

THE JOURNAL OF CLINICAL ETHICS

VOLUME 17, NUMBER 3

FALL 2006

At the Bedside

- 195 Beyond Respect for Autonomy
Edmund G. Howe

Features

- 207 The Case of A.R.: The Ethics of Sibling Donor Bone Marrow Transplantation Revisited
Douglas J. Opel and Douglas S. Diekema
- 220 A Compounding of Errors: The Case of Bone Marrow Donation between Non-Intimate Siblings
Lainie Friedman Ross and Walter Glannon
- 227 Duty and Altruism: Alternative Analyses of the Ethics of Sibling Bone Marrow Donation
Rebecca Pentz
- 231 The Courage to Stand Up: The Cultural Politics of Nurses' Access to Ethics Consultation
Elisa J. Gordon and Ann B. Hamric
- 255 Healthcare Organizations as Moral Communities
Mila Ann Aroskar

- 257 Nurses and Ethics Consultation: Growing Beyond a Rock and a Hard Place
Kathy Mayle

- 260 Physician-Nurse Relationships and their Effect on Ethical Nursing Practice
Teresa A. Savage

Autonomy

- 266 Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta
Marilyn E. Coors and Susan F. Townsend

Medical Education

- 275 Individuals, Systems, and Professional Behavior
Evan G. DeRenzo

The Journal of Clinical Ethics

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The Journal of Clinical Ethics, ISSN 1046-7890, is published quarterly: spring, summer, fall, winter. Subscriptions are by volume year.

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Subscriptions must be prepaid. All sales final. Prices subject to change without notice.

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The Journal of Clinical Ethics is indexed on MEDLINE, Social Sciences Citation Index, Research Alert, Current Contents/Social & Behavioral Sciences, and Cumulative Index to Nursing & Allied Health Literature, and is a peer-reviewed, refereed journal.

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At the Bedside

Beyond Respect for Autonomy

Edmund G. Howe

In this issue of *The Journal of Clinical Ethics*, in “Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta,” Marilyn E. Coors and Susan F. Townsend discuss the ethics of a pregnant woman’s right to put her own interests at risk for the sake of her fetus by choosing to have a cesarean section.¹ They assert that, under these conditions, it is essential that careproviders grant mothers absolute autonomy. The authors address whether or not these careproviders should be paternalistic, in an attempt to prevent the mothers from being harmed, in only this one situation. In principle, such conflicts may be more widespread. Parents may be harmed when they feel emotional pain virtually any time they must make decisions involving their child. I think of a recent study that explored the experience of parents who cared for children who were dependent on ventilators. Based on their findings, the authors con-

cluded these families should be fully informed of the demands and hardships that await them, which may encourage parents to change their minds about initiating treatment.²

Coors and Townsend, in considering only the more limited question, implicitly ask whether careproviders should always, absolutely respect parents’ autonomy, or, if not, when should they? (Throughout the remainder of this discussion, “parents” will be used to refer to either parents or a single parent.)

It may seem odd to even consider when, if ever, careproviders should not respect parents’ autonomy — aside from obvious exceptional contexts, such as when parents make certain choices that violate the law.³ Aren’t Coors and Townsend’s arguments for absolute autonomy all that need reasonably be said? I suggest that the answer is no, for two reasons that may not be self-evident. The first reason is normative. It is not clear to all careproviders, everywhere, that they should respect parents’ autonomy in any way that is close to this degree; the leading example of this is neonatologists in France. Kristina Orfali reports that many neonatologists in France oppose giving parents of severely ill neonates ultimate decision-making authority, and may consider U.S. laws that require this a

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perversion of the American legal system.⁴ Rather than responding to these conflicts by respecting parents' autonomy, French neonatologists use *certainty* or *uncertainty* "as a tool to manage difficult situations and families."⁵ They give parents information in terms of medical certainty, in telling them that it is *medically certain* that their child will die, rather than revealing that they are uncertain.⁶ Decisions regarding these children remain within the framework of medicine, and not ethics, and parents then have no reason to challenge these decisions.⁷ As this is the case, treatment can be withdrawn without clearly informing parents that an alternative exists.⁸

Part of the rationale is to reassure parents that everything is being done,⁹ and "to keep parents under control," and to protect them from "harsh realities."¹⁰ France is hardly a developing country, and the description of this practice is contemporary. This raises the obvious question: Should careproviders treat parents the same way in every country? Or should treatments differ and be more or less paternalistic, based on the values and sensibilities of those in each culture or country? This question, of *cultural relativism*, will be examined later.

The second rationale is that there are some relatively recent empirical findings that suggest that emotion, rather than reason, often dictates what we choose.¹¹ Some philosophers have asserted this for centuries.¹²

"Split-brain studies," or research on patients whose two brain hemispheres have been disconnected to treat them for intractable seizures, provide the first source of empirical data.¹³ These studies report, in a nutshell, that persons may not always be as capable of exercising true autonomy. It appears that we sometimes make decisions, particularly when we are uncertain, for reasons that are mostly emotionally driven. Most importantly, for the purpose of this discussion, these emotionally driven decisions may go totally against what we genuinely want, in many instances.

Neuro-imaging studies provide the second source of empirical data.¹⁴ The studies suggest that parts of our brains may make decisions and begin to act on those decisions before we real-

ize it. If this is accurate, there may be more justification for careproviders to be paternalistic, as this may be the only way they are able to protect parents from emotionally driven decisions. As a much more radical alternative, they might state that they are medically certain that a child will die, as French neonatologists are reported to do.¹⁵ The possibility that parents' unconscious emotions may determine their decisions — and determine them wrongly — is exceedingly important, as parents can determine a child's outcome. In this country, obviously, there are absolute legal limits to what careproviders can decide, but even if there weren't, parents in the U.S. would demand more autonomy than parents in France.¹⁶ As this is the case, the most appropriate ethical question may be not *whether* — or even *when* — careproviders should respect parents' autonomy, but, in light of the normative and empirical findings presented above, *how* should they respect parents' autonomy? Are there ways that careproviders can help parents be more truly autonomous, and so less vulnerable to being harmed? The answers are the focus of this commentary.

LEARNING FROM FRENCH NEONATOLOGISTS

Parents who are in a state of uncertainty are especially vulnerable to positive or negative suggestion, and so careproviders are at inordinate risk of doing enormous and permanent — although inadvertent — harm. Due to their medical authority, what careproviders convey, even if only by suggestion, is much more likely to "take" in parents. In light of the exceptional potential for negative effects, the perspectives and rationales of the French neonatologists mentioned above may suggest better insight. What they do may suggest ways that we can be of greater benefit to parents, while respecting their autonomy.

MEDICAL CERTAINTY AS A TOOL

Orfali and Gordon report that French neonatologists use *certainty* or *uncertainty* as a tool to manage difficult situations and families.¹⁷

They don't convey their uncertainty to parents. In France, decision making regarding neonates is viewed, by both careproviders and parents, as a purely medical exercise.¹⁸ In one neonatal unit, for instance, physicians either adjust the information they give to parents about a baby's clinical status to diminish the parents' hope for the baby's survival, or they present to them that the baby is dying naturally, despite the fact that the doctor has withdrawn certain treatments.

The team does this for many reasons. Chief are that the doctors wish to reassure the parents that everything is being done.¹⁹ They also want to protect them from feeling any guilt.²⁰ The withdrawal of ventilators, for example, is presented to parents as a test that will allow nature to take its course. If a baby can breathe without a machine, the baby will go home. If not, the baby will die.²¹ What are the results of this practice? French mothers of infants in one neonatal intensive care unit (NICU) were compared with U.S. mothers in the same situation. The French mothers "showed the highest level of satisfaction. . . . They also had fewer, if any, residual problems such as anger, depression, guilt, or regrets."²² A large majority of mothers in the U.S. unit expressed guilt.²³ Parents in this unit were informed about their baby's condition in either optimistic or highly uncertain terms. If the information was conveyed as uncertain, it increased the mother's anxiety.²⁴ Orfali and Gordon, who conducted the study, reached this conclusion: "The autonomy model does not seem to respond to the specific needs of being a mother of a critically ill baby in an NICU."²⁵ They continue: "Theoretical preferences for autonomy do not match the lived experiences of mothers in the NICU."²⁶ They add: "In the U.S., individuals bear . . . the psychological costs of their choices . . . it seems prudent [therefore] to reconsider the practice of autonomy in particularly stressful situations."²⁷

CULTURAL RELATIVITY AS A TOOL

Comparing careproviders' responses to parents of children in the NICU may raise some new questions. Should careproviders' response to parents be culturally relative? Should the response to parents be the same everywhere,

whether it is to protect parents, as in France, or respect their autonomy absolutely, as Coors and Townsend might seem to suggest? Many may find this discussion offensive, particularly those who believe that parents' closeness to a child is far too important for careproviders not to respect their autonomy absolutely. Some may criticize using cultural relativity in this context, as it might be seen as too generously concluding that what parents want is right, merely because they want it.

A deeper analysis might consider additional empirical data. Some recent findings suggest, for example, that individuals may differ from each other, often quite fundamentally, in ways that are likely hidden. These differences may warrant considerable, even dispositive, moral weight. Nisbett and colleagues have found, for instance, that Koreans and Americans may respond in totally different ways when their beliefs are challenged. When presented with weak arguments against their beliefs, Koreans are more likely to view their beliefs less favorably. Americans tend to respond in the opposite way. Americans tend to favor the beliefs they initially had. The implications of this finding for careproviders who counsel parents — and for cultural relativity — may be considerable. If careproviders contradict what Korean parents believe, it may prove helpful. If they contradict what American parents believe, it may entrench the parents' views. This may suggest that neonatologists should tailor what they say to parents, depending on the parents.

Beyond this initial (and necessary) question regarding cultural relativity, neonatal practice in France clearly suggests that parents may be exceptionally vulnerable. This might suggest that careproviders in the U.S. should reconsider how they can best respond to parents. What can we do differently here, under our laws, as they now apply? Careproviders have tremendous authority due to their unparalleled expertise in medicine, and the psychological effect this may have on parents is great. It may be underestimated by careproviders and parents. The emotional impact of careproviders' statements is manifested by what has been called "the white coat syndrome." The mere presence of a care-

provider can instantly penetrate patients' emotional defenses. Patients (and parents) may react with an autonomic stress response when a careprovider merely enters the room.²⁸

This potentially dangerous effect on parents is exacerbated by a well-studied and acknowledged tendency in careproviders to be unduly pessimistic regarding the outcomes of parents and children when children have special needs. Careproviders tend to underestimate how much meaning and joy parents and children may achieve in their lives later.²⁹ Careproviders may need to have this exceptional and unrealistic pessimism to continue to function emotionally. They see suffering and tragedy on a daily basis. Like parents, their emotions may cause them to have inaccurate beliefs. They may need to experience more emotional distance, perhaps as a defense against becoming too close.

This distancing has been noted universally and over time. This distancing, although emotionally necessary, may have a price when careproviders counsel parents. Careproviders cannot help but have their own view of what parents should do when they must make a decision such as whether to try to keep a child alive. Careproviders may be affected unduly by the distance they feel; they may respond in various ways. One response is for a careprovider to try to be persuasive. The doctors I quoted earlier, who reviewed the experience of parents caring for a child on a ventilator, noted: "An immediate interpretation of these findings is that families should be fully informed of the demands and hardships that await them, encouraging parents perhaps to decide otherwise."³⁰

Another doctor's recommendation is less paternalistic and more representative of U.S. physicians: he suggests that physicians first acknowledge that they cannot predict with certainty what they would do. They might say, for instance, he suggests, "I can only imagine what this must be like for you." Having said this, careproviders, if asked, should share their views.³¹

I suggest that there may be a serious problem with this second approach. Suppose, for example, that a doctor, whether earlier or later, recommends that parents withdraw the child's life-sustaining treatment. Suppose the parents

go against this and their child lives. Suppose, also, that the child has the worst possible medical outcome, for example, that the child is so severely impaired that he or she can never come home from the hospital. What the doctor recommended may continue to haunt the parents. Since the careprovider recommended they withdraw treatment, and they then went against the advice, this may add profoundly to parents' regret or guilt. This is especially likely due to doctors' exceptional authority. Regret or guilt may be added due to what a careprovider merely connotes, and this may especially be a problem when careproviders are unduly pessimistic. In this context, let us once again examine the recommendation of the careproviders who studied parents of children on ventilators: their recommendation was much like that of the authors of the studies in France, who said we may need to "rethink approaches that may impose preventable burdens on these children and their families."³²

We should also consider the harmful result, should a careprovider say, "I think you should continue giving life-sustaining treatment," but the parents choose to let the child die. This may be more painful for parents, particularly because they will always remain uncertain whether the child could have had a good (even if rare) outcome. The possibility I wish primarily to raise is that, to whatever degree careproviders express their views, it may affect parents negatively if parents make a different choice. This is in part due to careproviders' exceptional authority, as I have repeatedly said, but may be due also to a tendency present in us all: parents, as all persons, may have a tendency when things go sub-optimally to ruthlessly second-guess themselves. This may occur whether parents make choices that result in their child living or dying. They may respond with wholly unwarranted guilt and regret. This particularly is the case if their careprovider recommended that they make the opposite choice.

SPARING PARENTS HARM

What can careproviders do to try to prevent this? There are several initiatives they can take. First, they can say, "I have my own views, but

they reflect only my own life and values. There is no way that I could ever put myself in your shoes and know what is best for you. *You know better than anyone else, anywhere, what is best for you*, even if this decision seems uncertain now, and remains uncertain later. Our laws give this choice to you and you alone, and, in my opinion, it is right that they give this decision, ultimately, to you.”

The content of this statement is common knowledge. What may not be common knowledge, even to careproviders, is how important it is to say this explicitly to parents. It may be uniquely empowering for parents to hear at this time that they have greater expertise in this area *than anyone else in the world*. It is particularly important, due to careproviders’ singular authority.

In this context, parents are the wisest persons alive. They and they alone have the best sense of what raising their child would mean to them, for example. As a result, they may know best what may be best for their child.

The conclusions of the doctors who studied parents caring for children on a ventilator have been noted above. The authors noted the parents’ burden but also said this: “Yet . . . despite the enormous difficulties described by these families, they also reported deep enrichments and rewarding experiences that *they could not imagine living without*.”³³ Only the parents will know this about themselves. Careproviders can soften the somewhat frightening message that parents have absolute responsibility to decide, by informing parents that they must attempt to make the best decision that they can, even if later they question whether their decision was the right one.

The careprovider can say, “No one — not me or anyone else — can possibly tell you what you should do in this instance. It is of the utmost importance, now and always, that you realize and accept your human limitations. Whatever you decide, you can only decide what you believe is best for you and your child now. Whatever you decide now is the right decision, even if, later, you see things differently. It also is true, no matter what anyone else says — even other careproviders — now, or later.”

For some parents, to hear a careprovider say this may be life-altering, as it may prevent feelings such as lifelong guilt, if they later change their mind or their decision is criticized by others. Careproviders who say this may help “immunize” parents from later “stigma,” and the effects may be immense.

Why might careproviders be able to assist parents to this degree? First, because of careproviders’ authority. Second, the support of just one other person may be all that parents need. It is well-acknowledged psychologically that most of us need the support of only one other person to be able to withstand even the most extreme stress. Thus, with the support of only one careprovider, parents may be able to cope with stigma not only then, but thereafter, and cope far better than they would have “on their own.”

Careproviders may be able to assist parents still more if they are willing to share their own views, but with one condition: careproviders and parents must discuss the pros and cons together first. Careproviders can say, “I’ll share my views with you if you want, if you feel this would be helpful, but only if we first discuss together the possible harm of my doing this. I must insist on our discussing the pros and cons first, because this may not be a good idea. My fear is that if I share my views and it turns out that they differ from yours, what I say may make it harder for you to decide what to do. Further, if you decide to go against my views, your decision may trouble you more later. This might occur, even if you feel you are as certain as you possibly could be about what you want, and that you should make this decision wholly on your own. What do you think?”

For careproviders to share their views only under these conditions, rather than respect parents’ autonomy, is paternalistic. It may enable some parents to escape any guilt they might experience should they choose not to follow their careprovider’s advice. Careproviders may soften this further by pointing out to parents that there is a difference between a careprovider’s medical and moral expertise: their medical views are scientifically based, but their ethical views aren’t. Careproviders should know this,

but parents may not. Parents may feel merely that they want all the help and advice they can get.

Careproviders should add that they are willing to make decisions with parents — whatever this might mean — if this is what the parents prefer. Then careproviders must point out a potentially important risk. “What if, years from now, you change your mind and believe that you decided as you did because of me? That could be exceedingly hard to live with. You might want to make your decision now, wholly on your own, and I will give you only as much medical information as I can, but not my own personal, non-medically based views. The most important thing now could be that *you* make this decision in a way that you can still say, after 20 years, ‘We feel good about what we decided, because we, and we alone, made the best decision we could at the time.’ ”

Careproviders should say this explicitly because it is important that parents not feel regret to any unnecessary degree. It is important to reduce the possibility that parents will regret having deferred, even in part, their decisions to anyone else. Discussing this beforehand may decrease parents’ feelings of regret, because they may be able to choose with a clearer conscience. They will know that they carefully considered the various risks beforehand. The main loss to many careproviders is that parents may choose not to hear their careproviders’ views, and this may, in turn, alter the child’s ultimate outcome.

This is based partly on a presupposition that has been previously questioned: that careproviders’ personal views warrant moral weight. This should be questioned because equally expert and experienced careproviders may have diametrically different ethical views on what should be done for a child, even when they totally agree on all medical considerations. Given this, children in the same medical situation may end up with far different outcomes when the moral views of different careproviders are given moral weight. As a result, outcomes may be arbitrary when they depend on which careprovider with which moral view happens to be the child’s careprovider.

LESSONS FROM EMPIRICAL RESEARCH

As indicated above, recent empirical data suggests strongly that we often respond emotionally to events and then use our reason to come up with rationales after the fact to justify what we decided emotionally. In this way, we convince ourselves that what we have chosen, based on factors that are outside our awareness, is, in fact, what we really most want, but the opposite may, however, be the case. This speculation is supported by several kinds of research, as mentioned above: studies of patients whose brain hemispheres have been surgically disconnected to treat them for seizures that couldn’t be controlled in any other way, and studies involving brain imaging.

EMOTIONS MAY DRIVE DECISIONS

In most patients whose brain hemispheres have been disconnected, only the left hemisphere can read and speak, and the right hemisphere can only read. Thus, a written request can be given to the right hemisphere, but only the left hemisphere can explain why the person is doing what he or she is doing. For example, when one such person’s right hemisphere was presented the word “wave,” he waved. When asked why he was waving, he rationalized this behavior by claiming that he had just seen someone that he knew.³⁴ This research indicates that when a researcher makes a request to a patient’s right hemisphere by a written message, and then asks the patient why the patient did what he or she did, the patient’s left hemisphere didn’t receive the message, but nonetheless responds. The left hemisphere that speaks has no idea why the right hemisphere acted, nor, for that matter, that the right, non-speaking hemisphere exists. Regardless, the left hemisphere comes up with a reason.

Researchers, based on these findings, conclude that one of the “main jobs of consciousness . . . is to confabulate . . .”³⁵ The brain-imaging studies mentioned earlier support a similar possibility, that we make decisions “emotionally,” and rationalize them shortly thereafter. Libet, the leading researcher in this area, states,

“mental awareness can be delayed up to . . . 0.5 s [seconds].” He concludes, on this basis: “The initiation of the freely voluntary act appears to begin in the brain unconsciously, well before the person consciously knows he wants to act.³⁶ He adds in another piece, summarizing his research to date, “If one extrapolates [from] this situation (admittedly without direct evidence), then all mental events are initiated and developed *unconsciously*. Indeed most mental events are probably completely *unconscious*.”³⁷ The possibilities that these studies suggest are of the utmost importance to careproviders who seek to maximize parents’ autonomy: they suggest that in some, if not all instances, we may make choices that we view as expressing our autonomy when, in reality, the choices do not. We are, put simply, much like persons whose brains have been split, as it is as if some other part of our brain, outside our awareness, makes decisions for us. This possibility, assuming that this takes place, is especially likely to occur when we face uncertainty, because uncertainty can create powerful, different feelings than we normally would be likely to have. Here is the core point: our feelings may provide rare insights into what we really want; on the other hand, they may be wholly misleading.

GAINING INDEPENDENCE FROM EMOTIONS

When possible, it is important for careproviders to inform parents that the relationship between the intellect and the emotions is not at all “symmetrical.” As W.B. Irvine, a philosopher, states in his recent book, *On Desire*, only emotions have “veto power.” The intellect has only the “power of persuasion.” The intellect can, in fact, persuade, but it can do so only if it can invoke a stronger emotion than the one it wants to suppress.³⁸

With this awareness, parents can more rigorously question what they feel. Parents may be more able to choose what they really want to do, given the understanding that their emotional responses may either enlighten or mislead them. They may be more able to accept what they feel and act on it, regardless of their intellect and reasoning, or they may be more able to ignore their emotional responses, should they contra-

dict what parents rationally think they should do.

Let us consider each of these in turn. When feelings are helpful, parents may suddenly experience a powerful, felt awareness of what they really most want. As Irvine states, “certain aspects of the process of emotion and feeling are indispensable for rationality. At their best, feelings . . . take us to the . . . place in a decision-making space, where we may put . . . logic to good use.”³⁹ We often instantaneously experience what we really want in this way. This was described decades ago by Carl H. Fellner and John R. Marshall, who studied how persons respond when first asked if they would be willing to donate an organ. Many of these potential donors immediately had a feeling that determined their answer. Careproviders subsequently gave them information about the gains and risks of the procedure. To the potential donors who had already made a decision, this information generally made little difference. They had “emotionally” already determined what they would do.⁴⁰ As Irvine states, “Emotional commitment has a life of its own: it either happens or it doesn’t.”⁴¹

Spontaneous feelings can, however, bring about highly harmful results. Instantaneous emotional reactions may cause parents to think that they should, or even must, make a decision that they really don’t want to make. Guilt for taking their child’s life may, for example, “make them feel” that they should keep their child alive at all costs. Alternatively, parents may feel shame for making a decision that they fear is “overly selfish.” For example, parents may feel compelled to let a child who seems to be very badly off die, when what they want is to raise the child, even if she or he remains in the worst possible clinical state. This latter possibility may seem implausible, but it isn’t. The response of the parents of children who are chronically dependent on assisted ventilatory support exemplifies this; parents reported “deep enrichments and rewarding experiences that they could not imagine living without.”⁴²

Such sudden positive — or negative — feelings may arise at any time; any critical event, may, for instance, “shatter” parents’ “coping

process.”⁴³ It may be more important for parents to be aware of feelings that prevent them from choosing what they really want, than for parents to give positive feelings equal weight. Feelings may cause parents to make choices that depart radically from what they really want and from what seems reasonable. Such “harmful” feelings may occur not only instantaneously; they may exist from the moment their child is born, or even before.

