, team members' reactions to their patient's request to amputate her arm. Feelings of horror, pity, and helplessness were likely mixed together, and yet each reflects different assessments of "what's wrong" that, in turn, may justify different resolutions. The same mixture of feelings is described in the case about the patient with BPD and the splitting of his clinical team. A third limitation, ambiguity or lack of clarity, occurs when it is difficult to choose concepts and theories that have adequate and relevant explanatory power. In the case of the shaken infant, Spike acknowledges that society's criteria are unclear as to what constitutes a "good enough mother," such that the mother's request to see and hold her baby should or should not be granted.

In summary, an ethics consult is more thorough when past conversations and discussions are included in "knowing that." Yet whatever is considered a pertinent "fact" must be accurately understood relative to any uncertainty, ambivalence, or ambiguity.

KNOWING HOW

This type of knowledge involves the skills, abilities, and judgment to bring about a particular outcome. Someone "knows how" boiled eggs are made by going through all the necessary steps to produce an edible boiled egg. This kind of knowledge has been labelled "practical knowledge" in contrast to "knowing that," which has been labelled "theoretical knowledge."

Knowing how, the performative aspect of ethics consultation, often proves to be the most challenging and the most tiring. It includes such skills as clarifying the questions to be answered, determining how best to obtain required information, ascertaining which individuals need to be involved and which do not, mediating conflict, and "keeping moral space open."[16]

The importance of these skills reflects the dynamics and complexity of most health-related situations. We find the metaphor of a spider web useful for analyzing this type of knowledge. An ethics consultant helps identify those who are and should be involved and then supports these connections. When an ethicist, for instance, asks if the nursing home staff will be apprised of the substitute decision maker's record of treatment decisions and refusals, she or he is pointing to the responsibilities of the hospital team, those who will assume care of the patient. Because each connection differs depending on the history, responsibilities, character, and power of each party, consults can be broadly disparate, even though the central question is the same (for example, "Should this adolescent's preference be honored against parental wishes?"). These differences can make the web of connections hard to balance, which in turn makes the connections easy to break, threatening the whole network. The cases described by Skeel-Williams and Ford reflect the arduousness of trying to keep the appropriate people connected when different values, competing interests, changing work patterns, and strong emotions are involved. Based on our own practice as bioethicists, we have found that when a consult contributes to a sustaining and affirming network of relationships, it has a kind of aesthetic quality, just as a spider's web in a garden qualifies as an aesthetic accomplishment. Similarly, when the relationships cannot be preserved, we sometimes feel a regret that may

be similar to that felt when we see a tattered and abandoned spider's web. (We note that this metaphor has one shortcoming: a web is meant to snag a victim, food for the spider.)

A related skill often not explicitly discussed in articles about ethics consultation relates to the politics of engagement. This skill begins with a type of "knowing that," namely who inside and outside a healthcare organization has responsibilities, power, and authority to answer a question, address an issue, or resolve a problem. Such political acumen requires refined diplomatic skills to help link up the duties, rights, power, and influence to achieve an ethically positive outcome. Doing ethics consultations is often said to require courage. However, courage requires diplomatic skills when an ethicist must find ways for those who are powerful and advantaged to include, hear, and involve those who are invisible, vulnerable, or less powerful.

Some of the consults we have been considering nicely highlight the importance of an ethicist's diplomatic skills. Dudzinski's worry about her self-initiated meeting with the patient indicates her intuition that any interaction with a patient must first be justified. Reflecting on all the team meetings the stroke patient's family was asked to attend, Ford laments the family's increasing psychological burdens created by the changing of clinical teams. Spike's discomfort when the mother visits her baby in the ICU for the first time stems from his awareness that he is a poor substitute for the person who should be present on behalf of the patient as well as the clinical team, the attending pediatrician.

"Knowing how" is key for successful ethics consultations. Accordingly, training must include learning relevant skills, and provide opportunities for practice (and more practice) and time for self-evaluation.

KNOWING WHY

Knowing that a water molecule has one atom of oxygen and two atoms of hydrogen and knowing how it is formed (that is, electromagnetic attraction) is different from knowing why the molecule exists as it does: the electromagnetic charges of oxygen and hydrogen differ. According to Ryle, "knowing why" refers to stories that explain how a situation arises, unfolds, and ends. This characterization mirrors the concept of narrative. Narrative is an ethical and epistemic approach that has garnered considerable attention in bioethics in the past decade because it can help to deepen our understanding of the clinical situation that is "at hand."

In Zaner's article, the parents of the at-risk fetus are faced by the decision they have because of technological advances in fetal diagnostics, legal protection of parents' right to decide, continued social stigma and disadvantages for those with disabilities, and society's restrictions on women's access to abortion. The case in which Ford's help was requested grew from the public's high expectations of ICU care, a lack of consensus about futility as a sound basis for the rationing of care, and the erosion of trusting relationships in modern tertiary hospitals. Dudzinski's consult involved a confluence of the legal doctrine of informed consent, the continued subjectivity of pain reports, and disparate assessments of the body's sacredness (that is, the philosophical concept of embodiment).

Answering the question "How did we come to be here?" or "Why are we here?" is valuable for two reasons. First, it can offer much needed respite from the seriousness and urgency of the immediate situation. Skeel and Williams likely talked about the "whys" from time to time, to help the clinical team accept that they were not responsible for every disappointment and failure that occurred during their patient's hospitalization. Second, "knowing why" should help a consultant be proactive in identifying future quandaries and in situations of moral distress. As Ford notes, too frequently consultations are reactive, rather than proactive. Just as emergency medical care should not be the primary form of healthcare, we believe that "rescue ethics" should not dominate an ethicist's work. Like our clinical colleagues in emergency departments, when

ethics consultants continually try to rescue others, it can take a heavy emotional and psychological toll, and become an inefficient use of healthcare and personal resources.

KNOWING-TO-ACT-IN-THE-MOMENT

Mason and Spence's article was prompted by repeated observations of their graduate mathematics students: "as students are given something more general or less familiar, or a task requiring several steps, they are mostly at sea. They don't appear to know-to use what they have learned."[17] The authors came to see that there is a moment when a student knows to apply a particular theorem and when not to. Knowing-to-act requires "relevant knowledge to come to the fore so it can be acted upon," according to Mason and Spence.[18]

We were intrigued by these insights because we see the same complexity in teaching others to do ethics consultations. There is something more here than just decision making. Knowing-to-act relates to the concepts of agency, presence, and being that such theorists as George J. Agich, Zaner, Churchill, and Frank continue to examine. While Mason and Spence recommend creative practice to develop this type of knowledge, they concede that it is erroneous to believe that practice only "makes perfect." All too briefly, unfortunately, they describe Caleb Gattegno's pedagogical idea that "integration through subordination" hones knowing-to-act.[19] Integration through subordination involves repeating an activity while simultaneously directing one's attention to something else. We interpret Gattegno as advocating skilled habits plus cognitive openness to new stimuli. In other words, competence that is responsive, rather than rigid, and humble, rather than arrogant, in light of the inescapable complexity and dynamism of most situations.

Armed with knowing that, knowing how, and knowing why, what kinds of knowledge does an ethicist need for "knowing-to-act-in-the-moment"? The ethicists' testimonials provide diverse and subtle examples: knowing to not initiate a conversation or to begin a meeting (Dudzinski, Spike), knowing to visit a unit before staff go home to see how they are coping (Skeel-Williams), knowing to stop talking and listen (Zaner), and knowing to cease being involved (Ford).

Awareness is emphasized in the mathematicians' article. Along this line, another metaphor we employed in our analysis of ethics consultation was Taoism, a variety of ancient Chinese philosophical and religious traditions. The Tao is often translated into English as "way" or path. Followers of the Tao seek to find and follow the appropriate or fitting path forward or through a situation. Clarity of insight, wisdom, and concern for others assist one in following the Tao.[20] In an article about the role of ethics consultants, Churchill and Schenck repeatedly invoke Taoist concepts: a couple deciding about their at-risk fetus seek "to discern their proper place in the scheme of things,"[21] and for most patients and families, "the task [is] to find the path . . . to locate the right way."[22] Moreover, Taoism involves humility: in the context of ethics consultation, finding the most fitting way may involve other people, not the consultant herself or himself. This aspect, we believe, is key to skilled consultation because it is illegitimate for a consultant to assume that she or he is responsible for fixing a problem or telling others what they must do. As Zaner notes, "those whose circumstances pose the problem . . . are the ones from whom the resolution must come."[23]

All five of the ethics consultants' testimonials describe the ethicists' efforts to-act-in-the-moment in the all-too-human and unfolding situation they have joined. Sometimes they are successful, and sometimes they are not. Sometimes they are in limbo, all of which affirms the considerable complexity and sizeable risks of doing ethics consultation.

CONCLUSION

The different types of knowledge, Ryle's "knowing that," "knowing how," "knowing why," and Mason-Spence's "knowing-to-act-in-the-moment," contributed significantly to

our development of an introductory ethics training module for practitioners. Moreover, we routinely draw comparisons to what the practitioners had to learn to become technically competent clinicians, and ask them to reflect on their own situations; for instance, "What is it that you are aware of when you know-to refer your client to someone else?" Such comparisons reinforce that many of their technically related skills are very valuable for addressing ethical aspects of working with patients and colleagues. In the module, we also emphasize that it can be very risky to overlook past conversations in the "fact finding" part of an ethics consultation, just as not clarifying the degrees or levels of uncertainty, ambivalence, and ambiguity represents haste or carelessness and would not be tolerated in clinical decision making. The concept of the politics of engagement and associated diplomacy skills — too infrequently discussed explicitly — is also essential to successful consultation, given that the consultant is not a decision maker, but helps others to preserve or reach an ethically sound state of affairs.

Finally, sharing less-than-successful ethics consults is obviously personally hazardous, but certainly generous and brave. An initially benign question can prove complex and political. We close here with a metaphor that helps capture the experience of many consults. A children's board game, Chutes and Ladders, has a few hundred numbered squares, some connected by ladders that, if landed on, permit one to advance several steps at once. Some squares are connected by chutes that, if landed on, require one to go back several steps. The objective is to use dice to advance to the last square. In the context of ethics consultation, success would be an ethical resolution of the question or concern by those directly involved, within a relatively short time. Yet in working through a consult with diverse parties, there will be points when a shortcut appears, and the consultant has to decide whether to take it to expedite the process or to just continue step-by-step. Skipping a step may mean someone is not involved who should be, or that a possibly relevant policy is not sought. At other points, something will occur that reverses whatever progress has been made; perhaps the rehabilitation therapist unknowingly divulges privileged information to a patient, or a newly assigned psychiatrist reaches a very different diagnosis. We find that this metaphor helps clinical staff to comprehend more deeply that consultation is much more than knowing applicable laws and familiar ethical concepts and posing good questions. In sum, teaching staff how to work with an ethicist in a consultation requires a multifaceted and mentored training approach.

NOTES

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6. Dudzinski, see note 4 above.

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8. Skeel and Williams, see note 4 above.

9. Ibid., p. 205.

10. Ford, see note 4 above.

11. Ibid., 208.

12. Spike, see note 4 above.

13. Zaner, " 'But How Can We Choose?' " see note 4 above.

14. R.M. Zaner, "Power and Hope in the Clinical Encounter: A meditation on vulnerability," *Medicine, Health Care and Philosophy* 3, no. 3 (2000): 265-75; R.M. Zaner, *Ethics and the Clinical Encounter* (Lima, Ohio: Academic Renewal Press, 2004).

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17. Mason and Spence, see note 5 above, p. 136.

18. Ibid., 139.

19. Ibid., 156.

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21. Churchill and Schenck, see note 15 above, p. 396.

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Professional Clinical Ethicist: Knowing Why and Limits

Paul J. Ford

Clinical ethics consultation practice will continue to improve if we strengthen our understanding of the general issues, strive to improve our performance, and commit to investing time in each case to understand the context and history. These three elements require a personal openness to revising our beliefs, attitudes, and ideas, since a self-reflective honesty and integrity underpin such explorations. Learning and improving consultation must come from reflection of our own experiences as well as engagement with our peers who practice in other contexts. Clinical ethicists become either dangerous or irrelevant when they believe there is nothing more to learn and that all consultations can be solved by quickly plunking them into generic categories based on a single report. To this end, we do a disservice to our colleagues when we are unwilling to share our cautionary tales about the potential pitfalls of cases and emotional costs experienced as ethics consultants.

If clinical ethics consultants are relevant to the clinical environment, they must be effective. Starting from this premise, we can both help and harm a situation. Conversely, if we do not attempt to alter the situation in some way toward the good, then we are irrelevant and wasteful. In the circumstance I find myself, embedded within a large research teaching hospital, it is not a matter of whether I think of myself as a professional because this is assumed by those who consult me. It becomes a matter of my comporting myself to the highest level of practice as a professional. The fact that the discussion of clinical ethics as a profession has raged for more than 20 years should not hinder us from adopting the highest level of service and quality.[1] Our aca-

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demic debate and concerns about being co-opted should not be used as an excuse for lax personal standards for development. Just like the other professionals with whom I interact, I am expected to continually educate myself, improve the quality of my practice, and approach every case with a serious investment of time and energy.

In their article in this issue of *The Journal of Clinical Ethics,* Russell and Pape present a compelling discussion of basic obligations of clinical ethics consultants to perform well and to improve practice. In many ways, these compose basic elements of professional obligation. The authors provide an organization and analysis of three types of "knowing" that are relevant and useful to the actual practice of clinical ethics consultation. I applaud their use and application of the cases published in *JCE* in elucidating these themes.

When Denise Dudzinski and I organized the selection of cases cited in the article, and subsequently compiled an extended selection of cases in book form, we hoped that it would spark people to reflect on complex practice.[2] Almost every experienced ethics consultant we approached to contribute a case immediately identified several cases that fell into the "haunting" category. It was clear that these cases were not just those with sad outcomes. As Russell and Pape point out, they were cases with "uncertainty, ambivalence, or ambiguity," difficulties in the "politics of engagement," and potential powerlessness of consultants. The discussion presented by Russell and Pape highlights our obligations to approach our activities of clinical ethics consultation in a professional manner. These approaches of "knowing" entail strong education, improvement in performance, and careful attention to the histories and contexts of each consultation.

The strength of Russell and Pape's analysis lies in their attention to parsing out the different types of activities. Too often, the activities of ethics consultation are lumped together as if we speak about a monolithic activity of clinical ethics consultation. We undertake a variety of roles and tasks that are dictated by the nature of the interwoven webs of social relations, medical facts, and values.[3] Although Russell and Pape do not, and could not, articulate all of these types of activities, they provide a basis on, framework for, or approach with which a consultant could select an appropriate practical approach(es) in a particular case. These approaches clearly emerge out of the contingencies of the case rather than superimposed on it by a rigid definition. As far as the authors are able to take their discussion in this article, I have very little to criticize. So, below I will simply point out aspects of "knowing why" that need to be further articulated in order to avoid being mislead or waylaid in cases.

A major challenge to the "knowing why" in any clinic ethics consultation case involves the limits of pursuing the history of a patient, social circumstances, or institution. Although I agree with Russell and Pape that understanding the robust context of patients, families, healthcare providers, and institutions compose a fundamental component of unraveling or deciphering the individual web or cipher that presents itself as a case, we can be mislead by an unrestrained exploration of the context. There are several competing values that may limit or offset the unlimited pursuit of background information, which is fundamental in knowing the why of any complex situation. I put the difficulties in four broad categories: (1) relevance, (2) perseverance, (3) time constraints, and (4) types of knowledge.

Although it is important to understand the family dynamics of a particular patient's situation to decipher the values involved, there are limits to relevance and helpfulness. For instance, a patient's ex-wife might give you the following account: "Years ago, his current wife swindled a company and spent time in jail. Then he got back with me. Even though in the end, he went back with her, she doesn't really love him. After all, she cheated on him just two years ago."

Pursuing a line of inquiry related to the issues of jail time, swindling, marital cheat-

ing, or love may be irrelevant to the decision at hand. Further, in raising these issues with other family members, the consultant risks cultivating distrust and generating anger that will not assist resolution of the situation at hand. Finally, pursuing these issues may make the consultant a pawn in ongoing conflicts between family members, which could reduce the chance of helping build consensus. However, the ex-wife's statement should not be ignored, since it tells us something very important; the ex-wife has an oppositional relationship with the current wife. This is relevant and important as we structure conversations with large groups and as we parse information. Again, as consultants we must actively recognize that hearing this statement may naturally negatively influence our perceptions of the current wife and/or the ex-wife. We explicitly and intentionally "bracket" in our minds these accusations and remind ourselves that the statement may not be true. Independent of the truth, the statement would not discount the current wife from making good decisions in this particular case. The past does not necessarily dictate the quality of decision making in the present. Our performance of consultation should judge the current discourse and decision making against the backdrop of history and not by means of history. This includes understanding family dynamics while not becoming embroiled in them. The knowing "why" continuously must pass a test of relevance.

The usefulness of listening repeatedly to a story also has its limits. There are times when no matter how long or how often we listen, the patient or family demonstrates an inability to move to the present situation and circumstance. Long after the initial prompt for background information, the person perseveres in a retelling. We might hear things like: "But if my mother had received antibiotics two months ago, she might have been a surgical candidate today," or "I need to start at the beginning. Five years ago. . . ." In the first example, the family is stuck in the "what if" and cannot get to the decision at hand. Beyond the potential of wanting to know "who's responsible" or a legal suit, this behavior can be a coping mechanism to avoid a horrible decision that must be made in the present. By continuing to allow the past to be explored, the present can become obscured. As consultants, we need to be sensitive to when the past interferes with the present and redirect the conversation. In the second example, a person continues for hours in a meandering story that provides a very low yield of information. The performative aspect of consultation requires clipping, strong redirection, or pruning of these conversations when they begin to dominate the time and attention of those involved. When combined with the time-limited nature of consultation, discussed at more length below, these conversations can become a trap for the consultant. We must recognize that not all retellings of histories lead to better understandings of the "why," even if at first they have relevance.

The time constraints on both decision making and professional work hours mean that there are limits to the amount of knowing "why" that can be achieved. The ambiguities that necessarily pervade clinical ethics consultation force us to balance the maximal reduction of ambiguity with efficiency and timeliness of advice. Although consultants would always like to have a full understanding of the "why" in a situation, decisions usually must be made before fully knowing. This should not create paralysis for giving advice, since our practice is as imperfect as clinical medicine is.

To maintain transparency, clinical ethics consultants must provide advice in consultation, with the caveat that some facts have been assumed. We live with the fact that, in retrospect, the advice may have been wrong. If there is error, however, it should accrue from the use of incorrect information, not from poor reasoning. Due diligence should be used to check facts, and the consultant should not make quick judgments to serve simple expediency or the convenience of the healthcare provider, the family, or the consultant. At the

same time, practical time limits must be respected and acknowledged in the knowing "why."

Finally, the types of knowledge on which a consultant bases the knowing "why" are fundamental. We should always prefer firsthand accounts. In their stead, we often attempt to triangulate or find definitive proof for the "why" of a situation from multiple sources and references. In doing this it is easy to get caught up in the question of motivations in the "why." Given that motivations are usually mixed, we should seldom judge individuals on suspected motivation. Rather, our analysis must be centered on values and likely outcomes for the patient and the team. Again, before providing advice, we should carefully evaluate the level of knowing that we have for each of the facts in the case. Actually talking with the patient and/or surrogate is usually fundamentally important, rather than just relying on the filter of the healthcare providers. After all, it is not just family members who may supply less-than-reliable information. For instance, it may be important to talk with or read the note of the surgeon, rather than taking the word of the intern. We need to weigh each bit of information not only by relevance, as previously discussed, but also weigh information for certainty of coherence with known events, opinions, and facts.

These various challenges in the knowing "why" compose only one aspect of the rich activities we undertake as clinical ethics consultants.

Although there are many difficulties found in clinical ethics consultation cases, Russell and Pape remind us of the need for careful evaluation of our activities as consultants in complex clinical settings. My exploration of the limits and challenges of the knowing "why" points to complexities of our tasks as ethics consultation professionals. These are not practices that we can perfect through a brief weekend course. We need continuing ethics eduction, quality improvement, and investment in individual cases. These parallel some of the basic elements expected of our peers in other healthcare professions — physicians, nurses, social workers, and so on — and should be equally applied to clinical ethicists.

NOTES

1. R. Branson, "Bioethics as Individual and Social: the Scope of a Consulting Profession and Academic Discipline," *Journal of Religion and Ethics* 3, no. 1 (1975): 111-39.

2. P.J. Ford and D.M. Dudzinski, ed., "Cases that Haunt Us," Special Section, *The Journal of Clinical Ethics* 16, no. 3 (Fall 2005): 193-222; P.J. Ford and D.M. Dudzinski, ed., *Complex Ethical Consultations: Cases that Haunt Us* (Cambridge, U.K.: Cambridge University Press, forthcoming, 2008).

3. R.D. Orr, "Methods of Conflict Resolution at the Bedside," *American Journal of Bioethics* 1, no. 4 (2001): 45-6; P.J. Ford and A.R. Boissy, "Different Questions, Different Goals," *American Journal of Bioethics* 7, no. 2 (2007): 46-7.

Case and Commentary

Memento . . . Life Imitates Art: The Request for an Ethics Consultation

Sheila Otto

The resident called the ethics consult service with a request that someone guide them through an unusual problem: Who should consent to or refuse treatment in the case of a patient who has an aggressive lung cancer but who also has short-term memory loss?

Thoughts of the film *Memento* come to mind, in which the main character, Leonard Shelby, spends the entire movie trying to identify his wife's murderer.[1] Although the character in the film can recall details before his wife's death, he has complete recent memory loss. The film is a masterful enactment of a man trying desperately to cue himself into his recent past through a variety of techniques. Our patient, Mr. G, like the film character, had lost virtually all of his recent past.

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THE FIRST ETHICS CONSULT

In reviewing the medical record, Mr. G, a 58-year-old White male, had first been admitted after crashing his truck. It was determined that he had had a seizure at that time, although it was unclear if this was the cause or the result of the accident. He was released from the hospital but came back two weeks later with more seizures and mental status changes. During the diagnostic work-up that followed, an incidental finding on a computed tomography (CT) of his chest became crucial. Mr. G was found to have a very aggressive type of tumor, which can be treated early on, with a 15 percent rate of cure. The down side was that the chemotherapy regime would be very burdensome with expected side-effects of nausea, vomiting, fatigue, and hair loss. As this type of disease progresses, the impact of therapy becomes less potentially beneficial.

When this was first found, Mr. G's brother was brought into the conversation, as Mr. G had appointed him as his healthcare agent (proxy) upon admission.[2] He was asked to

make a decision about starting chemotherapy. Based on his knowledge of his brother's values and given the poor prognosis, he declined the chemotherapy. Because the medical team was unsure who should be making the decision, they asked for input from the ethicist.

The ethics consultant met with the patient and found him to be appropriate but with virtually no ability to recall what had been said an hour earlier. According to his care team, the patient had been told repeatedly that he had cancer, yet when the consultant visited hi,m he had no recollection of this whatsoever. In fact, he was unsure of why he had been in the hospital for two months (unrelated insurance/placement issues). The consultant asked whether the patient would choose chemotherapy in a theoretical situation, to which the patient replied that he would have to think about it. The consultant recommended that the proxy be the decision maker as the patient's ability to recall his condition impaired his ability to give fully informed consent about any treatment.

THE SECOND CONSULT

Mr. G had a number of adult children from whom he had been estranged. When he was hospitalized, they were notified and began to visit. Their relationship with their uncle, the proxy, was distrustful, and they began to question his decision to withhold therapy. When they visited their father, he seemed quite lucid and capable of decision making, so one daughter called the ethics service. This time a different ethicist was on call, and he felt uncomfortable leaving Mr. G out of the decision-making process since the patient was so lucid in the moment.

ETHICS GROUP REVIEW

The entire service convened (five consultants) to review the case. Questions raised in the group discussion included: What is the reason for the patient's memory loss and the prognosis for recovery of memory? What are the burdens and benefits of treatment for his cancer? Is his brother a true proxy, speaking in "his voice"? Did the patient appoint his proxy under duress? What reasons does the proxy have for withholding therapy? Has the patient been asked repeatedly about his thoughts on therapy? Is he consistent in his replies? Do the burdens of proposed therapy take on additional weight due to the fact that he will not be able to remember why he is having the symptoms? What is his current baseline in terms of symptoms? Is his current physical condition impairing his quality of life?

The oncologist was called during this meeting to address specific questions regarding the type of cancer, staging, therapy, and prognosis. Since a decision had been reached not to pursue active treatment, a thorough staging had not taken place since the initial diagnosis two months prior. The oncologist stated that if caught early, this cancer had a 15 percent curative rate and a 60 percent rate of response that would extend the patient's life, but likely only for about one year. However, because it was such an aggressive type of cancer, the two-month delay would necessitate staging now with the likelihood of further disease and worse prognosis. The chemotherapeutic regime would be rigorous with significant side-effects as mentioned earlier.

THE THIRD CONSULT

A third ethicist became actively involved after the group meeting. She spoke to the neurologist whose chart notes reflected a poor prognosis for regaining memory, although the etiology of the loss was unclear. There was a suggestion that brain metastases could be involved, but again, with the earlier decision not to be aggressive, the neurologist had no updated knowledge of the case, since he had not been involved for many weeks. When the attending hospitalist was queried, her response was to suggest that the ethics consultant speak directly with the neurology service, which, as mentioned, had not been involved

for some time. Oncology had signed off the case as well, and again the hospitalist was not clear about treatment options as she had only recently encountered the patient. The ethical issues of fragmented care of a complex patient are worrisome, but are topics for other articles.

VISITING THE PATIENT

The patient's room was easy to locate on the cancer floor because there was a large sign posted saying "G's room." This was to help the patient to find his room, if and when he wandered. A similar sign was posted over his bed, across from a wall of family photos.

The patient was quietly lying in bed when the ethicist, Ms P, introduced herself as a member of the ethics team who was there to assist Mr. G in making decisions, or at least making sure that we were respecting his wishes. He was asked about his living situation (couldn't remember), his designation of his brother as proxy (which he confirmed), and he was asked to identify persons (family members) in the photos (which he did without difficulty). Mr. G stated that he thought he was in the hospital but that he had no idea why. It was explained that his problems were twofold: (1) severe memory loss and (2) some newly diagnosed cancer. He readily acknowledged that he had a problem with memory but was shocked to hear that he had cancer. When asked about cancer treatments, he appropriately asked about side-effects. He was told that they would be nausea, vomiting, and hair loss, to which he shook his head. When pressed about whether he thought he might be interested in treatment, he said that it was a lot to think about.

LATER THAT SAME DAY

Ms P returned to the patient's room and asked if he remembered meeting her in the morning. He responded that she looked familiar, but he did not recall a morning visit. She again introduced herself and said that she was back to speak further about his wishes for treatment. He asked treatment for what? She gently said cancer. He again seemed shocked, asked if it was the bad kind, and when it was acknowledged that it was in his lungs, he began to cry. He then asked if he was being treated and was told no, that his brother did not think that he would want treatment. He said I have always said I didn't want to go through all of that. It's really about the quality of life and who wants to go through all of that? Ms P asked if he still felt that way, and he replied yes.

THE NEXT MORNING

Ms P made her final visit to Mr. G the next morning, since his daughter had requested a meeting to share her and her sisters' concerns about the treatment decisions. When Ms P approached the room, Mr. G was playing a card game with his granddaughter, very interactive and comfortable. She again introduced herself, and Mr. G again thought she looked vaguely familiar, agreeing to let his daughter ask questions and speak with the ethicist alone. The daughter told the tale of estrangement from the father, and more recently from the uncle who was thought to be withholding information from the daughters. The discussions of the day before were shared, and the daughter agreed with the plan to forego chemotherapy. After checking with the patient, permission was documented that medical information could be shared with the daughters.

DISCUSSION

Respect for patient's autonomy underpins decision making for healthcare in the United States. We expect patients to be informed about what is going on with their diagnosis and to consent or not to a proposed plan of care. However, when there is doubt about the patient's capacity to make such a decision, a thorough assessment is needed to evaluate this ability. One would be looking for a confirmation that he or she could understand the benefits, risks, and alternatives of any proposal and then be able to make a choice based on his or her values. In Mr. G's case, his inability to remember his diagnosis made the team

question his ability to consent to a treatment that he could not foresee or appreciate in terms of benefits and risks.

CAPACITY VERSUS COMPETENCE

The appointment of the patient's proxy was undertaken when he was first admitted, and he reconfirmed this on multiple separate occasions. Because capacity is, by nature, task specific, the staff were comfortable that the patient did have the capacity to complete this appointment, as it seemed logical and consistent. He was also not globally incompetent, as a demented or unconscious patient would be. The criteria needed to ensure decision making regarding chemotherapy was more complex and sophisticated than appointing a proxy, and this was the source of the struggle between beneficence (trying to do right by the patient) and respect for the patient's autonomy (incorporating him into the decision.)

CONFLICT ABOUT TREATMENT

The patient's adult daughters were notified when he was admitted. They visited and brought a number of pictures to display, as well as their children, in an attempt to reconcile after years of minimal contact. In the moment, Mr. G seemed very lucid and appropriate. They did recognize his amnesia, but were concerned that their uncle might be making decisions that he could make himself. The proxy was adamant that he would not want any further work-up or treatment.

Because Mr. G's prognosis for recovery was not good, in spite of some uncertainty regarding staging, and because the burdens related to the therapy would not be understood by the patient in light of their potential benefit, much of the team felt comfortable withholding chemotherapy. Commenting on the burdens of treatment, one person noted, every day he wakes up sick and vomiting, it will be like a nightmare because he has no clue why he feels this way. Even when he is told, he cannot retain the information. This was the view of the proxy as well.

The other side of the argument supported further staging just in case Mr. G's prognosis would be better than originally thought. Therapy could possibly benefit him by giving him more time. His current quality of life was hampered by his memory, but his breathing was not yet a problem. Because he was able to enjoy his family's visits immensely and repair past breaks with his family, why not buy as much time as possible? He was not physically uncomfortable as yet. These were strong arguments on both sides, but which would be more consistent with Mr. G's individual values?

WHAT IS THE "RIGHT" DECISION?

Based on the patient's responses — "I'd have to think about that; that's a lot to consider" — one could argue that he might have considered therapy, but counterbalancing that were his comments: "My brother is saying what I have always said: 'What good is it if you don't have a quality of life?'. I still feel that way."

One of the particularly difficult aspects of this case was the heart-wrenching response each time the patient was told he had cancer. He was always shocked, and even cried. Repeating the diagnosis to ask him yet again what he might do began to feel cruel to the consultant. In the end, most of those concerned seemed to feel comfortable allowing his proxy to make decisions. The daughters were also given permission, by the patient, to access his medical information, which solved the trust issue with their uncle. Mr. G was ultimately discharged to a supportive facility where he would be cared for with the goal of comfort-care.

FINAL QUESTIONS THAT LINGER

Was this the right choice for Mr. G? Staging had not been ordered because of the decision to withhold treatment. What if he could have been in the small percentage of patients who would have responded? What if his prognosis had not been so poor? Would we have

pushed harder for treatment? Would we have been more willing to accept his choice if he said yes to treatment, without involving a surrogate? Was he asked often enough to provide a consistent pattern? Did the discomfort of the consultant in repeatedly bringing up an unpleasant subject play out in protecting the patient or did it short-change him?

SUMMARY

This was a troublesome case, without complete consensus about the right thing to do. It seemed there were arguments on both sides: those who thought that the goal of comfort care without treatment was most consistent with his wishes, versus those who thought the additional testing and treatment might have produced a net benefit in spite of the burdens. Ultimately, the patient was placed in a facility with a do-not-resuscitate (DNR) order in effect and a plan for comfort care. He may live a few months or more. We all hope that whatever time he has is spent free of pain and symptoms, and that he is able to live a life of quality consistent with his wishes.

The main story line is consistent with actual events; however, there have been changes in terms of gender, disease, and relationships that have been included to protect the anonymity of the patient.

CONFIDENTIALITY

The names, genders, and family dynamics in this case have been disguised to maintain the confidentiality of the patient.