One example of such a feeling is chronic denial; such denial may help parents cope with a child’s very serious medical problems in the short run. It may help parents bear, for example, that their child may be so ill that he or she will never be able to leave the hospital. In the longer run, however, this same denial may blind parents from being able to see realistically what they can expect. For example, when a child is in the neonatal ICU, parents typically limit their hopes to the child’s day-by-day experience; they may focus only on their child’s survival, for example. As Orfali and Gordon state, “One can . . . interpret this response as denial.”⁴⁴ They add that this “overall inability of mothers to anticipate future quality of life problems while in the NICU is ‘problematic’ . . . regarding ‘any’ medical decisions these parents have to make.”⁴⁵

Such an exclusive focus on the child’s day-to-day survival may prevent parents from asking themselves more fully what the child’s survival will really mean to the child and to them. Further, each day that the child continues to survive, their bonding with him or her will increase, and their denial may increase as well. Their bonding may, in fact, be another feeling that exists early on, and may keep them from being able to more accurately anticipate their and their child’s likely future. If parents don’t realize this, they may not be able to choose what they really most want for themselves and for their child.

My purpose here is not to suggest, in any way, *what* parents should decide. My purpose is to indicate that careproviders can, in light of what we know, make some exceptional efforts to help parents, and possibly make a difference. By alerting parents to the possibility that their emotions may be either helpful or harmful, and

that these emotions may express what they truly want — or just the opposite — they may be freed to more truly decide what they really want to do. As Irvine states, “we can study the way we form desires and learn to distinguish those things that are really desirable, given our life plan, from those [that are not].”⁴⁶

How can careproviders help parents do this? They can encourage parents to ask themselves whether what they *feel* is or isn’t what they really *want*. Parents may not know to ask this; they may believe, on the one hand, that it is always wrong to act solely on the basis of what they feel. Perhaps they may feel that their emotions are wholly unreliable. On the other hand, they may believe that they have no choice but to accept what their emotions dictate; that is, that they can’t or shouldn’t ever act in a way that “betrays” what they feel. They may believe that if they have an emotion that goes against what they think they should do, they have no choice but to wait for their emotions to change, because they can’t do something other than what they feel. Both presuppositions will leave parents helpless.

In just a few sentences, careproviders can strongly influence or “nudge” such erroneous assumptions toward perspectives that enhance parents’ autonomy. Again, this is because many parents, consciously or otherwise, give careproviders exceptional authority. Careproviders thus can help parents make choices that they otherwise couldn’t make. Careproviders can say, for example, “Your feelings may help you to make decisions, but they also may make it harder for you to know what you really want most. This is because feelings may be the only or best indication of what you really want, on one hand, or they may strongly mislead you, on the other.”

A specific example that careproviders may use is the following true clinical case, cited by Irvine: a patient whose connection between her two brain hemispheres had been partially severed. Her left hand moved as if it was that of another person. Her left hand tried repeatedly to strangle her during the night when she fell asleep. It became necessary for her to protect herself by tying this one hand down before she went to sleep every night.⁴⁷

This case is an extreme example of how we can work against our own interests. Careproviders can also explain that some emotions emerge in times of crisis, and having a child's life in jeopardy may be the kind of crisis that triggers one of these different, latent emotional responses for the first time. Careproviders can continue, "You might want to keep close track of your feelings, and ask yourself regularly whether you think each feeling is a guide to what you really want, or is misleading you — or neither. You may not ever know, but by asking yourself repeatedly, you may be able to increase the likelihood of choosing what it is that you really want most."

Careproviders can help parents understand this by using the analogy of falling in or out of love. On occasion, people feel that they have "fallen in love," and, from a rational, objective perspective, the one they love may be the very worst person for them. The person may have, for example, a history of constant physical or emotional abuse.

People can also, in an instant, "fall out of love," and such momentary losses of feeling should not necessarily be an absolute guide to what we should do. We may experience such a loss of love after, for example, years in a "good marriage," and then our feelings of being in love may return. Such sudden changes even occur in persons who are most analytical; an example is the philosopher Bertrand Russell, who reported, "Suddenly the ground seemed to give way beneath me, and I found myself in quite another region."⁴⁸ He was with a three-year-old boy, and, previously, had taken no notice of him. Then, Russell took the boy's hand for just a few moments to lead him away from his mother so that he would not trouble her while she was experiencing some pain. Russell reports that, at the end of these five minutes, "I had become a completely different person. For a time, a sort of mystic illumination possessed me."⁴⁹

A careprovider can also say, "I will be most willing to help you with this process, if you feel that you would like me to." These initiatives may be especially helpful when parents are "on-the-fence" or highly torn as to what to do, and their emotions may serve as a tie-breaker. They

may be able to acquire greater independence from their emotions.

LEARNING FROM STUDIES OF PARENTS

Perhaps the greatest preventable loss that commonly occurs when an infant is born with special needs is that parents may lose the positive relationship they had with one another. As one parent stated, "It's your couple relationship that will really suffer . . . 80% of people with a sick child end up separated. . . ."⁵⁰ The birth of such a child may cause profound lifelong stress for a family. As another parent said, speaking of genetic conditions, "The diagnosis of an inherited condition can drop a bombshell into family relationships."⁵¹

There are several reasons that parents may lose their relationship. If, for example, the child dies, parents may find that being with their partner evokes memories of their child that are unbearable. Careproviders should tell parents that, at these times, they can help each other more than anyone else can.

HELPING PARENTS

When making difficult decisions, parents know firsthand what the other has gone through. Accordingly, each partner may find that the other is the most helpful support person they have, followed by their families, friends, and health professionals.⁵² As a first step, therefore, careproviders should point out how parents can be the best supports for each other. All too frequently, partners seek primary support from others. In one study of several NICUs, for example, a larger proportion of parents took into account their physicians' opinions than those of their partner.⁵³ Careproviders may be able to benefit parents by asking them to consider this, and by telling them there is one reason that they should seek support from each other above all else: it may be the only way they will stay together, and ultimately most benefit their child.

Careproviders can point out that partners sometimes discover this during a crisis. For example, Will Jimeno, a policeman, was trapped for 13 hours under the wreckage of the south building of the World Trade Center on 9/11.

While he was trapped, he talked with his wife on the phone. Previously they had argued over what to name their daughter, but at this time each agreed to go along with what the other preferred.⁵⁴ This is a paradigm for what each parent should try to do. Each should strive to say to the other, “I don’t want what you prefer but I can accept it, because this is what *you* want, and it’s so important to *you*.” Careproviders can also point out that after such a decision is made, one partner mustn’t ever blame the other later for the decision. Further, there can be no place for one partner to feel that he or she is “owed” a “payback” for sacrificing his or her view.

Careproviders can point out that the decisions parents will make may result in their having a wholly different style of life, and thus, even if they now agree on a decision, this may later change. I think of parents who initially chose to keep and raise a child who had most profound emotional and intellectual deficits. One stayed up to watch the child at night. Their child became an adolescent, and then was physically violent and could cause serious harm. One parent couldn’t accept the risk of being hurt, especially when careproviders said their son would do better in an institution. The other parent remained committed to continuing to care for the child at home. The parents couldn’t agree.

The importance of careproviders using this example is twofold: first, it helps parents anticipate possible outcomes, so they can then make a better choice. Second, it gives careproviders one more priceless opportunity to emphasize that we can only make the best decision that we can. The memory of these discussions may stay with parents.

HELPING PARENTS AS A COUPLE

Careproviders can help parents to seek help, which may enable parents to have a richer relationship. The primary gain we can have in a relationship is to be able to escape and transcend our emotional isolation. Parents often lack the capacity to recognize and share their vulnerability with a partner. If they can learn how to do this better, it may enhance their relationship during — and after — this most stressful, early decision making involving their child.

HELPING SINGLE PARENTS

Sometimes no other parent is available, or the other parent is unknown or long gone. In these instances, careproviders can explore with the single parent if there is anyone else who might want to help out. This initiative is surprisingly effective, probably because often there are such persons, but single parents assume they either wouldn’t want to help, or would help only from a feeling of obligation or pity. Careproviders can point out that asking for help may actually be doing the other person a great favor: How many of us, careproviders can ask, normally feel — after our children are grown, if we’ve had them — that we can make a really significant difference in someone else’s life?⁵⁵

If the parent can suggest someone, a careprovider can offer to contact this person on the parent’s behalf. The key here is to start wherever the other person is. “Would you be able,” the careprovider can ask, “to meet for just a minute, talk on the phone, or even only send and receive a message using the internet to help this parent?”

CONCLUSION

In this introduction, I have explored some of the questions Coors and Townsend raise in this issue of *The Journal of Clinical Ethics* regarding careproviders and parents. While careproviders can and should respect parents’ autonomy, in the traditional sense, as Coors and Townsend assert, they can also enhance parents’ autonomy.

The most difficult thing may be for careproviders to give up sharing their own personal views. One of the key thoughts careproviders should consider is the many ways that this may cause harm. I think in this regard of Kim, a child who was dying. She was offered many opportunities to participate in numerous research trials. Kim participated in many trials until her parents learned, in the last trial, that no child before had ever continued to survive. Kimberly’s mother reports that several weeks passed until she and her husband told the researchers, “No.” These days were, she says, “the longest days of our lives.”⁵⁶ What made this time

seem the longest, in part, was that many doctors mostly shared one and only one view: they did not tell Kim's parents that one medically reasonable and ethically justifiable choice was for them to not give Kim further experimental treatments. "Why do they not say there is another choice?" Kim's mother asks. "Why will they not say, 'Take Kimberly home, love her, and give her the most normal life you can?'"⁵⁷

NOTES

1. The consequential arguments for doing or not doing a cesarean section may vary according to the fetus's medical condition. See, e.g., R. Wadhawan et al., "Does Labor Influence Neonatal and Neurodevelopmental Outcomes of Extremely-Low-Birth-Weight Infants Who are Born by Cesarean Delivery?" *American Journal of Obstetrics and Gynecology* 189, no. 2 (August 2003): 501-6.

2. F.A. Carnevale et al., "Daily Living with Distress and Enrichment: the Moral Experience of Families with Ventilator-Assisted Children at Home," *Pediatrics* 117, no. 1 (January 2006): e48-60, p. e49.

3. See, i.e., J.A. Robertson, "Extreme Prematurity and Parental Rights After *Baby Doe*," *Hastings Center Report* 34, no. 4 (July-August 2004): 32-9.

4. K. Orfali, "Parental Role in Medical Decision-Making: Fact or Fiction? A Comparative Study of Ethical Dilemmas in French and American Neonatal Intensive Care Units," *Social Science and Medicine* 58, no. 10 (May 2004): 2009-22, sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4B2CFXC-1&_cov.

5. *Ibid.*, 10.

6. *Ibid.*, 12.

7. K. Orfali and E.J. Gordon, "Autonomy Gone Awry: A Cross-Cultural Study of Parents' Experiences in Neonatal Intensive Care Units," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 329-65, p. 352.

8. Orfali, see note 4 above, p. 11.

9. Orfali and Gordon, see note 7 above, p. 345.

10. *Ibid.*, p. 346. A recurrent argument also used by French neonatologists is that their own medical interventions have brought these critical situations. Therefore it is their professional duty

to correct them. Orfali, see note 4 above, p. 15.

11. W.B. Irvine, *On Desire* (New York: Oxford University Press, 2006).

12. Chief among these are St. Augustine, Hume, Schopenhauer, and Russell. See, i.e., *ibid.*, 115-9. Russell stated, for example, "the discovery of our own motives can only be made by observing our actions and inferring the desire which could prompt them." *Ibid.*, at 118, citing B. Russell, *The Analysis of Mind* (London: George Allen and Unwin, 1921), 30-1.

13. M.S. Gazzaniga, "Forty-Five Years of Split-Brain Research and Still Going Strong," *Nature Reviews Neuroscience* 6 (2005): 653-9.

14. B. Libet, "Reflections on the Interaction of the Mind and Brain," *Progress in Neurobiology* 78 (2006): 322-26.

15. Orfali, see note 4 above.

16. P. Alderson, J. Hawthorne, and M. Killen, "Parents' Experiences of Sharing Neonatal Information and Decisions: Consent, Cost, and Risk," *Social Science and Medicine* 62 (2006): 1319-29.

17. Orfali, see note 4 above, p. 12.

18. *Ibid.*, 10.

19. Orfali and Gordon, see note 7 above, p. 345.

20. *Ibid.*, 351. One parent states, "what if we had not resuscitated them . . . I am haunted by that," p. 342.

21. *Ibid.*, 352.

22. *Ibid.*, 353.

23. *Ibid.*, 349.

24. *Ibid.*, 347.

25. *Ibid.*, 348.

26. *Ibid.*, 349.

27. *Ibid.*, 356.

28. A.J. Engler, "Maternal Stress and the White Coat Syndrome," *Pediatric Nursing* 31, no. 6 (November-December 2005): 470-3.

29. E.g., "many HCPs [healthcare providers] hold negative prejudgements toward life with disability." Carnevale et al., see note 2 above, p. e58.

30. Carnevale et al., see note 2 above, p. e49.

31. A.A. Kon, "Answering the Question: 'Doctor, If This Were Your Child, What Would You Do?'" *Pediatrics* 118, no. 1 (July 2006): 393-7. Kon states, "It is appropriate to answer the parents' question, because this is a medical judgment," (p. 394).

32. Orfali, see note 4 above.

33. Carnevale et al., see note 2 above, p. e59.

34. Irvine, see note 11 above, p. 97.
35. Ibid.
36. Ibid., 93. Libet states: "There is a subjective referral backward in time to coincide with the time of the primary cortical response to the earliest arriving sensory signal," Libet, see note 14 above, p. 322.
37. Libet, see note 14 above, p. 324.
38. Irvine, see note 11 above, p. 76.
39. Ibid., 114.
40. C.H. Fellner and J.R. Marshall, "Kidney Donors — The Myth of Informed Consent," *American Journal of Psychiatry* 126, no. 9 (1970): 1245-51.
41. Irvine, see note 11 above, p. 74.
42. Carnevale et al., see note 2 above, p. e49.
43. Orfali and Gordon, see note 7 above, p. 344.
44. Ibid.
45. Ibid., 341.
46. Irvine, see note 11 above, p. 106.
47. Ibid., 95.
48. B. Russell, *The Autobiography of Bertrand Russell* (Boston: Little, Brown and Company, 1967), 220.
49. Ibid.
50. Carnevale et al., see note 2 above, p. e54.
51. R. McGowan, "Beyond the Disorder: One Parent's Reflection on Genetic Counselling," *Journal of Medical Ethics* 25 (1999): 195-9, p. 197.
52. S. Lee et al., "Acculturation and Stress in Chinese-American Parents of Infants Cared for in the Intensive Care Unit," *Advances in Neonatal Care* 5, no. 6 (December 2005): 315-28, p. 316.
53. J.C. Partridge et al., "International Comparison of Care for Very Low Birth Weight Infants: Parents' Perception of Counseling and Decision-Making," *Pediatrics* 116 (2005): 263-71, p. 265.
54. D. Thomson, "Oliver Stone's Trade Center Is Two Stories Short," *Washington Post*, August 9, 2006.
55. A good example is provided by a person who donated a kidney. After donating, the person said, "Criticism is not so painful because you know you did something good." Fellner and Marshall, see note 40 above, p. 575.
56. L. Markell, *Little One Laugh Little One Run* (Bloomington, Ind.: Author House, 2005), 89.
57. Ibid., 77.

Features

The Case of A.R.: The Ethics of Sibling Donor Bone Marrow Transplantation Revisited

Douglas J. Opel and Douglas S. Diekema

INTRODUCTION

Since its development in the 1950s, bone marrow transplantation (BMT) has become an increasingly common treatment for an expanding number of childhood diseases. Not only is it a mainstay of salvage therapy for childhood cancers such as leukemia, but it also offers the prospect of cure in several nonmalignant disorders such as aplastic anemia, immunodeficiency disorders, leukodystrophies, and some forms of juvenile rheumatoid arthritis and systemic lupus erythematosus.¹ As the therapeutic applications for BMT in children continue to broaden, so do the ethical dilemmas that surround those indications.² In pediatric allogeneic BMT, the recipient's chance for cure is best if the bone marrow comes from a human leukocyte antigen (HLA) identical donor, usually a sibling.³ Out of all pediatric BMTs from 1985 to 1990, 76 percent utilized HLA identical sibling donors.⁴ The ethical implications of the matched

sibling donor (MSD) BMTs are numerous, and include the nontherapeutic nature of bone marrow donation, the vulnerability of the minors involved, the inability of most minor donors to provide a valid consent, and the inherent conflict of interest that exists for the minor's parent or parents who consent to the nontherapeutic donation of bone marrow from one child so that the therapeutic outcome of another child can be optimized.⁵

The goal of discussing such dilemmas is ultimately to protect the rights of both the child recipient and the sibling donor. As minors, both participants are generally considered incompetent to make legally binding decisions regarding their healthcare. Therefore, parents are empowered to provide informed permission, and their decision is nearly always respected by the courts unless it poses significant risk to the child's health, well-being, or life.⁶ In making medical decisions for a child, the ethical duty of parents is to act in the best interest of the

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child. However, in MSD BMT, a conflict of interest arises since the interest of one child (the recipient) may conflict with the interest of the other child (the donor). To choose not to consent to sibling donation limits options for treatment to options that may be much less likely to benefit the child with the illness.⁷ Can a parent in this difficult situation adequately protect the interest of the child donor?⁸ Is this a situation where the courts or a guardian *ad litem* should determine whether the minor's best interests would be served by being a donor?⁹

While some data exists to aid decision making in these situations, there is much that remains unknown. The physical risks of the bone marrow aspiration procedure are known to be relatively minimal.¹⁰ However, there are aspects of risk that remain unexplored. Are there psychological risks to a child acting as an involuntary donor? What are the psychological risks of not donating? Do these risks outweigh the benefits? Although these issues are addressed on a routine basis when siblings are considered for participation in a BMT process, and child donors are often psychologically evaluated and counseled with regard to their ability to adjust, handle strong emotions, and deal with stress, little is known about the acute and long-term psychological effects of BMT in sibling donors, and much tends to be assumed.¹¹

We present the case of a 15-year-old convicted sex offender in need of a BMT. His case raises several important ethical issues related to BMT. First, this case prompts the need for a discussion of the appropriateness of high-cost medical treatments in the burgeoning juvenile incarcerated population.¹² We will argue that it would be unjust to deny a lifesaving opportunity to an incarcerated minor and that patients such as the one described in this case should be offered the same medical treatment afforded non-prisoners. Second, this case presents unique features that underscore the need to better understand the psychological effects of BMT in sibling donors. We will argue that psychological harm is a potential risk of any MSD BMT, that the potential for psychological harm should be given serious consideration in the assessment of potential risks and benefits of donation for

the sibling donor, and that any assessment of psychological risk must consider additional risk factors that might compound the risk of significant harm to the child donor. Finally, we will utilize a harm-based analysis to explore the question of whether the BMT should be allowed to proceed in a case such as this one.

CASE

A.R., a 15-year-old boy, presented with a two-week history of headache, sore throat, fever, and night sweats. Physical examination revealed subconjunctival masses, and a complete blood count disclosed a white blood cell count of 43,000. The patient was in state custody and incarcerated at a state correctional facility for a history of sexual assault of his younger sister, and was transferred to a tertiary care center where further tests confirmed the diagnosis of acute myelogenous leukemia (AML).

With a predicted cure rate of approximately 50 percent, the patient underwent intensive induction chemotherapy. His leukemia was initially refractory to standard induction therapy, but remission was ultimately achieved with intensive salvage chemotherapy. He suffered severe but anticipated toxicities, including admissions to the intensive care unit for sepsis and fungemia (the presence of fungi or yeast in the blood).

Despite continued aggressive conventional chemotherapy, an early bone marrow relapse (less than 20 percent blasts) was confirmed by cytogenetic evaluation six months after diagnosis. Options for treatment of his marrow relapse included a BMT immediately or further chemotherapy to induce a second remission followed by BMT. Given that his leukemia had already proven to be refractory to conventional chemotherapy and that further conventional chemotherapy would heighten risks for additional infectious complications prior to transplant, the patient and his mother chose to proceed with a BMT. A family and unrelated donor search initiated six weeks following diagnosis had identified his nine-year-old sister, L.R., the victim of his prior sexual assault, as an identical match. An identical match donor would optimize the chances for a good outcome, and the probability of relapse with BMT was estimated to be as high as 40 percent, with the probability of long-term disease-free survival and cure also estimated to be 40 percent. Due to the history of abuse, L.R. underwent a brief psychological assessment that concluded that she would be suitable as a BMT donor. This assessment was limited, however, by the fact that L.R.'s mother would not allow the psychiatrist to talk with L.R. about the past abuse, and would not allow her to be interviewed

alone. BMT was performed seven months after initial diagnosis and the recipient experienced a relatively uneventful course of donor engraftment. L.R. had an uncomplicated bone marrow harvest and post-operative recovery. A.R. was discharged back to the state correctional facility 10 months after his initial diagnosis, but suffered relapse 10 months later. He decided against re-induction chemotherapy, his mother did not challenge his decision, and he died two months after diagnosis of his relapse.

DISCUSSION

This case is unique because not only does it require one to address whether a convicted sex offender should be offered BMT, but it raises the much more complicated issue of whether his victim should be considered a potential donor. To our knowledge, this is the first such situation to appear in the medical and ethics literature, and it raises three distinct questions. First, should prisoners have access to costly medical interventions like BMT? Second, should parental permission for the use of bone marrow obtained from a minor sibling be considered valid? Finally, should a minor sibling be permitted to act as transplant donor when the recipient sexually assaulted her in the past?

PHYSICIANS' OBLIGATION TO PROVIDE OPTIMAL CARE VERSUS SOCIAL JUSTICE

The first question was whether A.R., as a sex offender, should have been offered a BMT at all. In 1976 the United States Supreme Court ruled in *Estelle v. Gamble* that under the Eighth Amendment an incarcerated individual has a right to medical care, as it is "but just that the public be required to care for the prisoner, who cannot by reason of the deprivation of his liberty, care for himself."¹³ While the Eighth Amendment requires that a prisoner not be denied medical care, it does not explicitly address just how much care should be provided. Much of the debate thus revolves around whether prisoners are entitled to high-cost medical treatments such as organ transplants.¹⁴ Proponents argue that prisoners should be entitled to the same healthcare as members of the general community,¹⁵ and that this includes even high-cost

treatments that are considered the standard of care for a given disease or illness. This level of care, the argument goes, is in line with the Supreme Court's interpretation of the basic concept underlying the Eighth Amendment: "nothing less than the dignity of man."¹⁶ Furthermore, some prisoners may serve their sentences, rehabilitate, and become reintegrated as contributing members of the community. It would be unfair to remove that opportunity by denying a level of healthcare that would be available outside of prison.¹⁷ Furthermore, for those who re-enter society, it is better for all that they enter as healthy citizens, thereby minimizing "the risk of poorer health to the community."¹⁸

Not everyone agrees with that sentiment, however, and the more expensive a medical treatment, the more people tend to disagree.¹⁹ The cost of providing healthcare to correctional institutions is estimated at \$3.75 billion a year,²⁰ and the inclusion of high-cost treatments would increase that amount even more. Further, how can society justify providing prisoners, who are guaranteed at least some level of healthcare by *Estelle v. Gamble*, better healthcare than many of its law-abiding citizens who remain uninsured or uninsurable and cannot afford even routine healthcare? Is it really right to grant a prisoner access to a very high level of healthcare when some law-abiding members of society have only limited access? Finally, some would argue that when high-cost treatments involve scarce resources (for example, kidneys or livers available for transplantation), a convicted murderer on death row should not have equal access.²¹ How can we make sense of these two conflicting views?

Around the time of *Estelle v. Gamble*, accreditation agencies were formed to help develop a standard of healthcare for prisoners.²² Today, organizations such as the American Academy of Pediatrics and the American Medical Association are represented on the board of directors of the National Commission on Correctional Health Care and routinely publish policy statements as guidelines for care in jails.²³ No guidelines have been established for prisoners in need of solid organ or BMT, however, leading to inconsistent care for those prisoners.

Navari and colleagues relate the case of an adult prisoner serving a life sentence for first-degree murder when diagnosed with chronic myelogenous leukemia (CML). In response to his need for a BMT, the authors state that such a prisoner should “receive the same health care as individuals who are not incarcerated and that the costs of care should play no greater role for prisoners than for other members of society.”²⁴ Other case reports of prisoners evaluated for transplant offer similar conclusions.²⁵ Jeffrey Spike advocates trying to avoid a “categorical exclusion” for prisoners, but states, “transplant center(s) should consider each case individually.”²⁶ In addition, J. Paul, responding to the case of an adult prisoner serving a sentence for third-degree murder who required a BMT for CML, wonders what “retribution is morally appropriate for a certain type of criminal.” He argues that BMT should not have been offered to the prisoner, nor should the prison system have paid for his care, because the “severity of his crime militates against either.”²⁷

Without consensus, then, we turn to the case of A.R. The decisions about whether A.R. deserves a transplant may be helped by first distinguishing him from others, based on two criteria. First, A.R. was not a prisoner on death row, and therefore was subject to a different set of considerations than those prisoners condemned to death who require lifesaving treatments. Second, A.R. did not require a solid organ transplantation. Solid organs are a scarce resource, and therefore are subject to discussions of rationing and justice, whereas bone marrow is not.

With these distinctions in hand, Lawrence Schneiderman and Nancy Jecker’s model of medical versus societal justice provides an appropriate framework in which to answer the question of whether A.R. should be offered a BMT. The authors argue that physicians “lack the moral authority to deny beneficial medical treatments on any grounds,” specifically on grounds of societal worth.²⁸ The nature of a patient’s crime should be irrelevant to the physician, they contend, and the decision to treat should be made solely on clinical grounds: this is medical justice. How to distribute scarce re-

sources, like a limited number of solid organs for transplant, lies within society’s realm: this is societal justice. A given society might consider convicted murderers or other criminals to be in violation of the societal contract, and, by virtue of that violation, not entitled to deprive those who have kept the social contract of scarce resources like organs. In that case, society might impose upon the medical field that only a “rudimentary decent minimum” be provided for convicted murderers.²⁹ However, if society feels that everyone, regardless of whether they are a criminal or not, deserves equal access to any and all medical care, those in the medical field should respect such laws. The point of Schneiderman and Jecker’s theory is that with a lack of consensus in society regarding how much medical care prisoners are entitled to, it is not within the moral realm of physicians to treat prisoners differently than any other patient. Whether a prisoner should receive a transplant should be governed strictly by the clinical situation, not the social situation, unless society has dictated otherwise.

Since the arguments surrounding the ethics of lifesaving medical treatments to a prisoner on death row fell outside the discussion involving the case of A.R., to deny him a BMT would constitute medical injustice, using Schneiderman and Jecker’s model. Refusing to provide A.R. with a potentially lifesaving BMT would be equivalent to the medical team handing him a death penalty in a situation in which society has already determined that his crime was not severe enough to justify death. Furthermore, since the BMT A.R. needed is not a scarce commodity, no one else would be deprived of a transplant if he received one, and therefore comparative justice principles did not apply. For these reasons, we argue that A.R. should have been offered the same medical treatment that was afforded to non-prisoners.

A CHALLENGE TO PARENTAL AUTONOMY

The second question that A.R.’s case raised was more difficult: was it ethical to ask L.R., the child sibling whom A.R. sexually abused, to donate her bone marrow to help save his life?

To get to an answer, we must first ask whether it is appropriate for any minor to be subject to a nontherapeutic medical procedure for the benefit of another. If there are conditions in which that is appropriate, we can then turn to whether that same minor should have been asked to donate when she had been the victim of a crime perpetrated by the recipient of her donation.

Under United States law, minors are generally considered incompetent to provide legally binding consent regarding their healthcare, so parents or guardians are generally empowered to make those decisions on their behalf, and the law has respected those decisions except when they place the child's health, well-being, or life in jeopardy.³⁰ In this case, the decision rested with the mother of both children (the father of the children was no longer involved as a decision maker). As long as the mother's decision did not place either of her children's health, well-being, or life in jeopardy, it would be legally respected. The situation A.R.'s mother found herself in, however, was inherently full of conflict: if she refused to allow L.R. to act as a donor, she placed A.R. at increased risk of death; yet, if she authorized L.R. to act as donor, she might have caused her daughter the potential harm of being forced to donate to a person who victimized her.³¹ While the courts do reserve the right to review the procedure of informed consent in situations such as this one, because "the parent's concern for their ill child may cloud their judgment for the safety of the donor,"³² it is not often exercised, and parents' decisions are usually respected without review.

Some authors have suggested that, to ensure that the interest of the donor is represented in an unbiased manner and therefore that surrogate consent be valid in the case of MSD BMT, a guardian *ad litem* should be appointed by the court.³³ When courts do exercise their prerogative "to review the procedure of informed consent in order to satisfy itself that the process of informing had been sufficient to give a clear estimate of the risks and benefits," as established by *Nathan v. Farinelli* in the Massachusetts Court, they have not usually assumed the position of surrogate parents, but instead rely on a court-appointed child advocate, or guardian *ad*

litem.³⁴ As advocate for the child donor, the guardian *ad litem* must judge "that transplantation is preferable to alternate therapy, that medical risks such as general anesthesia and blood loss are acceptable, that the parents and donor have indeed given their consent after being fully informed of the risks and benefits, and that the consent was not given under duress."³⁵ Despite the availability of this option, however, a guardian *ad litem* is only occasionally used in situations of MSD BMT, and, under most circumstances, this may be reasonable.

Through a model of decision making on behalf of children that advocates for trust in parental discretion in most situations, Lainie Friedman Ross offers an explanation for why.³⁶ In her model of "constrained parental autonomy," she breaks from the *best interest standard*, in which decisions are made on the basis that they are in the patient's best interests, and instead argues for promotion of a child's *basic* interests. By doing so, her model then allows parents to "trade the best interests of one child for familial interests as long as the basic needs of each child in the family is secured: abuse, neglect, and exploitation are prohibited, and children must be provided with goods, skills, liberties, and opportunities necessary to become autonomous adults capable of devising and implementing their own life plans."³⁷ In situations like the donation of bone marrow, where the degree of risk or harm to the sibling donor does not exceed a "minor increase over minimal risk," Ross's model of constrained autonomy "allows parents of intimate families to authorize bone marrow donation" as long as their authorization "simultaneously respects the child as the developing person that she is" and "does not sacrifice any of the child's basic needs." Ross's model therefore envisions a child's well-being in an intimate family as being fully intertwined with the well-being of other family members, and by donating bone marrow to help save the life of a sibling, a child serves to promote the well-being of the family, and indirectly, serves her or his own goals.³⁸ Others have also argued for a similar position.³⁹

Ross's model would argue for allowing a parent to have one child act as a bone marrow

donor for another family member in most situations. However, there are elements of the case presented that do not allow a direct application of Ross's model. A prerequisite of Ross's model is that it applies to an intact "intimate" family. The intimacy between family members fulfills Ross's intent to "respect the freedom of parents to balance competing claims of family members, provided that each child-member's basic needs are satisfied."⁴⁰ The more intimate a family, the more likely that enhancing the family's well-being will enhance the well-being of each child in the family, and the more one is able to respect the parents' decision making when one child is in the position to endure medical risk for another. Subjecting one sibling to the bone marrow donation process to help save the life of another child is thus, according to Ross, morally justifiable in an intimate family.⁴¹

We argue that this family intimacy may be compromised in the case of A.R. Foremost, A.R.'s past abuse of his sister introduced a destructive element into the family's ability to function in a healthy or intimate way. In addition, since being sentenced to a juvenile detention center nearly a year prior to his diagnosis, he was not physically around any family members; prior to his incarceration, he had not been living with his mother, the primary medical decision maker during his illness. Although contact with his mother and sister redeveloped once he was hospitalized, and even if that contact represented a genuine attempt to repair family relationships, it remains true that the relationship between A.R. and his family prior to his illness had been less than ideal. Such family conditions fall short of the prerequisites for Ross's constrained parental autonomy model, and should call into question whether a parent in this case should be permitted to trade the interests of one child for those of another.

Ross, in fact, imagines a similar scenario in which a sibling donor's refusal to participate might be so strong that it makes her willing to "rupture family bonds."⁴² In such a case, Ross contends that the donor must not be ignored: "it could be a grave mistake to allow a child's immature selfishness to override parental autonomy, particularly if there is a good chance

that the child will come to regret the decision at a later date . . . But it could be a more egregious error to ignore the child's dissent if her refusal is due to genuine non-intimacy."⁴³ Such a scenario could be a reality, Ross footnotes, if the donor, for example, refused because her sibling repeatedly raped her and her parents refused to protect her. Ross's hypothetical scenario bears some resemblance to A.R.'s case. Although his sister never vocalized a refusal to donate, it was not clear that this was something she was comfortable expressing. Her mother's desire to provide her son with the best possible opportunity for survival might have altered her ability to evaluate the impact of donation on L.R. We would argue that Ross's model of constrained parental autonomy was not applicable in such instances, as the break in family intimacy "moves the decision into the public forum."⁴⁴ A.R.'s mother should not have been relied upon to protect L.R.'s basic interests under such extreme conditions of family dysfunction.

In a situation like this, in which there was a reason to question whether parental permission adequately protected the interests of the donor, the appointment of a guardian *ad litem* should have been considered. The apparent lack of intimacy within A.R.'s family, the possibility that the interests of A.R. directly conflicted with the interests of L.R., the likelihood that this constrained their mother's autonomy and might have compromised her ability to protect L.R.'s basic interests and needs, the mother's refusal to allow a psychological assessment of L.R., and her desire to solicit L.R.'s willingness to donate, suggest the healthcare team should have sought the involvement of a guardian *ad litem* as an alternative to protect L.R.'s rights and interests.

There is legal precedent for disallowing transplant donation when there is a lack of established intimacy between sibling donor and recipient. In 1975, the Wisconsin Supreme Court denied the request to approve a kidney transplant from a 39-year-old institutionalized catatonic schizophrenic to his 38-year-old sister.⁴⁵ The court's reasoning was that "the death of the sister would not have resulted in mental anguish for the incompetent brother."⁴⁶ In contrast, the case of *Strunk v. Strunk* held that the

converse would also be true.⁴⁷ The two brothers were found to have such a strong emotional bond that the Kentucky Court of Appeals approved the transplant of the 29-year-old's kidney to his 28-year-old sibling, even though the donor sibling was an "institutionalized adult with the mental capacity of a 6-year-old."⁴⁸

Although both cases involve solid organ transplants, they underscore the importance of an intimate relationship between donor and sibling before a surrogate can reasonably consider the procedure to represent a benefit to the donor. Solid organ transplants convey more medical risk to donors than BMTs do, but the present case added the potential for psychological risk to a young donor who was subject to a procedure and donated her bone marrow to an individual who sexually abused her. The risks and benefits of donating under these conditions will now be considered.

FIRST, DO NO HARM

We have argued in the past that the harm principle is the actual standard used in courts and by medical providers to justify interfering with parental decisions.⁴⁹ Although the best interest standard is most frequently employed in such instances, it provides insufficient guidance for decision making regarding children: "the real question is not so much about identifying which medical alternative represents the best interest of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated."⁵⁰ The case we have presented raises the question of whether the harm to which the donor will be subjected by donating bone marrow under these circumstances is significant enough that her parent should not be allowed to authorize it.

What is the threshold above which a parental decision poses sufficient risk to a child that it should not be tolerated? Several possibilities have been suggested. Some commentators have identified the harm threshold as any decision that will result in loss of life, health, or some other major interest, and the deprivation of basic needs.⁵¹ Ross sets the harm threshold at a level at which a child is deprived of its basic

needs.⁵² Joel Feinberg suggests that the threshold is exceeded when a parental decision "interferes" with interests necessary for more ultimate goals like physical health and vigor, integrity and normal functioning of one's body, absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, and emotional stability."⁵³ Others suggest that any decision that places a child at significant risk of serious harm should be challenged.⁵⁴

How do the risks and harms of BMT donation compare to the harm-based examples cited above? Medically, the procedure is considered to be very low risk. It usually requires multiple needle aspirations from the iliac crests while the donor is under general or spinal anesthesia. Ross categorizes bone marrow donation as constituting a "minor increase over minimal risk," citing the risks associated with general anesthesia as posing the greatest risk.⁵⁵ Mortimer Bortin and C. Dean Buckner reviewed the complications associated with more than 3,000 allogeneic BMTs submitted to the International Bone Marrow Transplant Registry and Seattle Marrow Transplant Team from 1970 to 1983, and found a very small incidence of adverse effects (9/3,290, or 0.27 percent), the majority of which (5/9) were attributed to the use of general anesthetic.⁵⁶ Other risks and harms involved with BMT donation include infection at the puncture site, bleeding, transient bone pain, and minimal skin scarring.⁵⁷ Although it is not a trivial procedure, evidence suggests that BMT donation is exceedingly safe and the nonanesthetic complications relatively minor.

In this case, L.R. was physically healthy and free from any medical conditions that would either impede her ability to donate or to elevate the risk of physical complications. From a medical and physical perspective, the risk of donating bone marrow to her brother fell short of any suggested harm threshold. The medical and physical risks did not appear to place her at significant risk of serious harm.

The psychological aspects of MSD BMT, however, should have been included in the equation. "Emotional stability" and "integrity" were both factors that should have been considered in determining whether having L.R. act

as a bone marrow donor for her brother actually posed a significant risk of serious harm. Furthermore, a vital component to the psychological sequelae of MSD BMT was L.R.'s premorbidity. It was pertinent that she was psychologically at risk, and this must not be minimized. There is growing evidence that victims of sibling incest manifest emotional and behavioral problems that are as severe as those found among children who have been sexually abused by adults,⁵⁸ and the effects common to female victims of sibling incest include "mistrust of men," chronic low or negative self-esteem," and intrusive thoughts of the incest."⁵⁹ Such effects are crucial to the analysis of harm when the psychological aspects of MSD BMT are considered, in general.

L.R.'s mental status and emotional suitability to serve as a donor were evaluated. This was a 50-minute conversation with a psychiatrist. Since L.R.'s role as the victim of A.R.'s abuse was known to medical staff, there was considerable concern that the procedure might cause re-traumatization or other emotional distress. The interview included both the mother and L.R., but the mother requested that the abuse not be discussed with L.R., since that was in the past and would further harm her. If it was brought up. L.R. was described as polite, friendly, cooperative, and reflective in her responses during the interview. As the interview focused more on L.R. and the BMT, she became "slightly guarded" when asked about her brother and his illness, but not "inappropriately so." She was felt to have age-appropriate concerns and anxieties as well as an age-appropriate understanding of the process of bone marrow donation.

The evaluator concluded that the assessment of L.R. was hampered by her mother's guardedness toward the interview. While the evaluator found L.R. to be well-adjusted, happy, and possessing a genuine concern for her brother and his physical health, the evaluator noted that L.R. had never received any counseling regarding the abuse, and it was possible that L.R. simply "avoided overt manifestation of the trauma through defensive denial." In summary, however, the evaluator concluded, "this interview

did not provide any information to suggest that [L.R.] is at high risk of traumatization from the bone marrow transplant due to her previous experiences with her brother."

Recent evidence on the psychological impact of BMT on sibling donors might suggest otherwise. During the 1970s and 1980s, several anecdotal observations suggested that potentially serious psychological reactions might result from the donation procedure.⁶⁰ In the first systematic investigation of the psychosocial effects of BMT on donor and non-donor siblings (albeit small: 44 siblings, 21 donors, and 23 non-donors), Wendy L. Packman and colleagues found that "sibling donors reported significantly more anxiety and lower self-esteem than did non-donor siblings,"⁶¹ but donors had better adaptive skills in school than non-donors.⁶² While symptoms of post-traumatic stress presented equally in each group, the manifestation appeared to be different in each group: "donor siblings might respond with more internalizing behaviors, such as anxiety and depression, withdrawal . . . in contrast, non-donor siblings might respond with more externalizing behaviors such as attention and learning problems at school."⁶³ Such increased anxiety and low self-esteem in the donors may reflect that children may perceive surgical interventions as aggressive attacks on their bodies.⁶⁴ In fact, one sibling donor remarked, "I felt like I was the one being violated."⁶⁵ Overall, the six common themes that emerged among donors were that they:

1. Felt relieved and proud when picked to give bone marrow and after giving marrow,
2. Felt they had "no choice" and wanted to be more involved in the donation decision-making process,
3. Felt lonely and isolated after their surgery,
4. Developed a closer bond with the patient,
5. Reacted to the transplant by withdrawing and keeping their feelings to themselves,
6. Felt like a better person after the BMT and would give marrow again.⁶⁶

Although some positive aspects were present for some donors, it is disconcerting that many of the above themes denote a negative and potentially harmful experience. Furthermore,

Packman and colleagues' subjects in the study were mostly from two-parent homes (73 percent), were part of families who had not recently experienced other significant stressors, and were all part of successful BMTs,⁶⁷ healthy conditions that were not present for the young donor in this case. Yet, many donors in Packman and colleagues' study experienced significant anxiety and depression, and the potential for post-traumatic symptomatology at rates higher than siblings who did not donate. If sibling donors from apparently stable family environments suffered from feelings of powerlessness, loneliness, withdrawal, and isolation, it is not unreasonable to be concerned that these feelings might prove overwhelming to a donor whose family and psychological past appear to offer even less stability. Some also have found that sibling donors experience the donation procedure as "an act of robbery."⁶⁸ One could argue that a victim of sexual abuse has been robbed in a violent way once before, and should not be placed involuntarily in a situation that would cause her to feel that way again. The available data would seem to suggest that having L.R. donate bone marrow to A.R. poses a significant risk for serious harm to her psychological and mental health.

There is also data to suggest that in the event that a BMT recipient ultimately dies, a very real possibility in this case, the risk of suffering psychological harm may be even greater. One study compared the effects of BMT on pediatric-aged donors whose siblings ultimately died to those whose siblings did not.⁶⁹ In both groups, the psychological aspects of donating were more important than the physical aspects (100 percent and 86 percent in the successful and unsuccessful BMT groups, respectively), reinforcing the importance of seriously addressing the psychological consequences of BMT donation. All but one of the 15 participants in the study felt either forced to donate or that saying "no" was not an option. Common findings among the successful donor siblings group included increased self-esteem, fewer feelings of helplessness, a broadened view of the world, feelings that the process brought the family closer together, increased insight into their sibling's dis-

ease, and a greater likelihood of negative emotions if the sibling developed severe and long-lasting complications. For donors of unsuccessful transplants, anger, guilt, and blame were common emotions: "the positive and negative impacts, with feelings of guilt and blame, often overshadowed positive effects . . . ; in one case, the negative impact became predominant."⁷⁰ Further, the investigators report the donors said "it was hard not to feel responsible for the death of their sibling and that support was needed to overcome these feelings."⁷¹ The authors found that for those donors that lacked the "adequate emotional support . . . , resisting the development of negative feelings was harder."⁷²

While this study involved a small sample size (15 participants), it reinforces the potential for significant negative psychological impact on the sibling donor, especially if the transplant is unsuccessful. Those who were part of an unsuccessful transplant had more negative psychological effects, and those who were younger were more likely to believe they were forced to say yes. Years later, the authors note, these younger donors usually come to understand why they were forced to donate, but still requested "more influence and autonomy in deciding that 'no' was not an option."⁷³ These data would further suggest that the psychological risk to a young donor who had been assaulted in the past by the prospective recipient may be quite significant.