NOTES

1. J. Nolan and C. Nolan, *Memento* (Burbank, Calif.: New Market Capital Group, 2000).

2. NY State Proxy Law, 1991, Public Health Law article 29-c (2980-2994).

Memory Identity and Capacity

Jeffrey P. Spike

The situation of Mr. G described in "*Memento . . .* Life Imitates Art," a case in this issue of *The Journal of Clinical Ethics,* raises questions with which every ethics consultant must wrestle. It is an interesting case because it combines classic issues with some new twists. When one first reads it, the case includes the very types of prognoses that can make good decision making perplexing even for physicians. Is a 15 percent chance for a cure a good chance? Many people would think a 5 percent chance for a cure is small, and close to negligible when you factor in the amount of suffering that one must endure during treatment. Many of the same people might think 20 percent chance for a cure is a different matter, and worth the gamble. But 15 percent is confusing: high enough to be tempting, but low enough to make one worry about regretting the decision if you turn out (as is likely) to be in the other 85 percent. And that is before factoring in the question of whether extending life by a year is worth it, if much of that time would be spent with the typical and predictable symptoms suffered from chemotherapy. Is that extra year a benefit or a burden?

What makes Mr. G's case worthy of being singled out, however, is that it simultaneously raises another issue, one just as important to the successful practice of ethics consultation, but far less appreciated. After 10 years in the practice of hospital-based clinical ethics consultation, I reviewed my many cases and discovered that capacity issues are just as common as end-of-life issues. By my estimate, each is at least part of a legitimate ethics consult 80 percent of the time. As with Mr. G, both often appear together. And as is so often the case, what makes the situation so ethically difficult is the overlay of the issue of capacity upon the (end-of-life) consequences. It

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places the case at the intersection of two ethical planes, one deontological and the other utilitarian.

Clinical ethics is of course an amalgam, a mix of ethics, law, and medicine. Ethics, as a branch of philosophy, has had a lot to say about the importance of memory to personal identity. The vital importance of memory to personal identity has become widely accepted (if not universal) in philosophy, since the near -universal rejection of dualism and the existence of the soul in the late eighteenth century. Without a substantial soul, only memory seemed able to explain what makes a person the same person at different times. From this interdependent relationship, it would be natural to assume that a loss of memory means a loss of personal identity, and thus a person would lack capacity to make "their own" decisions. This seemingly natural series of links involves many assumptions, however, and some of them do not hold up.

There is not a one-to-one relationship of memory to capacity, and in fact a patient may have capacity despite very compromised memory.[1] The active involvement of at least three different ethics consultants in Mr. G's case certainly shows the difficulty he presented. One important lesson that might be drawn from his case is that to consider capacity as all-or-nothing is often a mistake, and one that can create additional problems. When one consultant decided to turn to a family member who was the proxy chosen by the patient, it raised doubts in the minds of some other family members. This is a common problem.

Consultants should avoid ever appearing to leave the patient out of the conversation, unless the patient has asked to not be involved. Thus good practice means often having conversations with the proxy in the presence of the patient, or at least telling the patient the decision that was made after meeting with the proxy. I counsel this approach even when a patient is in a coma, so the proxy doesn't feel guilt afterwards, as though he or she had deceived the patient.

The case before us is even more interesting because of the ability of the patient to participate in conversation. In a recent review chapter on decision-making capacity, I discussed another case that raised some of the same issues.[2]

THE CASE OF MRS. BENSE

Mrs. Bense is a 75-year-old widow with advanced vascular dementia and end-stage congestive heart failure. She listens to a description of the benefits and burdens of having a do not attempt resuscitation (DNAR) order, and when her physician recommends it, she agrees. But the next day she has no memory of the discussion, so her physician repeats the consent process, and she again agrees. Her physician wonders if she can have capacity when her memory is so compromised.

ANALYSIS

The analysis of this type of case reinforces the value of including, as a component to the definition of capacity, that the patient makes a decision c*onsistent with her or his past choices.* This is a way to test for authenticity of belief. The ethical goal is to have a patient make autonomous choices, or choices that reflect his or her personality and represent the patient's core values or deeply held beliefs.

Including the criterion of consistency over time to our assessment of capacity has at least two advantages: (1) it helps to identify decisions made in a state of panic or anxiety that the patient may later regret, and (2) it emphasizes the link between the concepts of decision-making capacity and surrogate decision making, since surrogates of incapacitated patients are expected to make decisions that are consistent with those the patient made when capacitated.

The condition of consistency over time also comports well with the ethical methodology of narrative ethics. Narrative ethics holds that a human life is best seen as a story:

it has a beginning, middle, and end, with each stage growing naturally out of earlier stages, and with identifiable threads woven through it that hold it together, such as the subject's personality, memories, values, goals, and social network. Memory is important, but is not the only source of strength with which to weave a life tapestry. At the edges one's story quite often frays. Judging someone to have capacity is then saying that the person ought to remain in charge of his or her life story, and have the right to decide its ending.

The cases of Mrs. Bense and of Mr. G demonstrate the potential importance of considering consistency over time. When physicians and ethicists discovered that the two patients had no memory of discussions the day before, they wisely repeated the entire informed-consent process. But when the patients made the same decisions again, it was appreciated that retaining the information wasn't necessary for the decision to be authentic and autonomous. Consistency sufficed for the team to be comfortable that the patients' choices represented their core values.

A fourth interesting consequence of adding consistency to the criteria for capacity is that the experts about consistency would be the persons who have best known the patient over time. Thus a capacity assessment in controversial cases will often have to include a family member, friend, or long-term careprovider who has known the patient well for an extended period of time (that is, since the patient indisputedly had capacity). Such expertise can be more important in cases of this type than a psychiatric opinion.

This appreciation of the limited importance of memory is also a reminder of a well-known yet easily overlooked fact about capacity assessment. The commonly used Folstein mini-mental state test does not assess capacity, and using it for that purpose is a mistake.[3] Folstein is designed to assess dementia, and is validated for that purpose. But it was never intended to be used to assess capacity. As a result, I would argue that a reference to a Folstein score in a psychiatry note responding to a request for a capacity evaluation is more of an indicator of confusion on the part of the consultant than the patient. Mrs. Bense and Mr. G would probably score less than a 15 on the Folstein, but were rightly judged to have capacity to refuse potentially life-sustaining treatment. (Interestingly, a patient can also score a perfect 30 on the Folstein and lack capacity, such as in cases of fixed false beliefs. The point is the same: the Folstein simply does not test for capacity.)

It is now a commonplace that any clinician should be able to assess capacity, and it does not require a psychiatric evaluation. I would add that any clinical ethicist is also a clinician while in that role, and must be able to have his or her own independent judgment of a patient's capacity. Capacity is one of the core issues in ethics consultation, and to feel that it lies in the domain of expertise of others would render ethics consultants nearly powerless in many of their consults. Some ethicists may fear this means having to have a clinical degree. But I do not mean anything of the sort.

Assessing capacity is not a technical skill requiring years of training, although it is a judgment requiring experienced, excellent communications skills and a finely tuned ear. Indeed it is more likely to be the technicians who find it hardest to do, because there is no physiological test, blood work, or scan that can replace good judgment.

What is needed for capacity assessment is a well-documented half-hour conversation with a patient about his or her illness and all of the reasonable treatment options. If the patient understands the options, makes a choice, and understands the consequences, then a note documenting those facts in the chart is adequate to determine that the patient has capacity and to legally justify orders crafted to achieve the patient's goals. It will be helpful if the note quotes verbatim a few of the questions asked of the patient and the patient's replies. These can prove enormously helpful

to the staff and the family later in the hospitalization, should the patient lose capacity. The role of the family in this case is then limited to helping us to assess that Mr. G has the capacity to make this decision himself.

CONFIDENTIALITY

While based on a true case, many details in the story of Mrs. Bense have been left out, and others changed, to assure that no one can easily identify the patient.

NOTES

1. J.P. Spike, "Personhood and a Paradox about Capacity," in *Personhood in Healthcare,* ed. D. Thomasma and D. Weisstaub (Dordrecht, the Netherlands: Kluwer Academic Publishers, 2001); J.P. Spike, "Capacity is Not in Your Head," in *Variables of Moral Capacity,* ed. D. Thomasma and D. Weisstaub (Dordrecht, the Netherlands: Kluwer Academic Publishers, 2004); J.P. Spike, "Narrative Unity and the Unraveling of Personal Identity: Dialysis, Dementia, Stroke, and Advance Directives," *The Journal of Clinical Ethics* 11, no. 4 (Winter 2000): 367-72.

2. J.P. Spike, "Assessment of Decision-Making Capacity," in *Reichel's Care of the Elderly,* 6th ed. (Cambridge, U.K.: Cambridge University Press, forthcoming).

3. M.F. Folstein, S.E. Folstein, and P.R. McHugh, "Mini-mental state: a practical method for grading the cognitive state of patients for the clinician," *Journal of Psychiatric Research* 12 (1975): 189.

Decision-Making Capacity, Memory and Informed Consent, and Judgment at the Boundaries of the Self

Omar Sultan Haque and Harold Bursztajn

Momentous decisions with uncertain futures impel us towards deliberation about the best next move. But most often we make decisions without conscious reflection about the process of doing so. As is the case with many features of our mental life, we find no need to scrutinize them until they malfunction.

Analogous to the famous and equally tragic cases of the American patient H.M. and of the British composer Clive Wearing, in the case before us anterograde amnesia has so swiftly dissociated the capriciously modular components of the mind.[1] The unfortunate circumstances present a number of multifaceted questions about treatment decisions at a time when even the word "decision" is called into question. And so we must ask and dissect things that, under non-pathological circumstances, arise routinely from prodded introspection.

WHAT IS IT LIKE TO BE AN ANTEROGRADE AMNESIAC?

The philosopher Thomas Nagel reminds us of the difficulties of penetrating to the depths of another person's first-person subjectivity in his thought experiment about attempting to imagine what it is like to be a bat, an animal with an entirely different apparatus of perception.[2] Thus the amnesiac's inner world could be effectively closed to us. We cannot know the intricacies of his waking moments, of his thoughts and feelings, and elaborate tricks of compensation employed to survive the day. What is it to be without the very features of mental life that keep our continuous personal identity intact? Nagel counsels modesty rather than claiming certainty of knowledge about such irreducibly subjective and private states of consciousness.

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However, an amnesiac is not a bat, but an impaired human. He is someone with whom we were wired to empathize. It therefore is no surprise that, although difficult to create, good art and creative imagining can at least hint to us at what it must be like. For example, in Christopher Nolan's screenplay *Memento,* the amnesic protagonist tells us of anterograde amnesia: "It's like waking. Like you just woke up."[3]

He gives us a few glimpses of his anxieties and struggles, and some that can help provide perspective as we discuss the ethical features of the case before us. Here, the protagonist describes waking in the morning to find his previously deceased wife not present:

> I don't even know how long she's been gone. It's like I've woken up in bed and she's not here . . . because she's gone to the bathroom or something. But somehow, I know she's never gonna come back to bed. If I could just . . . reach over and touch . . . her side of the bed, I would know that it was cold, but I can't. I know I can't have her back . . . but I don't want to wake up in the morning, thinking she's still here. I lie here not knowing . . . how long I've been alone. So how . . . how can I heal? How am I supposed to heal if I can't . . . feel time?[4]

DECISION-MAKING CAPACITY AND SUBSTITUTED JUDGMENT

Mr. G has lost all of his recent long-term memory but retains remote long-term memory, and cannot form new memories, with memories lasting less than one hour. The etiology of these problems is uncertain but began some time after a truck crash two weeks prior to evaluation, and included seizures.

It is important to remember that even in the face of selective incapacity in a cognitive domain, decisions about treatment may well be possible. We believe this may be the case with Mr. G. Although the mini-mental status exam is not especially useful for assessing decision-making capacity except in extreme forms of impairment, this situation may qualify.[5] It is uncertain what his exam results demonstrated as they are not detailed.

In the window of time in which Mr. G does live — something less than one hour we are told — he has a very selective deficit, however, and all signs indicate that his registration (allegedly follows commands, able to use visual cues in room and hallway), orientation (knows where he is), insight (he acknowledges his memory problems), judgment (appropriate reaction to news of illness), language, concentration, and short-term memory are intact. He shows some mild retrograde memory loss since the accident (not remembering where he lives), but in general his long-term and remote memory (from which he might derive access to his lifelong values and goals) are intact as demonstrated by recognition of family pictures, and relational bonding ("very interactive and comfortable") with even estranged daughters.

From what we have read in the case, Mr. G is able to reason, communicate, understand the proposed treatment and its alternatives, understand the risks and benefits of the proposed treatment and the risks and benefits of declining treatment, and his mental state seems to be stable over time, if selectively impaired in terms of memory consolidation, all the hallmarks of decision-making capacity.[6] He does not seem to have a complicating mood disorder that might thwart his judgment, even if he were assessed to have decision-making capacity on purely cognitive grounds.[7]

Regardless, Mr. G's inability to remember his diagnosis would not necessitate that he is unable to foresee or appreciate benefits and risks of treatment, but only that he would not be able to do so continuously in time, and only when prompted. The questions were raised, "Would we have been more willing to accept his choice if he said 'yes' to treatment, without involving a surrogate?" and "Was he asked often enough to provide a consistent pattern?" These seem to us to be the central ethical questions of the case. Was Mr. G able to make choices based on his values and his assessment of his situation, however brief? It would have been helpful for the case to detail more

of the attempts to elicit Mr. G's thoughts about treatment and its risks and benefits, considering the centrality of this question, his lack of global impairment, and the impression that he made on staff, that he was often "quite lucid and capable of decision-making."

Complicating the decision to treat Mr. G is the vital question of the likelihood of recovering or improving his memory, which cannot be ruled out based on one neurological evaluation with little follow up. We have no confirmation of ruling out metastases or other possible causes, since no mention is made of any imaging studies of the brain. We don't know for certain if this is permanent bilateral destruction of the medial temporal lobes (as in patient H.M.) or something else entirely. Although we are uncertain of the etiology of his memory impairment, we can — given his history — reasonably suspect that it is secondary to traumatic brain injury (TBI), which commonly causes problems in the acquisition of new information, especially episodic memory.[8] Recovery of memory after TBI represents a heterogeneous recovery curve, and some studies show three subtypes: slow progressive recovery, dramatic linear recovery, and initial dramatic recovery followed by significant decline at one year.[9]

Even in the face of a severe memory incapacitation, Mr. G may still retain his autonomy. But can his wishes be ascertained? That the consultant seems vaguely familiar is a hopeful sign. Making decisions about his future with the expectation of little to no changes in his cognitive functioning would be premature. His preliminary responses to a hypothetical situation of treatment, that he "would have to think about it, it's a lot to consider," and later, after shaking his head at the thought of the side-effects, that "it [is] a lot to think about," seem to be an appropriate response to a momentous, potentially uncertain but certainly painful, life-saving decision. Expecting moderate improvement in the months or years ahead may have provided incentive to probe Mr. G to make a decision about treatment rather than relying on the proxy. These considerations are even more complex, given his unexplored statement on another occasion that "I have always said I didn't want to go through all of that."

INFORMED CONSENT

That Mr. G was transiently unaware of his cancer made it difficult for him to consent to treatment on his own. Might he have been able, however, to consent with help? We do not get a sense of whether he actively forgot during the consenting process, or whether he was able to be informed, stabilized, and then brought at least partially through the informed consent process before he lapsed with unconsolidated memories. When Mr. G's daughters visited, the second ethics consultant found Mr. G quite lucid and capable of decision making, but we are unsure whether this means he was able to remember his cancer diagnosis, or whether this represented an improvement from his previous mental state? That staff was putatively able to provide information about Mr. G's condition and proposed treatment (either by a reasonable-person standard or subjective standard) and was able to check for understanding (asking him to summarize what had just been said) was a helpful sign. Involving a surrogate would have been necessary if this process failed or if Mr. G actively forgot too quickly, but it is unclear that either of these things occurred. Our concern is that this process should have been exhausted before the substituted judgment was instituted.

SURROGATE DECISION MAKING

That a healthcare proxy was obtained upon Mr. G's admission and reconfirmed thereafter has been confirmed. One need not doubt that Mr. G was capable of such an appointment. The question arises — on what basis was Mr. G said to be capable of giving permission to others to have access to his medical records (daughters), and said to be capable of appointing another person as the bearer of his autonomy (brother) — including all that these decisions imply about present and future continuity of personal identity and medi-

cal care — and yet not able to consent to treatment? If capacity is task-specific, why were there markedly different evaluations of capacity, given the similar cognitive mechanisms and requirements? Again, to us, the central ethical issue mentioned above requires reflection on the question of whether a surrogate was necessary. After all, any estimation on the part of the proxy as to what Mr. G might have desired in potentially life-saving treatment is superseded by even a modestly capable decision by Mr. G about attempts to save his life or avoid unnecessary suffering.

Even if Mr. G was grossly incapacitated by his amnesia (for example, if he could not hold a thought for more than 45 seconds) and no doubt existed about the need for a surrogate, the bar in this case for allowing a deferral of potentially life-saving evaluation and treatment might have been higher than others we may encounter. New York is one of the states that specifically declared a strict interpretation of substituted judgment: it requires that the decision of the surrogate about treatment is based on "clear and convincing evidence" that the patient had "a firm and settled commitment" about the decision under examination.[10] This standard would require not only that Mr. G had on some occasion mentioned a general wish against continuing life by artificial means. Rather, it would require that Mr. G expressed not wanting the particular treatment in question (chemotherapy) in the particular circumstance in question, or some other very similar expression.

On a separate matter, there seems no reason to suspect a conflict of interest or coercion concerning the surrogate chosen or the manner in which it was accomplished.

TREATMENT DECISION

We know that physicians, compared to their patients, have a tendency to underestimate patients' present quality of life, and are thus more likely to balk at life-sustaining treatments.[11] Similarly, the ability of physicians and nurses to predict patients' future quality of life and outcome is regularly lacking, especially in the most sick patients.[12] Predicting outcomes in cancer patients is notoriously difficult, even among specialists.[13] It is also important to be aware of the influence, or even bias, of one's own preferences on the perception of a patient's wishes for life-sustaining treatment.[14] Mr. G is 58 years old and, with significant family supports, potentially able to endure chemotherapy. One wonders if a compromise position would have been to at least stage his cancer to better contextualize any deferral of treatment?

Although it is true that, as Nietzsche says, "the advantage of a bad memory is that one can enjoy the same good things for the first time *several* times," the converse is also true.[15] The concern about waking up to nausea and vomiting, all the while unaware of even having cancer, is obviously legitimate. If Mr. G had consented, could a sympathetic system to provide information and symptomatic support overcome the hesitation to treat, based on side-effects? As we mentioned, Mr. G's post-TBI anterograde amnesia would probably have improved somewhat over time, and he already had signs of residual consolidation to long-term memory (that is, the consultant was consistently not a novel stimulus). On one view, all non-physiologic futility is normative futility, entailing a confluence of value judgments and probability estimates.[16] Upon potential improvement, who among us, at 58 years, would not look back and yearn for a 15 percent chance (or possibly better, after accurate staging) of cure, and 60 percent (or better) chance of one more year of life with friends and family?

Finally, a question exists as to whether intermediate care options were explored other than only comfort measures versus chemotherapy. Were palliative surgery or other medical treatments explored?

FAMILY AND CAREGIVER CONFLICT

The conflicts between Mr. G's brother and daughters seems to have been resolved, as all parties eventually agreed with the brother's estimation of Mr. G's wishes to forego thera-

py. There seem to have been no known family conflicts of interest or financial incentives or secondary gain. We cannot know whether subtle, indirect conflicts of interest were considered regarding the caregivers. For example, there is the possibility that administering cancer chemotherapy to a complicated memory-impaired patient such as Mr. G. could well have been a money-losing proposition, given the amount of non-reimbursable time such care would have required.[17] Moreover, the medical treatment of any neuropsychiatrically impaired patient can pose a problem for overworked medical careproviders when there can be an unspeakable — and thus unexamined — undercurrent of *de facto* triage in the life of hospital-based care.[18] Yet, giving Mr. G's caregivers the benefit of the doubt, the priority given to relational proximity of the brother seems appropriate, given Mr. G's estrangement from his daughters and their enthusiastic attempts to reconcile with him.

CONCLUSION

There are no easy answers in the case before us, only more questions . . . and more sadness.

Primo Levi, in his story "In the Park," creates an imaginary world in which others' memories of you congeal together and somehow provide a semblance of a self, but it is one that is as easily lost — as easily unmade, as made. In this excerpt from the story, the protagonist describes what it feels like to have one's sense of a (social?) self dissolve — traumatic brain injury in slow motion, if you will:

> Some three years after his arrival, Antonio noticed a surprising fact. When he raised his hands, as a shield against the sun, say, or even against a bright lamp, the light filtered through them as if they were wax. Some later time, he observed that he was waking earlier than usual in the morning, and he realized that this was because his eyelids were more transparent; in fact, in a few days they were so transparent that even with his eyes closed Antonio could distinguish the outlines of objects.
>
> At first he thought nothing of it, but toward the end of May he noticed that his entire skull was becoming diaphanous. It was a bizarre and alarming sensation: as if his field of vision were broadening, not only laterally but also up, down, and backward. He now perceived light no matter what direction it came from, and soon he was able to distinguish what was happening behind him. When, in mid-June, he realized that he could see the chair he was sitting on, and the grass under his feet, Antonio understood that his time had come: the memory of him was extinct and his testimony complete. He felt sadness, but neither fear nor anguish. He took leave of James and his new friends, and sat under an oak to wait for his flesh and his spirit to dissolve into light and wind.[19]

DISCLAIMER

The authors note no conflict of interest.

NOTES

1. Patient H.M. suffered from intractable epilepsy. In 1953, William Beecher Scoville resected H.M.'s temporal lobe structures, markedly decreasing the frequency of H.M.'s seizures, but with the unfortuate side-effect of immediate anterograde amnesia that continues to present. S. Corkin, "What's new with the amnesiac patient H.M.?" *National Review of Neuroscience* 3 (February 2002): 153-60.

Clive Wearing was a conductor widely renowned as an expert on early classical music. He developed a herpes simplex infection that caused a severe case of encephalitis, resulting in severe brain damage and anterograde amnesia. Although his short-term memory is nonexistent and his recall of both prior life events and general knowledge is impaired, he has shown a remarkable retention of his musical skills, including being able to conduct choirs and sight-read keyboard music at a level approaching his former functioning. A. Baddeley, *Essentials of Human Memory,* part of the Cognitive Psychology series (East Sussex, U.K.: Psychology Press Ltd., 1999).

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14. L.J. Schneiderman et al., "Do Physicians' Own Preferences for Life-Sustaining Treatment Influence their Perceptions of Patients' Preferences?" *The Journal of Clinical Ethics* 4, no. 1 (Spring 1993): 28-33.

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The Challenges of Amnesia in Assessing Capacity, Assigning a Proxy, and Deciding to Forego Life-Prolonging Medical Treatment

Catherine Myser

We make and remake ourselves through memory; we move through time like whales, filtering experience from our surroundings, digesting, repackaging, deciding what to keep and what to throw away. We assemble ourselves, piece by piece, from recollections. We are what we remember.

Memory, individual or collective, not only makes us what we are, but in a sense gives us the power to travel through time, projecting ourselves into the future. Our stories — at least some of them — will outlive us. And it's not hard to imagine a scenario in which our stories — our memories — become overwhelmingly important . . . [for example] in [apocalyptic science fiction] a handful of hardy survivors is spared, to be collectively confronted with the overwhelming task of . . . building the future and rebuilding the past. . . . From your rich accumulation of memories, you would shape the future, passing on a lifetime's supply of internalized input to your children and grandchildren, and all the other struggling members of your . . . tribe.

— Rebecca Rupp, *Committed to Memory: How We Remember and Why We Forget*

SPECIAL CHALLENGES OF MR. G'S AMNESIA IN ASSESSING CAPACITY

The 58-year-old Mr. G has "lost virtually all of his recent past." The etiology of his amnesia is unclear, but existing speculation is that it was due either to a recent truck accident resulting in seizures (or vice versa) and subsequent mental status changes, or to possible brain metastases (presumably affecting brain structures associated with memory). In any case, further neurological and oncological work-ups relative to Mr. G's amnesia have not been pursued. Despite this lack of relevant data, earlier neurology chart notes suggest that Mr. G has a "poor prognosis for regaining memory." All the same, Mr. G faces a series of complex medical and ethical decisions due to his unexpected diagnosis of "aggressive lung cancer. . . . very aggressive tumor" discovered during the same admission. This cancer "can be treated early on with a 15 percent

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curative rate and a 60 percent rate of response that would extend the patient's life, but likely only for about one year," but requires a chemotherapy regime that is "rigorous" and "very burdensome with expected side-effects" of nausea, vomiting, fatigue, and hair loss.

The first challenge in Mr. G's case study is thus to assess his capacity — carefully considering his amnesia diagnosis and prognosis — to distinguish if consent should be sought from Mr. G himself, or from a proxy decision maker (and if so, how he/she should be chosen), relative to whether possible life-sustaining chemotherapy treatments should be accepted or refused, including whether to pursue further diagnostic and prognostic information that might inform that choice. As the assessment of capacity is the legitimate "gatekeeper"[1] to latter components of the informed-consent process — disclosing information, ensuring understanding[2] and voluntariness, obtaining consent — I would argue that Mr. G's amnesia should first and foremost be as rigorously and comprehensively evaluated as possible, to determine his specific capacity relative to each task or decision systematically to be considered, and in order of priority.

In this context, it seems as if more extensive testing by the neurology service and/or a cognitive scientist or an expert on memory disorders (as possible, given Mr. G's current condition, but there is clinical precedent that it is possible) would offer very useful information. Another important consideration — also weighing Mr. G's diagnosis of amnesia and his prognosis — would be whether his capacity could be restored, even if it is judged at present to be inadequate to one or more of his current decision-making tasks. If so, it remains our ethical obligation to restore his capacity as possible, and only then take up making decisions about assigning a proxy and/or accepting or refusing further diagnostic information and treatment (although the urgency of this particular cancer diagnosis obviously limits that opportunity for the present). Also, there seems to have been little discussion of whether there would be additional useful strategies (beyond posting signs to help Mr. G locate his door and bed, and family photos posted in his room) to help manage Mr. G's amnesia, or to tap into any remaining long-term memory, and/or rehabilitate any specific current deficits in his memory function as possible. Curiously, it seems as though the diagnosis of cancer in this case, and the concurrent acceptance that the proxy decision maker was "adamant that [Mr. G] would not want any further work-up or treatment," may have superseded more precise neurological and amnesia and memory evaluation and capacity assessment, which unfortunately placed the (oncology) cart before the (neurology/amnesia/capacity) horse.

Although we cannot now secure this important data, I believe it is the lack of this core information that leaves Mr. G's daughters and healthcare team confused about his capacity to make various decisions, and causes considerable "lingering questions" and concerns — about Mr. G's capacity, his appointment of a proxy, and his proxy's decisions, at possible great cost to Mr. G — throughout the case study as told. In an actual case consult, we would begin by assiduously getting any and all such relevant facts about Mr. G's complex neurological and oncological conditions absolutely clear. As that is not possible in a case study that has been appropriately masked to protect the confidentiality of the patient and family, I ask the reader's indulgence to attempt at least some additional specificity, as a legitimate ethical analysis of the case would necessarily hinge on Mr. G's complex neurological status. I will therefore try to show how such data might clarify the series of decisions affecting Mr. G by hypothesizing as to his specific amnesia diagnosis. (Needless to say, this kind of hypothesizing is never appropriate in an actual clinical ethics consult, and certainly not by an ethicist who lacks relevant clinical expertise, including myself, and even physician-ethicists in specialties outside the particular clinical diagnosis and prognosis sought).

In an actual clinical consult, one would look to the relevant clinical experts for diagnostic and prognostic information on Mr. G's amnesia. In lieu of this — for the purposes of this case study only — the following brief review of some relevant literature will have to suffice as a substitute for the input that would normally and appropriately be sought from the relevant clinical experts. So I do not mean to establish any dangerous precedent (do not try this at home!). Rather, in a case study alone, this might be a useful hypothetical exercise, to illustrate a crucial gap in information, and why and how one could better proceed in making decisions while in possession of such core clinical information. I aspire only to specify Mr. G's "short-term memory loss" and "severe memory loss" further as possible, to adequately address challenges, including:

- Assessing such a patient's capacity,
- Securing such a patient's informed consent (directly or via proxy), and
- Interpreting such a patient's (or proxy's) acceptance or refusal of possible life-prolonging diagnosis and treatment.

A BRIEF LITERATURE REVIEW TO EXPLORE THE DIAGNOSIS OF AMNESIA

Different amnestic syndromes have very different characteristics, and it is thus valuable to focus on the most likely amnestic syndrome given Otto's description. Otto's analogy to the film *Memento* — in which the main character has a specific diagnosis of anterograde amnesia (AA) — in her title and in the body of her case study is telling.[3] Otto's shorthand description of Mr. G having "short-term memory loss" is more ambiguous, but one memory disorder expert acknowledges, yet also dismisses, such short-hand language also common in the context of AA, clarifying that in "anterograde amnesia . . . it's not that [one] loses memories, it's that [one] can't form them in the first place."[4] In other words, the main problem for a patient suffering AA is converting the "will-o-the-wisps" of new, time-limited "short-term memory" or "working memory" (the latter sometimes also referred to as "scratchpad memory" or "the blackboard of the mind") into "the solidities of long-term storage," a process called "consolidation."[5] Echoing these descriptions, the wife of well-known AA patient Clive Wearing characterizes his AA (with additional retrograde amnesia) thusly: "Every conscious moment is like waking up for the first time. New information 'melts like snow, not leaving a trace'."[6]

Despite losing the ability to retain new information, patients with AA (sometimes referred to as "pure memory disorder") retain intact immediate recall of new information within the scope of short-term memory or working memory. In addition, they retain the intact ability to retrieve information that was consolidated and stored before the onset of the memory disorder (remote recall), although this can be decreased somewhat if they also develop a measure of retrograde amnesia, thus losing a portion of their stored memories as well. They also retain other cognitive abilities, such as language and visual spatial processing, and their intelligence is usually normal. Certain implicit and procedural memories also remain substantially intact.[7] Residual learning capacities can include the following:

- Motor learning,
- Skill learning (with an absence, however, of explicit memory or declarative memory, so the patient will not remember the learning sessions or the details thereof),
- Repetition priming (for example, when an individual encounters stimuli on a study list — for example, words with similar word stems — it may influence the individual's successful performance on a subsequent test, for example, completing primed word stems with primed versus unprimed words),
- Personal semantic memory, favored by being learned slowly over an extended period of time (for example, an individual may be able to construct a cognitive map of the layout of a new house, moved into after the onset of the memory disorder, as

> the result of thousands of learning trials of daily locomotion from room to room, thereby encoding the location of each room relative to other rooms; this raises the possibility that an AA patient also might be able to acquire new vocabulary words if daily training is carried out over a period of years).[8]

More intriguingly for our purposes, brain and cognitive sciences researcher Suzanne Corkin of MIT argues that H.M., the most renowned AA (and retrograde amnesia) patient (studied by some 100 investigators over 54 years),

> has beliefs, desires and values that are always present, [for example] he believes that doing crossword puzzles helps him to remember words and is fun. He is altruistic. . . . His social behavior is appropriate and courteous. . . . He has high moral standards with respect to right and wrong in his personal conduct. . . . He has a conscience. . . . In addition, he has good insight into his memory disorder . . . a sense of humour, and often makes jokes. . . . [However] his ability to interpret and report internal states is diminished. Specifically he has an impaired ability to identify and respond to painful stimuli, and shows no difference in his ratings of hunger and thirst made before and after a meal.

Also, in the first five years of H.M.'s AA, "an extensive test battery failed to reveal any deficits in perception, abstract thinking, or reasoning ability."[9] Perhaps on the basis of these and other retained abilities, despite the deficits also described, an AA patient can seem relatively normal, at least in the moment. Rebecca Rupp reminds us, however, that "H.M. forgets all that has gone before. Enter a conversation with H.M., leave the room briefly, and upon your return, he will have forgotten who you are. Life has no continuity for H.M., the thread of his being was chopped off short [54] years ago. 'Every moment,' he once told a team of interviewing doctors, 'is like a waking dream'."[10]

Armed with the above brief specifications of AA in mind — but with no pretense of possessing either neuroscience or amnesia expertise or the actual facts of Mr. G's case — we can now consider the key ethical questions in Mr. G's case study in a somewhat more targeted fashion. This is important if for no other reason than to highlight how crucial getting this information would be for addressing any and all ethical issues in this case. Pointing out both this critical gap in data, and the need in any actual consult to seek further such diagnostic and prognostic information from the relevant clinical experts (first and foremost to assess patient capacity), would be a legitimate contribution from a consulting ethicist concerned with the ethical issues in this case study.