To be thorough, we must also recognize any potential psychological benefits that L.R. might have obtained from donating marrow to her brother. One might imagine that providing L.R. the opportunity to save her brother's life might have allowed for some forgiveness, a strengthening of their relationship, or might have enabled L.R. to "move on." Although there is little empiric data available to support that supposition, Packman and colleagues and Kendra MacLeod and colleagues do hint at such possibilities.⁷⁴ Other benefits to L.R. might have included a strengthened relationship with her mother, who clearly desired that L.R. act as donor. Alternatively, it is possible that L.R. might have felt some satisfaction in donating bone marrow to keep A.R. alive, so that he could live

out his sentence. L.R. may have interpreted the act of not donating as helping A.R. to “cheat” the system that was punishing him.

To optimize the likelihood of most of these benefits, however, it would have been essential to provide L.R. with emotional support, to allow her to move in a positive direction, post-donation. Here there is evidence of a suboptimal environment. When L.R.’s mother refused to allow staff to address the issue of past sexual abuse with L.R., it created an environment in which an open exploration of post-donation issues and feelings was probably hampered.

Given the potential for psychological harm, and the common feeling of “having no choice,” it was particularly important to obtain L.R.’s assent to donate bone marrow to A.R. While her age almost certainly did not allow for a full understanding of risks and benefits, she was certainly old enough to appreciate what she was being asked to do and why. The value of assent in this case was that it allowed L.R. to express whether she was willing to undergo this procedure voluntarily. If nothing else, assent in this situation might have allowed L.R. some sense of control and less a sense of being “forced” to do something she did not wish to do. The purpose of assent was not the same as consent in this case, that is, to make a formal assessment of risks and benefits, but rather to recognize that, under the circumstances, soliciting the willing participation of L.R. should have been a minimal requirement to minimize harm. Her assent, or affirmative agreement, should have been sought by the medical care team, and should have been sought in a way that would have helped to answer L.R.’s questions and to assure that she was truly willing to do what she was being asked to do.

It must also be emphasized that an MSD BMT was not the only therapeutic option that was available. While MSD BMT was considered the best option for cure of A.R.’s disease, patients with refractory AML can also be treated with an allogeneic BMT from a matched unrelated donor, an allogeneic BMT from an unmatched unrelated donor, further chemotherapy, or palliation. The decision to proceed to BMT in patients with refractory AML is a

complex process and involves taking into consideration a number of factors, only one of which is the type of donor available. While it is true that the likelihood of success was lower with an unrelated BMT as compared to a MSD BMT, it was not the case that pursuing a therapeutic option other than MSD BMT would have condemned A.R. to a certain death. In A.R.’s case, the advantage of having an HLA identical donor should have been weighed against the potential risks to L.R. Risk-benefit calculation can be a difficult task, and having to weigh the interests of one party against the interests of another increases that complexity. In cases when the interests of the recipient and donor align, it seems reasonable to focus primarily on the best available therapy. However, when there is concern about the potential for significant harm to a donor, it is important to consider whether acceptable therapeutic alternatives exist, to put those alternatives on the table for discussion, and to consider them seriously as a way to minimize risk to a vulnerable potential donor.

In summary, there were multiple reasons to be concerned about the potential for harm to the donor in this case. Psychological harm is a potential risk of any MSD BMT, and L.R.’s young age, less than optimal family environment, and past history of sexual assault at the hands of the transplant recipient all seem likely to have compounded the risk of significant harm. The harm to L.R. was likely to exceed any potential benefits. She was already psychologically vulnerable, and should not have been subjected to the further risks of low self-esteem, increased anxiety, the possible feelings of having “no choice” or of being the victim of an “act of robbery.” This situation offered significant potential to deprive L.R. of a basic need — her emotional stability — and negatively affect her ability to become “an autonomous adult capable of devising and implementing [her] own life plans.”⁷⁵ Physicians had a duty to “first, do no harm,” and allowing L.R. to donate her bone marrow to A.R. under these circumstances had the potential to exceed an acceptable level of risk for a nonvoluntary minor. In such cases, a minimal requirement should be a thorough psy-

chological assessment that includes time alone with the child. The goal of that assessment should be to establish a reasonable degree of certainty that the child donor will not be harmed by proceeding with the donation, and that the child feels that he or she has some choice in the decision. This assessment would ideally occur before any determination of compatibility, to minimize any pressure that might arise from the knowledge that the child is a potential donor. In addition, the appointment of a guardian *ad litem* should be strongly considered to provide an objective assessment of the child's best interests. Finally, we suggest that institutions that perform MSD BMT write policies to guide the process of testing for donor suitability, and create a process that minimizes any potential harm to a child donor, to the greatest extent possible.

CONCLUSION

The case we present raises unique and important ethical questions. We have argued that incarcerated minors should not be denied medical treatment that would be offered to minors who had not broken the law. Second, we have argued that an inherent conflict of interest exists for parents who must make decisions for two children in MSD BMT, and that appointment of a guardian *ad litem* should be strongly considered in any case when there is evidence that family structure is not intact and parental decision making is at risk of compromising any of a child's basic needs. Furthermore, we have reviewed evidence that suggests that BMT may cause significant psychological harm in otherwise psychologically well sibling donors, and that the potential for harm is likely to be greater when the potential donor is young and psychologically at risk. Such risks should be taken as seriously as medical risks in the process of evaluating siblings as potential donors. When the donation process poses a significant risk of serious psychological harm, the medical team should seriously consider not proceeding with sibling donation and fully explore alternative treatments. A comprehensive psychological assessment should occur before testing for compatibility to alleviate any additional pressure

that may be associated with being a potential donor with known compatibility.

NOTES

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5. Chan et al., see note 2 above.
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16. Posner, see note 13 above.

17. Thorburn, see note 13 above.

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20. Navari et al., see note 14 above.

21. Lowes, see note 14 above.

22. Thorburn, see note 13 above.

23. See note 12 above.

24. Navari et al., see note 14 above.

25. Cohen, see note 14 above; Schneiderman and Jecker, "A Different Kind of Prisoner's Dilemma," see note 14 above.

26. Spike, see note 14 above.

27. Paul, see note 14 above.

28. Schneiderman and Jecker, "Should a Criminal Receive a Heart Transplant?" see note 14 above.

29. Schneiderman and Jecker, "A Different Kind of Prisoner's Dilemma," see note 14 above; Schneiderman and Jecker, "Should a Criminal

Receive a Heart Transplant?" see note 14 above.

30. See note 6 above.

31. Interestingly, refusing to allow the BMT, in fact, might prompt state intervention anyway, as it would itself jeopardize the life of A.R.

32. *Nathan v. Farinelli*, Suffolk Eq. 74-87 (Mass. July 3, 1974); Williams, see note 8 above.

33. M.D. Levine et al., "The medical ethics of bone marrow transplantation in childhood," *Journal of Pediatrics* 86, no. 1 (1975): 145-50; Williams, see note 8 above; Brant, see note 8 above.

34. Williams, see note 8 above.

35. *Ibid.*

36. L. Ross, *Children, Families, and Healthcare Decision-Making* (New York: Oxford University Press, 1998).

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41. *Ibid.*

42. *Ibid.*

43. *Ibid.*

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45. *In re Pescinski*, 67 Wis. 2d 4, 226 N.W.2d 180 (1975); Williams, see note 8 above; Brant, see note 8 above.

46. Williams, see note 8 above.

47. *Strunk v. Strunk*, 445 S.W. 2d 145 (Ky App., 1969).

48. Brant, see note 8 above.

49. See note 6 above.

50. *Ibid.*

51. K.R. Wing, *The Law and the Public's Health* (Ann Arbor, Mich.: Health Administration Press, 1990); T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics* (New York: Oxford, 2001); R.B. Miller, *Children, Ethics, and Modern Medicine* (Bloomington, Ind.: Indiana University Press, 2003); Williams, see note 8 above.

52. See note 36 above.

53. J. Feinberg, *Harm to Others: The Moral Limits of the Criminal Law* (New York: Oxford University Press, 1984).

54. American Academy of Pediatrics, Committee on Bioethics, "Religious objections to medical care," *Pediatrics* 99, no. 2 (1997): 279-81.

55. See note 36 above.

56. See note 10 above.

57. Levine et al., see note 33 above.

58. M. Cyr et al., "Intrafamilial sexual abuse: brother-sister incest does not differ from father-daughter and stepfather-stepdaughter incest," *Child Abuse and Neglect* 26, no. 9 (2002): 957-73; J.A. Shaw et al., "Child on child sexual abuse: psychological perspectives," *Child Abuse and Neglect* 24, no. 12 (2000): 1591-600.

59. M. Laviola, "Effects of older brother-younger sister incest: a study of the dynamics of 17 cases," *Child Abuse and Neglect* 16, no. 3 (1992): 409-21.

60. L.C. Kinrade, "Preparation of sibling donors for bone marrow transplant harvest procedure," *Cancer Nursing* 10 (1987): 77-81; G. Pinegger-O'Connor and C. Bender-Gotze, "Treatment of underage bone marrow donors: Psychological aspects," *Munich Medizinische Wochenschrift* 122 (1980): 597-601; C.C. Pot-Mees et al., "Psychosocial consequence of bone marrow transplant in children: a preliminary communication," *Journal of Psychosocial Oncology* 5 (1987): 73-8; B.S. Rappaport, "Evolution of consultation-liaison services in bone marrow transplant," *General Hospital Psychiatry* 10 (1988): 246-351.

61. See note 4 above.

62. *Ibid.*; Packman et al., "Siblings perceptions," see note 11 above; Packman, "Psychosocial impact," see note 11 above.

63. See note 4 above.

64. *Ibid.*

65. *Ibid.*

66. Packman et al., "Siblings' perceptions," see note 11 above.

67. See note 4 above.

68. Pinegger-O'Connor and Bender-Gotze, see note 60 above.

69. MacLeod et al., see note 11 above.

70. *Ibid.*

71. *Ibid.*

72. *Ibid.*

73. *Ibid.*

74. Packman et al., "Siblings perceptions," see note 11 above; MacLeod et al., see note 11 above.

75. Ross, see note 36 above.

A Compounding of Errors: The Case of Bone Marrow Donation between Non-Intimate Siblings

Lainie Friedman Ross and Walter Glannon

INTRODUCTION

In this issue of *The Journal of Clinical Ethics*, Opel and Diekema describe the disturbing case of a nine-year-old, L.R., who serves as a bone marrow donor to A.R., her 15-year-old brother who has relapsed acute myelogenous leukemia (AML). A.R. is incarcerated because he had been found guilty of sexually assaulting L.R. In their analysis, Opel and Diekema consider three questions. First, should prisoners have access to costly medical interventions like bone marrow transplant? Second, should parental permission for the use of bone marrow obtained from a minor sibling be considered valid? Third, should a minor sibling be permitted to act as transplant donor when the recipient has sexually assaulted her in the past? Our answers

to the first two questions would be similar to theirs. Yes, A.R. should have access to costly medical interventions, and sometimes parents can authorize bone marrow donation between siblings. However, the wording of the third question leads Opel and Diekema to an analysis that fails to capture what is most disturbing about this case. The main ethical question is not whether it is permissible for a minor sibling to serve as a transplant donor for a recipient who sexually assaulted her. Rather, the question is, *Who should have protected a minor sibling from being asked to serve as a transplant donor to a recipient who sexually assaulted her?* The failure to protect L.R. from being medically evaluated, let alone from donating, is compounded by the social context in which her donation occurred: numerous parties had moral and le-

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gal obligations to protect her, but failed to do so, including her mother, the transplant community, and the legal and penal systems.

In this article, we will examine four questions: (1) When is it ethically permissible to ask children to serve as bone marrow donors? (2) When the relevant criteria do not hold and it is not permissible, whose obligation is it to protect the potential child-donor? (3) Is it ever ethically permissible for an individual to donate to a recipient who sexually assaulted her? and (4) What are the appropriate next steps?

WHEN IS IT ETHICALLY PERMISSIBLE TO ASK CHILDREN TO SERVE AS BONE MARROW DONORS?

Unlike solid organ transplantation, bone marrow donation requires a living source. Because of the importance of histocompatibility, siblings, whether adults or minors, are often the best source of bone marrow or stem cells.¹

Opel and Diekema cite Ross's arguments from *Children, Families, and Healthcare Decision-Making*, to consider when it is ethical for a child to serve as a bone marrow donor.² In that work, Ross was clear that such donations should only occur within an intimate family.³ Ross argued that within an intimate family, parents can authorize the donation by one sibling for another on the grounds that the well-being of one child is intertwined with the well-being of other family members. While the donor is being used as a means to promote the recipient's well-being, the donation serves to promote the well-being of the family (on which the donor's own well-being depends). As such, the donation serves the donor's goals, albeit indirectly.⁴ It also benefits the donor and treats her as an end-in-herself.⁵

In the case described by Opel and Diekema, there is no family intimacy. And in the book, Ross is very clear that children should not be asked to donate beyond the realm of intimacy. In fact, Ross specifically uses the case of not forcing a girl who is raped by her brother to serve as his living donor.⁶ Ross expressed concern about the parent's inability to protect her. Al-

though L.R. did not refuse to donate, and one could even describe her as having passively acquiesced, we believe that her mother should not have been allowed to authorize the intersibling donation because she failed to protect L.R. from her brother. Instead, the state had to intervene to protect L.R. by incarcerating A.R. Thus, the mother's ability to protect L.R. was shown to be inadequate. This is not to say that the mother was to blame for the assault. Clearly the state took this into consideration when it allowed her mother to continue to care for L.R. after her brother's incarceration.

Nevertheless, the mother had conflicting interests. She had two children, one of whom harmed the other. Ms R. had reasons to show mercy towards A.R. for what he did to his sister, but she cannot insist that L.R. do the same. Rather, Ms R. must provide L.R. with appropriate family support and protection. Ms R. must also help L.R. overcome her physical, emotional, and psychological trauma. Clearly L.R. needed therapy.⁷ The failure to seek this is worrisome: worrisome on the part of Ms R., who may have been in denial; worrisome on the part of the state that it did not ensure L.R.'s psychological well-being when decisions about custody and incarceration were being made.

In fact, we fear that Ms R. failed to provide L.R. with her basic needs of protection and the promotion of her self-respect.⁸ Ms R.'s decision to ask L.R. to visit her incarcerated brother was unduly demanding of L.R., particularly since she had not had adequate therapy to address the meaning of the assault. Maybe L.R. was taken along because there was nowhere to leave her; maybe her mother thought L.R. should forgive her brother; or maybe her mother did not perceive a problem, given that L.R. was no longer physically at risk. If Ms R.'s reason was pragmatic (that is, Ms R. had nowhere to leave L.R. while she visited her son), social services should become involved in protecting L.R. She required psychological and emotional support and strength to recover from the assault. L.R. needed help to heal successfully and to develop the capacities and maturity required to move beyond it. Her mother's refusal to allow L.R.

counseling is a sign that her mother failed to promote her recovery. Finally, if the reason L.R. was taken to visit her brother was because Ms R. did not perceive that L.R. was physically at risk, then the mother failed to see the emotional and psychological harm she imposed, and this in and of itself might have constituted child abuse or neglect. Thus, we have reason to question the mother's ability to protect and promote L.R.'s emotional and psychological well-being.

Even if one were to take a broader notion of parental authority, that parents can authorize a donation because it is minimal risk (a position we do not hold), we would still argue that the donation should not have been permitted because L.R. did not — indeed, could not — assent. For donation from a minor such as L.R. to be ethically permissible, two conditions would have been necessary: (1) she must not have been exposed to more than a minor increase over minimal risk;⁹ and (2) she must have assented to donation. Although the physical risks of bone marrow donation are at most a minor increase over minimal risk, depending on the method used, the potential risks to L.R. were much greater, given the history of assault. Asking her to donate exposed her to the risk of additional psychological harm beyond the harm from her brother's sexual assault. In addition, although there are no clear rules about what is required for assent, it is clear that mere non-dissent is not assent.¹⁰ L.R. could not assent because of the violence within the siblings' relationship and because of her lack of emotional maturity and strength. These points are critical to understanding both the ethical permissibility of asking and allowing L.R. to donate and the obligation to protect her from harm.

**WHEN THE CRITERIA ABOVE DO NOT
HOLD, WHOSE OBLIGATION IS IT
TO PROTECT THE POTENTIAL
CHILD-DONOR?**

As mentioned in *Children, Families, and Healthcare Decision-Making*, "It is significant that parents require the aid and expertise of health care personnel to harvest their child's

organ for transplantation."¹¹ The involvement of third parties moves the locus of decision making out of the private domain of the family. Thus, the transplant team had an obligation to protect L.R., an obligation that holds when a family is intimate, but holds to an even greater extent when the family is non-intimate and the potential donor is a minor.

L.R. needed protection from the moment her brother was diagnosed with AML. The decision to test blood samples of family members for histocompatibility (HLA testing¹² for HLA matching) is not just a minimal-risk phlebotomy.¹³ Rather, it should have been realized at that time that the decision to HLA type L.R. could lead to her being a complete HLA match, and how that would lead to a request for bone marrow donation. If the healthcare providers who sought consent to the blood draw had discussed the bone marrow typing and transplant process, they would have realized the profoundness of the request from the assault victim and the likelihood of further psychological harm to her. We would argue that in this case, L.R. should not have been asked to be typed for HLA matching by the physicians in charge of her brother's care, or by her own physicians, or by her own mother. L.R. was not protected by those who had an obligation to do so.

That said, we can imagine the case when healthcare providers did not know the full story and that L.R.'s mother did not appreciate the implications of the HLA matching. Although L.R. was found to be a complete HLA match, this did not mean that she was obligated to donate. The critical ethical issue here was not histocompatibility, but the potential for further psychological harm to L.R. in the wake of the ruptured intimacy of her family. Although we have argued that there is some degree of moral obligation for family members to donate to each other,¹⁴ our argument assumed that there was intimacy. When intimacy does not exist, there is no obligation. In fact, when no intimacy exists, not only is there no obligation, but one could also argue that there is reason to be suspicious of a desire or even an acquiescence to donate. It suggests that the donor may have such

a low level of self-respect, a lack of proper regard for her dignity and intrinsic worth, that she feels she owes something to the individual who assaulted her.¹⁵ Given that autonomous decision making presupposes a certain degree of self-respect, the victim's consent (or in the case of a minor, the victim's assent) should be understood as a cry for help and not as an autonomous choice.

Thus, the bone marrow transplant team, having learned that A.R. had sexually assaulted L.R., should not have allowed L.R. to serve as a donor despite her mother's authorization and her acquiescence. Critics may object that this is paternalistic. Recall that paternalism is the "the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden."¹⁶ But the situation at hand was not about interfering with an individual's decision about whether or not to donate, but whether to interfere with a parent's autonomy regarding authorization of *her child's donation*. The issue, then, was not about whether or not to respect individual autonomy, but parental autonomy. Proxy decision making is more restricted than individual autonomy because proxies have obligations to protect their recipient from harm. This means that individuals can expose themselves to greater risks than they can authorize others to assume.¹⁷

In fact, the team did otherwise. Psychological work-ups are often part of living donor evaluations. Clearly this is critical when the donor is a child who may not fully understand the procedures, or the risks and benefits, and that participation is non-obligatory. By acquiescing to her mother's insistence that L.R. not discuss the assault with psychiatry, the team provided L.R. with less protection than they would give competent adults. They unconsciously threatened L.R.'s self-respect by informing her that she should be "over" the assault or that the assault was at least not worth mentioning and not a factor in her voluntary decision to participate. The team reinforced any feelings of unworthiness, shame, and self-blame that L.R. may have ex-

perienced, feelings not infrequently experienced by assault victims.¹⁸ We do not consider it an exaggeration to say that the donation without proper preparation and counseling was a second assault on this young victim.

Thus, numerous parties failed L.R. The transplant community failed to acknowledge the psychological and emotional harms that L.R. faced when they considered her as a potential bone marrow donor for her brother. They also failed to provide L.R. with the minimum protection offered to all donors: a psychological examination that would have unveiled whether the benefits of her participation outweighed the potential psychological and emotional harms. Ms R. failed to protect L.R. by failing to provide her with the long-term and intensive psychological services she needed to successfully address the assault.¹⁹ The legal system failed to ensure that Ms R. was prepared to protect her daughter from further assaults of a psychological or emotional nature.

IS IT EVER ETHICALLY PERMISSIBLE FOR AN INDIVIDUAL TO DONATE TO A RECIPIENT WHO SEXUALLY ASSAULTED HER?

An individual who has been assaulted has reason to feel resentment towards her attacker. In *Forgiveness and Mercy*, Jeffrie Murphy argues that the primary value defended by the passion of resentment is self-respect, and that a person who does not resent moral injuries done to him is almost necessarily a person lacking in self-respect.²⁰

A competent adult woman may choose to overcome her resentment. To overcome resentment is not necessarily to forgive. She may forget the moral injury that caused her resentment; or she may choose to extinguish her resentment for her own peace of mind. The motivation for forgetting is not moral but serves to promote her own mental health.²¹

Alternatively, a competent adult woman can cease to resent and forgive her assailant. To forgive is a moral action, a deliberate action to overcome resentment motivated by regard for

the dignity and intrinsic worth of the other person.²² One could argue that, for a self-respecting person, forgiveness would be a form of liberation from resentment and an expression of the inviolability of one's dignity.

Thus a competent adult woman can overcome resentment and either show mercy or forgive her assailant. In fact, a competent adult woman can go further and aid an assailant. But to do so takes a psychological and emotional maturity and often requires third-party therapy, for prolonged periods of time.²³ But L.R. is not a competent adult woman, and, in fact, she was not allowed the tools to overcome her resentment, let alone to forgive. As such, her mother's action reinforced any shame, self-blame, or low self-esteem and self-respect that she may have felt, feelings that are common in victims of assault. Someday L.R. may forgive her brother, but clearly this requires a maturity and psychological adjustment that she was developmentally unable to attain at the time of this case, particularly given that she had not had a chance to even process the assault and its meaning in counseling.

Opel and Diekema suggest that "providing L.R. the opportunity to save her brother's life might have allowed for some forgiveness. . . ." They have the causality wrong. Whether or not L.R. overcame her resentment and either forgave her brother or showed him mercy was her prerogative; A.R. had no right to either.²⁴ To the extent that A.R. might have come to feel remorse for his actions, he should have sought her forgiveness, but he could not prompt or demand it. How L.R. proceeded was her decision, it was not about "allowing him to give her this opportunity."