RELEVANCE OF MR. G'S AMNESIA IN ASSIGNING A HEALTH PROXY

If Mr G's care team had been able to obtain detailed information regarding his amnesia from the neurology team, and/or if experts in cognitive science or memory disorders had been able to thoroughly evaluate his amnesia, it might have been possible to sort out these capacity questions relative to Mr. G's assigning a proxy as follows.

1. If Mr. G's appointment of his brother as proxy was the result of past discussions and decisions to have his brother serve as his proxy for any medical decisions for which Mr. G himself would, in the future, lack capacity, and
2. Mr. G could retrieve this information from his long-term memory,
3. There would be no reason to suspect that Mr. G did not possess the ability that would be directly relevant to the task of selecting and appointing a proxy decision maker.

According to the descriptions of AA above, Mr. G's access to such long-term memories could be retained, despite Mr. G's other described memory deficits in consolidating fu-

ture long-term memories. We are given no evidence to suspect that Mr. G. does not retain this ability, or access to his long-term memories, in which such discussions and decisions might generally have been stored. Thus Mr. G's clear recognition of his brother (and other family members from photos and in person), and repeated confirmations that his brother should serve as proxy — to interpret Mr. G's own longstanding values and beliefs about "quality of life" and the "benefits and burdens" of particular treatments, and apply these values and beliefs as best a proxy can to Mr. G's current medical condition and decision making — would not be problematic. The "consistency" of Mr. G's preferences in this regard might thus be accepted as a legitimate designation and confirmation of his proxy decision maker.

It would not be appropriate to accept Mr. G's brother as a proxy because it seemed "comfortable" or "logical" to the healthcare team, nor because the appointment of a proxy is a "less-sophisticated decision." In fact, proxy appointments are often plagued with considerable challenges and complexities. Rather, this proxy appointment would be acceptable because Mr. G would be judged on the basis of careful and comprehensive evaluation of his particular amnestic syndrome, to retain the abilities most relevant to appointing a proxy.

On the other hand, if the healthcare team or members of Mr. G's family suspect — or can clearly demonstrate — that no such past discussions or decisions regarding a proxy ever took place, and instead are able to determine that this proxy appointment, "made on [Mr. G's] admission," was somehow coerced and/or subjects Mr. G to coercion or manipulation and/or involves some ethically problematic aspect of the family's history of estrangement and mistrust (although these would have to be rigorously defined and demonstrated, and not rely on mere rumor or speculation), the healthcare team and/or family might have legitimate concerns.

Sadly, in the absence of an adequate evaluation or diagnosis regarding of Mr. G's amnesia, his daughters and care team cannot be reasonably certain about his abilities, and, as a result, are confused when Mr. G appears to be "lucid in the moment," but unable[33] to assimilate (consolidate) his cancer diagnosis or remember new care team members and crucial treatment discussions from hour to hour and day to day.

THE RELEVANCE OF MR. G'S AMNESIA IN DECISIONS TO FOREGO POSSIBLE LIFE-PROLONGING TREATMENT

If Mr G's care team had been able to obtain detailed information regarding his amnesia from the neurology team, and/or if experts in cognitive science or memory disorders had been able to thoroughly evaluate his amnesia, it might have been possible to sort out questions of capacity relative to his own current healthcare decisions, as follows.

1. Although Mr. G seems to have ongoing access to his long-term memories, which might include, for example,
   A. Episodic memories about family relationships, experiences, traditions, and values and
   B Semantic memories, including general knowledge about the world, for example, general definitions of concepts like *quality of life, cancer, side-effects, benefits and burdens of treatment*;
2. Mr. G is demonstrably no longer able (at present anyway — the question of whether his capacity can someday be restored remains undetermined by the neurology team or memory disorder experts) to consolidate memories of his current diagnosis and prognosis.
3. Such abilities are directly relevant to the task of making decisions about whether life-sustaining chemotherapy treatments should be accepted or refused, including whether to pursue further diagnostic and prognostic information that might inform that choice.
4. In other words, even if Mr. G retains the ability to retrieve long-term semantic

> memories about the general meanings of concepts like *quality of life* and *benefits and burdens of treatment,* he cannot form new memories to consolidate and process new diagnostic and prognostic information, in order to elaborate these general concepts specifically for use in making current and future decisions.

According to this reasoning, the above proxy appointment can be accepted on justifiable grounds (assuming no other concerns considered above remain, in which case another proxy could be sought), and obligations relating to the other components of informed consent — disclosing information, ensuring understanding and voluntariness, obtaining consent — transfer to Mr. G's proxy. Thus the team must now focus on informing Mr. G's brother and ensuring that he understands the information shared, so he has the best chance of applying his existing knowledge of Mr. G's core values, beliefs, and preferences to determine what Mr. G would want in his current condition. In this scenario, it is no longer repeatedly necessary to inform Mr. G of his cancer diagnosis and prognosis (he appears to have some insight as to his amnesia, which is not out of keeping with the brief descriptions of AA patients above). It is also not necessary to seek "consistency" of his expressed historic or current preferences as applied to a diagnosis he cannot retain, or to "theoretical situations" that he is unable to fathom, despite the fact that other retained abilities make him seem "quite lucid and capable of decision making." Continuing to treat Mr. G as if he possesses specific capacity relative to accepting or refusing possible life-prolonging treatment, when it has been established that he does not, is paradoxical, and merely serves to confuse Mr. G, and perhaps also his family and healthcare team. Thus, if the healthcare team and others had a better understanding of Mr. G's own precise amnesia syndrome (here using AA as an example for discussion purposes only), per appropriate testing and evaluation, Mr. G's apparently conflicting memory abilities and disabilities could be put into better perspective, clarifying the assessment of capacity, the appointment of a proxy, and the making of treatment decisions.

The lingering questions about whether Mr. G's brother is a "true proxy, speaking in '[Mr. G's] voice' " (although, as stated, this might be a rather high standard for any proxy to achieve) seem rooted in legitimate questions about whether Mr. G's brother has been given adequate information about Mr. G's diagnosis and prognosis, how that information was framed, and whether Mr. G's brother himself adequately understands that information. Ensuring that information is disclosed and adequately understood — transferred here to Mr. G's proxy — remains an obligation of informed consent. As such, it would be in keeping with ongoing autonomy-based obligations to Mr. G (via his proxy), and moreover ongoing beneficence-based obligations to Mr. G, for the healthcare team to explore further with Mr. G's brother what he understands of the core diagnoses and prognoses, and to ensure his adequate understanding of possible "benefits" and "burdens" of treatment, possible applications of "quality of life" (carefully avoiding subjective biases as possible), and how and why these concepts might fit with Mr. G's preexisting values, beliefs, and preferences. This is, after all, the precise ability Mr. G himself lacks (despite his own continued access to long-term semantic memories enabling him to report the generality, "I have always said I would not want to go through all that. It's really about quality of life and who wants to go through all of that"). These concepts and values must be newly considered, explored, defined, and weighed by Mr. G's proxy relative to Mr. G's new diagnoses and prognoses. It is particularly important to ensure that information is disclosed and adequately understood by Mr. G's proxy, given how "adamant" the proxy is, not only in refusing life-prolonging treatment, but in refusing further work-ups and information that might normally more fully inform this choice, especially considering the high costs either way to Mr. G.

These clarifications can perhaps be better understood by reflecting for a moment on Harvard psychologist and memory researcher Daniel Schacter's reminder, "memory involves more than just our remembrance of things past."[11] Rather, Schacter explains that our autonomy is reshaped as we go through life, making and remaking memories projected into the future, depending on how we convert the fragmentary remains of experience into the autobiographical narratives that endure over time, and constitute the stories of our lives. Mr. G's brother and proxy is now shouldering the burdens of uncertainty in this case study, and the healthcare team can only help him and Mr. G as best they can, by ensuring adequate information is disclosed and the proxy adequately understands the information, and gives voluntary consent.

NOTES

The quotations at the beginning of this article are from Rebecca Rupp, *Committed to Memory: How We Remember and Why We Forget* (New York: Crown Publishers, 1998), 8-9 and xv.

1. T. Beauchamp and R. Faden, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), 287.

2. Also, this gatekeeper and these latter components should not be confused, as capacity and understanding in particular often are, and may have been in this case.

3. It is worth noting, however, that the authenticity of the portrayal of AA in the movie *Memento* has been debated. On the plus side, one clinical neuropsychologist judges it to "accurately describe the problems faced by someone with severe anterograde amnesia," S. Baxendale, "Memories aren't made of this: amnesia and the movies," *British Medical Journal* 329 (2004): 1480-3, p. 1482. On the negative side, one neurobiologist has declared it to be "very unfaithful," and another expert in memory disorders regards a core misunderstanding reproduced therein to be a "howler,": J.R. Minkel, "Gene Expression: The Brain's Memory Code," 29 December 2003, *www.gnxp.com/MT2/archives/001537.html,* citing UC Irvine neurobiologist James McGaugh; L. Spinney, "Forgetfulness of Things Past," *Guardian*, 29 April 2004, *www.film.guardian.co.uk/features/featurepages/0,,1205937,00.html,* citing Sergio Della Sala of Edinburgh University. Moreover, the former clinical neuropsychologist and latter memory disorders expert both regard Walt Disney/Pixar's animated blue tropical fish Dory in *Finding Nemo* to be "the most neuropsychologically accurate portrayal of a [profound] amnesic syndrome" and "top of . . . amnesia class" in the movies, Baxendale, "Memories aren't made of this: amnesia and the movies," p. 1483; Spinney, "Forgetfulness of Things Past," citing Sergio Della Sala of Edinburgh University. Another commentator, a Los Angeles film critic who completed an impressively comprehensive analysis of the film, notes the film's "huge inconsistencies" with the "rules" of anterograde amnesia (as explained by the film's main character, an insurance investigator who previously researched this very amnesic syndrome that he himself now suffers, ironically "ruthlessly [denying] the [earlier] man's medical claim"). Klein surmises that the film's director may be injecting these inconsistencies on purpose, to pose an additional devilish puzzle for his viewers, but complains that "to build the plot around [these inconsistencies with the rules of AA] without giving us some hints seems like dirty pool," A. Klein, "Everything You Wanted to Know About 'Memento'," *Salon.com* 28 June 2001, *www.archive.salon.com/ent/movies/feature/2001/06/28/memento_analysis/.*

4. Spinney, see note 3 above, p. 6.

5. One cell biologist regards working memory as a "more complex entity . . . [enlarging] upon the earlier and simpler concept of short term memory," but the relationship between short-term memory and working

memory is still not well worked out. R. Rupp, *Committed to Memory: How We Remember and Why We Forget* (New York: Crown Publishers, 1998), 61, 65-6. See also D. Schacter, *Searching For Memory: The Brain, The Mind and The Past* (New York: Basic Books, 1996), 82-8.

See also D. Pendick, "Memory Loss at the Movies," *Memory Loss & the Brain: Newsletter of the Memory Disorders Project at Rutgers University*, 2002, *www.memorylossonline.com/spring2002/memlossatmovies.htm.* Pendick makes another distinction, arguing that short-term memory — defined as "the bin in which we store recent experiences and perceptions for minutes to hours while they are 'consolidated' into more enduring 'long term' memories") is not in fact possessed by AA patients, who instead operate in the realm of working memory (defined in a more limited way as "the bin that holds experiences for [mere] moments to seconds . . . [meaning that such a patient] can hold a conversation as long as the other person doesn't go on speaking too long [so he] might forget where the conversation started and get confused [but, like the main character in *Memento*] maintains his intelligence, his ability to reason, make logical arguments, express his thoughts, read a map, or keep a telephone number 'in mind' long enough to dial it."

6. L. France, "The Death of Yesterday," *Observer,* 23 January 2005, *www.observer.guardian.co.uk/print/0,,5107999-110648,00.html.*

7. National Academy of Neuropsychology, "Behavioral Neuropsychology: Amnestic Syndromes," 1997-1998, *www.nanonline.org/nandistance/mtbi/ClinNeuro/amnesia.html.* Causes of AA listed include: alcoholic Korsakoff Syndrome, traumatic brain injury, cerebral anoxia, tumors within or near the hippocampus, and dementia-related illnesses such as Alzheimer's disease.

8. S. Corkin, "What's New With the Amnesic Patient H.M.?" *Neuroscience* (20 February 2002): 153-160; pp. 154-6, 158-9.

9. W.B. Scoville and B. Milner, "Loss of Recent Memory After Bilateral Hippocampal Lesions," *Journal of Neurology, Neurosurgery and Psychiatry* 20 (1957): 11-21; p. 17.

10. Rupp, see note 5 above, p. 88.

11. Schacter, see note 5 above, p. 5.

Medicine and Public Policy

Harvard Medical School Public Forum: Insuring the Uninsured: Does Massachusetts Have the Right Model? 17 May 2007

Lisa Lehmann:

Good afternoon, my name is Lisa Lehmann, and I have the privilege of being your moderator this afternoon for our program on the Massachusetts healthcare legislation, in which we hope to critically examine this law. I want to begin by thanking Nir Eyal, Dan Brock, and Allan Brandt who were helpful in planning this event. Christine Moreira and Laura Horn provided fantastic administrative support without which this program would not have occurred.

Providing healthcare to all Americans is one of the most significant ethical and domestic policy challenges facing our country today. In the United States, 46.6 million individuals are uninsured, and in Massachusetts an estimated 536,000 individuals do not have insurance coverage.[1] Despite the pervasive dissatisfaction with healthcare in the United States, no consensus has emerged on how to reform the system.

Should reform be comprehensive or incremental? Should priority be given to reforming the financing system or to improving the organization and delivery of healthcare? Is the solution to develop individual mandates with subsidies, a single-payer system, or universal vouchers? These are some of the questions that we will consider this afternoon. In April 2006, Massachusetts enacted landmark legislation designed to achieve comprehensive healthcare reform. By July 2007, almost all Massachusetts residents will be legally required to have health insurance or face a fine. The Massachusetts plan has encouraged a national debate about how to address the problem of the uninsured. More than 20 states are now engaged in serious policy efforts to design their own healthcare reform initiatives. This forum will explore key details of the proposed legislation, to better understand if the Massachusetts legislation will be a successful and sustainable model that can solve our ailing healthcare system.

We have three wonderful panelists this afternoon. Our first speaker will be Dr. Katherine Swartz. Professor Swartz is Professor of Health Economics and Policy in the Department of Health Policy and Management at the Harvard School of Public Health. Her research interests focus on the population without health insurance and efforts to increase access to healthcare coverage, reasons for and ways to control episodes of care that

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involve extremely high expenditures, and how we might pay for expanded health insurance coverage. She recently completed a book entitled *Reinsuring Health: Why More Middle-Class People Are Uninsured and What Government Can Do*.[2] She was also a member of the Massachusetts Commission to Study the Effects of Merging Small Group and Individual Health Insurance Markets in Massachusetts. This was a commission that was required by the Massachusetts legislation that we're talking about this afternoon.

Our second speaker will be Dr. Michael Chin. Dr. Chin is a family physician who has worked in primary care at a community health center in Boston. The majority of his patients did not have health insurance, and it was this experience that motivated him to become involved in health policy surrounding the uninsured. In 2006, he joined the Commonwealth Health Insurance Connector as a senior policy analyst. Today he will share with us some of the key details of the law.

Dr. Marcia Angell is a senior lecturer in the Department of Social Medicine at Harvard Medical School. She is trained in both internal medicine and anatomic pathology. She joined the editorial staff at the *New England Journal of Medicine* in 1979, became executive editor of the journal in 1988, and was editor-in-chief from 1999 to 2000. Dr. Angell writes frequently in professional journals and the popular media on a wide range of topics, particularly medical ethics, health policy, the nature of medical evidence, the interface of medicine and law, and care at the end of life. She has been a vocal critic of the Massachusetts healthcare reform legislation with her opinions appearing in the pages of the *Boston Globe*. Please join me in welcoming our panelists. Professor Swartz will be our first speaker. *[Applause]*

Katherine Swartz:

Thank you very much, Lisa, for those kind introductory remarks. I am going to talk about changes in who lacks health insurance and why, and I'm going to focus more on national numbers rather than specific numbers for Massachusetts, in part because most of my data come from the country and not from the state of Massachusetts, but also I think the problems that this state is facing are common among all 50 states. And what I want most of all is for you to see that what's happened in Massachusetts is in a context of new pressures that are building on private health insurance.

To begin with, let me just talk about who lacks health insurance in the country. As Lisa said, we're facing a situation right now where basically one in six of non-elderly Americans do not have health insurance. And although the Census Bureau released some revisions to the estimate of 46.6 million uninsured (they had a computer error) and the new estimate is closer to 45 million, my reaction to the revision is that either way the number is huge — and really the point to focus on is that one in six non-elderly Americans do not have health insurance of any type.

The second point about the uninsured to note is the increase in the number between 2004 and 2005 — 1.3 million more people were uninsured. Almost all of those people lost access to employer-sponsored coverage, and that's important in the story that I'm going to be talking about here.

The third point I want you to remember is that 30 percent of the uninsured had middle-class incomes. I am defining "middle-class" somewhat arbitrarily as anyone with an income above the median household income. In 2005, the median household income was about $46,300 — so anyone with a family income above $46,300 would be in the middle-class by my definition. I know that I'm not taking account of the number of people who live in a person's family with this simple definition. But by using households (rather than families), I am encompassing single individuals and people who live in multifamily structures of households. I have found that in general if we talk about incomes relative to the poverty level, most of the public doesn't understand what we're talking about. But they can relate their own income to this somewhat

arbitrary threshold of middle-class income of $46,300.

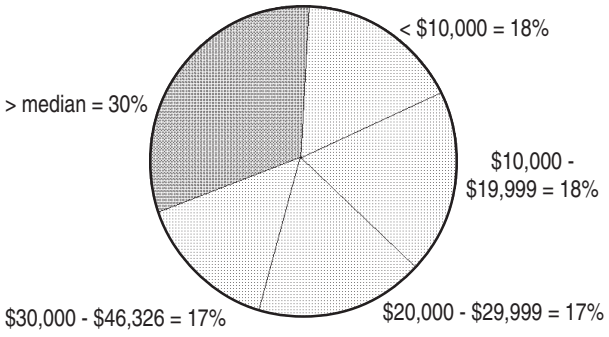
So the point I'm going to talk about is that not only do 30 percent of the uninsured have middle-class incomes, but also the issue of being uninsured has become a growing problem for the middle-class. One question I would like you to have in the back of your minds is: how can it be that someone who is a middle-class person does not have health insurance? What's going on here?

The last point I want you to remember about the uninsured is that almost three in five are young adults. They are between the ages of 19 and 44 years of age. This is a big shift over the last 25 years, and I'm going to talk more about this in the next couple of minutes in my brief overview.

The first pie chart [figure 1] illustrates the incomes of the uninsured and shows the point that 30 percent of the uninsured have incomes above the median household income threshold of $46,300. Clearly, however, most of the uninsured have very low incomes. They are people who cannot work or who are paid very low hourly wages and/or cannot work more than part time. For a variety of reasons, they have low incomes. Among the people who earn between $30,000 and $46,000 are some single individuals, maybe recent college graduates who, you know, clearly are middle-class. They may be earning $40,000 as new teachers of first grade, for example. Thus, even though I am saying that 30 percent of the uninsured are middle-class, there are clearly some people, especially if they live in single-person households, in the income range between $30,000 and $46,000 who also could be called middle-class. This point will come up again shortly.

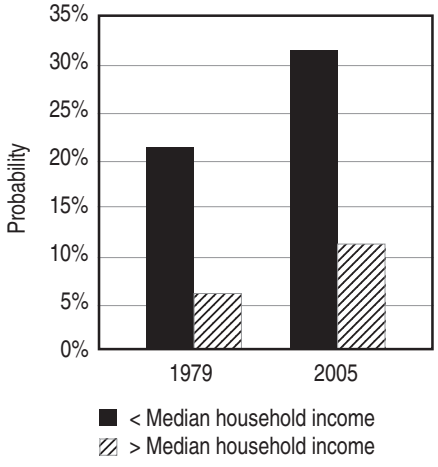
The second figure [figure 2] shows what's changed between 1979 and 2005 in terms of the simple probability of being uninsured. This figure is just for adults who are between the ages of 23 and 64; I have taken out college-age children on the grounds that there are lots of things going on with them, and people who are 65 and older are almost all covered by Medicare. What we see is that in 2005, a third of all adults whose incomes were not middle-class were uninsured. That fact should be shocking by itself. But the second point of the figure relates to the adults with middle-class incomes — in 1979, 6 percent were uninsured, and I've been looking at the uninsured numbers using the CPS [Current Population Survey][3] data starting with 1979. The percentage of adults who were middle-class without health insurance stayed at about

Figure 1. Income of Uninsured, 2005



Source: Katherine Swartz's analysis of March 2006 Current Population Survey (*http://www.census. gov/cps/)*; median household income in 2005 was $46,326.

Figure 2. Probability of Being Uninsured by Middle-Class Income for Adults, 1979 and 2005



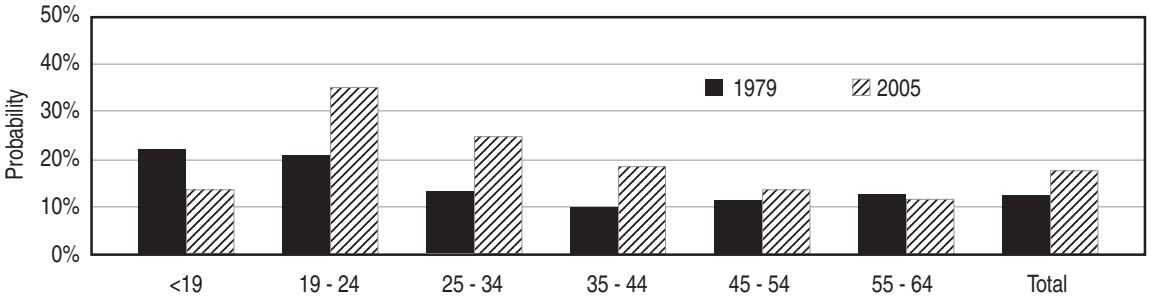
Source: Katherine Swartz's analysis of March 2006 Current Population Survey (*http://www.census. gov/cps/)*; for this figure, adults are defined as persons who are 23 to 64 years of age.

6 percent all the way through the 1980s and pretty much through the early part of the 1990s. But then around 1995, the percentage started climbing. And for the last five or six years, it's been climbing very rapidly, so that now, as you can see from the figure, 11 percent of middle-class adults are not insured. Part of the story I'm going to tell you is about why this fraction has increased so much, but the fact that one in nine middle-class adults is now uninsured is part of what has caught the attention, finally, of a lot of politicians. It is why there is political pressure to do something to increase access to health insurance for people who don't have health insurance.

Before I get to why being uninsured is increasingly a middle-class problem, let me quickly describe two other points about what has changed over the past 25 years in the characteristics of the uninsured. As the next figure about the simple probabilities of being uninsured by age shows [figure 3], we can all pat ourselves on the back for what's changed for children. The decline in the simple probability of being uninsured is a clear reflection of what's happened with the Medicaid eligibility expansions in the late 1980s and then the State Children's Health Insurance Program. People who are 19 to 24 years of age have always included a large fraction without health insurance. Some of this has to do with dynamics of very young adults taking jobs for a while and then going off and traveling or returning to school, or just first job problems in general. But what I want to focus on are 25 to 34 year olds and 35 to 44 year olds. We have had a sharp increase in the simple probability of being uninsured for those two age cohorts, so that 26 percent of 25 to 34 year olds are now uninsured and 19.5 percent of 35 to 44 year olds are uninsured — that is stunning. I worry about them if they get diagnosed with cancer, for example, or are in a car accident, which are the two biggest problems for people in these younger age cohorts, and also for women having children. But it is also not good for us as a society to have younger, generally healthier, people not in the risk pool of people covered by health insurance. So this is a problem not just for the individuals who don't have health insurance but for the rest of us. Particularly if you're a baby boomer, you want these people back in those insured risk pools.

The last figure [figure 4] has to do with how the simple probabilities of being uninsured have changed since 1979 for people who we can describe in terms of their educational achievements. I don't want to dwell on people who have not finished high school, because we've had big demographic changes over the last 25 years. But if you look at people who are high school graduates and those who have some college (which generally means the people have been to a community college and obtained some type of associate of arts degree; and note that community colleges are where most of the technical education in the United States is now occurring), there has been an increase in the simple probability of being uninsured in spite of people getting increased skills, especially technical skills. This is a

Figure 3. Probability of Being Uninsured by Age, 1979 and 2005



Source: Katherine Swartz's analysis of March 2006 Current Population Survey (*http://www.census. gov/cps/*).

worry. But then we also see that people who have college or post-graduate educations have had an increase in the simple likelihood of not having health insurance.

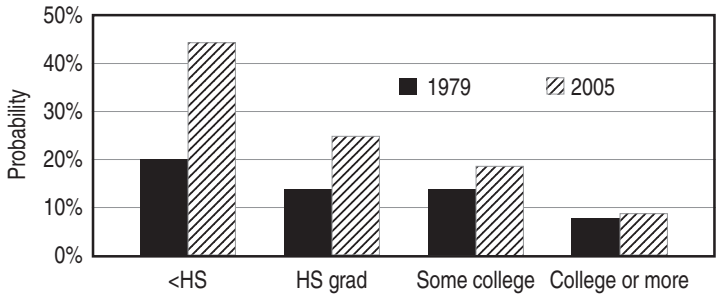
So the question is: Why? What's going on here? What should we as a society be worried about here? In answering these questions, the first thing I want to tell you is that between 1981 and 1984 this country suffered a severe recession — one that many of you I'm sure remember. We had an enormous decline in the number of manufacturing jobs as a result. The number slowly came back, but it never returned to the same level that we had in 1979. The percentage of all non-farm jobs that are in manufacturing has declined since 1979 from 22 percent to just under 10 percent. You may say to yourself, "Well, 22 percent is not so large. Who cares?" But I am a labor economist, and I can tell you that in the postwar era, manufacturing set the tone in this country for what one should expect from a good job — and a good job included employer-sponsored health insurance. The fact that the fraction of jobs that are in manufacturing has fallen to one in 10 means that that tone is missing from the discourse.

This decline in manufacturing jobs affected not only the people who lost the jobs — it also affected their children. If you think back to the education figure I showed you [figure 4], there were people who grew up in middle-class households and expected to be able to get well-paid jobs in manufacturing with just a high school education. After all, their parents had good blue-collar jobs in manufacturing, and they thought they would just go right into the steel mills, the automobile manufacturing, the durable goods kinds of manufacturing — and also be able to have good jobs with health insurance without going to college. But in fact, those jobs disappeared from the landscape here in the United States starting in the mid-1980s. The question is, where did all those younger people go? By the early 1990s, unemployment rates were declining, so clearly these younger people were finding employment. Where they found jobs was the service sector of the economy. The key fact to know about the service sector is that smaller firms (that is, with 50 or fewer employees) dominate the service sector. And importantly, smaller firms are far less likely to offer health insurance as part of the total compensation that they give their employees.

Starting at the end of World War II, we had a decline in the proportion of workers working in small firms. The decline continued through the 1950s, the 1960s, and the 1970s and bottomed out basically at the end of the 1970s, when around 37 percent of workers in the private sector were employed in small establishments. This fraction started climbing back up again, and by 2005, it was at 44 percent of all workers in the private sector. This, too, is an important part of the explanation that I'm telling.

The third change in the last 25 years that has affected who has health insurance is a change that started around 1996 to 1997, so

Figure 4. Probability of Being Uninsured by Education, 1979 and 2005



Source: Katherine Swartz's analysis of March 2006 Current Population Survey(*http://www.census.gov/cps/)*; for this figure, adults are defined as persons who are 23 to 64 years of age.

essentially only 10 years ago. There has been a change in the employer-employee relationship, so that we now have more people working as self-employed people or on a contractual basis, or through contract houses or temp agencies. Many more people are not technically "employees" where they work. This change in the employer-employee relationship is particularly affecting skilled, highly educated people in occupations like software engineers, hardware engineers, any kind of information technology, jobs related to broadcasting, writers, editors, people who are film editors, and so on.

For example, if you have a job in broadcasting and you do not work in one of the largest six cities in the United States, you are more likely to be a self-employed contractor than an employee of a broadcast studio or network station.

Teachers in community colleges and adjunct teachers in universities are frequently hired on a contract basis. Contract houses are virtually the same as temp agencies, although contract houses focus on placing professional people. Such people are being placed in companies that do not want to hire them as traditional employees. And the reason is that the companies would like not to pay the costs of health insurance and pensions.

This shift to hiring workers through contracts so they are not technically employees started with the accounting changes in 1993 to 1994 that required firms to show the expected future retiree pension and health benefit costs as liabilities on their financial statements. Today, we're talking about probably close to 9 percent or 10 percent of the working population, particularly people 25 to 44, who do not have the choice anymore of being an employee. Instead, they are hired on a contract basis, many of them earning relatively high incomes — and they are not getting health insurance as a fringe benefit.

It is important to note that between 1980 and 2005, after accounting for inflation, the cost of healthcare per capita has almost tripled. That provides a very strong incentive for employers to be looking to hire people on a temporary basis or a contract basis.

The changes in the uninsured over the past 25 years and the reasons for those changes have two outcomes worth noting. First, the growth in the number of middle-class people who lack health insurance, particularly the increased fraction of middle-class younger adults who are uninsured, is putting a lot of pressure on policy makers across the country. I don't know how many of you went to "meet-and-greet" events with candidates for Congress or state offices last fall, but I was impressed listening to people pressing candidates about health insurance and mentioning that they had grown children, or nephews, nieces, or neighbors' children, without health insurance.

The second outcome is that employers — both large and small — very much want to limit their healthcare costs. The recent sale of Chrysler to the private investment firm Cerberus is not an accident; it very much has to do with the healthcare costs as well as pension obligations of Chrysler. Small employers, too, are nervous about health insurance obligations. I don't know how many of you know people who have started small companies over the last 10 years, but I have yet to be in a conversation with somebody who has started a small company who offers health insurance to employees. Instead, the conversation usually is about how the person is running a "virtual" company where the person brings people in to help with a contract that he or she obtained. The person running the company does not hire employees *per se;* the workers are often known as 1099 employees because they are hired as consultants or associates for specific projects.

The increase in such practices and the increase in the probability of a middle-class person not obtaining employer-sponsored health insurance have led to the growth in support we are seeing across the country for public programs that will support private insurance markets and expand access to those markets. I just want to go through some of the

problems here in Massachusetts with the individual insurance market (which will be merged with the small group market on 1 July 2007) so you can see the setting in which Massachusetts was operating. If you try to buy individual (sometimes called "non-group") insurance, you are talking about paying very high premiums relative to what you would pay as an employee of Harvard University — that is, your share of the total premium that Harvard pays.

The reason for this is that there are much higher risks in the individual markets due to the potential for "adverse selection." Adverse selection occurs when purchasing health insurance is a voluntary decision, and the people who know something bad about their medical history or their own current health problems are more likely to purchase health insurance than people who think or know they are healthy. The insurance companies know that this occurs, and if you or I were running an insurance company, we would be very worried about the potential for adverse selection, too. The concern about adverse selection in the individual market causes insurers to include a risk premium in their premiums — this risk premium is payment for having to bear the risk that the insurer might have a run of people with extremely high healthcare costs, which is different from what you would expect from a normal draw of enrollees from the general population. Adverse selection concerns also are present in the small group markets, where small firms have to buy health insurance. Small firms face higher per capita premiums than large employers, but lower per capita premiums than individuals in the individual markets generally are quoted.

Because the premiums in the individual market are higher than in the group markets, various politicians have proposed providing tax subsidies as a way of helping lower income people buy individual health insurance. I think this will exacerbate the risk of adverse selection because it just gives money to lower income people, and the first in line applying for coverage will be people who know that they have a medical problem. More to the point, these proposals do not confront the adverse risk selection problem that insurers are facing, so insurers will just keep premiums high and collect the subsidies.

Another fact to understand about the individual markets is that they are pretty confusing. There are generally many choices with different premiums and different cost-sharing options. Particularly for younger adults who are contemplating the higher premiums and the confusing choices, the situation is very much like what it is for those of us in our fifties or sixties who are thinking about whether to buy long-term care insurance. We look at the complicated choices and say, "Tomorrow, I'll deal with it tomorrow." So one reason we see more of the 25 to 34 year olds and 35 to 44 year olds without health insurance is that basically they look at the choices in the individual market and say, "The premiums are high, and I'm not likely to be sick. It's confusing." — and they stay out of the market.

So how did policy makers in Massachusetts respond to this? First, they said one way to deal with the adverse risk selection problem is to require almost everybody to enroll in a health insurance plan, and the state would subsidize coverage for those with low incomes. That will go part of the way toward reducing the potential risk of adverse selection. This move is now being talked about rather easily in at least another 16 or 17 other states that are working on expanding access to health insurance. The conversation now is about state efforts to expand health insurance, and this implies that everyone is part of a social compact, and as part of that compact individuals have the responsibility to buy health insurance. That is a totally different conversation than we were having just 18 months ago. So requiring everyone who can afford to buy insurance to do so is the first thing that Massachusetts did.

Second, Massachusetts dealt with the concern about adverse selection in the individual market by merging the small group and individual insurance markets into just one mar-

ket. We will no longer distinguish between people purchasing coverage as an employee through a small firm or as an individual. The merger of the two markets will pool the risks of individuals who do not have employer-sponsored health insurance with the employees of small firms. I was a member of the commission to study the likely effects of merging the two markets, and we estimated that the premiums for people purchasing coverage through small firms might go up between 1 percent and 1.5 percent, but the premiums for individuals would come down by about 15 percent. This gives you some sense of how much the risk of adverse selection should decline with the merged pooling of the two markets; individuals will see substantially lower premiums.

A couple of other observations about what Massachusetts did. There is a strong sense of joint ownership of the uninsured problem: employers, healthcare providers, the state — and by "the state" I mean all of us as taxpayers, whether we are companies or individuals — should help pay for health insurance for everybody. And importantly, if we find that some things aren't working, we will fix those things. This sense of joint ownership extends not just to what was done already, but into the future as well. I think that is an enormous accomplishment of people in this state who worked on developing the legislation and then the past year's worth of work to implement the plan. Nancy Turnbull, who is sitting in the audience, deserves enormous credit for getting people to work together on this.

A second observation is that the Connector [Commonwealth Health Insurance Connector, discussed in more detail below] has done yeoman's work in defining the terms of the basic benefits package and the cost sharing that will be required of individuals, as well as defining what is affordable coverage. In the past year, the emphasis has been on expanding access to health insurance and getting everybody on the same boat or under the same tent. What comes next is trying to slow healthcare spending, because if we do not do that, the plan is going to come unglued. Other states also are saying they are going to expand health insurance access first and not be deterred by the problem of rising spending — and that it is easier to deal with the rising healthcare costs if everybody is under the same tent.

My third observation is about the Connector's clearinghouse role. The clearinghouse role allows people to enroll in a health insurance plan and then take their coverage with them if they change employers or are between jobs or become self-employed. That is a tremendous accomplishment. It reduces the dynamics of insurance coverage for many individuals, and it reduces the costs to insurers of having to dis-enroll and enroll people who otherwise would have spells without coverage.

The Connector's clearinghouse role also means that we have standardized policies, making it easier for people to compare the different health plans. In addition, employers, primarily small employers, can basically designate the Connector as their employer-group health benefits plan. This is a very important point that has been missed by a lot of the media coverage. Designating the Connector as the employer-group health benefits plan means that the amount the employer contributes to the premiums can be treated as pretax dollars. This is what happens here at Harvard University, when Harvard contributes money toward the premium costs of its employees. The fact that the employer contribution is not treated as taxable income is good for the employers, because they do not pay Social Security and Medicare payroll taxes on the contribution. It also is very good for employees, because they do not pay the payroll taxes and the marginal income tax on the employer contribution. Thus, small employers that previously have not contributed to their employees' health insurance costs can now obtain the same advantages as large employers by designating the Connector as their employer-group health benefits plan. This is very much like what goes on in New York City with a program called HealthPass, which en-

ables small employers to offer their employees choices in health plans. The small employer does not have to choose one health plan for all of its employees; HealthPass allows the employees to have a choice of about 24 different plans, and the employer simply pays the premium money to HealthPass. This is a significant part of the Massachusetts plan.

The questions that the Connector has wrestled with over the last 10 months are the same questions that other states are now confronting. Two questions in particular are at the center of these discussions: How should costs be shared between individuals and employers? And as a percent of income, what is an affordable amount that people should be required to pay? (We can repeat this question for companies as well.) The second question relates to who may receive subsidies and what the upper income ceiling will be for who is eligible for subsidies.

A large number of European countries are dealing with these very same questions. I will be happy to talk further about this in the question-and-answer period. But three countries in particular — Switzerland, the Netherlands, and Germany — provide interesting lessons for us. They are three of the four European countries with the highest percentage of GDP [gross domestic product] that is spent on healthcare.

So to sum up, I have tried to set the stage here for thinking about what is happening in Massachusetts. As a country, we are facing much larger pressures now to expand access to health insurance and in particular to think about people whose incomes are high enough to afford coverage, but who do not have access to employer-sponsored health insurance. We are working through this joint public/private ownership of the problem in a way that I've never seen in the 25 years that I've been studying the uninsured. This public/private joint-ownership-of-the-problem approach that the states are taking is very important — for one thing, it allows us to work through the implementation problems at the state level and learn what works well and what does not work before we try any of these ideas on a national scale.

Ultimately, of course, the problem of the uninsured is a national issue. We in Massachusetts are lucky. We had money to throw at this problem, for two years anyway. We had a relatively low proportion of the population without health insurance. That's not the case in states like Alabama, Mississippi, and Louisiana, where efforts to achieve universal coverage will not be viable without fairly large income redistributions toward those states. But we are a country, and the uninsured younger adults are a problem for all of us. Massachusetts has been a wonderful beacon in all of this, and it is clear that other states are picking up on the lessons from the Massachusetts plan as they literally cut-and-paste portions of the Massachusetts legislation into their own legislative proposals. That is a high complement to Massachusetts policy makers. *[Applause]*

Michael Chin:

Thanks for having me. My background is clinical, as a family physician, and I don't profess to be an expert like our other panelists are. So I'm going to mostly stick to the facts, and try to set the foundation for this discussion by describing what is the law that was passed in April of 2006 and what has happened in the last year because of the law.

So the topic that we're discussing is: Does Massachusetts have the right model? I'm going to give an overview of the goals of the reform law, and I think of the goals as being threefold: Number one is to increase access to health insurance. Or in other words, to decrease the number of people who are uninsured in Massachusetts. Number two is to address the rising costs of healthcare in Massachusetts, and number three is to improve the quality of healthcare in Massachusetts. So the law is not just creating one program to insure some lower income individuals in Massachusetts. As you can see, the law tries to address all three problems. It's a very broad and a very ambitious law. We're going to try

to zip through it in 15 minutes, so fasten your seat belts.

First, let me address the issue of *access.* There are many different ways that the reform law tried to increase access to health insurance. The first one is a program called Commonwealth Care, which is a program available to qualified individuals with a household income that is between 0 and 300 percent of the federal poverty level. It's subsidized so that the premiums individuals pay are between $0 and approximately $110 per month. It began in October 2006 and has already enrolled approximately 70,000 people. That's a lot of people; 70,000 people who probably wouldn't have insurance now currently do have insurance through this one program. Individuals in Commonwealth Care are enrolled in one of the private nonprofit Medicaid managed-care organizations, which includes Boston Medical Center HealthNet, Network Health, Fallon Community Health Plan, and Neighborhood Health Plan.

So that's one way that the law has addressed trying to increase insurance in Massachusetts. The second one is Commonwealth Choice. Unlike Commonwealth Care, which is subsidized, Commonwealth Choice is not subsidized. Premiums in Commonwealth Care are usually higher than the $0 to $110 per month. The Commonwealth Choice program began open enrollment this month, and we'll talk a little bit more about it later.

The next piece is young adult plans. These are health insurance plans that you can enroll in only if you're aged 19 to 26. We've just heard from Katherine Swartz that the young adults are a big percentage of the people who are uninsured in Massachusetts, and these young adult plans are targeting this problem. Previously these young adult plans were not available in Massachusetts, but today you can enroll with coverage beginning in July. The benefits may not be as comprehensive as some of the other plans, but as a result the price has been able to be lowered. And because the price has been lowered, it is more affordable and more accessible for young adults.

The name "The Connector" is short for the Commonwealth Health Insurance Connector, and that's the agency where I've been working, and it's the agency that among other things has been charged with implementing these two programs, Commonwealth Care and Commonwealth Choice.

Next are MassHealth expansions. Most of you know that MassHealth is the Medicaid program in Massachusetts. The law did call for expansions to MassHealth, and since the passing of the law, over 40,000 people were enrolled in MassHealth who were not previously insured.

I'm going to skip over discussing the "individual mandate." You've probably all heard about this, and we just heard about it from Katherine. Beginning 1 July, most individuals in Massachusetts aged 18 and above are required to have health insurance. This requirement is going to start in a month and a half, and that will likely increase the number of people who are compelled to buy insurance, and thereby help to decrease the number of uninsured.

There's a whole set of new employer responsibilities that were brought about by the law, including the Free Rider Surcharge, Fair Share Assessment, and new requirements of employers to have Section 125 plans. These are examples of some of the new employer responsibilities that are aimed at increasing the number of people who have access to employer-sponsored health insurance.

And then there are a couple of other things that are affecting insurers, and these may be referred to as market reforms. We just heard a lot about them from Katherine, including the merger of the small-group and non-group markets. The law also expanded dependent coverage, which is another example of a market reform, and we can talk about this more if we have time later.

I want to echo what Katherine has said about healthcare reform really being a shared responsibility. As you can see, this is not just the government making a program. There are new responsibilities for the government, there

are definite responsibilities for individuals, and there are new responsibilities for employers and for insurers. The problem of being without health insurance is a huge one nationally and in Massachusetts, and it's going to take all of us together to help fix that problem.

So we have just talked about access. As I mentioned, the law goes further and tries to address not just access, but also *cost* and *quality.* There are several ways that the law tries to address cost containment and rising costs in healthcare. I'm just going to mention one of them to stay under 15 minutes. We know that the average age of the uninsured in Massachusetts is about 37 years old. That's pretty young. Before the healthcare reform law, if that person on their own — not through an employer, but on their own — tried to get insurance, it would cost them over $300 per month. Today you can call the Connector or you can call up a carrier, and this 37-year-old person who lives in Boston can get coverage for as low as $184 per month. That's a big difference. And then if you consider some of the tax deductions that Katherine mentioned, then the cost can be even lower as a result of saving on taxes. So that's one example of how costs are trying to be contained.

So we've discussed access, and we've just mentioned costs. Let's briefly move to *quality.* The law tries to address the issue of quality in a couple of ways. The first is with the definition of "minimum creditable coverage." The law has charged the board of the Connector with defining what is minimum creditable coverage. Minimal creditable coverage is the criteria that any health plan in Massachusetts must meet in order to fulfill the individual mandate. That's a mouthful. So let me try to give an example: prescription drugs. The Connector board is currently deciding if minimum creditable coverage includes drug prescription coverage. If the board decides "yes," minimum creditable coverage should include drug prescription coverage, then an individual could buy a product that does not have drug coverage, but that individual may be considered not to have met the individual mandate, and might therefore face associated penalties. In other words, there are strong financial incentives to buy a plan that meets this minimum creditable coverage. There are strong financial incentives not just to buy health insurance, but also to buy creditable, quality health insurance.

So that's one way the law tries to address quality. I'll mention another: since August of 2006, the law called for and assembled a Health Care Quality and Cost Council. They meet about once every month, and their goal is not to address access, but instead to focus on how do we improve quality and how do we contain costs in Massachusetts.

Another way the law addresses quality is through increasing Medicaid reimbursement rates, and to introduce pay-for-performance measures in Medicaid.

An additional method for improving quality is through the formation of a Health Disparities Council that is charged with addressing the disparities in health among different racial or ethnic groups. This council has not yet been assembled, but one of its goals may be to try to improve the quality of care that ethnic groups are receiving in the state.

So we have talked about how the law attempts to improve access, cost, and quality. There are also several other aspects of the law, including what's going to happen to the "free care pool" in Massachusetts. There are lots of other parts of the law that we can get to if people have questions.

The moderator also has asked me to give a quick assessment and a one-year update. It's now been a little over a year since the law was passed. There clearly has been some early successes: about 70,000 people are enrolled in Commonwealth Care. Over 40,000 additional people have been enrolled in MassHealth. So within just a year, over a third of previously uninsured people in Massachusetts are now insured. That's pretty impressive to achieve in under a year. And there's also much more to come. Commonwealth Care is continuing to grow. Commonwealth Choice just started this month. The individual mandate and most of the new employer responsibili-

ties have not yet gone into effect. So it's going to be some time before we get an idea of the full impact and effectiveness of the reform law.

Are all these steps going in the right direction? It's a great question to ask, and I think some people are going to argue that even though you have early successes, in the long term, this law is not going to be the solution. I think some people — for example, if you're a proponent of a single-payer system — might say that the reform law is not a step in the right direction. And I think that's a great and healthy debate to have, especially when, like Katherine said, Massachusetts is very different than other states that have much higher rates of individuals without insurance. But I would say that many people both inside Massachusetts and outside of Massachusetts are looking at what has happened in just under a year in Massachusetts, and they are saying, "Hey, that's pretty impressive." And that's part of why we are seeing so many other states looking at the Massachusetts model and asking themselves, "What parts of the Massachusetts model can we adopt? What parts would work here in our state? What parts would not work here in our state?"

Finally, if you want to learn more, there's a new website (*www.MAhealthconnector.org*) that was launched a few weeks ago that has a lot more information. For example, if you want to find out how much insurance costs for your young adult son who's graduating this month, you can find out at this website. There is also a lot of general information about healthcare reform in Massachusetts that you can find on the website.

Are there challenges ahead? There definitely are challenges ahead, so if there's time during this forum, we can talk about what are the challenges that we foresee coming over the next year, and over the next couple of years. So I look forward to an interesting debate. *[Applause]*

Marcia Angell:

Massachusetts is certainly to be congratulated on seeking to extend healthcare to nearly everyone in the state. Every decent society should ensure healthcare, just as they do education, clean water, and police and fire protection. So it's a laudable goal, and it's certainly one that I share. But unfortunately, I'm afraid the Massachusetts plan will fail in the long run and probably the short run, too. I won't get into the fine points of the plan today because the problems are not at that level, but rather at the level of the plan's overall conception. So what are those problems? Well, I see five major ones.

Number one. The plan's success depends primarily on requiring individuals to buy their own health insurance in the private market — a highly regressive policy that forces the near-poor to pay a much higher percentage of their income on healthcare than their more affluent neighbors. Older, sicker patients will also pay more. The state pays the premiums for those beneath the poverty level and partially subsidizes them for those up to 300 percent of the poverty level. But above that (about $30,000 a year for an individual), people are on their own.

I checked the Connector's website and found that the least expensive plan for a 57 year old had a premium of about $4,000 a year, a $2,000 deductible, and substantial co-pays and co-insurance (35 percent co-insurance for hospitalization) up to a maximum of $5,000 a year. So as I calculate it, our hypothetical 57 year old with a $30,000 annual income could pay as much as $11,000 out-of-pocket, or over a third of his income. An individual mandate of this sort has never been attempted, and I believe it's unlikely to succeed. I call this the "Squeeze Blood from a Turnip Plan." In 2008, those who haven't purchased insurance will be fined half the premium of the lowest priced plan. I doubt the state will have the stomach to enforce that. I hope it doesn't.

Two. Health insurance is not the same thing as healthcare — not by a long shot. In the Commonwealth Choice plans on the Connector website, there's a clear trade-off between premiums, on the one hand, and deductibles and other out-of-pocket costs, on the other. The plans with the lowest premiums have the highest deductibles and other

costs, but those who select the cheapest plans are likely to be precisely those least able to afford high out-of-pocket costs. So they could end up with health insurance that they are reluctant or unable to actually use. Furthermore, the cheapest plans are also the least comprehensive. For example, they don't cover prescription drugs, which constitute a growing fraction of health costs. So even when people do seek healthcare, they may find the particular care they need is not covered by their stripped-down policy.

Three. The Massachusetts plan originally required all health insurance, even that provided by employers, to meet a minimum standard of coverage. But the Connector has backed away from that. Employers are supposed to pay a $295 per employee fine if they don't provide health benefits, but they are now considered to have met their obligation if they offer benefits to just 25 percent of their employees or contribute 33 percent of the premiums, no matter whether their employees accept the offer and no matter how skimpy the coverage. So the problem of underinsurance will remain widespread.

Four. No one seems to know where the money will come from to pay for the plan or whether there will be enough. Supposedly it will come mainly from the individual mandate (that is, the turnip), general state revenues (another turnip, given the current budget shortfall), a shift from the uncompensated care pool, and the paltry fine of $295 per employee on businesses that don't offer health insurance. But as one state legislator told the *Boston Globe* last year, "We don't know what it's really going to cost or where we're going to get the money. To some extent, you might call it a Hail Mary pass."[4] But let's assume we do scrape the money together. Then what? The major failing of this plan, the elephant in the living room, is that it contains no mechanism for slowing price inflation in healthcare. Yet health insurance premiums have been rising much faster than background inflation. The plan relies on market competition to hold down prices, but that's fanciful. It's certainly not doing that now. If prices don't continue to skyrocket, it will only be because benefits are cut. So even if we do find the money for this plan at the outset, it will quickly become too expensive, as well as increasingly inadequate.

Five. The bureaucracy to administer the plan will grow rapidly, as will the legal costs, and that will siphon off dollars that could be used, could better be used, for healthcare. Massachusetts already spends about 40 percent of every healthcare dollar on overhead, according to a 2001 report to the legislature by the consulting firm LECG. The plan requires the state to determine whether insurance is affordable and meets minimum standards. But these judgments can be challenged. As Jon Kingsdale said earlier this year, "There's going to be a court challenge" to whatever the board decides.[5] In particular, those just over the 300 percent poverty level who have to buy their own insurance in the private market will object that they, and not the state, should be able to decide what they can and cannot afford. And the appeals and lawsuits will probably be endless.

So those are the major failings that I believe will cause the plan to implode. To recap. One, the individual mandate is harsh and inequitable and probably will be unenforceable. Two, private insurers will offer plans that are either unaffordable or inadequate. Three, the plan does not address the growing problem of under-insurance, particularly in employer-sponsored plans. Four, funding is unsure and that problem will only grow worse since there is no way to control price inflation. Five, the plan will require a large bureaucracy whose decisions will be subject to constant challenges.

Now, already, the plan is unraveling. About 60,000 people have been excused from the individual mandate because they can't afford it. That's over 10 percent of the uninsured, and there are currently no plans to cover them. The minimum standards for coverage have been relaxed. They no longer include prescription drugs, for example. Em-

ployers and workers who originally would have had to upgrade their current insurance no longer have to do so. The idea is that these compromises will be dealt with later — by January of 2009. House Speaker Salvatore DiMasi explained the delays this way: "We're moving to universal insurance and then toward insurance that has substantial benefits. That's the key," he told the *Boston Globe*.[6] It certainly is. But it's wildly optimistic to believe that after people have signed up for stripped-down coverage and costs have continued to climb, there will be the money and political will to add to the benefit package.

Massachusetts is not the first state to come up with a plan to provide near-universal health insurance to its citizens, although it is the first to rely on an individual mandate. Maine tried it in 2003, Minnesota and Tennessee in 1992, to name a few. And, of course, Massachusetts made an earlier attempt in 1988. All were greeted with great enthusiasm and fanfare in the media. You should have seen the *Washington Post* stories about the Maine plan. And all failed and died with scarcely a whimper. What they had in common, and the new Massachusetts plan also has this, is that they left our current dysfunctional system essentially intact and simply tried to expand it around the edges. But this system relies on employers and private insurers whose incentives are really to provide as little healthcare as possible. In fact, I suspect that most employers will soon follow the big three American auto makers and look for ways to get out of providing health benefits altogether.

Private insurers, for their part, try to avoid the old and the sick and attract the young and healthy, and they vary their prices and coverage accordingly. They also do everything possible to shift costs to other payers and back to patients themselves through high deductibles, co-payments, and claim denials. The overhead costs of all this risk rating and cost shifting are staggering. So when this inequitable and wasteful system is left essentially intact, any attempt to expand coverage inevitably increases costs, and I think will increase costs unbearably. And that is what will happen in Massachusetts.

The only workable solution is a single-payer system in which everyone is provided with whatever care they need regardless of age and medical condition — that is, a system similar to Medicare, which is a single-payer system embedded within our larger private system. There would no longer be a private insurance industry that adds little of value yet skims 10 percent to 15 percent of the healthcare dollar right off the top. Employers, too, would no longer be involved in healthcare.

The most progressive way to fund such a system would be through income taxes that would be more than offset for individuals by eliminating premiums and out-of-pocket expenses. Over the years there have been many independent analyses of the costs of converting to a single-payer system, either within a given state or nationally. They included studies in the early 1990s by the General Accounting Office, the Congressional Budget Office, and consulting firms, such as the Lewin Group, hired by state governments and, in Massachusetts, by the state medical society. Most found that a single-payer system would initially cost roughly the same as the system it replaced, while providing universal coverage, and over time, it would be much cheaper.

Polls report that most people and most Massachusetts doctors, I might add, favor a single-payer system.[7] Even the *Boston Globe* called for a national single-payer system yesterday. In an editorial about the big three automakers' desire to transfer health costs to the auto workers union, it said, "It would make more sense for the federal government to oversee a national health system financed from taxes. The cost would be spread across the entire population, rather than borne by Chrysler or other companies that no longer enjoy the assured profitability of their best years."[8]

Nevertheless, the private insurance industry has managed to convince many people that a single-payer system is unrealistic. You hear that word over and over again: "Unrealistic."

But what is truly unrealistic is anything else. My greatest concern about the Massachusetts plan is that when it unravels, people will draw the wrong lesson. They'll assume that universal care at a cost we can afford is simply impossible and give up on it. It's not impossible. It's just unlikely to be achievable while leaving our dysfunctional healthcare system in place. *[Applause]*

Lisa Lehmann:

I want to thank our panelists for sharing their insightful perspectives with us. In just a minute, we'll open it up to you, our audience, for conversation and questions. We have two microphones that will be at the bottom of the floor on each side of the auditorium, and if you could please come up to the microphone and tell us your name and ask a question, we'll have the panelists respond to it.

I'll take the prerogative of getting us started, if I may. Marcia, you've really given us a cogent argument for a single-payer system, and that's not the route that Massachusetts has gone. I'm wondering if Kathy and Michael might be able to comment on your perspective on a single-payer system. Is that the way we should be moving? Why didn't Massachusetts go that route? What might be some of the pitfalls of a single-payer system?

Katherine Swartz:

Okay. So I'm going to answer a slightly different question. I don't think it's possible to go to a single-payer system like *that.* Instead, I see what Massachusetts has done, and what a number of other states are considering, as being steps toward perhaps a single-payer system. There is a great reluctance in most of the United States to not do away with private health insurance. If the Massachusetts plan doesn't work after whatever else we end up doing to fix some of the problems that surely will come, I see this step as moving toward something that looks like a single-payer system.

I guess I also see it more as a change in the conversation about how we pay for health insurance; and in particular really addressing the question of how much of the cost of healthcare should be borne by individuals, how much should be borne by employers, and how do we treat children or people who are not gainfully employed. Do we say that the costs for such people are the responsibility of all of us? And I would certainly go in the direction that children, for example, are the responsibility of the government, the state. (I'm using the word "state" to indicate society.) We should be investing in children because they're the future of the country. Employers should also be helping to pay for children's healthcare because they are future workers.

All of this essentially looks like we are drawing money into some central clearinghouse and then paying for healthcare as people need it. There are a variety of ways of paying for the care, one of which is to go through insurance companies.

But I want to come back to what I started with — I do not think we can go to a single-payer system overnight or within one year. I think of this more as a decade-long discussion, and we are moving toward that. And I think the cost of Medicare will hasten this shift as well — we will end up being in one system that everybody is in. Whether this is something which people who are currently 65 and older get grandfathered into the current Medicare and the rest of us move into a different system, I don't know. But I think the conversation about how we pay for healthcare in the country is going to involve all ages and not just people under 65.

Michael Chin:

I'll make two quick comments. I agree with Katherine that if the legislature had decided to switch to a single-payer system, it would be hard for me to imagine insuring people as quickly as we've done as a result of the current law. As we said, over 70,000 people in Commonwealth Care and an additional 40,000 in MassHealth have become insured. So that's pretty impressive numbers in such a short amount of time, which would have been very

hard to achieve if Massachusetts had tried to switch to a single-payer system.

A second comment is that the situation or the model that works in every state is going to be different, and in Massachusetts our rate of uninsured — around 6 percent of people in Massachusetts — is a lot lower than it is in other states. And also the percent of people who are already covered by employer-sponsored insurance is a lot higher than in other states. So, in that regard, maybe a single-payer system might make much more sense in states other than Massachusetts.

Lisa Lehmann:

Marcia, do you want to respond to those comments?

Marcia Angell:

Well, just briefly. What's standing in the way of moving to a single-payer system is the implacable opposition of the private health insurance industry and the pharmaceutical industry, which would have to face bulk purchasing by the state and price negotiations. So these industries are implacably opposed. In Massachusetts, the big hospitals were bought off by rate increases, and so they, too, have gotten behind the new plan. They all propagate the mythology that moving to a single-payer system would be terribly hard to do, that it would be very complicated. Well, there's nothing more complicated than this current plan. What you're seeing is "Harry and Louise"[9] all over again. We're told we just can't do the sensible thing.

Lisa Lehmann:

Thank you. Norm, do you have a question?

Norman Daniels:

Thank you, all of you, for very good presentations. My inclination is to agree with the criticisms that Marcia made of the plan. I just wanted to bring into perspective a couple of international and historical remarks, which maybe didn't appear in the 25-year time period that Katherine was talking about. If one goes back to 1993 and the Clinton effort at reform, the numbers of uninsured in the United States were roughly 33 million. So we've had over a 45 percent increase in the number of uninsured in just 15 years. At the same time, we've had deeper and deeper and more complicated entrenchment of the fragmentation of our health system and the entrepreneurial thrust to it with an ideology overlaid about competition. Competition is not going to solve these problems. Remember, Clinton had articulated at the beginning of that plan that single payer was out. So what we've seen in the aftermath of that is enormous growth, not only of the uninsured but the continuing rise of healthcare costs.

So I go back to a point that Marcia made in her remarks. It seems to me that we're stuck in a system that is spending 50 percent more than other developed countries per capita on healthcare, and it's doing it because of the very structure of the system that we have. Yet we were told by Clinton that you can't move away from that complexity in any direct or straightforward way, that it's politically impossible. I think if we are told that now, we are victims of obfuscation. It is not that complicated to expand Medicare or some other version of a single-payer system in this country.

What you really get are arguments about competition and a market ideology which pushes us in the direction of saying individual competition is necessary, but they do not turn us in the direction of what is done in other countries to establish a balance between monopoly and monopsony powers. That is what all other countries have been using to control their healthcare costs, at least in developed countries.

So my question, Katherine, really is why is it so complicated to move away from this system? I think it's not that complicated. I agree with Marcia, but I think that the real obstacles are political and the failure of some clear leadership around this. It was a failure in my view within the Clinton administration, and each time we have to face this problem a decade or after a failed effort at reform, the

problem is made worse by the magnification of the investments in entrepreneurial and fragmented healthcare.

Katherine Swartz:

I think that no one should mistake my answer to say that I do not want to go to some kind of single-payer system. But I don't think that for political reasons you're exactly right, that we can do this in any very short-term period of time. And the reason I believe that is I spend time every year in the West, and there is really intense opposition in the western states to the notion that we would move to a single-payer system tomorrow.

On the other hand, one reason I spent time trying to set the stage of what's going on in the U.S. with the uninsured is it is now clear to many people in states like Montana, Wyoming, South Dakota, North Dakota, Washington, Vermont, et cetera, that their children do not have health insurance. Their adult children don't have health insurance. Their grandchildren don't have health insurance. That is what is driving these state efforts to think about expanding access for self-employed people and employers that are very small, smaller than what are required of Massachusetts or Vermont to participate in these states' plans. The fact that there are so many people who work for these smaller firms or are self-employed who are worried about their access to health insurance, plus the fact that very large employers are saying they cannot afford to continue the obligations they have to the unions, means that there is growing support for public policies to help people buy private insurance on their own.

But I don't know that people really believe that we're going to get competition between insurance companies to keep the costs down. Insurance companies today do not bear risks. Marcia is absolutely right about that. Larger employers (any employer basically over 250 employees) self-insure. They do not buy insurance policies. They are paying insurance companies to be the third party administrator, so the insurance companies are not bearing risk. If you're talking about small employers below 250 employees down to say 50 employees, they're forced to buy policies, and those are the companies particularly that are now, if they're starting up or have already been offering health insurance to their employees, are back-pedaling away in terms of forcing their employees to pay more, just to keep the costs down. I really believe that over this next decade we are going to see an enormous shift in the conversation about who pays for health insurance, how much, what is it that we're buying — because the insurance companies do not want that risk.

The next question is what is it that the insurance companies are doing. Well, they're processing claims. It's just exactly what they do for Medicare on a contract. So we are moving toward a single-payer system with insurers processing claims. The question is, How do we get there — How do we get the country to move along? I'm clearly a Democrat, but Governor Mitt Romney did an enormous favor to this country by saying it is a requirement that people buy health insurance. That has changed this conversation into a discussion about being in a social compact.

Part of the social compact is an individual's responsibility as well. It's an eye-opener that we're now into that conversation. So do I think we're moving toward a single-payer system? Yes, I think we are. Do I think that there are problems Marcia has outlined about what's happening here in Massachusetts? I'm not in that boat. I think that we've done an enormous move forward, and now we can turn attention to trying to figure out how to slow down the growth in healthcare spending because we cannot afford it at the rate we're going.

So thinking of these as steps, and that we have achieved a joint ownership of this problem between employers, providers, and all of us as individuals — that's enormous. We should be very proud of that. I think that progress then opens the door for being able to resolve these issues that you've brought up, that Marcia has brought up, and that many of us have raised. But I don't want to repeat what

we did in the Clinton era of everybody throwing arrows at the problem. I think it is much better to be constructive about how do we fix this problem, what do we do next, how do we get more money into this system, and so on. That's the conversation we need to be having.

Lisa Lehmann:

So, Kathy, you've articulated a position that is very positive with regard to the idea of shared responsibility and the individual mandate. That is in stark contrast to the view that we heard from Marcia in which she suggested that an individual mandate is harsh, unenforceable, and not equitable. I want to ask Dan Brock, who is the head of the Division of Medical Ethics at Harvard Medical School, if he can comment on this idea of an individual mandate and shared responsibility. Is this mandate ethical? Is this ultimately a good thing?

Dan Brock:

In every other developed country there is some form of national health insurance that usually is paid for out of general tax revenues. Sometimes it comes through employers, but it's a shared financial responsibility. In Canada, in Great Britain — now that's a way of mandating that the community subsidize the overall costs of the healthcare system, and it allows us to do what used to be called "community rating," namely, in effect, the sick get subsidized by the well. Now, I have to think that is ethically justified, but I don't think the individual mandate is all that different from that other system that spreads the cost. What this is doing is spreading the cost by saying, "If you have incomes, it will be a subsidized premium that you'll pay." But instead of free riding and saying, "Well, I'm young and I'm healthy" — obviously, *I'm* not young, but many who are say — "I'm young and I'm healthy, and so I'll take my chances, and if I get really sick, I'll go to the emergency room, and I know the federal government requires me to be treated if I go to the ER." That's free riding, right. So this is a way of trying to insure that we avoid that free riding.