APPROPRIATE NEXT STEPS

Despite the HLA matching, A.R.'s physicians still had a chance to not procure bone marrow from L.R. As the case was described, bone marrow transplant was not the only therapeutic option. While we agree that A.R. had a right to medical care, even expensive medical care, he did not have a right to an HLA matched bone

marrow transplant without the voluntary consent of the donor.

Unfortunately, the team did perform the bone marrow transplant, and Opel and Diekema describe the subsequent events. L.R. donated her bone marrow, A.R. improved for 10 months while still incarcerated, and then relapsed. This led to another decision point: he could undergo more chemo, another bone marrow transplant, or forgo treatment. He chose the latter and died two months later.

We were not told whether L.R. and A.R. ever addressed the assault nor were we told whether A.R. apologized or asked for forgiveness. His death left many issues unresolved and had profound implications for L.R. in two respects. First, living donors often blame themselves for bad outcomes in their recipients.²⁵ Even with good outcomes, child donors may find their participation stressful.²⁶ Second, A.R.'s death may have made it more difficult for L.R. to process the assault. While the request for donation opened up opportunities to address the meaning of the assault, the opportunities were ignored, and now it is too late.

A.R. did L.R. wrong by assaulting her and by accepting her bone marrow without ensuring that he was forgiven and that her donation was voluntary. Ms R. did L.R. wrong by permitting her to be HLA matched and then by permitting her to donate. The transplant team did L.R. wrong by agreeing to her donation despite her mother's refusal to allow for a full psychiatric evaluation and treatment plan. Given the lack of intimacy, the team did wrong by not providing L.R. with a guardian *ad litem*. A guardian would have realized that a nine-year-old girl cannot morally forgive her assailant, particularly if she did not have the opportunity to process the events. All of the parties involved in this case failed to realize that the person at the greater risk of harm and who could and should have been protected was not A.R., but L.R. All parties did L.R. wrong by not providing protections at many levels.

Opel and Diekema agree. They conclude by focusing on the "potential for harm to the donor" and acknowledge that "the harm to L.R.

was likely to exceed any potential benefits.” They also hold that a thorough psychiatric assessment needed to occur before determination of compatibility. They propose appointing a guardian *ad litem* because of the ruptured intimacy. We agree with these recommendations.

These suggestions are no longer possible, given that L.R. has already donated. But there are next steps that should be undertaken for L.R. We owe L.R. a second chance at coming to terms with her assault. We owe L.R. an apology for ignoring her own needs in an effort to save her brother. We owe L.R. the protection afforded to the rest of us: to avoid exploitation. We owe her a promise that transplant centers will develop policies to ensure that no future potential donors will be asked to do what she was forced to do: to serve as a bone marrow donor when it was contrary to her self-respect and potentially contrary to her interests. It also occurred without any attempt to ensure that her assent was voluntary.

NOTES

1. See, for example, R. Delage, J. Ritz, and K.C. Anderson, “The evolving role of bone marrow transplantation in the treatment of chronic myelogenous leukemia,” *Hematology - Oncology Clinics of North America* 4, no. 2 (1990): 369-88; and K.J. Forte, “Alternative donor sources in pediatric bone marrow transplantation,” *Journal of Pediatric Oncology Nursing* 14, no. 4 (1997): 213-24.

2. L.F. Ross, *Children, Families and Healthcare Decision-Making* (New York: Oxford University Press, 1998), see chapter 6, “The Child as Organ Donor,” pp. 111-30.

3. *Ibid.*, 124-5.

4. *Ibid.*, esp. 112-5.

5. *Ibid.*; see also I. Kant, *Grounding for the Metaphysics of Morals* (1785), trans. J.W. Ellington (Indianapolis, Ind.: Hackett Publishing, 1981), par. 429.

6. Ross, see note 2 above, 121-3, and 129 n.

7. C.B. Draucker, “The psychotherapeutic needs of women who have been sexually assaulted,” *Perspectives in Psychiatric Care* 35, no. 1 (1999): 18-28; M.E. Smith and L.M. Kelly, “The

journey of recovery after a rape experience,” *Issues in Mental Health Nursing* 22, no. 4 (2001): 337-52; and J.A. Glaister and E. Abel, “Experiences of women healing from childhood sexual abuse,” *Archives of Psychiatric Nursing* 15, no. 4 (2001): 188-94.

8. J. Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard University Press, 1971), esp. 440-5.

9. The phrase “a minor increase over minimal risk” comes from the *Federal Regulations* regarding risks to research subjects. See specifically, Subpart D, Additional Protections for Children. Department of Health and Human Services (DHHS) (45 *CFR* Part 46, Subpart D), “Protections for Children Involved as Subjects in Research,” *Federal Register* 48 (8 March 1983), 9814-20; revised *Federal Register* 56 (18 June 1991), 28032, <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm>, hereinafter cited by its *CFR* number. Ross has argued that similar standards can hold for transplant donors. (See Ross, note 2 above, 112-3.) She has argued that in an intimate family, pre-adolescent children can be exposed to at most a minor increase over minimal risk in organ donation. (*Ibid.*, 112-20.)

10. The *Federal Regulations* are quite explicit that non-dissent is not adequate for assent. “Mere failure to object should not, absent affirmative agreement, be construed as assent.” See *CFR* 46.402 (b).

11. Ross, see note 2 above, p. 122.

12. Human leukocyte antigens (HLA) are histocompatibility antigens. They determine whether a donor and recipient are immunologically compatible.

13. This was the issue raised in *Curran v. Bosze*. Mr. Bosze and Ms Curran had twins and Ms Curran had legal custody of them. Mr. Bosze had a son, Jean Pierre, with another woman. Jean Pierre had acute undifferentiated leukemia (AUL), also known as mixed lineage leukemia, and needed a bone marrow transplant for treatment. Mr. Bosze asked Ms Curran to consent to a blood test for the twins, to determine whether the twins were compatible to serve as bone marrow donors for a transplant to Jean Pierre. Mr. Bosze asked Ms Curran to consent to the twins’ undergoing a bone marrow harvesting procedure if the twins were found to be compatible. After consulting

with the twins' pediatrician, family members, parents of bone marrow donors, and bone marrow donors, Ms Curran refused to give consent to the twins' undergoing either the blood test or the bone marrow harvesting procedure. That is, Ms Curran refused the blood test because she understood that it could lead to a bone marrow donation, which she did not perceive to be in her children's best interest. The court agreed. See, *Curran v. Bosze*, No. 70501, Supreme Court of Illinois, 141 Ill. 2d 473; 566 N.E.2d 1319; 1990 Ill. LEXIS 160; 153 Ill. Dec. 213; 4 A.L.R.5th 1163, 28 September 1990, Announced, 20 December 1990, 475.

14. W. Glannon and L.F. Ross, "Do Genetic Relationships Create Moral Obligations?" *Cambridge Quarterly of Health Care Ethics* 11 (2002): 153-9.

15. See, for example, H.H. Filipas and E. Ullman, "Child sexual abuse, coping responses, self-blame, posttraumatic stress disorder, and adult sexual revictimization," *Journal of Interpersonal Violence* 21, no. 5 (2006): 652-72; J.A. Quas, G.S. Goodman, and D. Jones, "Predictors of attributions of self-blame and internalizing behavior problems in sexually abused children," *Journal of Child Psychology & Psychiatry & Allied Disciplines* 44, no. 5 (2003): 723-36; P. Coffey et al., "Mediators of the long-term impact of child sexual abuse: perceived stigma, betrayal, powerlessness, and self-blame," *Child Abuse & Neglect* 20, no. 5 (1996): 447-55; and G.B. Rahm, B. Renck, and K.C. Ringsberg, "Disgust, disgust beyond description — shame cues to detect shame in disguise, in interviews with women who were sexually abused during childhood," *Journal of Psychiatric & Mental Health Nursing* 13, no. 1 (2006): 100-9.

16. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 4th ed. (New York: Oxford University Press, 1994), 274.

17. See, for example, A.E. Buchanan and D.W. Brock, *Deciding for Others: the Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989).

18. See, for example, C. Negrao et al., "Shame, humiliation, and childhood sexual abuse: distinct contributions and emotional coherence," *Child Maltreatment* 10, no. 4 (2005): 350-63; C. Feiring, L. Taska, and K. Chen, "Trying to understand why horrible things happen: attribution, shame, and

symptom development following sexual abuse," *Child Maltreatment* 7, no. 1 (2002): 26-41.

19. Glaister and Abel, see note 7 above; H.Y. Swanston et al., "Hoping and coping in young people who have been sexually abused," *European Child & Adolescent Psychiatry* 8, no. 2 (1999): 134-42.

20. J.G. Murphy and J. Hampton, *Forgiveness and Mercy* (New York: Cambridge University Press, 1988), see chap. 1, J.G. Murphy, "Forgiveness and Resentment," 14-34, 16.

21. *Ibid.*, 23-4.

22. *Ibid.*, 24.

23. Draucker, see note 7 above; Smith and Kelly, see note 7 above.

24. Murphy, see note 20 above, p. 29.

25. See, for example, V. Weisz and J.K. Robbennolt, "Risks and benefits of pediatric bone marrow donation: a critical need for research," *Behavioral Sciences & the Law* 14, no. 4 (1996): 375-91; and L.M. Terry and A. Campbell, "Protecting the Interests of the Child Bone Marrow Donor," *Medicine and Law* 22 (2004): 805-19.

26. W. Packman, "Psychosocial impact of pediatric BMT on siblings," *Bone Marrow Transplantation* 24, no. 7 (1999): 701-6.

Duty and Altruism: Alternative Analyses of the Ethics of Sibling Bone Marrow Donation

Rebecca Pentz

Douglas Opel and Douglas Diekema present a careful analysis of a difficult sibling donor case in this issue of *The Journal of Clinical Ethics*: 15-year-old A.R. and his mother chose to pursue a bone marrow transplant for his relapsed acute myelogenous leukemia (AML). The best HLA matched bone marrow¹ was that of his nine-year-old sister, L.R., whom A.R. was incarcerated for having sexually abused. Was L.R.'s participation as a donor for her brother ethically justifiable? Opel and Diekema divide the analysis of this case into three issues: (1) Should prisoners have access to bone marrow transplants (BMTs)? (2) Should parental permission be considered valid in this case? (3) Should a minor sibling who was sexually assaulted by the patient be allowed to donate bone marrow?

I agree substantially with the conclusions offered by Opel and Diekema — prisoners should have access to BMTs, but L.R. was at such risk for psychological damage that, at a minimum, a complete psychological assessment of the child without her mother present should

have been required. Opel and Diekema are skeptical that the donation met the physician's duty to do no harm. However, I would like to offer a different method of analyzing this case that I think fits better with the moral foundations of family decision making. I will not discuss the issue of prisoners' rights to BMT, agreeing completely with Opel and Diekema's analysis.

Undergirding the proffered analysis is the goal of protecting L.R.'s well-being. First, Opel and Diekema ask if the mother could have been a trusted decision maker who would protect L.R.'s well-being, since she was inherently conflicted, being the primary decision maker for her son as well as for L.R. There is no doubt that parents are conflicted as decision makers for transplant and sibling donation, and I have argued that this conflict requires that special protections be built into the process of sibling donation.² Opel and Diekema then consider Ross's view that L.R.'s well-being could have been protected as long as her basic interests were protected. They conclude that since the R. family lacked the intimacy required by Ross's model of constrained parental autonomy — A.R.'s abuse introduced a destructive element into the family and A.R. did not live with his mother — to enhance the well-being of the family would

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not necessarily enhance L.R.'s well-being. The authors then offer their own preferred analysis using the harm principle: parental decisions should be respected as long as they do not result in a harm that is higher than an appropriate harm threshold. They conclude, I think correctly, that although the physical harm from bone marrow donation does not exceed this harm threshold, the little empirical evidence that exists suggests that, for L.R., the risk of psychological harm could have well exceeded this threshold. Further, the mother's refusal to allow an unfettered psychological assessment made a determination of the potential for psychological harm difficult, if not impossible. The authors conclude, "the harm to L.R. was likely to exceed any potential benefits." Notice the framework throughout this analysis: How do we protect L.R.'s well-being by ensuring the proper decision maker for her?

In contrast to this approach, there is a thread in the bioethical literature that tempers the focus on the individual's well-being with various approaches to including family interests. I think one version of this family focus may provide a better justification for sibling donation in general and can inform the analysis of this case.

In his seminal article, "What about the Family?" John Hardwig argues that the medical attention to the patient's interests can allow the patient to shirk responsibility to the family.³ Hardwig therefore proposes that family conferences in certain cases be given decisional authority, so that the interests of the family can be treated on a par with the interests of the patient. James Nelson continues this concern for the family, arguing that family interests should be factored into medical decisions, with the patient's interests having a "rebuttable presumption of authority."⁴ Yet, Nelson also interestingly describes how loving families do not always try to maximize each member's well-being, and may somewhat cavalierly put members at risk to achieve family goals. For example, responsible, loving parents put small children in the car for a drive in snowy weather to go buy a bottle of wine for guests. Ross's view of constrained parental autonomy is in line with this literature

that allows parents to trade the best interests of the child for family interests *as long as the child's basic interests are not compromised*.

Some have pushed this emphasis on the family beyond suggesting that family interests must be considered to an account of family duties, namely that family members have obligations to one another.⁵ This view shifts the focus from rights and interests to family duties, a switch that may better explain the underlying intuition that in many cases siblings should donate bone marrow. Opel and Diekema are completely right in their analysis that the prevailing justification for sibling donation — that the donor benefits — is weak. The scant empirical evidence does not completely support this view. Further, this view requires that donations take place in intimate families in which the donor's well-being is enhanced when the family flourishes, which excludes dysfunctional and even partly functional families. Yet, the courts have frequently supported the even riskier donation of solid organs, and the general practice in oncology is to allow sibling donation of bone marrow without special review. Perhaps the true grounding for this consensus is not that the donor necessarily benefits, but that a sibling has a duty based on family relationships to undergo some risk for a sibling.

Let me sketch the family duty justification. Family members, because they are in family relationships, owe each other care, respect, and a certain level of sacrifice, regardless of whether or not the sacrifice benefits them. James Dwyer and Elizabeth Vig are correct, I believe, that different levels of relationship demand different levels of sacrifice — with parents owing their children more than siblings owe each other. And, as Benjamin Freedman argued, children owe their parents considerable duties.⁶ The relationships that undergird these obligations are social relationships, not biological. A child who has no social interactions with a sibling or parent does not have duties to that parent or sibling, even if biologically related to them.⁷ However, these duties do not hinge on the family being intimate or harmonious and functional. For example, a parent owes a wayward daugh-

ter the duty of care, even if she is disobedient and self-destructive. It may be that care is best shown by allowing the consequences of the daughter's actions to befall her without rescue, but this "tough love" would still be fulfilling the duty of care. Similarly, siblings still have duties to each other, even if their relationship isn't intimate. We expect an older brother to walk his younger brother home from school, even if, that month, he detests his younger brother. My account differs here from that of Walter Glannon and Lainie Friedman Ross, who believe that intimacy is the foundation for family obligations, although their use of "intimacy" may be closer to my use of "social."⁸ On the other hand, there are limits to these duties.⁹ Family relationships do not necessitate any level of sacrifice. We do not expect or allow parents to donate lungs to children, even if they want to. The sacrifice is too great. Dwyer and Vig, who claim that obligations are implicit in relationships, argue that sibling donations for transplants are justified if there is "a moral match between the relationship and the risks to the donor relative to the benefits to the recipient."¹⁰ This formula seems reasonable: a sibling may owe some risk for the potentially life-saving bone marrow transplant. Yet, given Opel and Diekema's analysis of the potential for harm to L.R., one might reasonably conclude that the risks, given her psychological vulnerability, may be too great to justify the donation.

There is another caveat in a family duty view that is particularly relevant to the case of L.R. It is possible to so fracture the relationship that undergirds the familial duty that the duty is no longer operative. Take, for example, an abused wife. Her abusive husband has fractured any relationship of care and respect by abusing his wife. She therefore no longer owes him care and respect and sacrifice. Similarly, I would argue that A.R. has so fractured the sibling relationship by sexually assaulting L.R. that any duty she had toward him is no longer operative. She does not owe him the sacrifice required in a bone marrow donation. Although I do not have a formula for exactly how fractured a relationship must be for duties to no longer be opera-

tive, and I do think duties are operative in mildly dysfunctional families, I do believe that criminal behavior toward a sibling or spouse qualifies as sufficient fracturing.

In short, I think the most cogent justification for our intuition that siblings should donate bone marrow is not that this donation benefits the donor either directly or through an enhanced family, but that the sibling, in many cases, owes this duty of sacrifice. But, in L.R.'s case, this duty is no longer operative due to the sexual abuse, and even if the duty were operative, the sacrifice could be deemed too great.

Yet, there may be a reason why L.R. could still be allowed to donate bone marrow to A.R. — altruism. Although the research is far from definitive, there is some indication that children as young as nine years old can act altruistically,¹¹ that is, act to benefit another without being motivated by either a material or social reward. Altruistic actions are morally praiseworthy and should be allowed, if not encouraged. For adults, altruistic acts that require great personal sacrifice are even more praiseworthy: "Greater love has no man than this, that he lay down his life for his friends." (John 15:13).¹² Yet, for a child of nine, we reasonably put limits on altruism, because we do not judge that a nine-year-old has the capacity for mature judgment nor for complete cognitive understanding of the situation. Therefore, once again, since the potential for harm may be great for L.R., we would be reluctant to allow her to act altruistically for her brother without a thorough psychological assessment, which could determine whether her altruism would bring such benefit to her that it outweighed the harm.¹³ If such an evaluation revealed that she understood that her brother's treatment of her was wrong, but that she wished to help him since he was still her brother, and she understood adequately the risks to herself, we might conclude that the donation should proceed. But if the evaluation revealed that L.R.'s motivation for offering to help her brother was not altruistic, but rather based on some masochistic view that she was a victim and deserved to be victimized again, the professionals should refuse to qualify L.R. for the

donation. Such an evaluation should be a prerequisite for donation, and should not have been dependent on the mother's choice.¹⁴

In sum, although I reach conclusions identical to Opel and Diekema's, I do so using a very different approach: siblings have duties to each other that include some personal sacrifice; these duties are not unlimited and do not require great sacrifice; these duties can be negated by fractured sibling relationships; and, finally, siblings can donate bone marrow altruistically, if, once again, the harm is not too great. Like Opel and Diekema's analysis, my analysis requires a careful weighing of harms. For a vulnerable child like L.R., the harms might have been too great.

NOTES

1. Human leukocyte antigens (HLA) are histocompatibility antigens, which are used to determine whether a donor and recipient are immunologically compatible.

2. R.D. Pentz et al., "Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity," *Cambridge Quarterly for Healthcare Ethics* 13, no. 2 (2004): 149-55.

3. J. Hardwig, "What About the Family?" *Hastings Center Report* 20, no. 2 (March 1990): 5-10.

4. J.L. Nelson, "Taking Families Seriously," *Hastings Center Report* 22, no. 4 (July 1992): 6-12.

5. C. Weijer, "Family Duty is More Important Than Rights," *Western Journal of Medicine* 174, no. 5 (May 2001): 342-3; B. Freedman, "Respectful Service and Reverent Obedience," *Hastings Center Report* 26, no. 4 (July/August 1996): 31-7.

6. J. Dwyer and E. Vig, "Rethinking Transplantation between Siblings," *Hastings Center Report* 25, no. 5 (September/October 1995): 7-12; Freedman, see note 5 above.

7. See note 2 above, p. 153.

8. W. Glannon and L.F. Ross, "Do Genetic Relationships Create Moral Obligations in Organ Transplantation?" *Cambridge Quarterly of Healthcare Ethics* 11 (2002): 153-9.

9. D. Steinberg, "Kidney Transplants from Young Children and the Mentally Retarded," *Theoretical Medicine* 25 (2004): 229-41.

10. Dwyer and Vig, see note 6 above, p. 11.

11. E.M. McGee, "Altruism, Children, and Nonbeneficial Research," *American Journal of Bioethics* 3, no. 4 (Fall 2003): 21-3; R.M. Nelson and W.W. Reynolds, "We Should Reject Passive Resignation in Favor of Requiring the Assent of Younger Children for Participation in Nonbeneficial Research," *American Journal of Bioethics* 3, no. 4 (Fall 2003): 11-3.

12. N. Eisenberg, *The Socialization and Development of Empathy and Prosocial Behavior* (East Haddam, Conn.: National Association for Humane and Environmental Education, 1983), http://www.nahee.org/research_evaluationPDF/Socialization%20and%20Development.pdf.

13. B.J. Seelig and W.H. Dobbelle, "Altruism and the Volunteer: Psychological Benefits from Participating as a Research Subject," *American Society for Artificial Internal Organs (ASAIO) Journal* 47, no. 1 (January 2001): 3-5.

14. Personal communication from B.J. Seelig, MD, a Professor of Psychiatry at Emory School of Medicine who has done extensive work on altruism, on 8 July 2006.

The Courage to Stand Up: The Cultural Politics of Nurses' Access to Ethics Consultation

Elisa J. Gordon and Ann B. Hamric

The Joint Commission on Accreditation of Healthcare Organizations¹ mandates that hospitals have a process for addressing ethical issues in patient care, and most hospitals in the U.S. (82 percent) now offer ethics consultation (EC) services to healthcare providers and patients.² EC is a service provided by an individual consultant, team, or committee whose purpose is to improve the process and outcomes of care by helping clinicians to identify, analyze, and resolve ethical problems that arise in specific clinical cases.³ Ethics consultations are touted by bioethicists as helpful in making medical decisions. Several studies report that ethics consultations for patients in intensive care units were effective in reducing the number of days spent in the hospital and intensive care units, in reducing healthcare costs for nonbeneficial treatment, and in helping 70 percent to 95 percent of the physicians and nurses surveyed to resolve ethical conflicts.⁴

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Despite the generally favorable evidence supporting ethics consultation, there is concern about the underuse of such services by physicians, nurses, and other healthcare professionals.⁵ Specifically, nurses and resident physicians may face barriers to requesting EC. Studies suggest that such barriers are related to hospital policy regarding who may request an EC and traditional power structures within the medical professional hierarchy.⁶ The underuse and/or lack of access to ethics consultants is problematic because both patients and the healthcare professionals who are involved in the care of patients can be adversely affected. Yet little is known about barriers to requesting EC.