Now I want to ask one question, which is about the title of this forum: Does Massachusetts Have the Right Model? And one way to interpret that is, has it got it right in terms of a plan that other states can mimic to some degree? There are several facts that make it not too likely that this can be widely imitated by other states. We live, as we know, in the most liberal state in the country, and so there's more concern with dealing with this problem. As was pointed out in Kathy's presentation, we have a relatively low uninsurance rate in comparison with other states. As we know, it's nearly twice that overall in the country. And we live in a relatively wealthy state, in comparison with other states that have higher rates of uninsurance.

So I would think more conservative states with a much bigger problem in terms of numbers of uninsured and less wealthy states are going to have an awful — even assuming we can make it work in Massachusetts — are going to have an awful hard time following suit and making it work in Louisiana and Mississippi and Alabama and Arkansas and so forth and so on. So I wonder what some of you think about the potential in other states.

Katherine Swartz:

That's a great question. So it's true that California, for example, sent people here and people from here went there to talk. The governor's people basically did a cut-and-paste of parts of the legislation here, as well as the legislation in Vermont.

One key difference between the Massachusetts and Vermont legislation is that Vermont has a "blueprint for health" that talks about certain health problems or public health problems that are not the responsibility of a single employer or a single insurance company. The blueprint for health's initial issue is people who are overweight because Vermont has a large number of people who are overweight, like most other states, and type 2 diabetes is a big problem there.

So a similar blueprint for health initiative is in the California proposal of Governor Arnold Schwarzenegger. But then there are

differences where, for example, California is trying to finance its plan, not with a nominal $295 per employer that does not offer health insurance, but instead a 4 percent tax on payroll of employers that do not provide health insurance. The 4 percent tax on payroll may be an opening gambit that the legislature in California will negotiate over — I don't know.

The other states that I have been in discussion with have focused much more on their small group and individual insurance markets. What intrigues these states is, first of all, Massachusetts' decision to merge the small group and individual insurance markets — something that as I said earlier has been under the radar of most people's attention. But the second issue that these states are interested in is what I've been proposing as one part of a package that states might consider: reinsurance. Illinois and Montana, for example, are very seriously talking about reinsurance. Michigan is as well. New York State has reinsurance already in a program for low-income people and is thinking about expanding that. So all of these are different pieces —

Bud Relman:

Would you explain what you mean by "reinsurance"?

Katherine Swartz:

Yes. I've been proposing a reinsurance program whereby a government program would take responsibility for most of the costs of people who, in any given year, have extremely high medical expenses. So if you think about the medical expenditure distribution in the United States, you all know that 10 percent of the population is responsible for 70 percent of medical spending. But the top 1 percent of that distribution is responsible for about 28 percent of all medical spending. To be in the top 1 percent of the expenditure distribution last year, you would have had to have medical spending above $50,000 for the year. This goes back to what I was saying earlier, that the insurance companies in the individual market, as well as the small group market, tack on what I call a "risk premium," because they are very worried about people who might have these extremely high costs. So if a reinsurance program would pay for, let's say, 90 percent of all costs of people who are in that top 1 percent, the reinsurance program would pay 90 percent of the expenses above $50,000. And importantly, the reinsurance program doesn't just drop the premiums by the 28 percent of all spending; it drops it more than that, because insurers no longer have an incentive to include the risk premium in the premium to compensate for the possible adverse selection. Premiums really come down.

In the case of Healthy New York, which is a program for low-income people and is the only program in the country right now that uses this kind of reinsurance, the premium costs are less than half of the premiums in the standard individual market in New York State. The package of benefits is somewhat leaner compared to the standard market, but the insurers are the same managed-care plans and the physicians are the same. So this indicates to me that there is a risk premium in the individual (and small group) market.

What we want is for premiums in the individual and small group markets to come down sharply enough that younger, healthier uninsured people will start buying insurance. If more younger and healthy people come into these markets, it will stabilize the markets, and the premiums will stay lower. Massachusetts chose to merge the small group and individual markets to reduce individual premiums and stabilize the market, but government-sponsored reinsurance is on the back burner in the legislation. I think that people are looking at this as a way of bringing in these younger, healthier people and getting them to buy health insurance.

I want to make one more point before Bud comes in on this. Marcia's right to worry about the people who are older and whose incomes are just above the ceiling for getting subsidies. For an individual, the income eligibility ceiling for a subsidy is three times the poverty level. The poverty level for an individual is $10,000. So when she was saying $30,000, it's because that would be 300 percent of the pov-

erty level for a single individual. But for a family of four, the poverty level is $20,000, and therefore $60,000 of income is the point at which a person would not be eligible for the subsidies. Michael might want to talk more about this — but the Connector was caught by how much money the state had available for subsidies.

The Connector expanded the income ceiling for eligibility for subsidies as much as they could and then worked backward in terms of figuring out what is a minimum credible insurance policy. I also want to make the point that if you lived in Wyoming, were self-employed, had a family of four, and your income was around $30,000 to $35,000, the kind of health insurance policy that you could get in would cost you about $700 or $800 per month for a family policy. You would be facing at least a deductible of $5,000, more likely $10,000 now. And the policy would not cover any well-baby care, any immunizations, or any well-adult care.

What is being offered here through the Connector is far better than what you would be facing in most other states if you had to buy individual coverage. And I think that point needs to be brought back into this discussion. Again, it's part of what the state is trying to accomplish, trying to move forward. Do I think that the state is going to try and put more money in for subsidies in the future if it can? Yes. Do I think it's going to add more options about covering prescription drug coverage? Yes. Think of this as the baby was just born, and the baby hasn't walked yet. I don't want to throw that baby out with the bath water. I think it's more important to think of this as progress toward getting universal health insurance coverage, and, most likely, single-payer coverage in this decade because we cannot sustain what's going on right now. It's going to have to involve a different conversation about how we pay for health insurance and what it is we're paying for.

Lisa Lehmann:

Marcia, do you want to comment on that?

Marcia Angell:

Yes. I'm very uncomfortable with the rhetoric of shared responsibility in this context. Shared responsibility, as Dan Brock pointed out, is what you do when you pay your income taxes, and everybody is in a universal system. You're sharing responsibility in proportion to your ability to pay. What this plan does is to hit the poor and the near-poor much harder than wealthy people. Those with the least disposable income have to pay a higher percentage of their income. So this is not something, Kathy, that I would celebrate ethically. It's hardly a virtue of the plan that it is hardest on the most vulnerable. As for the baby, there's an expression in medical school that when you're learning how to do a procedure, such as a lumbar puncture, you "watch one, do one, teach one." We haven't even "done one" yet, and we're already presuming to teach other states how to provide universal care. I want to see what happens to this baby. Maybe it's stillborn, but let's just see what happens.

Lisa Lehmann:

Bud, do you have a question?

Bud Relman:

I have an observation and then a question. First the observation: I think too much attention has been given in this discussion, and in the Massachusetts plan, to getting everyone covered with health insurance, and not enough attention to the central problem, which is cost. It is the ever-rising cost of healthcare that is making insurance unaffordable by so many. We need to solve the problem of rising costs before we can expect to have universal coverage.

And now the question for the panel: Do they think it makes more sense to attack the healthcare problem as a whole, rather than simply try to achieve single-payer insurance reform? Shouldn't we be looking at how to reform the delivery system at the same time, in order to make it more efficient and affordable?

Lisa Lehmann:

Thanks very much for that excellent observation and question. Before I ask Michael to respond to the question, I want to elaborate on it a little bit. Michael, you suggested in your presentation that, in fact, this legislation is trying to address cost. But the example that you gave for that was the way in which the premiums that people have to pay are decreased. But the reality is that a decrease in premiums is associated with a decrease in benefits, and that's really not what we mean when we talk about controlling costs. Bud's comments are really on that point. When we're talking about controlling costs, we're talking about the escalating costs of high technology healthcare, especially the tremendous costs that we give to the elderly at the very end of life, and the question is, What does this plan do to control rising healthcare costs? What is Massachusetts going to do to control costs? And can we move forward without really dealing with the high cost of healthcare itself, not just by reducing the premiums associated with these health plans?

Michael Chin:

I completely agree with what a lot of people have been saying. You can insure everyone — whether it is in the current system that Massachusetts has or even in a single-payer system — and costs are still going to be a problem. So I agree completely that cost is really something we need to pay attention to. And the legislature — these are really smart, intelligent people, and that's why they made a bill that wasn't only about access. It was also a bill that tried to address quality and cost. I think access gets talked about a lot more because it's very visible, and people can attach numbers to it. But people are trying to address quality and cost as well.

For example, this is what the Health Care Quality and Cost Council is trying to address, and in some ways I think their job is even harder than what the Connector is charged with, because trying to stop the national and international rise in healthcare cost is very, very difficult. The Council is talking about ways to do that, whether it is by trying to lower the number of hospital-acquired infections, or trying to increase the amount of people who are prescribing through electronic means, so that we decrease medical errors. These are things they are looking into that will hopefully increase quality and decrease costs. But it's very hard, if not harder, than getting people access to insurance.

Lisa Lehmann:

Okay, great, Rashi, do you have a question?

Rashi Fein:

I agree with Kathy but . . . It would be wonderful to have a conversation, I think that's what you called it, over the next decade. But if we're going to have a conversation, it would seem to me that it is incumbent on those who do favor a single payer not to retreat from that conversation by saying they favor single payer, but it's not practical. Because that's been the history going back to Bill Clinton, who spoke to the governors and said a Canadian-like system is much better but. . . . He didn't say "but it's impractical," because he didn't want to confess that he couldn't accomplish it. So he used a different word. It would seem to me that the problem with the Massachusetts program, if you like a single payer, is that it heads in the wrong direction and does not contribute to the discussion that we ought to be having.

It would be, I think, very difficult to have a single payer tomorrow, but to say that's the problem is akin to setting up a straw man. I don't think that anybody in favor of a single payer feels that you could, in a practical sense, suddenly redirect all the funds that come today from employers to health insurance companies without being engaged in a tremendously difficult war over what goes to wages, what goes to taxes, et cetera. But it would seem to me that if one is in favor of single payer, that one ought to head in that direction by stating this is where we want to end up and here are five steps that take us there. Cover all

children on a single payer. Two years from now cover all people 18 to 30 on a single payer. Two years later 30 to 40, 45, or work down, but work in a way where people can see the end goal of a system that is not inherently different from what is being phased in.

The Massachusetts plan doesn't contribute to movement toward a single payer, neither does it enlighten us for purposes of that discussion. Indeed, I think it does something that is harmful. It continues to say, in effect, the employment linkage is not broken, it's the way we've had it, and it's the way we ought to continue it. And I think the problem with linking insurance to employer, not only is it problematic in how do you get all employers, but it is the antithesis, I think, of the kind of competition we ought to have between employers. It is not that Chrysler or Ford or General Motors have been more lavish in their health insurance benefits than Toyota or Honda, it is that Toyota and Honda have younger employees with lower healthcare costs, no retirees, thus again lower health costs, and they're located in Arkansas and places which are not as expensive medically as Michigan and Ohio.

So it would seem to me that we're heading in the wrong direction. Does that mean that we have done evil? No, there are 60,000 people who have insurance, and that's an improvement. Have we contributed to the dialogue, discussion, conversation that would bring us closer to a single-payer system more like Medicare? I don't think so. I think, in that sense, we've set things back.

Katherine Swartz:

I'd like to respond to that. The Netherlands has essentially a single-payer system. There are contributions from individuals and from employers, different taxes, however you want to think of it. Children are the responsibility of the state, and then they have about 25 or 26 different insurance plans. But the rates at which providers are paid are set by the national health board, and similar things happen in other countries as well. I think the way to think about what's happened here in Massachusetts is that the Connector is allowing people who work for small employers to break away from the idea that only the employers are responsible or the organizing force for health insurance. HealthPass New York is really the model for this — the employer pays into the Connector which is gathering up premium money from many employers, which is just like what happens in the Netherlands. Then the employees can choose whichever health plan they want. This step has been missed by most people thinking about what's going on here in Massachusetts.

I think employers want to get out of being in the business of paying for health insurance as fast as they possibly can. This is going on across the country, not just Massachusetts. That's why this conversation is really accelerating about what share of health insurance costs do we want employers to pay. I don't think we want employers to get off the hook on this. They are benefiting from having very healthy employees and having healthy children who will become healthy employees. They have a role here, too. So, in that sense, we are moving toward a universal payer.

In answer to Bud's question, I think that we cannot be controlling healthcare costs without having what looks like Medicare setting reimbursement rates and saying everybody's in this tent together. What's really driving our healthcare expenditures are, as Lisa said, the high cost, high-tech procedures, and diagnostic tests, like radiological scans. Why are we paying radiologists so much more than we are paying primary care physicians?

Having that kind of conversation along with discussions about how we will pay for healthcare is what we are moving toward, and I think we will do it within this decade. I also think employers want out of paying for health insurance, and therefore the rest of us have a responsibility to set the structure of that conversation and not let the employers get out of paying a share of the costs for health insurance in this country.

Julie Silverhart:

I'm Julie. I'm originally from New Mexico and came to Massachusetts for my medical training. Currently I am doing a geriatric fellowship and am the coordinator of Massachusetts Physicians for a National Health Program. I realized sitting here that I've never tried to understand how a liberal-minded person, especially a bright group like you who are health policy specialists, could miss the boat on why single payer is our country's only viable option. I understand why a chief executive office of an HMO [healthcare maintenance organization] supports our current for-profit health insurance system since he/she has much to gain with respect to his/her paycheck. Similarly, it makes sense that Blue Cross/Blue Shield shareholders must be ecstatic about our Massachusetts health reform bill because Massachusetts HMOs will get "subsidized" a significant sum of money by having this mandate on the poor and near-poor people. That is, our state will force individuals to buy inferior quality health insurance, those individuals who can't afford that premium might get some government assistance, and the HMOs make out like bandits because they have a captive pool of insurance buyers getting government assistance to further fill HMO purses.

I also don't understand how you can say it would be so difficult, complicated, and impractical to switch over to a single-payer system, when what we have right now is both incredibly complicated and completely inadequate. Our current healthcare system commits countless injustices to Americans and is wasting money that we don't have. Many of us here are physicians and have seen people who are not able to get the care they need because they don't have insurance. It is wrong to force these people to spend their already meager incomes on health insurance that we know will have high deductibles and be lacking in many areas.

I disagree with Katherine Swartz's earlier comment that because this reform, our "baby," is better than what Wyoming offers its residents, we should therefore be pleased with ourselves. I agree with Dr. Marcia Angel, that you're not saying much when your claim to fame is being "better than awful."

As I stand here with my two-month-old infant, I remember the preparations I made for his arrival. I worked hard to do things right for him and give him the best possible beginning in life. I wouldn't have been happy to just offer him a bit better than "awful." If we have the ability to do something to switch, to make a change, then why don't we put our energy into the right place and move forward united for a single-payer system? Research has shown that the majority of doctors and the majority of the American population want a single-payer system. So when there's popular support, when we know that it would save money and provide care for everyone, I'd like to understand why you're putting your efforts into this reform that takes us further from single payer, as it just digs a deeper hole of debt for individuals, our state, and a bigger purse for HMOs?

Katherine Swartz:

Me?

Julie Silverhart:

Both of you. Why aren't you for single payer? Was there some shift that changed you from single payer?

Katherine Swartz:

I think you missed part of where I am. I was very careful to say that I'm not saying I do not want a single-payer system. I'm saying, "Think of this as a strategy game," and we have a game plan that will take us out over another decade. The goal is to think through how we are going to achieve universal coverage. I want greater access to healthcare. As for what is going on in Massachusetts, people are getting subsidies to purchase policies — that's the first thing.

Second, the deductibles are much higher than I think most people on the Connector board expected to have when they started working out the details of the Massachusetts

plan. But the deductibles exempt three visits to a physician per year, so the Connector is clearly saying they want to make sure that people will come in for preventive care. And if you get sick, three visits total per year ought to cover at least one sick visit. After three visits, you have to pay the deductible. I may be wrong on this, but I believe that maternity care is totally taken care of under this. So don't get caught by thinking that the deductibles are terribly onerous.

The third point I want to make about this is that the Connector is being very careful about affordability issues and who will not be able to afford policies sold in the state. For people whose incomes are just above where the subsidies go away, the Connector is making exceptions. They are agreeing that the policies are not affordable for some of these people.

What do I expect will happen this next year? The Connector will increase the subsidy level, and they will make arrangements for these people to get some other kind of coverage. So it's not so white and black — this is very nuanced.

I was not on the Connector board, and I don't mean to defend everything they have done. But I think you have to see what they have done as an enormous effort to try to be fair to all sorts of people and that, although there are problems, the Connector and others are going to attack those problems one by one.

And meanwhile, we really need to be paying attention to the fact that more and more employers in the United States want to limit what they are paying for employer-sponsored health insurance. We ought to be thinking about what we want employers to contribute for our healthcare. They are going to benefit from a healthy population and work force. I sound like a broken record here — but I think this is the bigger issue that is overtaking us without our realizing it.

Lisa Lehmann:

Thank you. Please join me in thanking our panelists for a very lively and engaging conversation. *[Applause]*

NOTES

1. "Income, Poverty, and HealthInsurance Coverage in the United States: 2005, Table 8," *http://www.census.gov/hhes/www/hlthins/hlin05.html.*

2. K. Swartz, *Reinsuring Health: Why More Middle-Class People Are Uninsured and What Government Can Do* (N.Y.: Russell Sage Foundation Press, 2006).

3. Current Population Survey is a joint effort of the U.S. Bureau of Labor Statistics and the U.S. Census Bureau, *http://www.census.gov/cps/.*

4. Quotation is presented as a statement by an unnamed legislator to *Boston Globe* reporter Joan Vennochi in M. Angell, "Healthcare plan needs dose of common sense" (editorial), *Boston Globe,* 17 April 2006, *http://www.boston.com/news/globe/editorial _opinion/oped/articles/2006/04/17/healthcare_plan_needs_dose_of_common_sense/.*

5. Commonwealth Health Insurance Connector board director Jon Kingsdale, quoted in A. Dembner, "Sticker shock for state care plan: Average premium of $380 outlined," *Boston Globe,* 20 January 2007, *http://www.boston.com/news/local/articles/2007/01/20/sticker_shock_for_state_care_plan/.*

6. A. Debner, "State may give insured more time to upgrade," *Boston Globe,* 16 March 2007, *http://www.boston.com/news/local/articles/2007/03/16/state_may_give_insured_more_time_to_upgrade/.*

7. D. McCormick et al., "Single Payer National Health Insurance Physician's Views," *Archives of Internal Medicine* 164 (2004): 300-4.

8. "Creative Destruction at Chrysler" (editorial), *Boston Globe,* 16 May 2007, *http://www.boston.com/business/articles/2007/05/16/creative_destruction_at_chrysler/.*

9. "Harry and Louise" is the name given to a television commercial that was paid for by a health insurance industry lobbying group in opposition to the Clinton proposed healthcare plan. It featuring a middle-class couple portrayed by actors Harry Johnson and Louise Claire Clark.

Law

Legal Trends in Bioethics

Sigrid Fry-Revere and Sheeba Koshy

Readers who learn of cases, laws, or regulations that they would like reported in this column are encouraged to e-mail Sigrid Fry-Revere at *sfryrevere@cato.org*.

GENERAL INTRODUCTION

The laws governing bioethics issues are confusing and sometimes contradictory because of several types of tensions inherent in our legal system. Legislatures and courts work in different time frames and with different priorities. The U.S. constitutional guarantees of separation of church and state and individual rights make bioethics issues involving personal, moral, or religious convictions particularly contentious.

Each state also has its own constitutional protections, some of which clearly mirror those in the federal Constitution, but others don't.

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Legislatures and courts play different roles in our constitutional republic. Legislatures are by nature democratic and can react relatively quickly to changes in the political climate. Courts, on the other hand, are inherently antidemocratic. As a matter of fact, their main constitutional function is to protect the rights established by our various constitutions from violation by legislative action. Courts are also inherently conservative in their reaction to events because they are bound by precedents and procedural processes that are designed to assure that major philosophical changes happen gradually.

Legislatures and courts, in the area of bioethics, also act under the existence of two contrary presumptions. Legislatures tend to act with a presumption in favor of prevailing moral beliefs. The courts, on the other hand, have the structural and theoretical obligation to protect individuals from majoritarian decisions that unnecessarily violate their constitutionally protected freedoms. They also have an obligation to uphold the separation of church and state. So, in bioethics cases, courts often have to deal with preventing governments, either through legislation or other state action, from imposing moral or religious preferences on individuals who might not agree.

Thus courts tend to show greater deference to individual choice than legislatures do, and tend to become more cautious the more divisive the issue.

An understanding of these inherent tensions between legislative and judicial action and the various individual interests being balanced by the courts will make it easier to understand legal trends in bioethics.

It is also important when considering trends to watch how far bills that are introduced advance even if they do not pass. For example, a bill that is introduced and quickly moves through several committees and is voted on by one chamber but not the other before the legislative session ends has a better chance of passing if reintroduced at the next session than a bill that was introduced but never even voted on in committee. If a bill is listed as having died or failed, that means it was voted down either in committee or by one of the legislative chambers. The success of such a bill is not likely even if it is reintroduced in the following legislative session unless there is an election that sufficiently changes the composition of the legislature or some other intervening event rejuvenates the bill's chances. If the session ends without a bill being voted on by both chambers, it has failed; but it has a better chance if it is reintroduced in a later session than if it is voted down. A bill that is reintroduced also probably has a better chance than a bill that is never even voted on in committee. The reason that some bills are listed as having died due to the end of the session, while other bills are still listed as active, is that some states have one-year legislative session cycles and other states have two-year cycles.

Please note that cases, laws, and regulations listed in earlier columns will not be repeated unless there has been a change in status since the last reporting period. Updates on previously reported cases, laws, and regulations are marked with an asterisk (*).

Subject headings are not listed alphabetically. Sections are listed in descending order with those subjects with the most activity or the most significant activity listed first. It is important to note that the order of subject headings can vary from one issue of "Legal Trends" to the next depending on what subjects have the most legal activity in any given quarter.

INTRODUCTION TO "LEGAL TRENDS IN BIOETHICS" FALL 2007

The most troubling development in this quarter is the extent to which legislators continue to intervene in the patient/physician relationship by trying to regulate the relationship down to the smallest specifics of what is said and done. These developments are a great threat to both physicians' and patients' autonomy, but while there have been many attempts to pass such invasive legislation, at this point few of such bills have actually made it into law. It will be important to watch the next two issues of "Legal Trends" if someone is interested in seeing how many of such bills actually do end up as laws.

The issue of medical tourism is not new to bioethics, but it is on the brink of attracting more attention in U.S. courts and legislatures. There is no separate heading in "Legal Trends" for "medical tourism," but it is important for anyone interested in the subject to regularly check the "Legal Trends" subheading dealing with interesting developments in other countries. In this issue, for example, some Canadians are seeking a police investigation into an assisted suicide in Switzerland. Physician-assisted suicide is legal in Switzerland, but illegal in Canada. At issue is whether Canadians have a legal right, under Canadian law, to travel to Switzerland to avail themselves of a practice that is illegal in their own country. In the United States there is a constitutional right to travel, which would make it legal for the patient seeking physician-assisted suicide to go to Switzerland (there is no case directly on point, but the basic principle is well-established in U.S. constitutional jurisprudence), but even in the U.S., as in Canada, it may be possible to prosecute someone who

assists that person in getting to Switzerland. This could be considered aiding and abetting a suicide. The Canadian suit has not even been filed yet, and no such case exists in the U.S., but it is an interesting issue to watch. It may come up as it did in Canada with respect to traveling to Switzerland, where it is legal for physicians to assist foreigners in committing suicide (this is not true in the Netherlands); it is also likely to come up in connection with people suffering from kidney disease traveling to Iran, the only country where it is legal to purchase kidneys, and in other situations in which the legality of the activity is not the issue but the price of medical treatment.

THE RIGHTS OF MATURING INDIVIDUALS AND THEIR PARENTS

PRE-BIRTH (SEX, FERTILITY, CONTRACEPTION, ABORTION, FETUSES, EMBRYOS, AND STEM CELLS)

The abortion debate continues to be waged on several fronts, including "informed-consent," "parental notification," "whether fetuses are recognized under the law as persons with respect to certain crimes," "conscientious objections," and "access to abortion procedures, medications, and information." Of noted interest is a Texas court case that has the potential of deciding that frozen embryos are persons with a right to life. Currently, all states except Louisiana consider frozen embryos to be property and prohibit the implantation of such embryos unless both parties that contracted for the creation of the embryo agree. If the embryo is recognized as a person, the standard changes to what is in the best interest of the embryo, and most would agree that implantation is in the embryo's best interest.

It is also interesting to note that, while in the U.S. the trend is toward restricting abortions, in foreign countries the trend is to loosen restrictions.

The stem-cell research debate is still being waged mostly on the funding front, with several states having voted to financially support one form or another of stem-cell research, but few having as yet distributed the promised funds. For a detailed analysis of stem-cell research laws and stem-cell research funding, see the Cato Institute Policy Analysis by Sigrid Fry-Revere and Molly Elgin entitled "Stem Cell Research Funding: Boon or Boondoggle," (anticipated publication date October 2007).

Another interesting development in the stem-cell debate sheds some light on the interplay between politics and law in the U.S. Usually when a constitutional right is at issue, one would think that once the right has been confirmed or denied, that would end the discussion, but that is not necessarily so, particularly not in situations in which the constitution is easily amended. For example, in Missouri last November, a constitutional amendment was passed that guaranteed the right of scientists to pursue any stem-cell research legal under federal law. A ballot drive is currently under way and gaining momentum to pass a constitutional amendment to do exactly the opposite, that is, to prohibit anyone in the state of Missouri from engaging in stem-cell research. It is important to ask oneself whether laws that rise to the level of constitutional importance have any value beyond everyday legislatively promulgated laws if they can be so easily changed.

Recent Cases, April - June 2007

***Federal.** On 18 April 2007, the U.S. Supreme Court handed down its ruling in the combined cases of *Gonzales v. Carhart* and *Gonzales v. Planned Parenthood*. They are cited only by the name of the first case. The Court overturned two circuit court decisions and found the Partial-Birth Abortion Ban Act of 2003 constitutional. The federal act in question is now the law of the land. No state can allow partial-birth abortions unless it is to save the life of the woman having the procedure. See the Summer 2007 issue of "Legal Trends in Bioethics" for a more detailed discussion of the Court's findings.

The U.S. District Court for the Southern District of Ohio ruled on 21 June 2007 that an Ohio law that only allows members of religions with "historically held conscientious objections" to opt out of paying union dues. The plaintiff had refused to pay union dues to the National Education Association because she said the union supported abortion rights. *Katter v. Ohio Employment Relations Board*, U.S. Dist. Ct., S.D. Ohio, No 2L07-CV-43 (21 June 2007).

***Kansas.** Kansas Attorney General Paul Morrison announced on 27 June 2007 that he has reviewed all the charges against Dr. George Tiller's clinic filed by Phill Kline during Kline's tenure as state attorney and found no reason for prosecution. He has also reviewed half the charges filed against Tiller personally and finds most of these unjustified. Kline twice tried to file charges against Dr. Tiller for allegedly performing 15 illegal late-term abortions in 2003. Each time, the criminal charges were thrown out by Sedgwick County, Kansas, District Judge Paul Clark on jurisdictional grounds — that is, Kline didn't have the authority to file such charges. Kline promises to continue to investigate. Kline lost the Kansas attorney general race in November 2006 to the Democrat Paul Morrison, a vehement supporter of abortion. "Kansas AG Morrison Ends Investigation of Planned Parenthood Affiliate Accused of Illegal Late-Term Abortions, Drops Half of Tiller Charges," 28 June 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=45890&dr_cat=2,* accessed 14 August 2007. See related legislation under Kansas below.

Texas. On 5 July 2006 a petition for review of a state court of appeals decision in *Roman v. Roman* was filed. The state supreme court is expected to decide shortly whether or not it will hear the case. At issue is the proper disposition of three frozen embryos never implanted because the couple divorced. The husband did not want the embryos implanted and won at the lower court level. The wife is appealing. This is a case of first impression in Texas, and is seen as a case that could lead to considering embryos as persons with a right to life. *Roman v. Roman*. Tex. Sup. Ct. (no. 06-0554).

Recent Laws and Regulations, April - June 2007

***Alabama.** The session ended without further action on H.B. 128, H.B. 329, and S.B. 59, which were introduced in the state legislature to restrict abortions. Three bills were introduced in the state legislature to restrict abortions. One bill was introduced that defines personhood as beginning at fertilization. A second bill, also in the state house, criminalizes abortions with the exception of cases in which the woman's life is in danger or cases of rape or incest. A third, introduced in the state senate, would prohibit abortions except for the "extreme case where the pregnancy threatens the life of the mother." H.B. 128, H.B. 329, S.B. 59, 2007 Gen. Assem., Reg. Sess. (Ala. 2007).

The session ended without further action on H.B. 28, which was introduced in the state house to prohibit the cloning of human beings. The Regenerative Medicine Enhancement Act would also provide for penalties and civil fines for violations. H.B. 28, 2007 Leg., Reg. Sess. (Ala. 2007).

The session ended without further action on H.B. 530 that was introduced in the state house to establish the Umbilical Cord Blood Banking Act. The act provides for the dissemination of information to pregnant women regarding umbilical cord blood donation. H.B. 530, 2007 Leg., Reg. Sess. (Ala. 2007).

***Arizona.** The session ended without further action on H.B. 2770 that was introduced in the state house making appropriations to the Department of Health Services for a regenerative tissue repository and for research in regenerative medicine involving non-embryonic stem-cell research. H.B. 2770, 48th Leg., 1st Reg. Sess. (Ariz. 2007).

***Arkansas.** The session ended without further action on H.B. 2806, which was intro-

duced in the state house. The bill protects embryonic stem-cell research, including somatic cell nuclear transfer. The Regenerative Medicine Enhancement Act also bans human reproductive cloning. H.B. 2806, 86th Gen. Assem., Reg. Sess. (Ark. 2007).

California. A.B. 34 is in committee. The bill involves significant ongoing funding from the California General Fund in the form of grants to umbilical cord blood banks. A.B. 34, 2007-2008 Leg., Reg. Sess. (Cal. 2007). This bill is similar to A.B. 40, A.B. 482, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

Colorado. The session has ended without movement on two bills introduced in the state senate dealing with the personhood status of a fetus. One would make abortions criminal unless necessary to prevent the death of the mother. The other amends the state criminal code to define the fetus as a separate victim apart from its mother in homicide cases. S.B. 143, S.B. 71, 66th Gen. Assem., Reg. Sess. (Colo. 2007).

Connecticut. The session has ended without movement on a bill introduced in the state house to amend the state criminal code to include "unborn person" as a person under the code. H.B. 6067, Gen. Assem., Jan. Sess. (Conn. 2007).

There has been no further action on two bills related to stem-cell research. One bill bans human cloning by whatever means. More specifically, it prohibits human cloning through the use of somatic cell nuclear transfer. H.B. 6918, Gen. Assem., Jan. Sess. (Conn. 2007). The second bill establishes an umbilical cord blood bank for the collection, processing, and storage of cord blood units. H.B. 7158, Gen. Assem., Jan. Sess. (Conn. 2007).

Delaware. The session ended without movement on a bill introduced in the state house to encourage certain stem-cell research within ethical guidelines. The bill would allow research on donated embryos under 14 weeks old, ban human reproductive cloning, and establish a committee to develop and adopt guidelines for publicly funded research involving the derivation or use of human embryonic stem cells. H.B. 76, 144th Gen. Assem., Reg. Sess. (Del. 2007). A similar senate bill that focuses on banning human reproductive cloning has been withdrawn. H.B. 76, S.B. 5, 144th Gen. Assem., Reg. Sess. (Del. 2007).

Florida. The session ended with the defeat of two virtually identical bills to amend the state criminal code to define an "unborn child" as a separate victim from the pregnant woman carrying the child. H.B. 71, S.B. 234, 109th Gen. Assem., Reg. Sess. (Fla. 2007).

Two virtually identical bills were introduced in the state legislature to establish the Stem Cell Research and Ethics Advisory Council. The Florida Hope Offered through Principled, Ethically Sound Stem Cell Research Act provides for both a donated funds program and a research grant program from the Biomedical Research Trust Fund. Funding is limited to adult stem cells, amniotic, cord blood, and placental stem cells and does not include embryonic stem cells. The house bill died in the house while the senate bill died in committee. H.B. 1065, S.B. 2496, 2007 Leg., Reg. Sess. (Fla. 2007).

There was no further action at the close of the session in a house bill to allow funds from the Biomedical Research Trust Fund to be used on embryonic stem cells. A similar senate bill died. H.B. 555, S.B. 0750, 2007 Leg., Reg. Sess. (Fla. 2007).

A bill died without any action being taken; the bill attempted to establish the Biomedical Research Advisory Council as the exclusive source of certain biomedical research grant and fellowship awards; it prohibits use of funds for research with certain human embryonic stem cells or human cloning. H.B. 7079, 2007 Leg., Reg. Sess. (Fla. 2007).

Georgia. The session ended without movement on a bill to place on the November 2008 ballot an initiative that would define personhood as beginning at fertilization. There is no language in the bill indicating exceptions when an abortion might be permitted. H.R. 536, 149th Gen. Assem., Reg. Sess. (Ga. 2007).

There was no further action on a bill that would impose a near total criminal ban on abortion. The bill provides for an exception if a physician makes a medically justified effort

to save the lives of both the mother and the fetus and the fetus does not survive. The bill also provides for a penalty of life in prison or the death penalty for both women and doctors found in violation of the law. H.B. 1, 149th Gen. Assem., Reg. Sess. (Ga. 2007).

On 24 May 2007, the governor signed a law that established the Newborn Umbilical Cord Blood Bank to encourage non-embryonic stem-cell research. Ga. Act. 247 (2007).

Hawaii. The session ended without movement on two virtually identical bills that would ban partial-birth abortions. H.B. 787, S.B. 129, S.B. 129, H.B. 787, 24th Leg., Reg. Sess. (Haw. 2007). (The bills are no longer necessary since the U.S. Supreme Court in *Gonzales v. Carhart* upheld the federal ban on partial-birth abortions.)

There was no further action on two bills introduced in the state senate to amend the state criminal code to consider the "unborn child" as a separate victim in an assault against a pregnant woman. S.B. 206, S.B. 1903, 24th Leg., Reg. Sess. (Haw. 2007).

There was no action on two bills that would permit all forms of stem-cell research. The state house version has been referred to committee. The senate version has been deferred until next year's session. H.B. 364, H.B. 1261, 24th Leg., Reg. Sess. (Haw. 2007).

***Illinois.** Two bills involving stem-cell research were defeated. The first would allocate $25 million annually for the next five years to stem-cell research, including embryonic stem-cell research. The second would ban human cloning and the sale of human embryos. These bills died at the end of the session. H.B. 1039, H.B. 1038, 94th Gen. Assem., Reg. Sess. (Ill. 2006).

There has been no further action on a bill introduced in the state senate that would ban abortions at as early as 12 weeks. There is no exception for protecting the mother's life or health after the 12th week of pregnancy. S.B. 100, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

There has been no further action on a bill to allow pharmacies to dispense emergency contraceptives to women without a prescription. H.B. 1077, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

There has been no further action on two bills introduced in the state house and the senate creating the Stem Cell Research and Human Cloning Prohibition Act. It permits research involving the derivation and use of human embryonic stem cells and human adult stem cells from any source, including somatic cell nuclear transplantation. H.B. 138 and S 1324, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

There has been no action on a bill introduced in the state house and the senate appropriating $25,000,000 from the Tobacco Settlement Recovery Fund to the Illinois Regenerative Medicine Institute for the purpose of awarding grants for stem-cell research. H.B. 139 and S.B. 1136, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

Both houses passed a bill to direct the Department of Health to establish a statewide network of cord blood stem-cell banks. The bill is currently awaiting approval from the governor. S.B. 19, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

Indiana. The session ended without further action on S.B. 203. The bill was introduced in the state senate allowing for the adoption of an abandoned embryo. Also, it criminalizes the intentional destruction or discarding of an abandoned human embryo and the trafficking of an embryo, ovum, zygote, or fetus. Exceptions to this rule include adult or fetal stem-cell research. S.B. 203, 2007 Gen. Assem., Reg. Sess. (Ind. 2007).

Kansas. The governor vetoed a bill on 22 May 2007 that would have required physicians who perform late-term abortions to provide the state with information about the women undergoing the procedure. S.B. 357, 82nd Leg., Reg. Sess. (Kan. 2007).

The session ended without further action on two bills that were introduced in the state legislature to amend the definition of person for purposes of the criminal code to include "unborn child." H.B. 2006, S.B. 2, 82nd Leg., Reg. Sess. (Kan. 2007).

The Kansas House Federal and State Af-

fairs Committee voted to approve a resolution that would force Attorney General Paul Morrison to reinstate the criminal charges against physician George Tiller for allegedly performing illegal late-term abortions. See original legal action reported above. H.R. 6018, 82nd Leg., Reg. Sess. (Kan. 2007).

The session ended without further action on five bills that were introduced in the state and house that relate to stem-cell research: the first would ban somatic cell nuclear transfer; the second would ban the funding of embryonic stem-cell research. The third would ban the creation of chimeras; the fourth encourages non-embryonic stem-cell research by offering a 50 percent tax credit for donations to the adult stem-cell research fund; the fifth would ban cloning. H.B. 2252, H.B. 2255, H.B. 2403, H.B. 2291, H.B. 2098, 82nd Leg., Reg. Sess. (Kan. 2007).

Kentucky. The session ended without further action on two abortion-related bills that were introduced in the state legislature. A house bill would "ban state constitutional protection for a woman's right to choose." A senate bill would amend existing abortion waiting requirements to require a 24-hour period between when a woman receives state-mandated information and performance of the abortion procedure. H.B. 251, S.B. 179, 2007 Leg., Reg. Sess. (Ky. 2007).

Louisiana. The governor signed into law bills on 12 July 2007 that would ban "partial-birth" abortion in the state and create criminal penalties for physicians who perform the procedure. H.B. 614, S.B. 161, 2007 Leg. Reg. Sess. (La. 2007).

The session ended without further action on a bill that was introduced in the state house that would prohibit the use of public funds for human cloning. H.B 881, 2007 Leg. Reg. Sess. (La. 2007)

Maine. The Senate refused to act on a bill introduced in the state house to create a $20,000,000 stem-cell research bond. Had the bill survived, the bond was to be used to expand research in adult stem cells and embryonic stem cells, establish a public umbilical cord blood bank, aid in the development of umbilical cord blood banks, and establish an umbilical cord advisory council. H.P. 985, 123rd Leg., Reg. Sess. (Maine 2007).

Maryland. The session ended without further action on a bill that was introduced in the state house prohibiting the creation of an embryo with a predominantly or partially human genetic constitution. H.B. 871, 423rd Gen. Assem., Reg. Sess. (Md. 2007).

The session ended with an unfavorable report by the finance committee concerning a bill that was introduced in the senate prohibiting a person from performing or attempting to perform human cloning. S.B. 362, 423rd Gen. Assem., Reg. Sess. (Md. 2007).

Massachusetts. There has been no action on two bills that were introduced in the state legislature to repeal a pre-*Roe v. Wade* criminal ban on abortion. H.B. 173, S.B. 831, 185th Gen. Assem., Reg. Sess. (Mass. 2007).

***Michigan**. There has been no action on four bills introduced in the state legislature to codify the Michigan Civil Rights Commission's declaratory ruling into law. H.B 4295, H.B. 4296, S.B. 41, S.B. 42, 94th Leg., Reg. Sess. (Mich. 2007).

There has been no action on a bill introduced in the state senate that would allow for embryonic stem-cell research by amending the current state code to allow the use of human embryos for non-therapeutic research. S.B. 52, 94th Leg., Reg. Sess. (Mich. 2007).

There has been no action on a bill introduced in the state house to increase the penalty for human cloning. However, scientific research or cell-based therapies are exempt from the penalty. H.B. 4617, 94th Leg., Reg. Sess. (Mich. 2007).

Minnesota. The session ended without further action on three bills introduced in the state legislature to place an initiative on the ballot for November 2008 to amend the state constitutional provision protecting a woman's right to choose an abortion. S.B. 1235, S.B. 1234, H.B. 2378, 85th Gen. Assem., Reg. Sess. (Minn. 2007).

The session ended without further action

on similar bills proposed by the state house and the senate establishing criminal penalties and appropriations in a state policy for stem-cell research. S.B. 100, H.B. 34, 85th Gen. Assem., Reg. Sess. (Minn. 2007).

Mississippi. The governor signed a bill that would implement a near total ban on abortions in Mississippi in the event that *Roe v. Wade* is ever overturned by the U.S. Supreme Court. The law would only allow abortions in the case of rape, incest, or to prevent the mother's death. S.B. 2391, 2007 Reg. Sess. (Miss. 2007).

Missouri. The state senate passed a bill on 18 May 2007 that would designate facilities performing second or third trimester abortions as "ambulatory surgical centers." Such a designation gives the Department of Health and Senior Services increased regulatory control over such facilities. S.B. 370, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

The session ended without further action on a bill that was introduced in the state house to ban abortions in all cases except when the woman is in danger of death. H.B. 990, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

The session ended without further action on a bill that was introduced in the state house establishing the Umbilical Cord Blood Bank Program to collect and provide researchers with umbilical cord blood for scientific research on human stem cells. H.B. 216, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

The session ended without further action on a bill that was proposed, modifying the state constitution to forbid engaging in human cloning. H.J.P. 23, S.J.R. 10, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

Nevada. The session ended without further action on a bill that was introduced in the state senate to amend the state criminal code to include "unborn child" as a separate victim apart from the pregnant woman. S.B. 299, 74th Gen. Assem., Reg. Sess. (Nev. 2007).

The session ended without further action on a bill that was introduced by the senate authorizing the Nevada Institutional Review Board to engage in various activities related to non-embryonic stem cells. S.B. 361, 74th Gen. Assem., Reg. Sess. (Nev. 2007).

New Hampshire. There has been no action on a bill that was introduced in the state house to amend the state homicide code to include "unborn child" as a possible victim. H.B. 177, 160th Gen. Assem., Reg. Sess. (N.H. 2007).

New Jersey. There has been no action on a bill authorized by the house requiring hospitals to notify pregnant women of their option to donate umbilical cord blood. H.B. 312, 2007 Gen. Assem., Reg. Sess. (N.J. 2007). This bill is similar to A.B. 2591, S.B. 2736, and S.B. 1091, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).

The state legislature passed a bill on 20 June 2007 that authorizes a referendum for the November election to ask voters to approve borrowing $450 million over 10 years to fund stem-cell research. A.B. 2828, S.B. 1471, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).

There has been no further action on two bills introduced in the house prohibiting the use of public funds for stem-cell research and repealing the statute setting forth public policy on stem-cell research. A.B. 3950, A.B. 3949, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).

New Mexico. The session ended without further action on a bill introduced by the state senate permitting biomedical research on limited categories of human embryonic stem cells, prohibiting human cloning, and amending the Maternal, Fetal and Infant Experimentation Act. S.B. 894, 48th Leg., Gen. Assem., Reg. Sess. (N.M. 2007). This bill is similar to S.B. 1232, 48th Leg., Gen. Assem., Reg. Sess. (N.M. 2007).

New York. There has been no action on two bills introduced in the state legislature to amend the criminal code to include "unborn child at any stage of gestation" in the definition of person. S.B. 3117, A.B. 5777, 230th Gen. Assem., Reg. Sess. (N.Y. 2007).

There has been no further action on three bills introduced in the state legislature that would allow nurses and pharmacists to dispense emergency contraceptives without a prescription. S.B. 3579, S.B. 1940, A.B. 5569,

230th Gen. Assem., Reg. Sess. (N.Y. 2007).

There has been no further action on a bill introduced in the state senate authorizing stem-cell research, requiring informed-consent, and prohibiting human reproductive cloning. S.B. 01257, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill introduced in the state senate to create the New York Stem Cell Research Institute. S.B. 02923, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill introduced in the state house allowing the department of health to review research regarding the donation of umbilical cord blood and advising healthcare practitioners to inform pregnant women of their option to donate umbilical cord blood. A.B. 1365, 230th Reg. Sess. (N.Y. 2007). This bill is similar to A.B. 155, A.B. 2915, and S.B. 1265, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill introduced creating a public umbilical cord blood banking program within the state Department of Health to promote public awareness of the potential benefits of umbilical cord donation. A.B. 5081, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill creating the Human Cloning Prohibition Act that makes it unlawful to perform or attempt to perform human cloning and imposes penalties for violations. A.B. 5393, 230th Reg. Sess. (N.Y. 2007). This bill is similar to S.B. 2032, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill that was proposed in the state senate that would authorize stem-cell research, requires informed-consent, prohibits the sale of embryonic tissue, and authorizes state funds for such research. S.B. 1257, 230th Reg. Sess. (N.Y. 2007). This bill is similar to S.B. 268, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill proposed in the state house that would provide a limit on the use of state funds for stem-cell projects or research to those that have the greatest potential for near-term clinical benefit. A.B. 8428, 230th Reg. Sess. (N.Y. 2007).

There has been no further action on a bill proposed in the state house that would create the New York Stem Cell Research Institute and provide for the appointment of the New York State Stem Cell Board. S.B. 2923, 230th Reg. Sess. (N.Y. 2007).

North Carolina. The session ended with no action on two bills that were introduced in the state legislature to amend the criminal code of North Carolina to include "unborn child" as a victim that is separate from the pregnant woman carrying the child. H.B. 263, S.B. 295, 148th Gen. Assem., 2007 Sess. (N.C. 2007).

There has been no action on a bill introduced in the state senate that would appropriate $8 million to the Wake Forest Soldier Regenerative Medicine Institute for stem-cell research. S.B. 715, 148th Gen. Assem., 2007 Sess. (N.C. 2007).

There has been no action on a bill proposed in the state house that would prohibit human cloning. H.B. 572, 148th Gen. Assem., 2007 Sess. (N.C. 2007). This bill is similar to S.B. 896, 148th Gen. Assem., 2007 Sess. (N.C. 2007).

There has not been any action on a bill proposed in the state house enacting the Stem Cell Research Health and Wellness Act to permit stem-cell research under limited circumstances and appropriate funds to the Health and Wellness Trust Fund for allocation of the grants. H.B. 1837, 148th Gen. Assem., 2007 Sess. (N.C. 2007).

North Dakota. A bill introduced in the state house to impose a total ban on abortions did not pass out of committee. H.B. 1489, 61st Gen. Assem., Reg. Sess. (N.D. 2007). A similar bill was introduced that would impose a similar ban but allows an exception if the woman's life is in danger. H.B. 1466, 61st Gen. Assem., Reg. Sess. (N.D. 2007).

The session ended without further action on a bill introduced in the state senate that defines personhood as beginning at fertilization. S.B. 2400, 61st Gen. Assem., Reg. Sess. (N.D. 2007).

On 27 April 2007, the governor signed into law a ban on abortions, except if the woman's life is in danger, in the event that *Roe v. Wade* is overturned by the U.S. Supreme Court. N.D. Cent. Code 12.1-31 (N.D. 2007).

Ohio. There has been no action on a bill proposed in the state senate allowing for stem-cell research and establishing an institutional review board to review research involving the derivation and use of human embryonic stem cells. S.B. 63, 127th Gen. Assem., Reg. Sess. (Oh. 2007).

There has been no action on a bill proposed in the state senate prohibiting human cloning. S.B. 174, 127th Gen. Assem., Reg. Sess. (Oh. 2007).

Oklahoma. A bill was passed by the state senate on 16 May 2007 that would prohibit the use of state or federal funds for abortions. S.B. 714, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

The session ended without further action on a bill introduced in the state house that would make the state's pre-*Roe v. Wade* abortion ban enforceable if the case is overturned. In the meantime it would ban all abortions unless the mother's life is in danger. H.B. 1014, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

There has been no action on two bills introduced in the state legislature that prohibit the distribution of mifepristone, a medical abortion pill. S.B. 715, H.B. 2181, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

There has been no action on a bill introduced in the state senate to allow government officials to search offices and medical files of abortion providers without cause, warrant, or announcement. S.B. 617, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

The session ended without further action on a bill introduced in the senate directing the University of Oklahoma Health Sciences Center in collaboration with the Commissioner of Health to establish and maintain a public umbilical cord blood bank. S.B. 139, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

There has been no action on a joint resolution introduced in the state legislature that would allow researchers to perform any stem-cell research permitted under federal law, but the measure also bans cloning. H.J.R. 1010, 51st Leg., 1st Sess. (Okla. 2007).

Oregon. The state house passed a bill on 21 June 2007 that would authorize the state to spend $160,000 over the next 18 months to examine the issue of using public funds for stem-cell research. H.B. 1801B, 74th Leg. Assem., Reg. Sess. (Or. 2007).

The session ended without further action on three bills introduced in the state house to amend the state criminal code definition of a human being to include "unborn child." H.B. 3272, H.B. 3240, H.B. 2802, 74th Leg. Assem., Reg. Sess. (Or. 2007).

The state house passed a bill amending existing emergency room law to allow dispensing emergency contraceptives to women older than 18 without a prescription. H.B. 2154, 74th Leg. Assem., Reg. Sess. (Or. 2007).

The session ended without further action on a bill introduced to establish the Human Stem Cell Research Committee and the Human Stem Cell Research Fund. The committee would create guidelines for stem-cell research, while the fund would obtain public and private funds for the purpose of dispensing grants. H.B. 2801, 74th Leg. Assem., Reg. Sess. (Or. 2007).

The session ended without further action on two bills introduced in the state house that would make human cloning a crime. H.B. 2662, H.B. 2929, 74th Leg. Assem., Reg. Sess. (Or. 2007).

The session ended without further action on a bill introduced in the state house establishing the Human Stem Cell Research Committee in the Department of Human Services. H.B. 2801, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

Pennsylvania. There has been no action on a bill introduced in the state senate to amend the state criminal code to include "unborn child" as part of the definition of person. S.B. 589, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

There has been no action on a bill intro-

duced by the state house providing for umbilical cord blood banking. It also requires healthcare practitioners to give pregnant patients information regarding umbilical cord donation. H.B. 874, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

Rhode Island. The session ended without further action on two bills introduced in the state house to amend the state criminal code to include "unborn child" in the definition of "another." H.B. 5261, H.B. 5234, Gen. Assem., Jan. Sess. (R.I. 2007).

The session ended without movement on two bills introduced in the state legislature that would make the protections under *Roe v. Wade* permanent. S.B. 119, H.B. 5462, Gen. Assem., Reg. Sess. (R.I. 2007).

The session ended without further action on identical bills introduced in the house and the senate that would provide protection from discrimination to all healthcare providers who choose not to participate in a healthcare service that violates the conscience of the healthcare provider. H.B. 5274, S.B. 452, Gen. Assem., Reg. Sess. (R.I. 2007).

The session ended without movement on a bill introduced in the house that would permit stem-cell research to be conducted in this state with informed written consent from both parties involved in the creation of the embryos. H.B. 6082, S.B. 452, Gen. Assem., Reg. Sess. (R.I. 2007).

The session ended without further action on a bill introduced in the senate that would require health professionals to inform their patients of the option of donating umbilical cord blood to umbilical cord blood banks. H.B. 634, S.B. 452, Gen. Assem., Reg. Sess. (R.I. 2007).

South Carolina. The state senate passed on 16 May 2007 a law that would allow, but not require, pregnant women seeking an abortion to view an ultrasound image of their fetus. S. 84, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

The session ended without further action on four bills introduced in the state legislature defining personhood as beginning at fertilization. H.B. 3284, H.B. 3697, S.B. 313, S.B. 3815, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

The session ended with no action on two bills introduced in the state house that would define person to include "unborn child" under the state's civil and criminal codes. H.B. 3019 (civil), H.B. 3171 (criminal), 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

There was no further action on S.B. 0173. The bill was introduced in the state senate to allow embryonic stem-cell research, but also bans the buying and selling of pre-implantation embryos. The Biotechnology Act of 2008 would also ban human cloning. S.B. 0173, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007). A related bill enacted the Human Cloning Prohibition Act to make it unlawful for a person to perform or participate in human cloning and engage in commerce related to human cloning. H.B. 3299, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

South Dakota. The session ended without further action. A bill passed the state house that would impose a ban on abortions except when the mother's life is in danger or in cases of incest or rape. If enacted by the state senate and signed by the governor, the measure will be automatically included on the 2008 general election ballot. H.B. 1293, 82nd Leg. Sess. (S.D. 2007).

Tennessee. The session ended without further action on two identical bills that were proposed in both the house and the senate. The bills require licensed hospitals to offer pregnant patients the option to donate umbilical cord blood to a certified cord blood bank if the donation can be made at no expense to the patient or hospital. S.B. 1350, H.B. 1339, 105th Gen. Assem., Leg. Sess. (Tenn. 2007).

There has been no action on two bills proposed in both the house and the senate enacting the Newborn Umbilical Cord Blood Initiative Act of 2007. H.B. 1326 and S.B. 760, 105th Gen. Assem., Leg. Sess. (Tenn. 2007).

Texas. The session ended without further action on a bill introduced in the senate that would ban abortions unless it is necessary to

prevent a woman from dying. This law would take effect if *Roe v. Wade* is overturned by the Supreme Court. S.B. 186, 80th Leg. (Tex. 2007). A similar bill that was introduced in the house did not have enough votes to be voted out of committee. H.B. 175, 80th Leg. (Tex. 2007).

There has been no action on five bills and a resolution introduced in the state legislature relating to stem-cell research. Two identical bills ban human cloning and other uses of human tissue by institutes of higher education, but do not restrict nuclear transplantation to develop therapies. Another also bans cloning more generally. A fourth bill would create a program to provide grants and loans to institutions of higher education and advanced medical research facilities to conduct stem-cell research. And a house bill would establish the Texas Institute of Regenerative Medicine, authorize the issuance of bonds for the purposes of the institute, and prohibit the legislature from prohibiting stem-cell research. H.B. 1829, S.B. 56, H.B. 2704, H.B. 1486, H.B. 537, H.J.R. 43, 80th Leg. (Tex. 2007).

On 17 May 2007, the governor signed into law a bill regarding umbilical cord blood options. Ch. 104 80th R.S. (2007).

The session ended without further action on a H.B. 1533. The bill has been proposed by the house relating to the ban on human cloning and providing penalties. H.B. 1533, 80th Leg. (Tex. 2007). Similar bills include H.B. 2704, S.B. 646, H.B. 1829, and S.B. 413, 80th Leg. (Tex. 2007).

Utah. H.B. 235 was not voted out of committee. The bill was introduced in the state house and, had it survived, it would ban all abortions except if: the woman's life is in danger, under certain limited health circumstances, and if the pregnancy is a result of rape or incest. The law would have become effective if *Roe v. Wade* were overruled. H.B. 235, 57th Leg., Gen. Sess. (Utah 2007).

Virginia. The session ended without action on H.B. 2124. The bill was introduced in the state house and would ban abortions except to prevent the death of the mother. The law would go into effect if the U.S. Supreme Court overturns *Roe v. Wade*. H.B. 2124, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

A bill that defines personhood as beginning at fertilization was not voted out of committee. H.B. 2797, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

There has been no further action on five bills introduced in the state house regarding stem-cell research. Two would allow embryonic stem-cell research within the guidelines established by an oversight committee established by the bills. A third would assure returns on venture capital investments in biotechnology. A fourth provides funding for stem-cell research. A fifth offers a tax credit for contributions to stem-cell research. H.B. 2857, H.B. 1768, H.B. 1697, H.B. 1939, H.B. 2820, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

Washington. There has been no further action on H.B. 1163 and H.B. 173. These two bills were introduced in the state house relating to stem-cell research. One creates a human stem-cell research advisory committee and establishes funding for stem-cell research. Another would restrict funding to research not involving somatic cell nuclear transfer. H.B. 1163, H.B. 173, 60th Leg., Reg. Sess. (Wash. 2007).

There was no further action on H.B. 1336. The bill was proposed in the state house and allows for research involving human embryonic stem cells, germ cells, and adult stem cells from any source, including somatic nuclear transplantation after the ethical implications are considered. H.B. 1336, 60th Leg., Reg. Sess. (Wash. 2007). This bill is similar to H.B. 1732, 60th Leg., Reg. Sess. (Wash. 2007).

The session ended without further action on H.B. 1730. The bill was proposed in the state house and concerned the use of state funds for human stem-cell research. It declares that individuals may donate human embryonic stem cells for research if the human embryonic stem cells are obtained from blastocysts that are generated by *in vitro* fertilization and the donors have given informed-con-

sent. H.B. 1730, 60th Leg., Reg. Sess. (Wash. 2007).

West Virginia. The session ended without further action on three bills, H.B. 2036, H.B. 3058, and S.B. 695. The bills were introduced in the state legislature to ban abortions. One would ban all abortions with no health exception. The other two would ban abortions as early as 12 weeks with no exceptions. H.B. 2036 (general ban), H.B. 3058, S.B. 695 (after 12 weeks), 78th Leg., Reg. Sess. (W. Va. 2007).

There was no further action on H.B. 2140. The bill was introduced in the state house to include "unborn child" as part of the definition of "human being" for purpose of the state homicide laws. H.B. 2140, 78th Leg., Reg. Sess. (W. Va. 2007).

Wyoming. The session ended without further action on S.B. 118. The bill was introduced in the state senate that would amend state homicide laws to include an "unborn child" as a separate victim from the pregnant woman carrying the child. S.B. 118, 59th Leg., Reg. Sess. (Wyo. 2007).

Interesting Developments in Other Countries

People's Republic of China. The PRC's policies for enforcing its one-child policy is raising eyebrows. Recently in the southwest of the People's Republic, enforcement raids resulted in women being forced to have abortions as late as nine months into their pregnancies. Also the fines for violating the law can be as high as $9,000, and when a family cannot afford to pay the "social child-raising fee," government officials destroy homes and seize belongings as punishment, even as soon as three days after the fine was assessed. Unrest resulted in attacks on family planning officials and the torching of government buildings. Riot police were sent into four different towns in Guangxi Province to quell the violence. Officials report that their one-child-per-family policy will not change, but that some enforcement measures will be reconsidered. "Clashes in Southwest China Over One-Child Policy Prompts Officials to Ease Penalties," 23 May 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=45092&dr_cat=2*, accessed 14 August 2007.

Egypt. In July the government announced a complete ban on female circumcision after a 12-year-old died during the operation. While technically a ban has existed for 10 years, an exception in the law allowed the operation to be performed by qualified doctors in exceptional circumstances. The new ban is absolute and no exceptions will be allowed. It is estimated that currently 90 percent of all Egyptian women are circumcised, whether Muslim or Christian. Magdi Abdelhadi, "Egypt forbids female circumcision," *BBC NEWS*, 2 July 2007, *http://newsvote.bbc.co.uk/mpapps/pagetools/print/news.bbc.co.uk/2/hi/middle_east/6251426.stm*, accessed 2 July 2007.

India. The Minister for Women and Child Development announced a government plan to create a national registry of all pregnancies and abortions performed in the country as a means of curbing sex-selective abortions and infant mortality. "India to Create National Registry of Pregnancies, Abortions to Reduce Sex-Selective Abortion, Infant Mortality," 16 July 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report .cfm?DR_ID=46231&dr_cat=2*, accessed 13 August 2007.

***Mexico.** On 24 April 2007 lawmakers in Mexico City overwhelmingly voted to legalize abortion within the first three months of pregnancy. This is the first time abortion has been legal in Mexico City's history. Manuel Roig-Franzia, "Mexico City's Legislature Votes to Legalize Abortion," *Washington Post*, 25 April 2007, p. A11.

Mozambique. The government is considering lifting or at least loosen its ban on abortions because more than 40 percent of serious pregnancy complications treated at the central hospital in Maputa are a result of illegal abortions, and abortions account for 11 percent of maternal deaths in the country. "Mozambican Government Reviewing Abor-

tion Ban, Justice Minister Says," 11 June 2007, *Kaiser Daily Women's Health Policy Report, http://www. kaisernetwork.org/daily_report.cfm?DR_ID=45474&dr_cat=2,* accessed 14 August 2007.

Poland. Government officials are appealing a European Court of Human Rights ruling that ordered the government to award damages to a Polish woman who was denied an abortion despite warning from her physicians that she would become blind if she continued the pregnancy. "Polish Government to Appeal European Court of Human Rights Ruling that Rights of Polish Woman Allegedly Denied Abortion Were Violated," 21 June 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ ID=45724&dr_cat=2*, accessed 14 August 2007.

Portugal. A law legalizing abortions in the first 10 weeks of pregnancy went into effect on 15 July 2007. "Portugal Law that Loosens Abortion Restrictions Comes Into Effect," 17 July 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=46263 &dr_cat=2*, accessed 13 August 2007.

Representatives from 10 African Countries called for legalization of safe abortions at a conference of women leaders in Nairobi, Kenya, on 26 June 2007. "Leaders of 10 African Countries Call for Legalization of Safe Abortion to Help Reduce Maternal Mortality Rate," 28 June 2007, *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=45892&dr_cat=2*, accessed 14 August 2007.

AFTER BIRTH (PREMATURE INFANTS, NEWBORNS, AND CHILDREN)

The battle over abortion continues to cause fluctuations in the specific requirements for parental consent and notification laws. It is worth asking whether these debates adequately consider the best interests of the young women affected. More than half of the U.S. states require parental consent before a minor can get a tattoo or a body piercing. In some of those states, no such consent is required for an abortion. Is there, or can there be, any consistent criteria for determining when a minor is old enough to make decisions on his or her own? Should the seriousness, the inherent health risk, or the permanence of the decision play a role in determining whether notice or consent is required? If yes, then do these factors make notice and consent requirements more or less reasonable?

One non-abortion related law that deserves special attention is "Abraham's Law," passed in Virginia in March 2007, which was accidentally left out of the last column of "Legal Trends." In Virginia, child abuse laws were amended to exclude from the definition of neglect a situation in which parents and their child of at least 14 years agree to refuse treatment when the child is suffering from a life-threatening situation. The legislature found that a child who is 14 or older is "sufficiently mature to have an informed opinion on the subject of his medical treatment." See the "Life-and-Death Decisions" section below.

Also see the "Unconventional Treatment" section below, in which a Missouri law allowing midwives to deliver infants at home is discussed.

Recent Cases, April - June 2007

***Illinois.** Status unchanged. The Illinois Supreme Court issued rules necessary to implement the state Parental Notice of Abortion Act, Ill. S. Ct. M.R. 21173, in January. But the act still remains unenforceable. The state's attorney general has filed a motion to have those rules put in place, but the matter is still pending.

***Missouri.** The state supreme court decided in *Planned Parenthood of Kansas and Mid-Missouri, Inc., et al. v. Jeremiah W. (Jay) Nixon, et al.* The court upheld the Missouri parental consent law that gives parents and prosecutors the right to sue adults who help minors get an abortion without complying with state parental consent laws, which re-

quire either direct parental consent or court approval. The court held that the "aid and assist" language in the law must be narrowly construed not to include providing information and counseling so it does not violate the First Amendment right to free speech. *Planned Parenthood of Kansas and Mid-Missouri, Inc., et al. v. Jeremiah W. (Jay) Nixon, et al.*, No. Missouri S. Ct., No. SC87321 (1 May 2007).

Recent Laws and Regulations, April - June 2007

Connecticut. The session ended without further action on H.B. 5807. The bill was introduced in the state house and mandates parental notice prior to a minor obtaining an abortion. H.B. 5807, Gen. Assem., Jan. Sess. (Conn. 2007).

Georgia. The session ended without action on H.B. 526. The bill was introduced in the state house and would require parental notice before minors could receive contraception. H.B. 526, 149th Gen. Assem., Reg. Sess. (Ga. 2007).

Hawaii. The session ended without further action on three bills: H.B. 786, S.B. 1904, S.B. 205. They were introduced in the state legislature requiring parental notice. A fourth, H.B. 788, required parental consent before a minor can obtain an abortion. H.B. 786, S.B. 1904, S.B. 205, H.B. 788, 24th Leg., Reg. Sess. (Haw. 2007).