This study examined the factors affecting nurses' and residents' awareness, utilization, and perceptions of the EC service in one institution. The residents' perspective was published elsewhere.⁷ Following a review of relevant literature, this article presents study results on nurses' perceptions of risk, power dynamics, and regret in requesting EC.

BACKGROUND

Requesting an EC must be understood within its broader political and sociocultural contexts, particularly given the role of hospital

policies and the power dynamics that are inherent in hierarchical relations among healthcare professionals. The following section provides background information on policy and inter-professional factors influencing access to EC, and briefly reviews literature on nurses' efforts to resolve ethical dilemmas and the professional obligations that influence nurses' responses to ethical dilemmas.

POLICY

Barriers to requesting EC may be related to hospital policy. Hospital policies vary as to which type of healthcare professional may request an EC,⁸ and the procedures by which they can do so. A 2001 national survey of hospitals ($N = 346$) found that 62 (19.4 percent) of 322 hospitals with ethics committees restricted access to EC to physicians or attending physicians.⁹ Even though any healthcare professional may technically request an EC at most institutions, not all request EC equally, in practice.¹⁰

Inequity in access for all healthcare professionals to EC services raises questions about justice for several authors. Indeed, the need to "help assure that all relevant parties share equal access to and participation in bioethics discussions, and to help assure that bioethics consultations are conducted fairly"¹¹ is central to bioethics scholars' efforts to promote the utilization and/or regulation of EC services.¹² Ensuring that all professionals involved in the clinical care of patients have equity in attaining the resources available to them may actually have health consequences for providers. Perceptions of unfairness due to having little recourse to resolve conflicts within one's institution was found to have jeopardized the health of hospital employees in one study.¹³

FACTORS THAT INFLUENCE REQUESTS

While little is known about what factors influence the request for a consult, empirical research and anecdotal evidence suggest that professional and political factors related to power and authority may trigger or inhibit requests for EC.¹⁴ Empirical research, albeit more than a decade old, shows that ECs are requested predominantly by physicians (ranging from 57 percent

to 88 percent).¹⁵ Anecdotal evidence indicates that some physicians become angry when other members of the healthcare team request an EC because physicians perceive consults as interfering with their medical decision making; consequently, nurses and residents may fear retaliation from attending physicians if they request ethics consultations.¹⁶ Nurses and physicians in training have much at stake when they speak up: they may risk being ridiculed or being seen as disloyal team members and as unprofessional.¹⁷ These risks constitute serious barriers for nurses and residents seeking to resolve ethical dilemmas and ameliorate moral distress.

There is little direct research on healthcare professionals' decisions about requesting EC. A national survey ($N = 344$) of internists' attitudes about EC reveals that most (72 percent) considered consultations to provide information that would be useful in addressing future ethical dilemmas. However, others were hesitant to seek EC, believing that the consultations are too time consuming (29 percent), make situations worse (15 percent), or that consultants are unqualified (11 percent).¹⁸ A 1992 survey study of the effectiveness of five ethics committees in Canada reported that physicians, nurses, and administrators maintained different views about the importance of ethics committees.¹⁹ Physicians perceived ethics committees as irrelevant to their practice for the following reasons:

- Medical decision making was considered to be the physician's responsibility,
- Consultations appeared to interfere in the care of patients,
- Physicians lacked confidence in committee members,
- There was little time to obtain help, and
- Physicians felt confident to make ethical decisions themselves.

In contrast, nurses had little knowledge of the existence of ethics committees, but those who did felt they had no direct access to them due to existing institutional power structures. Physicians and administrators expected that nurses would not take the initiative to manage ethical dilemmas by going to the ethics committee, but would rather go through their nurse

supervisors, who confirmed that this was the accepted practice. A qualitative study from 1992 of 12 male senior physicians similarly found that most avoided requesting EC because they perceived consultation as an intrusion into the doctor-patient relationship, a loss of control over the interaction, and an abdication of a physician's responsibility to a patient.²⁰ These studies suggest that attending physicians' perceptions of EC can affect nurses' willingness to request consultation.

While a few ethnographic studies have examined the cultural processes involved in ethics consultation services or hospital ethics committees,²¹ little research has specifically investigated the cultural dynamics and politics shaping both the process of gaining access to EC and the determinations of whether EC is even considered as a worthwhile resource. Cate McBurney's ethnographic study of one Canadian Catholic hospital's ethics committee, however, indicated that its ability to resolve ethical problems was hindered by multiple factors, including barriers to access based on the committee's authority and membership.²² Of particular note is her finding that those lower in the medical hierarchy, specifically nurses, had to obtain the endorsement of those who held authority and power to access the ethics committee. In addition, members of the hospital ethics committee dismissed nurses' ethical concerns as communication problems and undermined nurses' credibility by framing their concerns as emotional problems. By these measures, nurses were not viewed as moral agents. Such practices by the ethics committee served to reinforce the status quo of the hierarchy within the healthcare setting.²³ Just as the healthcare system can be considered a culture, EC services and individual patient care units can be viewed as subcultures of the healthcare system. Understanding ECs and hospital units as subcultures helps to make sense of the social dynamics surrounding the use of EC services.

NURSES' APPROACHES TO ETHICAL DILEMMAS

While relatively little is known about how nurses resolve ethical dilemmas,²⁴ studies re-

port that nurses desire to actively participate in ethical decision making but feel constrained from doing so — often by institutional factors.²⁵ For example, nurses can feel powerless in their ability to effect a resolution to ethical dilemmas due to physicians' dominance, a lack of knowledge of possible alternatives,²⁶ or uncertainty about how to carry out what they view as the right action.²⁷ Numerous factors influence nurses' moral actions including external (physicians, the law, the administration), procedural (the existence of an ethics committee, policy on who may request an EC), and individual factors (demographics, socialization to follow orders, sanctions on past actions, fear of job loss, lack of courage).²⁸

Although the nursing literature recognizes and promotes collaborative teamwork as the preferred vehicle for providing care for patients,²⁹ nurses in many "real world" settings feel unable to collaborate with physicians in practice. The presence or absence of collaborative teamwork may also influence whether nurses take an active role in addressing ethical dilemmas. One study reports that nurses perceived the quality of collaboration and communication with physicians more negatively than did the physicians surveyed.³⁰ Nurses reported more difficulty in speaking up when they saw a problem with the care given to patients, felt that they had little input into making decisions, and perceived that their input was not well received, compared with the reception of input from physicians.

NURSES AS ADVOCATES FOR PATIENTS

Nurses' approaches to resolving ethical dilemmas are commonly based on their professional role as patient advocates. *Advocacy* refers to "actively support[ing] patients in speaking up for their rights and choices, in helping patients to clarify their decisions, in furthering their legitimate interests, and protecting their basic rights as persons."³¹ In addition, being an advocate is seen as a moral obligation for nurses, often predicated on the perception of patients as vulnerable due to illness.³² Advocacy is identified as a core responsibility in the American Nurses Association's *Code of Ethics*.³³ Literature

reviews indicate that this facet of nursing's professional identity has been increasingly noted in the past 20 years.³⁴ Despite the professional obligation to be a patient advocate, occasions arise that can keep nurses from fulfilling this obligation. In such situations — usually characterized by ethical conflicts or disagreements — nurses may experience what is known as *moral distress*.

MORAL DISTRESS

First defined in the context of nursing practice by Andrew Jameton, moral distress for nurses is a phenomenon that occurs when a nurse knows or believes she or he knows the ethically correct action to take in a particular situation, but is constrained from taking that action because of some obstacle, be it lack of time or supervisory support, institutional or legal constraint, or physicians' power.³⁵ Jameton distinguished between *initial* moral distress, when a nurse first encounters a difficult situation and recognizes a problem, and *reactive* distress, which Jameton described as the negative emotional response a nurse experiences when she or he is unable to or fails to act on the initial distress.³⁶ Moral distress is characterized by frustration, anger, anxiety, guilt, compromised integrity, and psychological disequilibrium. Because moral distress involves a perception that personal or professional values or core ethical obligations are being violated, it carries serious consequences: emotional withdrawal from patients and co-workers; painful feelings such as anger, guilt, or depression; physical symptoms; and burnout or leaving a position or the profession altogether.³⁷ While other providers, including physicians, can and do experience moral distress,³⁸ the phenomenon has been primarily recognized and discussed in the nursing literature.

RESEARCH METHODS AND DESIGN

STUDY SITE

The study was conducted at a Catholic academic teaching hospital in the Midwest U.S. At this institution, any person involved in a patient's care can request an EC by calling the

ethics department. The policy on EC requires that the person requesting the consultation be responsible for personally (or by delegation) notifying the attending physician of the consult because the attending physician is regarded as the leader of the medical team. The policy specifically stipulates that *notifying* the attending does not mean *asking* the attending for permission to pursue the consult. The EC service has been in existence for more than 25 years. It is routinely utilized in the institution; 23 ECs were requested in 2005. Informal feedback has been uniformly positive.

STUDY DESIGN

The study employed a sequential, multi-method approach that included a survey questionnaire followed by an in-depth interview. This approach was used to assess the range of perspectives on EC and to explore them in depth. A self-administered survey was distributed to all in-patient registered nurses ($N = 881$). The surveys were distributed directly to nurses either by the nurse managers or by placement in their individual mailboxes. Surveys were distributed twice with a reminder postcard delivered between surveys, to increase the response rate, as validated by Don A. Dillman.³⁹ The two-page questionnaire contained 18 open- and closed-ended questions about nurses' knowledge and use of the EC service and demographic information.

The survey included three additional measures. First, one measure asked nurses to rate their perceptions of how receptive four medical team members, the patient, and a family member/surrogate were to their request for an EC on a 5-point Likert scale (1 = very receptive, 5 = very unreceptive). The second measure, the Decisional Regret Scale, consisted of six items originally developed to determine patients' decisional satisfaction with undertaking a medical regimen.⁴⁰ This scale was adapted (in wording and by adding one item) to determine nurses' decisional satisfaction with requesting or not requesting an EC (Cronbach's $\alpha = 0.87$). The third measure was a 100 millimeter visual analog scale (VAS) on which respondents rated their perception of risk involved in re-

questing an ethics consultation from “not at all risky” to “very risky.” Scores were the number of millimeters at the mark.

Nurses could indicate their interest in participating in an in-depth, semi-structured interview on the survey. During the interviews, the nurses were asked about their perceptions and experiences regarding the hospital’s EC service, and to describe their experience with ECs. Interviews lasted on average 30 to 45 minutes. All interviews were tape-recorded and conducted in the principal investigator’s office or in a private conference room near the medical unit. Consent for the survey was presumed to have been granted when respondents completed and returned the self-administered survey. Preliminary consent was obtained upon scheduling the interview, and oral consent was obtained after nurses reviewed an information sheet about the study. Nurses were asked as part of the consent process if their interviews could be tape-recorded, and they were assured that no identifying information would be included in the study if their narrative was used. Additionally, for narratives quoted at length below, we received explicit consent to use these quotations. Approval for the study was granted by the institution’s Review Board.

STATISTICAL ANALYSIS

Descriptive statistics were used to analyze the data using statistical software.⁴¹ Short responses were coded and analyzed using descriptive statistics. *T*-tests were used to test differences between means. Differences in proportions were tested using Pearson’s *chi*-square test or Fisher’s exact test if expected frequencies were less than five. The Friedman and Wilcoxon signed ranks tests were used to examine how nurses ranked individual medical team members’ levels of receptivity to the request for an EC.

CONTENT ANALYSIS

The tape-recorded interviews were transcribed verbatim. Nurses’ responses to open-ended questions were thematically analyzed. Thematic analysis entails the systematic search for themes and repetitions that emerge from the

data;⁴² it is an iterative process in which an initial set of participants’ responses are coded and a preliminary coding scheme is developed. The codes then are applied to a new group of nurses’ responses, the coding scheme is revised to adjust for these new responses, and modified codes are applied to the previous set of responses, continuing in this manner until no new codes emerge.⁴³ Most of the respondents gave multiple reasons for requesting or not requesting an EC.

We intentionally did not include any identifying information about the nurses, even though specifying the nurses’ clinical units might help place a given narrative in its clinical context, and even though we found that nurses’ age was a significant variable in their decisions about requesting EC. Some nurses in particular expressed reservations about using their quotation in full, out of fear of retaliation in the workplace. To protect their confidentiality, we worked with the nurses whose quotes had sensitive material to re-state their narratives in a way that accurately reflected their key ideas, while assuring their anonymity. This effort was as important as protecting the confidentiality of respondents, and was a key ethical obligation of the researchers. The efforts to protect nurses’ narratives indicate one challenge in doing this type of research: nurses can be so fearful of being “found out” when they disagree with those in power that they become silent and unwilling to speak up or to have their stories described. This may be one reason why there is so little direct empirical evidence on nurses’ views of ethical conflict.

RESULTS

RESPONDENTS

Of the 881 nurses who were given the survey, 504 (57 percent) completed the survey. Of these 504 nurses, 93 (19 percent) indicated their interest in being interviewed, and of these 93 nurses, 83 (89 percent) participated in the interview. The mean age of the survey respondents was 38 years; 95 percent were women; and they had an average of 14 years of nursing practice (see table 1). Differences were noted between

TABLE 1 Characteristics of Respondents Surveyed ($N = 504$) and Interviewed ($n = 83$)

	Nurses surveyed		Nurses interviewed		Significance*
	Years	Range	Years	Range	
Age in years	38	21 - 61	42	24 - 62	$p = 0.0005$
Years in practice	14	< 1 - 40	17	< 1 - 40	$p = 0.003$
	Nurses surveyed		Nurses interviewed		Significance*
	<i>n</i>	%	<i>n</i>	%	
Gender					n.s.
Female	478	95	77	93	
Male	26	5	6	7	
Race/ethnicity**					n/a
White	—	—	73	88	
African-American	—	—	1	1	
Hispanic	—	—	3	4	
Asian	—	—	6	7	
Religion**					n/a
Roman Catholic	—	—	52	63	
Protestant	—	—	26	31	
Jewish	—	—	3	4	
Other	—	—	2	2	
Employment status					n.s.
Full-time	332	66	57	69	
Part-time	150	30	26	31	
Highest RN degree					$p = 0.003$
AD or diploma	117	23	24	29	
BSN	317	63	41	50	
MS, MSN, DNS, or PhD	56	11	17	21	
Role/title					$p = 0.01$
Staff nurse	438	87	68	82	
Advanced practice	23	5	8	10	
Nurse administrator	22	4	7	8	
Clinical specialty					n.s.
ICU	248	49	49	59	
Med-surg	116	23	19	23	
OR/ER/RR	106	21	10	12	
MCN	34	7	5	6	
EC request status					n/a
Requested an EC	40	8	16	19	
Wanted to, didn't	76	15	22	27	
Never wanted to	388	77	45	54	

NOTE: Some figures do not total 100, because some respondents did not respond or data were missing.

* Tests of significance based on comparisons between nurses who were interviewed and nurses not interviewed.

** Some data were not collected at the time of the survey, preventing comparison between those who completed the survey and those who completed the survey and the interview.

those nurses who completed only the survey versus those interviewed in age, years in practice, highest degree earned, and role/title (see table 1). The nurses who completed an interview were older, had more years of clinical experience, and were more likely to be an advanced practice nurse or in a managerial role than the nurses who completed a survey, but did not complete an interview.

AWARENESS OF EC SERVICES

The majority of the nurses surveyed (62 percent) were aware of the availability of the EC service, but only 25 percent indicated that they knew how to request an EC. Nurses had learned about the service, on average, six years prior to the survey. Half of all of the nurses surveyed (52 percent) reported having learned about the EC service in the following ways:

- Being involved in a case in which an EC was conducted or observing an EC in their unit (25 percent),
- Orientation (21 percent),
- Co-workers (20 percent),
- Word of mouth (8 percent),
- Staff meetings (7 percent),
- Hospital newsletters (5 percent),
- Nursing classes (5 percent), and
- Don't remember/other (7 percent).

It is interesting that 2 percent of the respondents learned about EC through the survey itself, although they had worked at the institution for an average of 11 years.

EXPERIENCE REQUESTING ECs

Of the 504 nurses who completed the survey, 76 (15 percent) reported they had wanted to request an EC in the past but had declined to do so. This figure is almost twice as many as those who had actually personally requested a consult ($n = 40$; 8 percent); 25 percent ($n = 10$) of those who requested an EC actually experienced some form of repercussion for doing so, most notably, anger from an attending physician. These nurses reported that physicians yelled at them or gave them the "silent treatment," humiliated them in front of the medical team, told them to stop taking care of certain

patients, and even threatened their jobs. One nurse related how she had gone only so far as to give a patient's wife the telephone number for the EC service because the case was a conflict between the patient and the attending physician, and, consequently, the following occurred.

- RN: The nursing supervisor is telling me to stay out of it, or you know, there'd be problems. Oh yeah.
- EG: And, did you feel that your job was on the line in this particular case?
- RN: Yes. Yeah, yeah I did.
- EG: Did they say anything about that?
- RN: Well, no because I, I, like I said, I did drop it. I just got a phone number for the um —. I gave the ethicist's phone number and the patient advocate phone number to the, the wife. And I, I told her where I stood. I said, "I'm, I'm told I'm to stay out of it, here, call."
- EG: And so did the nurse supervisor tell you explicitly that your job was on the line?
- RN: Yeah, she — yeah, she did. [Case #0349.]

More than one-third (38 percent) of those who requested an EC reported being hesitant, or, more accurately, afraid to do so. Since their reasons for being hesitant coincided with the reasons given by nurses who wanted to but did not call a consult, they will be examined in the section on barriers to requesting EC.

Were the nurses who requested an EC different from those who did not? The nurses who did request an EC had significantly more experience (19.4 years versus 14.6 years; $t = 3.084$; $p = .003$), and were significantly older (42.6 years versus 38.5 years; $t = 2.594$; $p = .011$) than those who wanted to, but did not, call an EC.⁴⁴

BARRIERS TO REQUESTING AN EC

Of the 504 nurses who completed the survey question about how risky requesting an EC would be to themselves, 70 percent ($n = 264$) reported on average 32 mm (range, 0 - 100). Nurses who wanted to, but did not, call for an EC rated the perceived risk of calling for an EC as slightly, but not significantly, higher than nurses who called for an EC (43 versus 34 mm; $t = -1.396$, $p = .166$). We construed a rating of 50 mm and higher as a significant perception of risk. The proportion of nurses who rated the

level of risk between 50 mm - 100 mm was largest among nurses who wanted to, but did not, request an EC (47 percent), compared to nurses who did request an EC (38 percent), and the remaining nurses who never considered requesting an EC (22 percent). This finding suggests that experience with having called an EC tempered nurses' perception of risk in asking for one.

We also compared nurses by their level of regret in their decision to request or not request an EC. Nurses who requested an EC reported significantly less regret in their decision than nurses who desired to, but did not, request one (14.07 versus 53.22, $t = -9.066$, $p < .001$, $n = 86$).⁴⁵

The nurses who wanted to, but did not request, an EC reported several reasons for not requesting one. These reasons included, in decreasing order of identification:

1. Lack of awareness or not knowing how to request an EC,
2. Fear of adverse repercussions,
3. Resolution of the case or someone else eventually requested an EC,
4. Emergent situations created time constraints, and
5. Lack of availability of EC on the night shift.

Given their prevalence, the following discussion examines nurses' fear of three repercussions:

1. Incurring physicians' anger,
2. Destabilizing relationships with members of the healthcare team, and
3. Threats to employment.

Attending Physicians' Anger

Nurses reported that calling an EC can make physicians angry. Nurses used the following expressions to describe why they think physicians may be angry when an EC is called: "interference," "their judgment is being questioned," and "overstepping my boundaries." When asked why physicians' anger was a problem, nurses explained that the anger was directed at them: in some cases, nurses noted that physicians expressed their anger about ECs through verbal abuse, retaliation, threats and/

or actual repercussions (for example, reporting the nurse to the nurse manager). One nurse described her perceptions about physicians' anger:

RN: Anger and yelling from the attendings who feel their judgment is being questioned. They tend to avoid asking further opinions or consulting the nurses on [patient] related issues after an ethics consult. [Case #0578.]

Strained Working Relationships

Nurses were also concerned that requesting an EC would damage or strain their working relationships with attending physicians and other members of the healthcare team. The nurse quoted above recounted the interaction she had with a physician following her consult request. This example illuminates the gravity, albeit temporary, of the impact of the consult request on their inter-professional relationship.

RN: We have a pretty good relationship with most of the attendings here. . . . A lot of the attendings think they're the only ones who could ever request an ethics consult, and they feel that we're going over their head. So, I think the risk is just with the attending and nurse relationship there — that are they ever going to trust you again, or if you want something in the future or recommend something, will they actually go along with it.

EG: Well, how is your relationship now after having called this consult with that attending?

RN: Actually, it's about the same as it was before. I mean, there hasn't really been a change. For the first few days, he was angry about it.

EG: How can you tell?

RN: Well, he would come around and if a nurse would ask, you know, "Do you think we could try this?" He would say, "No, the physician decides." So, for the first few days, he was like that, and then gradually got over it. So, I think it was just the initial pouting phase that he was showing his authority that he's the doctor. [Case #0578.]

Similarly, another nurse who requested an EC related the following.

RN: I know the attending was very angry with me because I didn't go to him first. He said that I should have gone to him, and then we could have discussed it, and then pursued it together. [Case #0639.]

Nurses also reported fearing the nursing staff would “hold grudges” against them or criticize them because they called for a consult. Moreover, they reported that they feared that their reputations would be damaged if they were to ask for an EC. Several noted that they would be ostracized or alienated; some believed that they would experience a loss of respect or trust by co-workers; and others reported that they would be labeled as a “trouble-maker” and become known for going over the heads of those in authority. One nurse also feared being labeled and stigmatized by other nurses as “nurse Kevorkian” for offering the option of “no treatment” to terminally ill patients. [Case #0781.] One nurse explained how a request for an EC adversely affects the nurse’s relationship with the health-care team:

RN: You don’t feel like you’re a member of the team. . . . Nurses will be reluctant to make the call, and then by the time they do, they often feel like, “I’m backed in a corner, no one has addressed my concerns about, you know, either from a medical perspective or from the patient’s family perspective. So I have nowhere else to turn but to call the ethics consult.” And then by that time, you kind of feel like you’re being, um, you’re outside the system, you know. You’re, you’re going beyond the scope of the patient’s care team instead of including them. [Case #APN-1.]