Missouri. The session ended with no action on H.B. 617. The bill was introduced in the state house to require parental consent for access to contraceptives. H.B. 617, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

New Hampshire. On 29 June 2007, the state legislature repealed existing parental notification laws, and the governor signed the repeal into law. NH Ch. 265 (2007), *http://www.gencourt.state.nh.us/legislation/2007/HB0184.html.*

New York. There has been no action on A.B. 2560 and A.B. 3217. The bills are two abortion consent-related bills. One would require parental notice and the other parental consent prior to a minor receiving an abortion. A.B. 2560, A.B. 3217, 2007-2008 Gen. Assem., Reg. Sess. (N.Y. 2007).

North Carolina. The session ended without further action on two abortion consent-related bills introduced in the state legislature. The house bill would require parental notice when minors were granted access to contraceptives. The senate bill would require that parental consent to an abortion be either personally signed or notarized. H.B. 103, S.B. 481, 148th Gen. Assem., Reg. Sess. (N.C. 2007).

Oregon. The session ended with no action on H.B. 3234. The bill was introduced in the state house to require parental notice prior to a minor receiving an abortion. H.B. 3234, 74th Gen. Assem., Reg. Sess. (Ore. 2007).

Tennessee. The session ended without further action on H.B. 1441 and S.B. 1795. These two bills were introduced in the state legislature to require parental notification when a minor seeks an abortion. H.B. 1441, S.B. 1795, 105th Gen. Assem., Reg. Sess. (Tenn. 2007).

Vermont. The session ended with no action on H.B. 473. The bill was introduced in the state house to mandate parental notice before a minor receives an abortion. H.B. 473, 69th Leg., Reg. Sess. (Vt. 2007).

Washington. The session ended without further action on H.B. 1321. The bill was introduced in the state house and would mandate parental notice before a minor could receive an abortion. H.B. 1321, 60th Leg., Reg. Sess. (Wash. 2007).

West Virginia. The session ended with no action on seven bills introduced to modify parental notice laws. Two eliminate the option that parental notice can be given by phone and increase the waiting period between notice and the abortion procedure to 48 hours. A third requires that parental notice be notarized. A fourth requires written parental consent. A fifth allows a physician bypass provision, but requires 48-hour notice. And two eliminate the physician bypass option and modify the time in which a judge must rule if a minor seeks waiver of the notice require-

ment — one lengthens the period from 24 hours to three days, the other lengthens the period to five days. H.B. 3128, S.B. 544 (48-hour prior notice; no phone notice); H.B. 3187 (notarized parental notice); H.B. 2219 (written parental consent); H.B. 2037 (allows a physician bypass 48-hour notice); H.B. 2151 (three days), S.B. 72 (five days), 2416 78th Leg., Reg. Sess. (W. Va. 2007).

Interesting Developments in Other Countries

United Kingdom. In Britain, a Human Tissue and Embryos Bill is being considered, which, among other things, would require birth certificates to identify whether a donor egg or sperm or both were used to conceive the child. Backers of the bill suggest that not to require such information on a birth certificate makes the government complacent in a lie. Mark Henderson, "Birth certificates 'should tell donor children who their real parents are,' " *TimesOnline,* 1 August 2007, *http://business.timesonline.co.uk/tol/business/law/article2176357*.

VACCINES

Mandatory childhood vaccine is one of those issues where the rights of parents and the state sometimes collide. There is a growing general mistrust of both pharmaceutical companies and the government, leading some parents to question their motives when issues involving mandatory childhood vaccine are raised. Some parents object on religious grounds, some on moral grounds, some because they see the specific vaccination program under discussion as a waste of money, some because they believe the drug hasn't been tested enough, and others because they simply feel it is their prerogative as parents to decide. All these issues are being raised with respect to mandating the HPV (human papillomavirus) vaccine, and many legislators who originally rushed to introduce bills to mandate the vaccine now have second thoughts.

Recent Laws and Regulations, April - June 2007

***Federal.** The session ended without any action on H.R. 1153. The bill was introduced in the U.S. House of Representatives and would prohibit federal funds to be used by states who make the HPV vaccine mandatory. H.R. 1153, 110th Cong. (1st Sess. 2007). However, a similar provision passed on 18 July 2007 as part of the House Labor, Health and Human Services, Education Appropriations bill. The amendment prohibits federal funds from being used by states to implement requirements that a student be vaccinated for human papillomavirus (HPV), as a condition of school admittance. Press Release of Rep. Phil Gingrey, "House passes Gingrey amendment to keep HPV vaccination a family decision," 19 July 2007.

Gardasil, Merck's HPV vaccine, has been adopted by all 55 of the CDC's Vaccines for Children Program immunization projects. This is a program that provides vaccines at no cost to children ages nine to 18 covered by Medicaid, the Alaska native and American Indian Children program, and some other uninsured children programs. *Kaiser Daily Women's Health Policy Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=46298&dr_cat=2*, accessed 18 July 2007.

Arkansas. The state senate committee voted down a bill that would have restricted the amount of mercury allowed in vaccines. S.B. 911, 86th Gen. Assem., Reg. Sess. (Ark 2007).

California. There has been no action on A.B. 16. The bill was introduced in the state assembly and would require all girls entering the sixth grade to receive the HPV vaccine. The bill includes an opt-out provision. A.B. 16, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

Colorado. On 29 May 2007, the governor signed into law a bill that would require middle school girls to receive the HPV vaccine. The bill includes an opt-out provision and requires health insurers to cover the cost of HPV vaccines. 25 Col. Rev. Stat. 4 (2007).

Connecticut. The session ended without action on three HPV-related bills. The bills were introduced in the state legislature. One would require all 12-year-old girls to be vaccinated. A second would require the state's insurance program to cover HPV vaccines for low-income families. And a third would require the health department to develop HPV immunization standards. H.B. 6085, H.B. 5485, S.B. 86, 2007 Gen. Assem., Jan. Sess. (Conn. 2007).

District of Columbia. Congress approved a city council bill that would require girls entering the sixth grade to receive the HPV vaccine. The provision has an opt-out provision. D.C. ST. §7-1651.04.

Florida. A bill concerning the HPV vaccine failed in committee. The bill was introduced in the state house to require all girls entering the sixth grade to receive the HPV vaccine. There is an opt-out provision. H.B. 561, 2007 Leg., Reg. Sess. (Fla. 2007).

Georgia. The session closed without movement on S.B. 155. The bill was introduced in the state house to require all girls entering the sixth grade to receive the HPV vaccine. There is an opt-out provision. S.B. 155, 149th Gen. Assem., Reg. Sess. (Ga. 2007).

Illinois. There has been no action on H.B. 115. The bill was introduced in the state house and would create an awareness campaign concerning HPV and cervical cancer; provide parents with information; and require the HPV vaccine for girls entering sixth grade unless their parents choose to exempt them. H.B. 115, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

A similar piece of legislation regarding the HPV vaccine was approved by both houses and is awaiting the governor's signature. If not signed by August 27, 2007, the bill is considered vetoed. The bill was introduced in the state senate and would require the HPV vaccine for girls ages 11 through 12, but allows parents to opt out. It would also require the school to track the number of immunized children attending the school. S.B. 937, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

Kansas. There has been no movement on H.B. 2227. The bill was introduced in the state house and would require all girls entering the sixth grade in the state's public schools to receive an HPV vaccine. The bill includes an opt-out provision. H.B. 2227, 82nd Leg., Reg. Sess. (Kan. 2007).

Kentucky. The session ended without movement on H.B. 345. The bill would require middle school girls to receive the HPV vaccine. The bill includes an opt-out provision. H.B. 345, 2007 Leg., Reg. Sess. (Ky. 2007).

Maryland. On 24 April 2007, the governor signed a bill that would establish an HPV vaccine subcommittee in the Cervical Cancer Committee of the Maryland Comprehensive Cancer Control Plan. It would also provide for the membership and duties of the HPV vaccine subcommittee and require this subcommittee to submit an annual report to the Cervical Cancer Committee by 1 September 2007. Md. Ch. 191 (2007).

Massachusetts. There has been no movement on S.B. 102. This bill was introduced in the senate and would require sixth grade girls to be vaccinated against HPV before entering school; those with medical conditions would be exempted. The bill would also provide for universal coverage of the vaccine. S.B. 102, 185th Gen. Assem., Reg. Sess. (Mass. 2007).

Michigan. There has been no movement on two bills introduced in the state house dealing with HPV vaccines. One would require parents to provide school officials with a statement from a physician indicating whether or not a sixth grade girl has received an HPV vaccine. The other would mandate the vaccine, but also includes an opt-out provision. H.B. 4164, H.B. 4104, 94th Leg., Reg. Sess. (Mich. 2007). Similar bills were introduced in the senate, S.B. 132 and S.B. 133, 185th Gen. Assem., Reg. Sess. (Mich. 2007).

Minnesota. The session ended without movement on H.B. 530 and S.B. 243. Lawmakers in both chambers introduced bills to mandate the HPV vaccine for all girls aged 12 and older. Both bills have opt-out provisions. H.B. 530, S.B. 243, 85th Leg., Reg. Sess. (Minn. 2007).

Missouri. The session ended without movement on H.B. 802. The bill was intro-

duced in the state legislature and mandates that girls entering the sixth grade prove that they have had the HPV vaccine or begun the immunization series (with intent to complete the three-dose vaccination). It allows parents to decline the vaccine for their daughters on medical or religious grounds, but they must sign an informed-consent from and receive information on the relationship between HPV and cervical cancer. H.B. 802, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

The session ended without movement on a similar bill, S.B. 514. The bill was introduced in the senate and would provide parents with information on HPV, cervical cancer, and the HPV vaccine. Also, it would require sixth grade girls to be vaccinated against HPV with an exception for religious and medical exemptions. S.B. 514, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

Nevada. On 15 June 2007, the governor signed into law a bill that would require insurance companies to cover the cost of HPV vaccinations. Nev. Ch. 527 (2007).

New Jersey. S.B. 2286/A.B. 3920 passed both houses and is awaiting the governor's signature. The identical bills were introduced in the house and the senate and would mandate the distribution of information regarding HPV to parents and guardians and require vaccination of seventh to twelfth graders. It also proposes a public awareness campaign. S.B. 2286, A.B. 3920, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).

New York. There has been no movement on S.B. 4394. The bill was introduced in the state senate and would require the HPV vaccine for females born after 1 January 1996. The bill includes an opt-out provision. S.B. 4394, 2007 Leg., 230th Reg. Sess. (N.Y. 2007).

There has been no movement on a similar bill introduced in the state house that would require the HPV vaccine but allows for religious exemptions. A.B. 5810, 2007 Leg., 230th Reg. Sess. (N.Y. 2007).

Ohio. There has been no movement on a bill that was introduced in the state house that would require girls entering sixth grade to be vaccinated against HPV. The bill is currently in committee in the house. The bill has an opt-out provision. H.B. 81, 127th Gen. Assem., Reg. Sess. (Ohio 2007).

Oklahoma. There has been no movement on S.B. 487. A bill was introduced in the state senate that would require the HPV vaccine for all girls before entering the sixth grade. S.B. 487, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

South Dakota. The governor signed into law a bill that provides $9.2 million to voluntarily vaccinate at no cost to South Dakota's females between the ages of 11 and 18. H.B. 1061, 82nd Leg. Sess. (S.D. 2007); act of 26 March 2007, Ch. 201, 2007 S.D. Laws (to offer an HPV vaccine initiative, transfer funds, and declare an emergency).

Texas. The governor mandated by executive order that all girls entering the sixth grade receive the HPV vaccine, but that order is being challenged by the legislature and the Texas Attorney General. Tex. Exec. Order RP65, 2 February, *http://www.governor.state.tx.us/divisions/press/ exorders/rp65*, accessed 27 April 2007.

Vermont. The session ended with no movement on H.B. 256. This bill was introduced in the state house and would require girls entering the sixth grade to be vaccinated against HPV. The bill does include an opt-out provision. H.B. 256, 69th Leg., 2007 Sess. (Vt. 2007). A similar bill was enacted in the state senate, S.B. 139, 69th Leg., 2007 Sess. (Vt. 2007).

Virginia. On 11 April 2007, the governor signed into law a bill requiring all sixth grade girls to be vaccinated against HPV. The bill includes an opt-out provision. Va. Ch. 858 (2007).

Interesting Developments in Other Countries

Canada. Several Canadian provinces are considering providing Gardasil at government expense to sixth-grade girls. Kerry Gillespie, "Girls to get cancer vaccine," *Toronto Star*, 2 August 2007, p. A 1, A18.

United Kingdom. The U.K. Department of Health's Joint Committee on Vaccination and Immunisation has advised the British government to mandate HPV vaccines for 12- and 13-year-old girls starting in 2008. Ian Sample, "Girls could be offered cervical cancer jab by autumn 2008," *Guardian*, 21 June 2007.

INFORMED CONSENT

Informed consent is a legal principle that can be understood as shifting some of the risks for treatment from the provider to the patient who has "assumed the risk" after being fully informed. What constitutes being fully informed from the patient's perspective is clearly the essence of informed-consent, but, from a legal perspective, what a reasonable person would want to know creates certain specific disclosure requirements. These requirements can come from standard medical practice, reasonable expectations on the part of patients, and from government standards for disclosure. When disclosure requirements are clear, the question arises whether a provider who complies with those requirements can be held liable if a patient suffers an unanticipated adverse event or one the government established standard did not require the provider to disclose. Of specific interest is that the U.S. Supreme Court has granted *certiorari* in a case in which a medical device manufacturer's defense is that it should not be held liable for the plaintiff's injuries because it complied with all of the labeling requirements of the U.S. Food and Drug Administration (FDA). The Court is also considering granting *certiorari* on a similar case involving a drug manufacturer.

Recent Cases, April - June 2007

Federal. The U.S. Supreme Court granted *certiorari* on 25 June 2007 in *Charles R. Riegel, et ux v. Medtronci, Inc*. The case involves an angioplasty procedure in which the catheter balloon reportedly burst, causing complications for the patient. Medtronci claims it should not be susceptible to suit under state law because the device was already subject to federal regulations with which it complied to receive FDA approval. *Charles R. Riegel, et ux v. Medtronci, Inc*. S. Ct. (U.S. No. 04-0412).

The U.S. Supreme Court is also considering *certiorari* in the case of *Wyeth v. Levine*. In this case, Diana Levine suffered the amputation of her arm as a result of being injected with the Wyeth anti-nausea drug Phenergan. Levine argued and won at the state level (Vermont) that Wyeth was negligent in its failure to provide adequate warnings of a known danger of injecting Phenergan directly into a patient's vein. Wyeth's position is that the jury should not have been allowed to consider Levine's claim because Wyeth's label for Phenergan complied with FDA regulations for prescription drug labeling. The Court's decision as to whether or not it will hear the case is expected within the next two months. *Wyeth v. Levine*. S. Ct. (U.S. no. 06-1249).

***Louisiana.** In *Brown v. Louisiana, State of*, the Louisiana Court of Appeals reversed and remanded a trial court's summary judgment. The court found that a failure to inform a patient of more conservative medical approaches to a hysterectomy could be a violation of informed-consent, justifying damages for negligence. The issue needs to go to a jury and cannot be decided by summary judgment. The case was returned to the district court for jury selection and awarding of damages. A hearing is scheduled for 29 June 2007. No. 06-709 (La. Ct. App. 2 November 2006).

*A lawsuit was filed alleging that Governor Rick Perry violated state law by exceeding his authority when he mandated that Texas sixth graders be vaccinated against the HPV vaccine. *John and Jane Does 1-3 v. Rick Perry*, 1d. No. 07-000-553 (Travis County, Texas; filed 22 February 2007). Case is moot because governor Perry said he would not veto a legislative bill blocking state officials from carrying out his executive order. Associated Press, "Texas governor backs down on HPV vaccine bill," MSNBC, 9 May 2007, *http://www.msnbc.msn.com/id/18575675*. The bill to block the governor's executive order mandating the vaccine was passed 25 April 2007.

Recent Laws and Regulations, April - June 2007

Connecticut. The session ended without action on an abortion-related bill introduced in the state legislature, H.B. 6108. The house bill would require that, prior to the performance of an abortion, a physician or counselor must provide the woman seeking an abortion with an ultrasound photograph of the fetus for the purpose of helping women make informed decisions about abortion. H.B. 6108, Gen. Assem., Jan. Sess. (Conn. 2007).

On 16 May 2007, the governor signed into law a bill that would assure that sexual assault victims receive information about and access to emergency contraception. Conn. Pub. Act. 07-24 (2007).

Florida. Two virtually identical bills failed in committee, H.B. 1191, S.B. 1156. The bills were introduced in the state legislature to assure that sexual assault victims receive information about and access to emergency contraception. H.B. 1191, S.B. 1156, 109th Gen. Assem., Reg. Sess. (Fla. 2007).

Georgia. The governor signed into law Act 207. The law requires every woman seeking an abortion to undergo and review a voluntary ultrasound of her fetus before an abortion may be performed. The attending physician must either offer to perform one or provide the patient with a list of providers, facilities, and clinics that can perform the procedure. The senate is insisting upon its version, which the house is now considering. GA. Act. 207 (2007).

Hawaii. The session ended without movement on H.B. 762, H.B. 466, S.B. 1110, and H.B. 1067. The four bills were introduced in the state legislature to assure that victims of sexual assault receive information and access to emergency contraceptives. H.B. 762, H.B. 466, S.B. 1110, H.B. 1067, 24th Leg., Reg. Sess. (Haw. 2007).

Indiana. The session ended without movement on S.B. 172 and S.B. 135. The two bills were introduced in the state senate to amend the language of current abortion-informed-consent requirements. Both laws also require an 18-hour mandatory waiting period between the time when the woman receives such information and the actual abortion procedure. S.B. 172, S.B. 135, 115th Gen. Assem., Reg. Sess. (Ind. 2007).

Kentucky. The session ended without movement on S.B. 80. The bill requires physicians to provide a patient with information pertaining to fetal pain at various stages of an abortion procedure. Specifically, the bill would require physicians to administer anesthetic to a fetus of 20 weeks gestational age or older prior to performing an abortion and include fetal pain information as part of the informed-consent process. Under the bill, any violation of these requirements is a Class D felony. S.B. 80, 2007 Leg., Reg. Sess. (Ky. 2007).

Maine. On 12 June 2007, the governor signed into law a bill to increase awareness about cervical cancer and the HPV vaccine. Maine Ch. 73 (2007).

Massachusetts. There has been no movement on H.B. 1687 so far. The bill was introduced in the state house to amend existing pre-abortion requirements to require a 24-hour period between when a woman receives state-mandated information and performance of the abortion procedure. H.B. 1687, Gen. Assem., Reg. Sess. (Mass. 2007).

Minnesota. On 4 May 2007, the governor signed into law a bill that would assure that sexual assault victims receive information and have access to emergency contraceptives. Minn. Ch. 42 (2007) The session has ended and a similar bill, H.B. 1442, was not acted upon. H.B. 1442, 85th Gen. Assem., Reg. Sess. (Minn. 2007).

Missouri. The session ended without movement on H.B. 1225. The bill was introduced in the state house and would require women to view an ultrasound as part of the informed-consent process prior to an abortion. H.B. 1225, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

New Hampshire. There has been no movement on H.B. 744. The bill was introduced in the state house and requires specific content for informed-consent disclosure prior to an

abortion and a 24-hour waiting period between when the woman receives such information and the procedure. H.B. 744, 160th Gen. Assem., Reg. Sess. (N.H. 2007).

New York. There has been no movement on A.B. 2531. The bill was introduced in the state assembly to create provisions for advance directives concerning the disposition of cryopreserved embryos and gametes. A.B. 2531, 2007 Leg., 230th Reg. Sess. (N.Y. 2007).

There has been no movement on A.B. 5720. The bill was introduced in the state assembly and requires specific informed consent and a 20-hour waiting period between when a woman receives the required information and the abortion procedure. A.B. 5720, 230th Gen. Assem., Reg. Sess. (N.Y. 2007).

North Carolina. On 31 May 2007, the governor signed into law a bill that requires school officials to provide the parents and guardians of children in grades five through 12 information about the HPV vaccine. Ch. SL 2007-59 (2007).

The session ended without movement on H.B. 961 and S.B. 968. The two bills were introduced in the state legislature to assure that victims of sexual assault receive information and access to emergency contraception. H.B. 961, S.B. 968, 148th Gen. Assem., 2007 Sess. (N.C. 2007).

Oklahoma. The session ended without movement on S.B. 105. The bill was introduced in the state senate and would assure that victims of sexual assault receive information and access to emergency contraceptives. S.B. 105, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

Oregon. The session ended without movement on H.B. 3415. The bill was introduced in the state house and dictates the content of informed consent and requires that there be a 24-hour waiting period between when information is disclosed and an abortion procedure. H.B. 3415, 74th Leg. Assem., Reg. Sess. (Or. 2007).

Pennsylvania. There has been no movement on H.B. 288 and S.B. 730. The two bills were introduced in the state legislature to assure that victims of sexual assault receive information about and access to emergency contraceptives. H.B. 288, S.B. 730, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

Rhode Island. The session ended without movement on H.B. 5849 and S.B. 472. The two bills were introduced in the state legislature and would require specific information to be disclosed during the informed-consent process and a 24-hour waiting period between such disclosure and the abortion procedure. H.B. 5849, S.B. 472, Gen. Assem., Jan. Sess. (R.I. 2007).

South Carolina. The session ended without movement on H.B. 3766. The bill was introduced in the state house requiring a 24-hour waiting period between required informed-consent disclosure and the abortion procedure. H.B. 3766, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

The session ended without movement on another pair of bills that would require women who are seeking abortions to view an ultrasound of their baby as part of the informed-consent process. S.B. 84, H.B. 3355, 117th Gen. Assem., 1st Reg. Sess. (S.C. 2007).

South Dakota. The session ended without movement on S.B. 187. The bill allows a healthcare facility to refrain from providing emergency contraception or even information about emergency contraception. S.B. 187, 82nd Leg. Sess. (S.D. 2007).

Tennessee. The session ended without movement on H.B. 1989 and S.B. 2073. The two bills were introduced in the state legislature to ensure that sexual assault victims receive information about emergency contraceptives, but the bill does not require the provision of emergency contraceptives, and it includes exemptions from the rule for certain hospitals. H.B. 1989, S.B. 2073, 105th Gen. Assem., Reg. Sess. (Tenn. 2007).

Texas. The session ended without movement on S.B. 1567. The bill was introduced in the state senate and would require doctors to tell women seeking an abortion that the state will pay them $500 if they choose to put their child up for adoption instead of having

an abortion. S.B. 1567, 80th Leg. (Tex. 2007).

There has been no movement on H.B. 2161. The bill was introduced in the state house to ensure that sexual assault victims receive information and access to emergency contraceptives. H.B. 2161, 80th Leg. (Tex. 2007).

Virginia. The session ended without movement on H.B. 2301. The bill was introduced in the state house and requires specific disclosure as part of informed consent and a 24-hour waiting period between disclosure and an abortion procedure. H.B. 2301, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

There was also no movement on H.B. 2808. The bill passed the state house and requires all women considering an abortion to undergo an ultrasound. H.B. 2808, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

West Virginia. The session ended without movement on H.B. 2439. This bill was introduced in the state house to modify existing informed-consent requirements and require a 24-hour waiting period between disclosure and an abortion procedure. H.B. 2439, 78th Leg., Reg. Sess. (W. Va. 2007).

The session ended with no movement on H.B. 2031. The bill was introduced in the state house and requires all women seeking an abortion to undergo an ultrasound procedure, whether medically indicated or not. H.B. 2031, 78th Leg., Reg. Sess. (W. Va. 2007).

There has been no movement on a similar bill, H.B. 2134. This bill was introduced in the state house to assure that sexual assault victims receive information and have access to emergency contraceptives. H.B. 2134, 78th Leg., Reg. Sess. (W. Va. 2007).

Wisconsin. The state senate passed a bill on 16 May 2007 that would require hospitals to inform rape survivors that emergency contraception is a highly effective way to prevent pregnancy and provide the medication if requested. S.B. 129, 2007 Reg. Sess. (Wis. 2007).

Wyoming. The session ended without movement on H.B. 144. A bill was introduced in the state house that would require specific informed consent and a 24-hour waiting period between disclosure and an abortion procedure. H.B. 144, 59th Leg., Reg. Sess. (Wyo. 2007).

ORGAN AND TISSUE PROCUREMENT

Recent Cases, April - June 2007

***Federal.** Ongoing case. The Eighth U.S. Circuit Court of Appeals (Minnesota, Nebraska, North Dakota, South Dakota, Eastern and Western Districts of Arkansas, Northern and Southern Districts of Iowa, Eastern and Western District of Missouri) in *Wash. U. v. Catalona* is reviewing the lower court's ruling that Washington University in St. Louis owned the tissue samples that William J. Catalona, MD, had collected for prostate cancer research while at the university. The U.S. District Court for the Eastern District of Missouri held that the informed-consent documents signed by Catalona's patients, which specifically gave the doctor the patients' tissue samples and included the patients' right to withdraw from the study and request that their tissue samples be destroyed, were "inconsequential" in its decision to grant full property rights to the university. Appeal No. 06-2286 (8th Cir. 15 May 2006). The case was argued 13 December 2006. A decision should be forthcoming shortly. Appeal No. 06-2286 (8th Cir. 13 December 2006).

Recent Laws and Regulations, April - June 2007

Federal. The Charlie Norwood Living Organ Donation Act clarifies that "paired donations" do not violate the National Organ Procurement Act's prohibition against receiving "valuable consideration" for organs. The house version, H.R. 710, has passed the House and the Senate while the senate version, S. 487, has passed the Senate and is in the House Committee on Energy and Commerce. H.R. 710, S. 487, 110th Cong. (1st Sess. 2007). The act was never sent to the President for his signature, but the U.S. Justice Department issued

an opinion to the General Counsel of the U.S. Department of Health and Human Services (DHHS), clarifying that paired donation does not constitute "valuable consideration" and thus does not violate the National Organ Transplant Act prohibition on selling organs. UNOS News Release, "Justice Department Finds Paired Donation Consistent with Federal Law," 28 March 2007, *http://www.unos.org/SharedContentDocuments/Organ _Donation_ Memo.pdf*.

Arkansas. On 29 March 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. Ark. Stat. tit. 12, §§ 12-325 (2007).

Idaho. On 23 February 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. Idaho. Stat. tit. 39, § 3703 (2007).

Iowa. On 5 April 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. Iowa Stat. tit. 4, § 142(c).

***New Jersey**. On 4 May 2007, the governor signed into law a bill that would require the New Jersey Motor Vehicle Commission to share organ donor information with federally designated organ procurement organizations. The governor has indicated that he will sign the bill. N.J. Ch. 80 (2007).

Also in New Jersey, a bill was withdrawn from further consideration that would have amended the New Jersey Anatomical Gift Act to require that those involved in organ procurement not ask for an anatomical gift if they have reason to believe that the gift would be contrary to the decedent's wishes or religious beliefs. The amendment further would have barred the anatomical gift if a person who is listed in the state list of potential surrogates indicates that such a gift would be contrary to the decedent's wishes or religious beliefs. S.B. 2378, 211th Leg., Reg. Sess. (N.J. 2007).

New Mexico. On 3 April 2007, the 2006 Revised Uniform Anatomical Gift Act became law. N.M. Stat. tit. 7, § 7242 (2007).

North Dakota. On 9 April 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. N.D. Stat. tit. 23, § 0601 (2007).

***South Carolina**. The session has ended without movement on S.B. 131. The bill was introduced in the state senate and would require all patients to indicate, at the time of admission to a hospital, whether or not they are an organ or tissue donor, or both, and, if not, whether the patient or the patient's family would be willing to discuss organ or tissue donation, or both, should the patient become a potential donor during his or her stay in the hospital. S.B. 131, 117th Gen. Assem., Reg. Sess. (S.C. 2007).

There also was no movement on S.B. 417. The bill was introduced in the state senate and would allow prison inmates to donate organs and bone marrow in exchange for commuted sentences. S.B. 417, 117th Gen. Assem., Reg. Sess. (S.C. 2007).

South Dakota. On 26 March 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. S.D. Stat. tit. 34, § 2640 (2007).

Utah. On 7 March 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. Utah Stat. tit. 26, § 2800 (2007).

Virginia. On 11 April 2007, the governor signed into law the 2006 Revised Uniform Anatomical Gift Act. Vir. Stat. tit. 32, §§ 1-290.

UNCONVENTIONAL TREATMENT

The most important development for this section, and perhaps one of the most important in the "Legal Trends" column for this issue of *The Journal of Clinical Ethics,* is the District of Columbia U.S. District Court of Appeals decision in *Abigail Alliance v. Von Eschenbach* (described below). Technically, this decision should not be reported until the next issue of "Legal Trends," but because of its significance, it is included here. The D.C. Circuit Court's decision is a blow to personal autonomy, but the court's decision was not unexpected. If the court had ruled otherwise, the whole FDA drug approval system would

be in jeopardy, as would the existing system for determining drug manufacturers' liability for adverse events.

The failings of informed consent and our tendency to turn to government to protect us from unanticipated dangers made the *Abigail Alliance* decision all but inevitable. For those who are pro-autonomy, it is easy to say, "If informed consent is real, and not just a legal fiction, then patients should be allowed to assume the risk of taking unproven drugs, particularly if the patient is terminally ill and all other avenues of hope have been exhausted." Unfortunately, however, the informed-consent process is often flawed, and, as a result, the government has taken on the role of performing preliminary risk assessments to help prevent the most dangerous risks from being taken, not only out of a paternalistic interest in protecting patients from their own erroneous risk assessments, but also because the system for disclosing risks and patients' expectations when taking experimental treatments are flawed. This has created an understandable tension between those who want to exercise their autonomy in a way that requires high- risk medical treatment (the *Abigail Alliance* case) and those who want to be protected from even being offered high-risk medical options. (Consider the case of Jolee Mohre, who was offered an experimental arthritis treatment which may have killed her. Sigrid Fry-Revere, "When It's Life or Death, Who Makes the Call?" *Los Angeles Times*, 16 August 2007) The FDA drug approval process tries to balance these interests. In theory, the more testing before a drug is made readily available, the safer and more effective it will be, but also, the later it will become available to those who may benefit.

If the D.C. Circuit had recognized the right of terminally ill patients to use highly experimental and unproven drugs outside the strict controls of FDA-regulated clinical trials, drug companies would be under constant pressure to sell drugs to patients before product testing is complete; they would lose the little bit of control they have under the existing clinical trial system for assuring informed consent and the corresponding legal protection afforded them by providing experimental treatment under government-sanctioned conditions. Imagine the nightmare of possible informed-consent violations and the ensuing cascade of lawsuits if pharmaceutical companies sold drugs that hadn't been fully tested, and allowed private physicians with no experience dealing with the drugs in question to monitor their administration. To protect themselves against such liability, drug companies would have to become the "bad guys" and say "no" to selling drugs before they had been fully tested, or go ahead and sell the drugs but risk unprecedented levels of product liability litigation. Given the litigiousness nature of our society, it is understandable that drug companies would be hesitant to open themselves up to such potential lawsuits, regardless of whether they would eventually win, because patients would assume the risk of unexpected outcomes when they purchase an unapproved medication. Under the current system, drug companies are shielded from being pressured into selling drugs to desperate patients before they are fully tested because, simply put, it is the government, and not the drug companies, who says "no."

For these reasons, it was predictable that the U.S. Court of Appeals for the D.C. Circuit would decide against the Abigail Alliance and the interests of the terminally ill patients it represented. Furthermore, if the U.S. Supreme Court agrees to hear the case, which it is not likely to do, the same outcome can be expected. Before patients' rights to take risks can be expanded, the informed-consent process needs to be improved. Then, and only then, is there a chance that such cases might succeed.

Recent Cases, April - June 2007

Federal. On 7 August 2007, the U.S. Court of Appeals for the District of Columbia Circuit decided in *Abigail Alliance v. Von Eschenbach* that terminally ill patients do not

have a constitutional right to access medications that have not been approved by the FDA. The Abigail Alliance and the Washington Legal Foundation argued that terminally ill patients who did not qualify for participation in ongoing clinical trials or otherwise qualify to obtain experimental drugs through existing FDA access programs should have a right to purchase those drugs directly from pharmaceutical companies and take them under the supervision of their own physicians. The U.S. District of Columbia Court of Appeals did not recognize this "other right to life" argument, and the Alliance has decided to appeal to the U.S. Supreme Court. U.S. Ct. App. D.C., 7 August 2007 (Case no. 04-5350).