Threats to Employment

Nurses perceived that they might lose their jobs by calling for an EC, as nurses were directly threatened by a physician, or witnessed other nurses be threatened or lose their jobs over this. [Cases #0564 and #0448.] Nurses also feared they would be reprimanded by their nurse manager or by the attending physician. In addition, nurses believed that their managers might make their work assignments more difficult, that is, assigning night shifts or extra charting. Others related that there would be negative notes in their employee record, and their salaries would be affected. As one nurse noted, “It would be held against me for yearly evaluations and merit increases.” [Case #0811.] Nurses specifically perceived that physicians had the power to affect their job status. Although physicians could not directly fire a nurse (although they could

threaten to do this), nurses explained that physicians could inform the nurse manager about a nurse’s problematic behavior. This could lead to a reprimand or being written up. It is noteworthy that nurses perceived physicians as having sufficient power over them to affect their job status. Indeed, Mary C. Corley maintained, “physicians are not reluctant to identify nurses as incompetent and to report them to administration.”⁴⁶ In such situations, perception can be as powerful as reality.

CASES

The following two cases illustrate many of the concerns that nurses identified, including power dynamics and the lack of support from nurse managers, departmental chairs, and administrators when facing ethical dilemmas. Three nurses described these two past situations, still powerful in their minds after many years. In both situations, attending physicians with very good reputations operated on patients who had poor outcomes. These physicians were seen as powerful and intimidating by the nurses, who wanted to call for an EC but did not, for fear of retribution.

In the first case (reported by two nurses), the physician blamed the staff for the patients’ poor outcome, but the nurses suspected medical error. As one nurse reported, “I was afraid that I would be reprimanded for second-guessing the surgeon because he . . . was so intimidating.” [Case #0313.] In the second case, the nurse became uncomfortable because the patient was clearly dying, yet the physician was telling the patient’s wife that the patient would survive the surgery. The nurse talked with the fellow about writing a do-not-resuscitate (DNR) order for the patient. Thereafter, the fellow talked to the patients’ wife about this possibility. When the fellow did this, he was reprimanded by the attending physician and removed from the case. Because the nurse witnessed this response, she was even more reluctant to call for an EC.

In both cases, the nurses felt a lack of support from the medical and nursing leadership on their units — as one nurse noted, “the nurse

manager did not want to rock the boat or make waves in this case.” [Case #0448.] The nurses reported feeling afraid to request a consult because they did not feel that their unit leadership (both physician and nurse) would back them up. One nurse even felt that this lack of support extended to higher administration. For these nurses, there was a great deal at stake in requesting an EC; they reported feeling powerless and experienced significant moral distress in the aftermath of these cases. One nurse noted:

RN: I felt disappointed with myself because I didn't feel I did the right thing. I felt frustrated, angry, disappointed, sad for the wife and for him [the patient]. [Case #0448.]

As these cases depict, institutional structures, professional roles, and inter-professional relationships have not always been adequate to support nurse respondents who faced moral dilemmas. The nurses' perception of a lack of institutional support and the adverse consequences of requesting an EC strongly affected their decision making. It is clear that many nurses were unable to pursue what they believed to be the morally right course of action and experienced moral distress as a result.

REQUESTING AN EC

Perceptions of Others' Receptivity

Nurses were asked to rate their perceptions of how receptive the other medical team members were to their actual requests for an EC, to measure perceived differences in the team members' responses. Nurses perceived attending physicians, resident physicians, and housestaff as significantly less receptive to their requests for an EC than nurse managers and other staff nurses, respectively (Friedman's *chi-square* = 43.985, $p < .001$, $n = 28$; Wilcoxon's $z = -3.982$, $p < .001$). When a patient's family was involved in the case, nurses rated the family as more receptive to a request for an EC than were physicians (Friedman's *chi-square* = 32.380, $p < .001$, $n = 21$; Wilcoxon's $z = -2.506$, $p < .012$).

Nurses thought that attending physicians were less receptive in terms of two commonly held views of ECs. According to the nurses, attending physicians seemed to consider an EC as a form of defeat, because ECs are often re-

quested late in a patient's stay in the hospital, typically when little more can be done for the patient. ECs are therefore associated with "giving up" on the patient. As one nurse noted:

RN: We told him [the attending physician], "We called the ethics consult." And he said, "I don't really think we needed to do that, I think we don't need to give up yet." [Case #0578.]

Nurses also reported that physicians perceived a request for an EC as tantamount to "going over their head" or as interfering with medical decision making. According to one nurse,

RN: As far as risk, it's just the typical risk of, you know, physicians can tend to get a bit defensive sometimes when they feel that somebody is questioning their judgment because it's their patient. And a lot of times, what I've seen, they don't like third parties stepping in and really directing the care because it's their patient." [Case #0593.]⁴⁷

These nurses' perceptions of physicians' negative attitudes toward ECs are corroborated by a national study that found that 41 percent of the physicians surveyed were hesitant to seek assistance for ethical dilemmas.⁴⁸

BEING AN ADVOCATE FOR PATIENTS

Given commonly shared perceptions of the attending physician's power over them and fears of potential adverse consequences of calling an ethics consultation, how did the small group of nurses ($n = 40$) decide to request a consult? Nurses who requested ECs indicated that they felt professionally compelled to advocate on behalf of patients against treatment decisions that they perceived to be impeding quality care. Specifically, nursing's professional framework of patient advocacy was understood as enabling informed consent, providing for patient and family choice, and preventing suffering.

CASE

A specific case, representative of other cases, provides insight into the reasons nurses felt compelled to request an EC. In this example, the nurse recounted the second patient case in which she called for an EC for a little boy who

nearly drowned, and for whom the neurosurgeons were asking the parents to consent to the placement of both a tracheostomy and a gastrostomy tube.

RN: The consents were being thrown in their [parents'] face, and they [the parents] did not, per se, ask me. . . I just felt that they weren't well informed about what this really means. We can tell you we're going to put a hole here and a hole here, but they don't — I just didn't feel like the whole big picture had been given. And so I called. And then apparently over the weekend — this had repercussions. . . . Again, I was scared to call, but I did, and then when I came back to work on Monday, apparently over the weekend, it was terrible. Again, the [physician] found out that the ethics committee was called, and he was livid. . . . But the big question was, "Who did this, who called, who did this?" And, I felt like shit — excuse my French — when I got back to work. I'm not sorry I called by any means, but I did feel . . . like . . . I'm sorry, I didn't mean to cause a ruffle in anybody's feathers. [Case #0781.]

The style with which this nurse recounted this scenario, with false starts and repetition, reflected her discomfort with the experience.

ADVOCACY THROUGH ENABLING INFORMED CONSENT

As with many other nurses, the impetus to request an EC in this case had to do with ensuring that patients and/or families were fully informed of all the available treatment options, and the implications of the treatment options that were offered — or what this nurse referred to as "the big picture." Nurses who initiated ECs generally perceived the consent process as ethically problematic due to patient-physician dynamics that were characterized by poor information giving and questionable voluntariness in patients' decision making. According to a number of nurses who were interviewed, it is common for physicians, particularly surgeons, to focus on "fixing" a patient's immediate, short-term clinical problems, to the detriment of providing information about post-hospital or long-term outcomes and quality of life. In addition, such focus on the immediate clinical problems reflects an atomistic approach toward treatment,⁴⁹ which clashes with a holistic approach

toward patient care that is characteristic of a nursing perspective.

Another related issue is that nurses were concerned that patients' informed consent was obtained hastily, which could undermine a patient's ability to engage in thoughtful decision making. A key element of informed consent — voluntariness — was not respected by such a hurried approach, nor was self-determination. The nursing literature similarly recognizes that physicians who technically obtain a patient's informed consent, but do not do so in the spirit of informed consent as an interpersonal process, pose an ethical problem for nurses.⁵⁰

ADVOCACY THROUGH PROVIDING CHOICE

In this case and other cases, the nurse wanted to inform the parents about the option to refuse the offered treatment, even though that choice would have resulted in the child's death. One factor that makes providing the option of no treatment difficult for healthcare professionals is the cultural context of avoidance of death. There is still a strong tradition in hospital and biomedical culture to treat at all costs, so as to prevent death from occurring.⁵¹ For many physicians, in particular, death is still equated with failure.⁵² As the nurse in the case stated,

RN: And the days of, you know, "let's-not-talk-about-it" *should* be over in my opinion, but they're not. [Case #0781.]

She explained that being able to overcome this ethos by providing the parents with what she later called "choice" made her feel as though she was acting in an ethical way:

RN: For my own ethics — I guess I felt like if I didn't call, or if I didn't somehow just give an option of — well, I guess where I'm coming down to say is an option of not doing these tubes and letting the child die. . . . And nobody talks about it, God forbid, you know. So, for my own sanity and ethics-wise with myself, I felt good about doing it." [Case #0781.]

The "technological imperative" — the proclivity of healthcare professionals to use high technology treatment because it is available — may compel a medical team to pursue treatment

even when a patient is clearly declining beyond medical benefit and there is little possible improvement in the quality of life that can be gained. In other words, the patient's quality of life entered into the nurses' moral reasoning in terms of the right way to care for patients. Recent research and nurse scholars recognize that a value conflict occurs when physicians appropriately desire to use new treatments to improve a patient's condition, but nurses perceive the use of the new technology as prolonging a patient's suffering.⁵³

ADVOCACY THROUGH PREVENTING SUFFERING

Another reason nurses gave for requesting an EC was to minimize patients' suffering. This concern is framed in direct contradistinction to the technological imperative, as this statement by a nurse indicates:

RN: I didn't want to see the surgeon, who is like gung-ho surgery, I didn't want her [the baby] to go through a big surgery only to die. It just, it just didn't seem appropriate. . . . [The surgeon] had this thing where, "We should at least try." And you know, sometimes it's just not, it's just not, it's not the moral thing to do, to put somebody through that much pain and that much suffering only if they're going to die anyway. Why do that? And why do that if you're going to be in a bad situation when you get done? Because if she — even if she lived through this heart surgery, she'd still have to go home to an alcoholic mother — I don't think so. I was willing to adopt her, but uh, [chuckling] they [other nurses] called me her mother. You know, I named her. Her mother didn't even name her." [Case #0254.]

The suffering of the patient here is framed in terms of worsening quality of life. The nurse's conception of quality of life is linked to the patient's relationship to her mother. Neonatal intensive care nurses commonly perceive babies who have little parental contact in the neonatal intensive care unit as having a poor quality of life.⁵⁴

Overall, advocating for a patient played a major role in nurses' willingness to request an EC, and provided nurses with a framework to interpret and respond to ethical dilemmas. Acting on their obligation to be an advocate for

patients gave nurses the moral fortitude to face and navigate the power dynamics within a situation by initiating an EC. Additional statements by nurses to this effect include the following:

RN: [It was the right thing to ask for an EC] because I would not have been happy with myself sending her off to surgery without making sure. . . . [Case #0469.]

RN: I feel like I'm my patient's advocate, and if he felt that people weren't listening to him, then I get to find somebody who would. [Case #0639.]

Acting as an advocate in the context of asking for an EC seemed to be a strategy some nurses used to ensure that physicians would stop providing what the nurses perceived as false hope in a situation, or that the preferences of the patient and family would be considered more centrally in the treatment plan. On a more subtle level, being an advocate served as a way for nurses to express the moral imperative to do what they considered to be the "right thing."

OVERCOMING FEAR

While nurses were motivated to request an EC by their professional role as patient advocate, understanding how they overcame their fears to do so can shed light on moral distress and the role of moral courage herein. How did some nurses deal with the power dynamics within the cultural context of a hospital that made most nurses too intimidated to pursue an EC? The reasons relate to the nurses' strategies for requesting the EC, their sense of moral outrage about a case, and the degree of family involvement.

Strategies for Making a Request

The nurses said that the strategies they used in requesting an EC enabled them to act. Some nurses said they undermined or bypassed an attending physician's power by sidestepping the hospital's policy to make anonymous EC requests. This meant that they did not disclose to the attending physician that they were the one who requested the EC. Others did not even tell other staff nurses. These actions can be construed as a form of "responsible subversion," in which nurses "bend the rules" to benefit a

patient.⁵⁵ Sally A. Hutchinson considered this behavior to be responsible when “nurses use their best nursing judgment to decide what rule to bend, and when and how to do it,” based on their knowledge of the patient, their experience, and their ideology or philosophy of care.⁵⁶ Such behavior is subversive, as it violates rules made by hospital and nursing administrators or physicians; it occurs in response to conflict between systems or people.⁵⁷ Nurses bend rules in three different circumstances, one of which — when nurses “believe their behavior is indicative of good nursing judgment” — is applicable to nurses in this study.⁵⁸ Although bending the rules has been touted by some nurse scholars as a requisite to providing “good (ethical) care,”⁵⁹ as we discuss below, we do not support responsible subversion in these situations because it does not lead to improved communication within the healthcare team.

Other nurses reported they told their nurse manager about their desire to request an EC, and usually received encouragement to pursue this further. In those supportive situations, nurses reported they called for an EC, but then their nurse manager notified the attending physician. A small subset of the nurses said they felt confident requesting an EC when they had a good working relationship with the attending physician, a supportive nurse manager, the support of other staff nurses who encouraged them to make the call, and when they became nurse managers themselves.

Moral Outrage

Some nurses explained that they overcame their hesitancy to request an EC by the sheer moral outrage generated by a case. One nurse explained how her anger enabled her to pursue an EC:

RN: I was mad that I was hearing one thing and that the family was being told another. I don't want to say the family was given false hope because, you know, who knows what can happen, it's a brain injury, we don't know anything about the brain really, when it comes to it. . . . I talked to the mom after the doctor got done talking to them. I said, “What did you get out of that?” And she said that she thought that from what he said, that she's [the patient's] going to get up and walk right

out of here — when there was no way, there was absolutely no way that could happen, no way. If anything, she'll be able to blink her eyes and move a finger or something. And we were told that and . . . then you try to get them [the family] into the thinking that it's not going to be like that. And they're being told one thing [by physicians], and the nurses are trying to portray another. And then so I was angry that the mom was sitting there, you know, “Okay, let's get up and walk out of here,” when it wasn't going to happen. . . . The mom asked, you know, if things aren't going to go the way they are, “I'd like to consider pulling her off the ventilator.” And so, it was one of those things — quality of life and what's going to go on there — I don't want to say I was “for” pulling her off the ventilator, but I'm all for, you know, good quality of life, and I didn't think there was going to be any. The doctor said to the nurses there probably won't be any, and she [the mother] was prepared to do that, to take her off and let her go peacefully. And then the doctors come in and say, “We've seen kids just bounce right back from this.” And then she kind of pulled away from that [decision to withdraw the ventilator]. And now I think she's [the patient's] laying in a [hospital] bed somewhere. [Case #0784.]

This example is noteworthy for the lack of unified communication within the healthcare team. What is especially frustrating to many nurses, including the nurse in the case above, is the tension over who discloses what kind of information to patients. Although nurses may know the prognosis or results of laboratory tests after having discussions with physicians, nurses are not sanctioned to disclose such information to patients. Yet patients and families ask nurses for this information because they are generally more proximate and accessible to patients than are physicians.⁶⁰ As such, nurses are “caught in the middle,” between upholding their commitment to patients and simultaneously being an agent of physicians.⁶¹ Consequently, in situations of conflicting perspectives and inadequate communication, nurses may struggle with physicians over how information is framed and relayed to patients. In other words, some nurses practiced a sort of “damage control,” that included requesting an EC to align patients with their view of medical reality, in an effort to en-

sure that decisions made by the patient (or family) were more informed.

Involvement of the Family

Nurses pursued ECs with less concern over repercussions for themselves when it was a patient's family who drove the request. In these cases, nurses took the initial steps to request an EC. When families drove a request for an EC, attending physicians seemed to be more aware of, or took into greater consideration, the family's concerns and the poor prognosis of the patient. For example, one nurse described why she did not feel she had anything at stake when she requested an EC for a family:

RN: In that particular case, the surgeon went along, and let us help, you know, because the family was questioning and looking for more help. And I think they saw the ethics consult in that situation as a resource that would take care of the family and make them feel better and all when they [the physicians] didn't have the time or the inclination to spend that kind of time with the family talking to them, you know. . . .

EG: Why was it the case that in this particular case the surgeons were okay with it, but in so many other cases not — ?

RN: Because the CT [computerized tomography] scan had pretty much said, neurologically, this patient is not going to recover, so it doesn't matter what you do.

EG: Given that there were all these complications, and you know, your sense of hesitancy, how did you feel okay enough to go ahead and call this consult?

RN: Because the family was basically struggling so hard with — and saying things, they were verbalizing, "Mom probably wouldn't have wanted this," and asking questions, "What would happen if we didn't do any more?" And, very often, families don't understand you can withhold feeding, you can withhold medication, you can withhold or take off a ventilator that's been started, you can turn off vasoactive drugs if they're only serving to keep a blood pressure artificially elevated in prolonging what's going to be the inevitable anyway. You can do all of that, but patient's families don't understand that. They think death occurs when you've run out of all options and they never think if someone's on a mega dose of Levophed or other vasoactive drugs, to say, "Well, could we turn that off?" Or, they'll ask, "How long do you think it's going to be?" Which you usually can't answer, but you know sometimes,

days on those drugs — and the ending is going to be the same. So, when they start asking a lot of questions and all the rest of that, it makes it easier to say — and sometimes it doesn't even go to an ethics consult because you can go to the physician and say, "They're asking questions about what we're doing and all the rest and —" But if the family's forceful enough, lots of times the surgeon will do that [request an EC] without us having to say we need it. [Case #0501.]

Crosscutting all of the ways nurses overcame fears of requesting an EC is the finding that this set of nurses had more years of nursing experience than those who did not request an EC. For most nurses, greater experience enabled them to have established a better doctor-nurse relationship, to have gained more clinical expertise, and to know how a doctor might respond. Experienced nurses who had not requested an EC reported that, despite declining to call a consult in the past, their greater experience gave them (or would give them) the confidence to do so in the future. According to one nurse:

RN: Hindsight is 20/20, and a couple years older, realizing that, you know, he was wrong, not me, and it was not my fault, and that I should have, I should have called. I will in the future if I see something I don't like because it would make — certainly make me feel better. I'd feel like I'd done all I could, and people need to be called on — when they do something wrong." [Case #0313.]

DO NURSES WHO REQUEST AN EC DEMONSTRATE COURAGE?

In this study, given the context of power dynamics in the hospital,⁶² and the repercussions that nurses anticipated from requesting an EC, one might ask whether the subgroup of nurses who requested an EC could be characterized as exhibiting moral courage. "Moral courage" can be defined as "a willingness to act — even if against public opinion, authority, tradition or current standards, with acknowledgment of the possible outcome of the choice."⁶³ Speaking up and consequently risking one's job can be an act of moral courage.⁶⁴

Based on these definitions, it appears that nurses who requested an EC did exhibit courage. One nurse explained how she was able to

set her fears aside and proceed with requesting an EC:

RN: Because I'm gutsy anyway. [laughs] I guess I was standing up for my own personal feelings of trying to help versus, "Oh, let me just pretend this isn't happening and I'll let it slide under the rug." [Case #0781.]

This same nurse also explained how, alternatively, other nurses avoid requesting an EC because they are

RN: Too scared, they're scared of getting in trouble. . . . I think they're afraid of the doctor. Yeah, what, what can they [doctors] do? Nothing, but nurses are just so geared — women, first of all, then nurse — throw it all together, and you've got disaster! [laughs] But that's my perception anyway. They're just — and they're not going to bother. If they can sleep at night without — [calling the consult] — then go ahead. [Case #0781.]

This nurse's reflection on colleagues who "pretend this isn't happening" illustrates that the emotional withdrawal seen in some nurses can be a consequence of unrelieved moral distress.

Another way to view moral courage is to consider how nurses felt about their decisions to request, versus not request, an EC when they thought one was indicated. One might anticipate that courageous people generally do not regret their actions in the face of risks because they perceive their acts as the morally right thing to do. Accordingly, one could expect that nurses who requested an EC, even if they experienced repercussions, would not regret doing so. This hypothesis was supported: nurses who did request an EC reported a significantly lower level of regret in their decisions than the nurses who desired to but did not make a request. This difference suggests two things. First, those who requested an EC did not allow fear to get in their way and were satisfied with their decision to pursue an EC. Second, those who did not request an EC, but who wished that they had, clearly expressed disappointment and regret over their decision. This latter group reported feelings of reactive moral distress from not being able to act on behalf of their patients or to influence ethical decision making, as has been reported.⁶⁵ According to one nurse who wanted to, but did not, request an EC, courage was nec-

essary. In the following recollection, the nurse noted various factors, including physicians, timing, and politics, that set the context of adversity and required courage:

RN: But you don't let people die from pneumothoraxes, from air accumulation in the chest. I don't think whether they were DNR, or not. Do you know what I mean?

EG: Mm hm.

RN: That was my opinion. But I was not supported at all. And there really wasn't time to get them a, an ethics consult, you know like to rally an ethics consult.

EG: Really?

RN: I mean, I don't think.

EG: What was the time frame like, how soon — ?

RN: You know maybe there was enough time. And I didn't realize I had that avenue. And I don't know if it was because [one parent] was a physician in the hospital, politically there was just — I don't know. But I was so berated in that situation, I didn't have enough courage to then, you know, I just was like, okay, I'm wrong, I'm bad, that's it. [Case #0256.]

This comment illustrates Jameton's concept of reactive moral distress, especially the regret and self-criticism the nurse felt because she did not act.

DISCUSSION

Our findings indicate that nurses' decisions about whether to request ECs can be embedded in institutional and social processes. Other studies confirm that ECs and clinicians' decisions to request them are complex social processes.⁶⁶ Specifically, our findings are similar to Canadian studies that report that nurses lacked knowledge of ECs or were hindered from accessing ethics resources by power dynamics.⁶⁷ ECs are meant to be resources to assist health-care teams who face difficult challenges — in this study, that crucial fact seemed to get lost in the negative inter-professional politics between nurses and physicians.

Key findings are that a lack of awareness of the ethics consultation service and not knowing how to request an EC were major impediments to the use of the EC process. These inter-related factors are arguably the easiest to remedy through education. As many nurses noted,

they learned about the EC service through a variety of avenues, both formal and informal; for example, orientation and word of mouth. While exposure to the EC process through multiple sources can reinforce nurses' awareness, it may result in uneven learning and decreased utilization of a crucial resource.