*On 21 February 2007, a suit was filed by the Americans for Safe Access against the DHHS and the U.S. Food and Drug Administration (FDA) in an Oakland, California federal district court for allegedly violating the federal Administrative Procedure Act by publicly releasing "false and misleading statements" about the benefits of the use of medical marijuana. The suit is calling for the DHHS and the FDA to retract and correct statements that there are no sound scientific studies supporting the medical use of marijuana. The government filed its response on 25 May 2007, and the case is now pending before Judge William Alsup for his decision. *Americans for Safe Access v. Department of Health and Human Services and Food and Drug Administration*, No. 007-01049 (C.D. Ca., Filed 21 February 2007).

Colorado. On 22 June 2007, a private citizen, Damien LaGoy, filed suit against the Colorado Department of Health and Environment claiming its five-patient per marijuana provider rule was arbitrary and unfair. On 3 July 2007, the Denver District Judge granted a temporary injunction preventing the state from enforcing its five-patient rule. As yet, no date has been set for a trial on the merits. D. Montero, "Pot law on hold," *Rocky Mountain News*, 4 July 2007.

Missouri. The Missouri State Medical Association filed suit in June 2007 to enjoin implementation of a law allowing midwives to deliver infants without supervision by a trained nurse or doctor. The midwife provision of an insurance law was challenged on grounds that it was passed without adequate opportunity for discussion; it was added to an insurance-related bill without notifying legislators of the change in the bill. Cole County Circuit Court placed a temporary injunction on the law in June and a permanent injunction on implementing the midwifery portion on 7 August 2007. The group Missouri Midwifery Supporters plans to appeal the case to the state supreme court. "Missouri Judge Issues Permanent Injunction Against State Law That Would Allow Midwives to Deliver Infants at Home," 10 August 2007, *Kaiser Daily Women's Health Policy Report,, www.kaisernetwork.org/daily_report.cfm?DR_ID=46799&dr_cat=2*, accessed 11 August 2007.

Recent Laws and Regulations, April - June 2007

***Federal.** The FDA is still considering regulations to expand its current Compassionate-Use Programs that make experimental drugs available to individuals or groups under certain circumstances. The rules make drugs available during all stages of development, including during Phase I testing, and allow manufacturers to charge the cost of making and providing the drugs, but not to make a profit. Such regulations would allow patients to use drugs before safety trials have been completed (Phase I) and before testing for efficacy has even begun (Phase II). "Expanded Access to Investigational Drugs for Treatment Use," 71 *Fed. Reg.* 75147 (14 December 2006).

California. On 11 April 2007, the Palm Desert Public Safety Commission voted unanimously to adopt a permanent ban on the licensing of medical marijuana dispensaries, even though the city attorney had presented the commission with a draft law to allow such dispensaries. K. Kaufmann, "Palm Desert commission votes for ban on medical marijuana

dispensaries," *Desert Sun*, 12 April 2007, *http://www.thedesertsun.com*, accessed 13 April 2007.

Missouri. A bill signed into law by the governor on 1 June 2007 includes a provision that allows midwives to deliver infants without a trained nurse or physician's supervision. H.B. 818, 94th Gen. Assem., Reg. Sess. (Mo. 2007). See discussion of judicial injunction of law above.

Rhode Island. On 21 June 2007, the state legislature overrode the governor's veto of H.B. 6005. This new law will permanently legalize medical marijuana use in the state. Such use was already legal under a law passed in January 2006, but that law was set to expire on 30 June 2007 unless the legislature acted. Ch. 72 (R.I. 2007).

Washington. The session ended without movement on H.B. 1395. The bill requires the state department of health to determine the quantity of marijuana that could be considered a reasonable 60-day supply. The existing law, Initiative 692, passed with 59 percent voter approval in 1998. It allows doctors to recommend but not prescribe marijuana for people suffering from intractable pain, but only allows a 60-day supply to be possessed by any individual at one time. This bill is intended to create a clear line for law enforcement and individual patients. H.B. 1395, 60th Leg., Reg. Sess. (Wash. 2007).

LIFE-AND-DEATH DECISIONS

There are three interesting events related to life-and-death decisions in this edition of "Legal Trends." For the most important one, please see the discussion of the *Abigail Alliance* case above. The second involves medial tourism and Canadian — not U.S. — law. See the discussion below under "Interesting Developments in Other Countries." The third is reported in this section: Virginia law allows children as young as 14 to refuse life-saving treatment if their parents agree. See the "Virginia" section below.

There is considerable overlap between life-and-death decisions and the discussion of unconventional treatment. Please check the "Unconventional Treatment" section above for possible life-and-death-related cases and laws.

Recent Laws and Regulations, April - June 2007

California. There has been no movement on the California Compassionate Choice Act. The act would allow adults to request that medication be prescribed to provide comfort and to assure a peaceful death if suffering becomes unbearable. The act would also establish procedures by which to implement such requests. A.B. 374, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

***Georgia.** The governor signed an act effective 1 July 2007 that revises Georgia's advance directive laws. Among other things, the law combines Georgia's living will and durable power of attorney provisions into one form. It also provides for the creation of a website for the purpose of providing consumers information on the cost and quality of healthcare in Georgia. Ga. Act. 48 (2007).

Hawaii. The session ended without movement on H.B. 675. The bill was introduced in the state house to allow aid in dying. H.B. 675, 24th Leg., Reg. Sess. (Haw. 2007).

Kansas. The session ended without movement on A.B. 2176. The bill was introduced in the state assembly, and sought to create a presumption that all state residents would want artificial nutrition and hydration even if there are known desires to the contrary, unless there is clear and convincing evidence of an express, informed wish to withdraw nutrition and hydration in the "applicable circumstances." A.B. 2176, 82nd Leg., Reg. Sess. (Kan. 2007).

New Hampshire. There has been no movement on H.B. 244. The bill was introduced in the state house and prohibits life-saving treatment from being withdrawn from developmentally disabled persons or persons who once were mentally competent but have lost that competency. Life-sustaining treatment

could not be withdrawn even if the patient had previously indicated such wishes while competent. H.B. 244, 160th Gen. Court, Reg. Sess. (N.H. 2007).

***New Jersey**. There has been no movement on virtually identical bills introduced in the state legislature that would require surrogate decision makers to make healthcare decisions in accordance with a patient's religious beliefs. A.B 3514, S.B. 2380, 212th Leg., Reg. Sess. (N.J. 2006).

***Texas**. The session ended without movement on S.B. 28. This bill was introduced in the state senate and would, among other things, provide for transferable physicians' orders and prohibit healthcare providers or insurance companies from requiring advance directives as a condition for receiving healthcare services. S.B. 28, 80th Leg. (Tex. 2007).

There was also no movement on a bill introduced in the state house that clarifies that advance directives can be used to request continuation of life-sustaining treatment. H.B. 1094, 80th Leg. (Tex. 2007).

Vermont. The session ended without movement on the Patient Control at the End of Life Act. The act would have decriminalized aid in dying. The house bill failed to be voted out of the house. H.B. 44, S.B. 63, 69th Leg., Reg. Sess. (Vt. 2007).

Virginia. This important law is included here because it was accidentally left out of the last "Legal Trends." On 22 March 2007, the governor signed into law a bill that allows for an exception to the state social services regulations dealing with parental child abuse and neglect. This law, commonly known as "Abraham's Law," amended the state code to allow parents who wish to withhold life-saving treatment from their child to do so without risking medical neglect charges if the child is at least 14 years of age and has given an informed "opinion" with which the child's parents agree. Va. Code Ann. §§ 63.2 -100.

Wisconsin. There has been no movement on S.B. 151. The bill was introduced in the state senate and permits an individual, of sound mind and over 18 years of age, to request, in writing, medication from a physician for the purpose of ending his or her life. S.B. 151, 2007 Reg. Sess. (Wis. 2007).

Interesting Developments in Other Countries

Canada. Ramesh Sharma, MD, of Vernon, British Columbia, has pleaded guilty to counseling or aiding suicide under Sec. 241 of the Criminal Code of Canada. He could be imprisoned for up to 14 years. He will be sentenced on 11 June 2007. H. White, "Canadian Doctor Pleads Guilty to Attempted Assisted Suicide Charge," *LifeSiteNews.com*, 4 April 2007.

An anti-euthanasia group is calling for a police investigation of the death in **Switzerland** of Canadian citizen Elizabeth MacDonald, who traveled to Switzerland to die in accordance with Swiss physician-assisted suicide laws. There is no claim that any Swiss laws were broken, but that the Right to Die Society of Canada, which counseled MacDonald on her option to go to Switzerland, and the person who accompanied her there might be guilty under Canadian law of assisting a suicide. L. Fraser, "Probe into assisted death sought," *ChronicleHerald*, 25 June 2007, *http://thechronicleherald.ca/print _article.html?story=843395*.

United Kingdom. The Mental Capacity Act of 2005 will incrementally go into effect between April and October 2007. Under this act, patients are permitted to write advance directives that specifically refuse treatment if their illness meets statutorily specified conditions or to appoint what the British call "lasting powers of attorney," that is, durable powers of attorney or healthcare proxies. Patients can refuse and request the withdrawal of life-saving/life-sustaining treatment including the withdrawal of nutrition and hydration. Under the law, if physicians or nurses refuse to comply with qualifying patients' directives, they could be prosecuted for "willfully neglecting" an incapacitated patient or for assault. A copy of the act can be found at *http://www.dca.gov.uk/menincap/legis.htm*.

THE RIGHT TO ACCESS AND CONTROL MEDICAL INFORMATION (INCLUDING MEDICAL TESTING, PRIVACY, AND DISCRIMINATION BASED ON TEST RESULTS)

Concerns about the disclosure of genetic testing and the effect of such disclosures has prompted several lawmakers to introduce legislation to prevent genetic discrimination. (Testing-related developments are reported in the HIV section of this column.)

Recent Cases, April - June 2007

***California.** Ongoing litigation. *Taus v. Loftus, et al*. is a case in which a child abuse victim gave permission (at age 17) — and so did her father — to be interviewed, and for the taped interview to be shown for "educational purposes." A case study was published that referenced "Jane Doe," but other identifying information was disclosed about the young woman when the researcher gave presentations about the case, including videotaped interviews with the subject in which the subject's first name was used by the researcher, and the city where the subject lived as a child was disclosed. Based on this information, in conjunction with information disclosed in the researcher's published case study, reporters discovered more about the case and published allegedly defamatory remarks about the subject and the researcher's claims regarding her recovery of repressed memories. 2005 Cal. App. Unpub. LEXIS 3048, 22 media L. Rep. 1545. *Taus v. Loftus, et al.*, 2006 CA S. Ct. S133805. On appeal, the opinion was affirmed in part and reversed in part, and the matter is remanded to the court of appeals for further proceedings. 2007 Cal. LEXIS 2340 (26 February 2007) (Case # S133805).

Recent Laws and Regulations, April - June 2007

***Federal.** There has been no action on a bill that was introduced in the House that, among other things, will encourage the use of electronic health records. The bill was referred to the House Ways and Means Committee Subcommittee on Health on 25 April 2007. S.B. 1952, 110th Cong. (1st Sess. 2007). Colby Itkowitz, "Clinton to Reintroduce Health IT, Respite Care Proposals," *Congressional Quarterly*, 17 February 2007, Health-Beat.

The FDA, however, is working on a proposed rule to regulate the electronic health records that are transferred directly from a medical device to a database. The justification for such regulation is that such records are part of the device itself. Jason Miller, "FDA to propose rule on e-health records," *Government Health IT*, 5 June 2007, *http://govhealthit.com/article102901-06-05-07-Web&printLayout*, accessed 6 June 2007.

There were two bills introduced in Congress that would make it illegal for an employer or health insurer to access genetic information and then make either insurance coverage or decisions regarding the hiring, firing, or promotion of an employee based on such information. The house version of the Genetic Information Nondiscrimination Act was passed and the senate version is still in the senate committee. H.B. 493, S.B. 358, 110th Cong. (1st Sess. 2007).

Connecticut. The session ended without movement on H.B. 5743. The bill was introduced in the state house and would require that newborns be given a deoxyribonucleic acid (DNA) test and that the results be entered upon the birth record and shared with the child's parents. H.B 5743, 2007 Gen. Assem., Jan. Sess. (Conn. 2007).

The state plans to use a $5 million grant to develop and implement an electronic health records system for 35,000 Medicaid beneficiaries. The bill is currently in the joint committee on public health. S.B. 88, 2007 Gen. Assem., Jan. Sess. (Conn. 2007).

***Iowa.** A bill to implement electronic health records systems incrementally throughout the state died in committee. H.B. 2637, 81st Gen. Assem., 2nd Sess. (Iowa 2005).

New York. There has been no movement

on A.B. 03284 and S.B. 01633. The two bills were introduced in the state legislature and would create a genetics advisory council. The council would be charged with advising the governor and legislature on issues relating to genetic tests, access to information, privacy, and counseling. A.B. 03284, S.B. 01633, 2007 Leg., 230th Reg. Sess. (N.Y. 2007).

***Ohio.** There has been no action on H.B. 692. The bill was introduced in the state house and would limit the liability of hospitals, among other things, for the genetic screening of newborns. The bill died at the end of the last general assembly. H.B. 692, 162nd Gen. Assem., Reg. Sess. (Ohio 2006).

Oklahoma. The session ended without movement on S.B. 617. The bill was introduced to allow government officials to search offices and medical files of abortion providers without cause, warrant, or announcement. S.B. 617, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

Vermont. The Vermont Department of Health has established an electronic registry for advance directives. The Vermont Advance Directive Registry can only be accessed by authorized healthcare providers, funeral directors, and crematory operators. Any information sent over the internet will be encrypted. Vt. Stat. Ann. tit. 18, § 231 (2007).

OVERSIGHT: PATIENT TRUST

Recent Laws and Regulations, April - June 2007

Federal. The Prescription Drug User Fee Amendments of 2007 have passed both houses of Congress, but in different versions. They are currently under consideration by a joint conference committee in which differences will be reconciled. Action is expected in the fall. Funding under the current Prescription Drug User Fee Act expires on 30 September 2007. Currently, user fees compose approximately half of the FDA's budget for its drug review oversight. Some new measures included in these bills are new authority for the FDA to require pharmaceutical companies to conduct post-market safety studies, to create a computerized network for tracking adverse events, and to regulate pharmaceutical marketing. Both bills place new restrictions on the financial interests FDA advisory committee members may have in pharmaceutical companies. The House version also included new authority for the FDA to approve generic versions of biotechnology medications (the Senate is considering a separate bill to do the same thing S. 1695). H.R. 2900, S. 1082, 110th Leg., Reg. Sess. (2007).

Alabama. The Hospital Infections Disclosure Act failed in the state legislature. The bill was introduced to require the reporting and disclosure of hospital infection rates. S.B. 409, 2007 Leg., Reg. Sess. (Ala. 2007).

Arkansas. The Health Facility Infection Disclosure Act of 2007, which requires the reporting and disclosure of hospital infection rates, was signed by the governor on 3 April 2007. Ark. Law Act 845 (2007).

***California.** There has been no movement on a bill that was introduced in the California Assembly to establish an Office of Patient Advocate in the State Department of Public Health. The bill passed out of the Health Committee on 7 March 2007 and was re-referred to the Appropriations Committee. 2007 Text A.B. 52 (4 December 2006); A.B. 52, 2007-2008 Gen. Assem., Reg. Sess. (Calif. 2007).

Delaware. A bill requiring the reporting and disclosure of hospital infection rates has passed both houses of the state legislature and is awaiting the governor's signature. H.B. 47 substituted by HS 1, 144th Gen. Assem., Reg. Sess. (Del. 2007).

Massachusetts. There has been no movement on S.B. 1269. The bill was introduced in the state senate to require the reporting and disclosure of hospital infection rates. S.B. 1269, 185th Gen. Court, Reg. Sess. (Mass 2007).

Michigan. There has been no movement on H.B. 4158. The bill was introduced in the state house to require the reporting and disclosure of hospital infection rates. H.B. 4158,

2007 Leg., Reg. Sess. (Mich. 2007).

Minnesota. The session ended without movement on S.F. 755. The bill was introduced in the state house to require the reporting and disclosure of hospital infection rates. H.F. 1076, S.F. 755, 85th Leg., Reg. Sess. (Minn. 2007).

Oregon. On 27 July 2007, the governor signed a law that would require the reporting and disclosure of hospital infection rates. Or. Ch. 838 (2007).

Pennsylvania. The state legislature unanimously passed a bill on 14 July 2007 that would require more stringent reporting requirements for patient infections to state authorities. S.B. 968, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

Texas. The session ended without movement on two virtually identical bills, H.B. 1398 and S.B. 288. The bills were introduced in the state legislature and would require the reporting and disclosure of hospital infection rates. H.B. 1398, S.B. 288, 80th Leg. (Tex. 2007).

Washington. The governor signed a law, effective 22 July 2007, that would require the reporting and disclosure of hospital infection rates. Wa. Ch. 261 (2007).

HIV

There have been two important developments this quarter. The first is a loosening of informed-consent requirements in some states. The second is that more states are requiring HIV testing in a larger variety of situations.

Recent Laws and Regulations, April - June 2007

Federal. There has been no movement on a resolution introduced in January in the U.S. House to allow the distribution of condoms in prisons. H.R. 178, 110th Leg., Reg. Sess. (2007).

By the end of 2007, all states and D.C. will be required to report their HIV cases by name, not anonymously, if they wish to receive funding from the DHHS under the federal Ryan White Grant Program. 42 U.S.C. § 201.

*The FDA is considering changing its policy that prohibits men who have sex with men from ever donating blood. The American Red Cross, the American Association of Blood Banks, and America's Blood Centers believe it would be more reasonable to prohibit such men from donating only if they have had sex with another man within 12 months instead of ever in their lifetime. FDA Workshop on Behavior-Based Donor Deferrals in the NAT Era, Wednesday, 8 March 2006, Lister Hill Auditorium, National Institutes of Health, Bethesda, Maryland.

Arkansas. On 9 March 2007, the governor signed a bill that would require state prison inmates to receive an HIV test before being released. Ark. Act. 271 (2007).

California. There has been no movement on S.B. 443. The bill was introduced in the California Senate and would allow HIV-positive men to use their own sperm in fertility treatments (note: there is a process by which the sperm can be washed). S.B. 443, 2007-2008 Leg., Reg. Sess. (Calif. 2007).

A bill that would eliminate requiring written informed consent for an HIV test passed the state assembly on 6 June 2007 and is currently working its way through the state senate. A.B. 682, 2007-2008 Leg., Reg. Sess. (Calif. 2007).

District of Columbia. Congress is considering lifting the ban on city funding for needle-exchange in Washington, D.C. "House Committee Approves Appropriations Bill That Would Remove Ban on City Funding for Needle-Exchange Programs in Washington, D.C.," *Kaiser Daily HIV/AIDS Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=45534&dr_cat=1*, accessed 18 June 2007.

Georgia. The governor signed a bill that would require doctors to offer all pregnant women an HIV test effective 1 July 2007. Women can opt out of the test, but such refusal becomes part of their medical record. GA. Act. 60 (2007).

Illinois. A bill to allow condom distribution in prisons died in committee. H.B. 686, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

The governor signed on 27 June 2007 a bill that drops the requirement that patients sign a written informed-consent form before receiving an HIV test. S.B. 929, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

Maine. The session ended without movement on S.P. 180. The bill was introduced to amend the state's HIV testing laws to bring them in line with the September 2006 recommendations of the U.S. Centers for Disease Control and Prevention (CDC), which suggest that HIV testing become a part of routine medical care. The bill drops the requirements for written consent and pre-test counseling that now exist under state law. The bill has an opt-out provision. S.P. 180, 123rd Maine Senate, Reg. Sess. (ME 2007).

New Jersey. A bill passed the state legislature on 21 June 2007 that would require pregnant women and some infants to receive HIV testing. S.B. 2704, 95th Gen. Assem., Reg. Sess. (N.J. 2007).

New York. The state legislature passed a bill on 22 June 2007 that requires suspects indicted for rape to be tested for HIV. A. 40-A, 230th Gen. Assem., Reg. Sess. (N.Y. 2007).

Tennessee. On 12 June 2007, the governor signed a bill that requires convicted sex promoters to be tested for HIV. H.B. 1775, 105th Gen. Assem., Leg. Sess. (Tenn. 2007).

Interesting Developments in Other Countries

***Kazakhstan.** On 27 June 2007, 21 doctors were convicted of criminal negligence because they provided HIV-tainted blood transfusions to 100 children at a children's hospital, who subsequently tested positive for HIV. "Doctors in Kazakhstan Convicted for Criminal Negligence Following HIV Outbreak Among Children Who Received Blood Transfusions," *Kaiser Daily HIV/AIDS Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID=43062&dr_cat=1*, accessed 14 August 2007.

***Libya.** On 16 July 2007, the Supreme Council commuted the death sentences of five Bulgarian nurses and a Palestinian doctor who had been convicted of intentionally infecting 426 children at Al Fateh Children's Hospital in Benghzi, Libya with HIV-contaminated blood products, after a $460 million compensation package for the families of the HIV-positive children was arranged through an international fund supported by several countries including Bulgaria and other Balkan nations. "Libya's Judicial Council Commutes Death Sentence for Medical Workers in HIV Infection Case," *Kaiser Daily HIV/AIDS Report, http://www.kaisernetwork.org/daily_report.cfm?DR_ID =46290&dr_cat=1*, accessed 13 August 2007.

CONSCIENTIOUS OBJECTIONS (HEALTHCARE PROVIDERS AND RELATED PROFESSIONS)

U.S. conscientious objector laws have their roots in the U.S. Bill of Rights First Amendment Free Exercise Clause and variations thereon that exist in the states. The basic rule is that governments can't force individuals to do things (including saying things) that they believe to be against their religion or to be otherwise immoral. Generally, an accommodation for those who raise a conscientious objection must be made unless their exercise of that freedom would directly put someone else at risk. This is why conscientious objection, rarely a problem in most contexts, can quickly become problematic in healthcare, in which a person's access to care may be affected.

It is important to note that the First Amendment prohibition is against governments, not private individuals, and perhaps the best first step toward dealing with such issues is through contract and notice. Healthcare providers can contract to have their moral views on certain issues respected by not requiring that they perform certain procedures or discuss certain medical options, but then patients need to be given notice of that particular healthcare provider's position and, if appropriate, be provided information on how

to find a non-objecting healthcare provider.

Recent Cases, April - June 2007

California. The state supreme court has agreed to hear a case involving two physicians who refused to provide IVF treatment to a lesbian couple. The state supreme court granted review on 14 June 2006, but is accepting briefs until October 2007. After that the court will set a date to hear the case. *North Coast Women's Care Medical Group, et al. v. Superior Court of San Diego County, Guadalupe T. Benitez (Real Party in Interest)*. Cal. Supreme Ct. Case. No. S142892.

Recent Laws and Regulations, April - June 2007

Missouri. The session ended without movement on four bills dealing with conscientious objections. The first two bills would allow pharmacists and related professionals to refuse to provide or dispense contraceptives in most circumstances. But the other two bills would require a pharmacist to fill any valid prescription. H.B. 412, S.B. 285, H.B. 156, S.B. 72, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

There has been no movement on a bill introduced in the state house to allow for conscientious objection to participation in any medical services in most circumstances. The Missouri bill also allows insurance companies to refuse to provide coverage for any service that conflicts with the entity's policies. H.B. 434, 94th Gen. Assem., Reg. Sess. (Mo. 2007).

New York. There has been no movement on S.B. 2317 or S.B. 2344 yet. The two bills were introduced in the state senate and would prohibit pharmacists from refusing to provide or dispense contraceptives in most circumstances. S.B. 2317, S.B. 2344, 230th Gen. Assem., Reg. Sess. (N.Y. 2007).

Oklahoma. The session has ended with no movement on S.B. 555. The bill was introduced in the state senate and would require pharmacies and pharmacists to fill all valid prescriptions. S.B. 555, 51st Gen. Assem., Reg. Sess. (Okla. 2007).

Pennsylvania. There has been no movement on two bills introduced in the state legislature that would require a pharmacy or pharmacists to fill valid prescriptions. H.B. 730, H.B. 316, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

Rhode Island. The session ended with no movement on S.B. 452. The bill was introduced in the state senate and would allow healthcare providers to refuse to perform abortions or sterilizations on moral grounds. S.B. 452, Gen. Assem., Jan. Sess. (R.I. 2007).

There was no further action on two bills introduced in the state legislature that would allow certain individuals to refuse to perform any medical services in most circumstances. S.B. 452, H.B. 5274, Gen. Assem., Jan. Sess. (R.I. 2007).

South Carolina. The session ended without further action on two bills that would allow certain individuals to refuse to participate in medical services in most circumstances and to allow pharmacists and related professionals to refuse to dispense contraceptives. H.B. 3283 (general), S.B. 126 (pharmacy related), 117th Gen. Assem., Reg. Sess. (S.C. 2007).

Vermont. The session ended without further action on H.B. 315. The bill was introduced in the state house and would allow certain individuals and entities to refuse to perform medical services under most circumstances. It also allows insurance companies to refuse to cover any services that conflict with the entity's conscience or religious beliefs. H.B. 315, 69th Gen. Assem., Reg. Sess. (Vt. 2007).

Virginia. A bill that would require pharmacies to fill valid prescriptions failed in committee. H.B. 2842, 2007 Gen. Assem., Reg. Sess. (Va. 2007).

West Virginia. There has been no movement on five bills dealing with conscientious objections. The first four bills would allow hospitals, pharmacists, and related professionals to refuse, under most circumstances, to dispense substances that could be used as part of an abortion-related procedure. The last bill would prohibit the same from refusing to pro-

vide or dispense contraceptives. H.B. 2903, S.B. 639 (hospitals), H.B. 2092, S.B. 743 (pharmacists), H.B. 2416, 78th Leg., Reg. Sess. (W. Va. 2007).

HEALTHCARE COVERAGE

Many of the sections in "Legal Trends" deal with healthcare funding. Those listed here deal specifically with those judicial and legislative actions attempting to create equity in healthcare coverage or some form of "universal" healthcare.

Recent Laws and Regulations, April - June 2007

***Federal**. A resolution was introduced in the U.S. House that would require insurers to cover mental illness at the same level as they cover physical illness. The bill has been referred to House Ways and Means committee Subcommittee on Health. H.R. 1424, S.B. 558, 1101th Leg., Reg. Sess. (2007).

***A** bill was introduced in the U.S. House that would provide universal health insurance to all U.S. residents. The AmeriCare Health Care Act would create AmeriCare, a program that would use Medicare to provide health insurance to U.S. citizens who don't receive coverage through their employers and whose annual income falls below 300 percent of the federal poverty level. The bill has been referred to the Subcommittee on Health, Employment, Labor, and Pensions. H.R. 1841, 110th Leg., Reg. Sess. (2007).

Colorado. The governor signed into law on 15 May 2007 a bill that would establish an Office of Health Disparities and two councils to work on eliminating health disparities in the state. S.B. 242, 66th Gen. Assem., Reg. Sess. (Colo. 2007).

Connecticut. The session ended without further movement on a bill introduced in the state house to implement universal healthcare coverage in the state. H.B. 6655, 2007 Gen. Assem., Reg. Sess. (Conn. 2007).

Illinois. There has been no action on a bill called the Illinois Healthcare For All Act. The bill's objective is to expand the state insurance plan. S.B. 5, 95th Gen. Assem., Reg. Sess. (Ill. 2007).

Kansas. The governor signed into law on 10 May 2007 a bill that subsidizes health insurance premiums for families with incomes up to the federal poverty level. S.B. 11, 82nd Leg., Reg. Sess. (Kan. 2007).

Louisiana. The governor signed on 27 June 2007 legislation to redesign the state-funded healthcare system. The new system would include electronic tracking of patients and medical networks of care. S.B. 238, 2007 Leg. Reg. Sess. (La. 2007).

Massachusetts. On 1 July 2007, "An Act Providing Access to Affordable, Quality, Accountable Health Care" went into effect. The law requires all state residents to obtain health insurance, provides residents who have an annual income below the federal poverty level with free care, and provides residents who have an annual income of up to three times the federal poverty level with state subsidized healthcare. Mass. Gen. Laws Ann. Ch. 58, §§ 1-147 (Mass. 2006).

Minnesota. The session ended without further movement on H.F. 1856. The bill was introduced in the state house and would provide universal health coverage by 2011. H.F. 1856, Leg. 85, Reg. Sess. (Minn. 2007).

North Carolina. On 27 July 2007, the governor signed into law the Mental Health Equitable Coverage Act, formerly HB 973, which would require health insurers to provide the same level of coverage for treatmentof severe depression, schizophrenia, or other mental illnesses as they do for physical illnesses. N.C. Sess. Laws Ch. 268 (N.C. 2007).

Rhode Island. Regulations took effect on 1 April 2007 that would require state hospitals to provide care free of charge to any uninsured resident with an income at or below 200 percent of the federal poverty line. R.I. Gen. Laws, Ch. 23, §17.14 (R.I., 2007).

The governor signed into law on 27 June 2007 a bill that requires businesses with 25 or more employees to offer workers the oppor-

tunity to purchase health insurance with pretax income. Regulations will be promulgated by the state Department of Labor and Training. The law goes into effect in 2009. S.B. 448, Gen. Assem., Jan. Sess. (R.I. 2007).

Texas. The state senate passed on 10 May 2007 a requirement that insurers provide coverage for mental healthcare at the same level as physical healthcare. S.B. 558, 80th Leg. (Tex. 2007).

Virginia. The session ended without further movement on a bill introduced in the state senate that would require health insurers to cover the cost of stem-cell transplants. S.B. 991, 2007 Gen. Assem., Reg. Sess. (Va. 2007). Senate: Pursuant to Section 2.2-2504 of the Code of Virginia.

Washington. The session ended without further action on H.B. 2098 and S.B. 5930. The two bills were introduced in the state legislature to phase in universal health coverage over a five-year period. S.B. 5930, H.B. 2098, 60th Leg., Reg. Sess. (Wash. 2007).

MENTAL ILLNESS

There are no specific cases or laws to report at this time, but it is worth noting that there has been a concerted effort on the part of the U.S. Department of Justice to divert mentally ill individuals away from the criminal justice system and into treatment programs. In the last 10 years, the number of special courts specifically designed to handle cases involving the mentally ill have grown in number from four to 120. This is clearly an indication that society's understanding of the role mental illness plays in criminal behavior and how best to deal with mentally ill criminals is changing. This shift in attitude could have a significant affect both on the criminal justice system and the mental healthcare system. Estimates are that one-third to one-half of all prison inmates suffer from some form of mental illness. See Bridget Kuehn, "Mental Health Courts Show Promise," *Journal of the American Medical Association,* 297, no. 15 (18 April 2007): 1641-43. Also see mental health parity laws reported in the above "Healthcare Coverage" section.

NEW TECHNOLOGIES (NANOTECHNOLOGY AND MORE)

This is a new section in this issue of "Legal Trends." Bioethics and science journals are replete with discussions of nanotechnology, but there has been relatively little discussion of any government action concerning such new technologies and how they should be regulated — if at all.

Recent Laws and Regulations, April - June 2007

Federal. The FDA Nanotechnology Task Force issued its report on 25 July 2007. The report essentially concluded that there was no need for the FDA to rush to regulate the advertising of nanotechnology. The FDA should consider each product using nanotechnology on a case-by-case basis, since there is nothing inherent about nanotechnology that warrants a special form of labeling or special warnings to consumers. FDA, "Nanotechnology: A Report of the U.S. Food and Drug Administration Nanotechnology Task Force," 25 July 2007, *http://www.fda.gov/nanotechnology/taskforce/report2007.html*.

DECISION-MAKING CAPACITY/ COMPETENCY

Please also see the discussion above, under the "Life-and-Death Decisions" section, of "Abraham's Law."

Recent Laws and Regulations, April - June 2007

Arizona. A bill failed in the state senate on 20 June 2007 that was passed by the state house on 8 March 2007. The bill spells out specifically what constitutes the conditions under which a minor is mature enough to ter-

minate a pregnancy without parental consent. Current judicial practice is to consider two types of factors: is the young woman mature enough to make the decision and/or would terminating the pregnancy be in the young woman's best interest. This bill would eliminate the second option from the states "judicial bypass" provisions for allowing minors to have abortions without parental consent. H.B. 2641, 48th Leg., Reg. Sess. (Ariz. 2007).