Another key finding is that hospital policy on accessing an EC directly influenced nurses' decisions about requesting one. The process of notifying physicians about an ethical issue, although necessary, presented its own moral dilemma for nurses — particularly in cases when the nurse disagreed with a physician's medical approach. Rather than viewing this step as simply one of notifying a physician, nurses perceived it as attaining a physician's approval to pursue an EC before they could do what they believed was right. For many nurses who participated in this study, there was always the possibility that a physician would not agree to pursue a requested EC or to respond in a way that the nurses feared. As a result, by requiring nurses to initially present their concerns to a physician rather than to an ethics consultant, hospital policy placed some nurses in a difficult position. A physician's decision to not seek an EC or to respond punitively when a nurse requested an EC further undermined the nurses' standing as moral agents. That is, the nurses' moral agency became contingent upon a physician's moral agency. In such situations, nurses' moral concerns were addressed only when a physician concurred with a request for an EC, or the nurse took it upon herself to anonymously request a consult.

It is noteworthy that many times a nurse's request for an EC was based on significant failure in communication between the nurse and the physicians on the team. It was clear that many nurses in this study did not know how to talk to physicians as colleagues, and vice versa. In these cases, nurses either had not openly expressed their concerns to treating physicians, or they tried but did not feel that their concerns were heard or considered. Physicians who were not consulted were understandably angry in cases when a nurse had apparently not discussed her or his concerns before initiating an

EC. It is questionable in these cases whether a good outcome resulted — even if the patient was helped, it is clear that the effect on the team itself was negative.

In most situations, requesting an EC seemed to be “a last resort” for nurses, to deal with moral distress and fulfill the obligation to advocate for patients. In this hospital, even the act of notifying a physician about an ethical issue appeared to be difficult, given the negative repercussions, perceived risks, and potential damage that such an action could cause in nurse-physician working relationships. Nurses in this study recognized physicians' negative perceptions of ECs as a challenge to their decisional role, and those prevailing perceptions influenced many nurses to avoid addressing ethically questionable situations. Some of the nurses' narratives are noteworthy for how marginalized nurses felt their concerns were, even though they were deeply involved in caring for their patients. Many nurses who requested an EC had already experienced significant moral distress before they sought an EC, although some had not.

It appears that, regarding gaining access to EC in this hospital, a traditionally structured medical hierarchy continues to exist, and that an institution's policy and structures can perpetuate lack of access to EC in ways that are counterproductive to building collaborative teams and resolving ethical conflicts. Physicians have traditionally had considerable power over nurses in the context of medical care,⁶⁸ which has been attributed to traditional differences in gender, age, social status, education, economics, and decision-making authority.⁶⁹ Although these power dynamics have diminished somewhat due to nurses' increased professional standing, these power dynamics and their negative repercussions have been noted to resurface in the context of ethical dilemmas.⁷⁰ In this study, social structures reflected the ethical climate of the institution, specifically one in which nurses were not always supported to be, and did not act as, full partners in caregiving teams. Daniel F. Chambliss noted the pervasive view of the nurse as subordinate that contributes to a negative cycle of decreased trust and respect

within physician-nurse relationships and the impact of this view on the care of patients: “Here, then, may begin a cycle: doctors don’t trust nurses; nurses, not trusted even when they are correct, slack off.”⁷¹ Specifically, physicians’ anger at nurses undermined nurses’ capacity to work collaboratively on the healthcare team. Yet nurses’ responses may have strained the physician-nurse relationship, and may have actually hindered providing care. Such interactions are not only a problem for nurses, but also for the team as a whole, and, ultimately, for patients. The lack of administrative support for nurses to request an EC was a further barrier. In systems in which even the act of speaking up is seen as carrying sufficient risk that it requires moral courage, it should come as no surprise that the majority of nurses stay silent.

The professional status and gender of nurses in the present study may have contributed to their reluctance to openly present alternative options to address ethically charged patient cases to attending physicians. Since nurses are predominantly female, gender can compound their interactions with physicians, even during ECs. Some bioethics scholars attribute their finding that staff nurses often “*publicly hide* their ethical concerns out of fear of reprisal” to American patterns of gendered discourse, in which many women seem to require encouragement to voice their opinions (emphasis added).⁷² Susan B. Rubin and Laurie Dorfman have observed that nurses are much more “out-spoken” when discussing ethics among other nurses than when physicians are a part of such discussions.⁷³

The nurses in this study resorted to a variety of tactics, including responsible subversion, to make their voices, and those of their patients, heard. For many nurses, these tactics were the only ones they felt were available to manage their ethical dilemmas. Although responsible subversion may have had a positive immediate affect on nurses and their patients, we do not condone these tactics because of the negative long-term effects they incur. Specifically, this practice, because it does not lead to open and responsible communication, perpetuates a dysfunctional team by creating an adversarial dynamic between physicians and

nurses. Recall that the nurse who requested an EC during a weekend did not foster communication within the team. Responsible subversion can reinforce negative stereotypes of nurses. Moreover, and perhaps most importantly, the net result of such tactics is that no needed changes occur within the healthcare institution and the inter-professional dynamics of healthcare teams; consequently, nurses’ moral distress may continue unabated, with damaging effects.⁷⁴

In light of these findings, the question emerges whether nurses’ courage in the face of ethical dilemmas and policy constraints is necessarily good. At least two views are possible. In one view, nurses’ courage can be helpful to the patients and their families who need advocates. But a broader perspective is that the very need for courage to address an ethical dilemma reflects a problem with the larger hospital environment that created the need in the first place. It should not require an act of courage for any healthcare professional to do what he or she thinks is the right thing for patient care, much less to raise a question or a concern.

A team model cannot exist when recourse to resolving dilemmas with equal respect for members is not available to each member of the team. When all team members have equal access to EC, they can better address their own moral distress, reinforce inter-professional and intra-professional relationships, and, most importantly, better serve patients. The benefits of having access to EC services go beyond obtaining help to resolve ethical quandaries. One study noted that beneficial reasons for requesting ECs were to clarify ethical issues, make management decisions, document support for decisions already made, clarify options for the care of patients, lessen fear of legal liability, improve communication, and mediate disputes.⁷⁵

Hospital policies that encourage open access to EC services may serve to reduce nurses’ moral distress.⁷⁶ By focusing on the experience of nurses, our research responds to what has been recognized as a myopic perspective within bioethics, namely, down playing the importance of nurses in ethical decision making.⁷⁷ As

Chambliss notes, "medical ethics is geared primarily to physicians. . . . nursing, which will actually carry out many of the decisions [of physicians], has no place in the discussion."⁷⁸ Our findings indicate that even if nurses are not granted "a place in the discussion," they still feel compelled to act in ways that ensure their moral integrity and improve the care of patients. The context of ethical dilemmas and professional obligations gives some nurses the moral impetus to challenge the power of physicians and their control over the decision-making process, by requesting ECs, while other nurses are unable or unwilling to do this. As such, the findings of this study contribute to nursing's perspective of how power relationships between nurses and physicians affect responses to ethical dilemmas.

LIMITATIONS OF THIS STUDY

Several limitations of the study must be noted. First, the results of this study may not be generalizable to nurses at other hospitals.⁷⁹ As noted, hospital policies vary regarding who is entitled to request an EC, and the procedures that address ethical issues.⁸⁰ The nurses' reports in this study must be interpreted within an institutional context that some nurses viewed as suppressive and hierarchical. Hospitals with more egalitarian organizational structures may exhibit different patterns in nurses' experiences of requesting ECs. The views expressed by the nurses included in our study may not be generalizable to nurses treating out-patients, since the ethical issues that arise in an out-patient environment will likely differ from those that emerge in an in-patient setting. Additionally, our interviews did not include the actions that nurses took prior to requesting an EC; thus, the extent to which these nurses made efforts to communicate with physicians about ethical dilemmas could not be determined.

This study focused on the nurse-respondents' points of view. Further research on physicians' perspectives on nurses' efforts to address ethical dilemmas would complement these findings. It is interesting that a recent

study found that physicians seek ECs infrequently despite encountering ethical difficulties daily, partly due to a desire to avoid conflict.⁸¹ Physicians' interactions with nurses are only mentioned twice in the study, one of which was an explicit decision by a physician to leave "nurses and other people out of the process."⁸² As with our findings, these authors found that, for physicians, ethics consultation is also seen as a last resort, rather than as a primary source of help in ethically problematic situations.

RECOMMENDATIONS

Greater efforts must be taken by hospital administrators to ensure that healthcare professionals are aware of the services available to resolve ethical issues. This awareness depends on learning how to identify ethical dilemmas, which is not a straightforward task, particularly because physicians and nurses tend to identify and respond differently to ethical dilemmas.⁸³ Organizations must ensure that EC services are made available to nurses as well as to other healthcare providers who are directly involved in patients' care. Institutions can become more responsible by establishing mechanisms to ensure that attending physicians, nurse managers, and administrators support nurses' access to the EC resources that are needed to resolve ethical dilemmas. In one important sense, such support can help improve team communication by encouraging all clinicians to openly discuss their concerns with ethics consultants. In addition, impediments to utilization of EC services should be reduced. The negative perspective of physicians and other caregivers should be directly addressed, to clarify the goals and utility of ECs as a resource to aid and support providers faced with difficult ethical situations. As discussed in the context of residents who faced similar problems as nurses in gaining access to EC, to "effectively provide such services, institutions must recognize and be responsible for the culture of authority that inhibits the use of ethics consultation services. . . ."⁸⁴ Other scholars support similar proposals to address power structures in institutions.⁸⁵

Open acknowledgment and discussion of moral distress among all careproviders can do much to diminish the intensity of this phenomenon. Strategies for both nurses and physicians to use to deal with moral distress should be discussed and implemented in caregiving teams.⁸⁶ Addressing ethical concerns openly and promptly is especially important to minimize the damaging effects of moral distress. Nurses must take responsibility for bringing their concerns to physicians and to the team, without waiting for situations to become emotionally charged and fraught with moral distress. Any careprovider who requests an EC should be supported, and the request should be seen as no different from seeking any consultative resource for a vexing clinical problem.

Mutual respect and healthy role modeling by senior clinicians, nurse managers, and attending physicians may serve to encourage early and open communication of concerns, build collaborative processes within teams, clarify role expectations, and address any fears about requesting an EC. Such activities could be designed as role play exercises, and be videotaped and used to educate nursing staff and physicians. Most of the successful interventions to improve decisions made at the end of life in ICUs have involved nurses in structured ways that improved communication between physicians and nurses, and brought nursing and physician perspectives together with those of patients and their families.⁸⁷ Eric J. Thomas and colleagues recommend that nurses and physicians receive training in conflict resolution, methods to improve assertiveness, listening skills, and conducting collaborative rounds.⁸⁸ Such training should ideally occur in interdisciplinary educational forums, beginning with initial professional education. Interdisciplinary ethics education can help careproviders learn to appreciate the roles, responsibilities, and perspectives that each discipline brings to the care of patients and to resolving ethical dilemmas. Such education can empower nurses with strategies to initiate communication with physician colleagues, and alert them to alternative ways to resolve ethical dilemmas. This recommen-

dation is reinforced by Gordon DuVal and colleagues, who found that physicians who were more knowledgeable and experienced in ethics were significantly more likely to request an EC.⁸⁹ We anticipate that the same would be true for nurses as well.

CONCLUSION

Requesting an EC is a social process that can have real consequences for nurses, healthcare teams, and patients. Most of the nurses in this study either lacked knowledge of EC or were hindered in requesting an EC because of powerful institutional and inter-professional obstacles. The nurses who requested an EC demonstrated an essential feature of courage in the service of advocacy: doing what they believed was the right thing, regardless of potential adverse consequences. But this courage came at a price, and frequently was only invoked when a nurse struggled with moral distress and communication in the healthcare team had broken down. Moral courage should not be required of healthcare providers to obtain an EC, given the value of ECs to those involved in the care of patients.

ACKNOWLEDGMENTS

Special thanks go to all of the nurses who participated in this study and shared their stories of the ethical dilemmas they encountered. We also thank Jessica Gacki-Smith for her diligent research assistance. We are also grateful for input on earlier versions by Marijo Letizia and Craig Klugman. An earlier, shorter version of this article was presented at the 101st Annual Meeting of the American Anthropological Association in New Orleans on 21 November 2002.

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18. DuVal et al., "A National Survey of U.S. Internists' Experiences," see note 5 above.

19. Storch and Griener, "Ethics Committees in Canadian Hospitals," see note 6 above.

20. Davies and Hudson, "Why Don't Physicians Use Ethics Consultation?" see note 5 above.

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22. McBurney, "Ethics Committees and Social Change," see note 14 above.

23. It is certainly true that ethical conflicts commonly arise from poor communication regarding beginning-of-life and end-of-life issues. B. Hoffmaster, "Anatomy of a Clinical Ethics Consultation," *Human Studies* 22 (1999): 53-68; C.M. Breen et al., "Conflict Associated with Decisions to Limit Life-Sustaining Treatment in Intensive Care Units," *Journal of General Internal Medicine* 16 (2001): 283-9. However, in McBurney's study, the cases motivating nurses to request an EC dispel the misapprehension that their concerns were solely communication-based, because they reflected actual ethical dilemmas. For example, nurses wanted to abide by the wishes of a family of a dying patient to not give the patient anything by mouth out of fear of aspiration, having been told by the physician that the patient had difficulty swallowing. Yet nurses also wanted to do what they thought was best for the patient who kept pleading for sips of water (see p. 190). Nevertheless, relegating nurses' ethical concerns to the realm of communication problems is not unique to McBurney's hospital. At least one other

hospital in the U.S. (where the first author has had personal experience serving on the ethics committee and consultation service) has a two-tiered system of ethics resolution. In this system, physicians may contact the official ethics consultation service, but non-physicians must contact the nurse-run program for assistance with ethical dilemmas. Similar to McBurney's study site, the non-physicians were presumed at this second U.S. site to have communication problems, rather than face legitimate moral quandaries.

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McBurney, "Ethics Committees and Social Change," see note 14 above; Gacki-Smith and Gordon, "Resident Physicians' Access to Ethics Consultations," see note 6 above.

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Healthcare Organizations as Moral Communities

Mila Ann Aroskar

This research project on social processes and barriers involved in the use of ethics consultations in a hierarchical hospital setting provides another example of the ongoing challenges that confront hospital nurses who strive to carry out their ethical obligations to patients. Physicians' power and dominance are powerful factors that influence the behavior of nurses in cultures that still support this power and dominance in many clinical settings. Several nurses in this study experienced moral distress and were often required to weigh risks and practice a form of moral heroism in requesting an ethics consultation to meet their ethical obligations to patients. Additional research is described that illustrates the ongoing nature of such issues in clinical settings that have plagued nurses for decades.

Forty years ago, physician and noted ethicist Edmund Pellegrino expressed serious concerns regarding the working relationships of physicians and nurses in patient care: "While some of our mutual concerns are matters of resources and techniques, a more urgent concern is of human organization and relationships. The

focal human problem that we have not yet solved is how best to employ the particular skills of each of the health professions synergistically to the benefit of the patient."¹ Consideration of Pellegrino's concerns in the 1960s lead this author to argue, 40 years later, that issues of human organization and working relationships in hospitals have never become a top priority in today's health scene, in which economic concerns and the use of the latest technologies dominate. Yet, inherent in the working relationships of healthcare professionals and caregivers are significant ethical obligations such as respect and avoiding harm to both patients and to the people who provide their care. Educators of health professionals have recognized for decades the importance of interdisciplinary learning and have made many efforts to realize this in professional curricula. Still, interdisciplinary education efforts founder, as critical goals of technical knowledge and expertise take priority in crowded curricula over the so-called softer areas, such as communication skills, human relationships in complex organizations, and professional ethics. Development of collaborative practice models in patient care settings have often suffered a similar fate, as they require sustained institutional and professional commitment.

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Would it make any significant difference in patient care outcomes and the development of more collaborative professional relationships to change our focus, in the current culture of healthcare, from communities of technical expertise and business investment to a focus on moral communities of healthcare in which patients, families, health professionals, and caregivers are all accorded respect and accountability in the patient care decision-making process? In such moral communities, inclusive patient care conferences would be an essential and valued part of the care and decision-making processes. They would be carried out to practice primary prevention of some of the ethical crises that lead to moral distress, the need for nurses and others in hospital hierarchies to become moral heroes to carry out their professional obligations to patients, and the need for ethics consultations in situations of tension, conflict, or perceptions of “giving up” on patients. In this author’s experience, ethics consultations were often the first and only opportunity for health professionals to share their knowledge of complex patient care situations face-to-face and to reflect on decision-making choices and their probable consequences.

One can speculate that significant risks and fears of negative consequences in the use of institutional ethics resources would decrease if nurses (and others) practiced in patient care settings where nurses could trust that administrators and their nursing and medical colleagues were knowledgeable about, and supported, the ethical behaviors and values that are promulgated in the ethical codes of all the health professions. In addition to advocating for patients, examples from the American Nurses Association *Code of Ethics for Nurses with Interpretive Statements* speak to nurses’ responsibilities for preservation of personal and professional integrity and the development of healthcare environments that incorporate respectful collegial interactions, support of peers, and identification of issues that jeopardize caregiver integrity, respectful relationships, and patient care outcomes.² Gordon and Hamric’s study, and others noted in their article, support the need for

changes in the culture and organization of working relationships in patient care settings. Hospitals earning the designation of Magnet Hospitals for nursing practice may also provide clues for action, including hospital policy review, development, and implementation.

How many more research projects will be conducted before healthcare leaders in clinical and education settings marshal the will and the courage to change professional curricula and healthcare environments in which both patients and their caregivers suffer the damaging consequences of such hierarchical cultures? Comprehensive education of practicing nurses, nursing students, and others about institutional ethics resources is but a first step on the challenging journey to development of morally responsible healthcare cultures, in which nurses can carry out their ethical obligations to patients without fear of reprisal.

NOTES

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Nurses and Ethics Consultation: Growing Beyond a Rock and a Hard Place

Kathy Mayle

With the penetration of the managed-care environment back in the early 1990s came the realization that the hospitals' internal environments were forever changed. Business (that is, systems processes) could no longer operate in the same manner to provide quality patient outcomes while constraining costs and increasing patients' satisfaction.

A more obvious result of the managed-care environment on hospitals was that nursing care was the only reason many patients were admitted to a hospital. Physicians now see most patients outside the acute-care system. The caregiving team should be envisioned as a partnership between the doctor, the patient and/or family, as well as the nurse. In other words, all parties should be included in the overall care of patients to make clinical decisions that are in the best interest of the patient and promote his or her well-being.

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The nurses' work in hospital systems has drastically changed since yesteryear. Patients in a "managed environment" move relatively quickly in, through, and out of the system. Nurses have less time to sit and establish bonding relationships with patients and their families. And yet, with such constraints, nurses do this, and are the patients' advocates. *Nurses are ethically bound to do good for patients*. Hindering this commitment is the nursing workforce shortage. Nurses are still expected to do all aspects of their jobs, but with fewer people and less support. It is not surprising that nurses' requests for ethics consults should appear to be emotional requests. Due to how hospitals operate, nurses "in the trenches" essentially answer to two bosses:

1. They must follow physicians' orders, as bound by their licensure and outlined in their state's nursing practice act.
2. They are accountable to nursing (as well as hospital) administration.

Nurses who are caught in an ethical dilemma are caught between a rock and a hard place. On the one hand, system processes allow a nurse to request an ethics consult; on the

other, system processes provide little support or education for doing so, given the perceived unbalanced power relationship between the doctor and nurse.

The Gordon and Hamric research article has raised three areas in need of consideration.

ORGANIZATIONAL ETHICS

The structure that permits ethics consultation must not limit its access to a few employees if consultation is to serve the best interest of patients. Policies and procedures for ethics committees and ethics consults must have “top-down” support. System processes should be ironed out to ensure that the functions of an ethics committee are strategically integrated into the mission, purposes, and goals of the overall system. Administrators must clearly communicate to physicians, nurses, and other healthcare professionals their position and expectations regarding the ethics committee and ethics consults. Anyone who is knowledgeable and involved in a patient’s care should be able to call on the ethics committee for clinical issues and moral dilemmas as outlined in hospital policy.

A nurse, serving ethically as the patient’s advocate, should not be hindered from requesting an ethics consult, if warranted. The nurse should call the attending physician to inform him or her on what is being done, but certainly not for authorization. Hospital administration should educate, support, and encourage its staff to request or participate in ethics consults. Hospitals should create a culture such that nurses are free to call for an ethics consult without fear of retaliation from nursing supervisors or physicians.

Once again, the reason why a nurse, doctor, patient, family member, or other healthcare professional would call an ethics consult is that *it is in the best interest of the patient to improve quality outcomes*. Therefore, it is the responsibility of hospital administration to ensure that this situation is managed and controlled, and if not, care is hindered, and nurses’ hands become tied by the system.

EDUCATION

Education on the role of the ethics committee should be conducted throughout the system and continued during each new hire’s orientation. This education should include a review of the policies and procedures and the processes that are in place for requesting an ethics consult. In addition, educational considerations should be thought through on multiple levels, as follows.

THE EDUCATION OF NURSES

Nurses need to be assessed as to their educational needs, as this relates to ethics. Certainly, nurses’ education will not be able to cover all of the nuances of ethics as a discipline, but perhaps nurses could be taught how to contextually frame and communicate their “ought” questions to other healthcare professionals. Newer nurses may need additional support from nursing supervisors in navigating through the decision-making process to call for an ethics consult. The foundation of nurses’ decision making should be based on the principle of beneficence, which gives nurses firm footing on which to take an assertive stance. Additional support may be needed in dealing with interpersonal dynamics, when a nurse is faced with an angry physician who may feel that his or her authority has been usurped. The automatic response should be that the right action was taken, based on both policy and good, solid reasoning — to do good for the patient.

THE EDUCATION OF DOCTORS

Physicians should be further educated on why someone other than themselves would call for an ethics consult. Nurses, who are integral members of the caregiving team, spend incredible amounts of time at patients’ bedsides. Nurses serve as advocates for patients, and this role must be respected. Physicians should envision and utilize the ethics committee and the ethics consult team as a tool to provide and enhance patient outcomes of the highest quality.

THE EDUCATION OF PATIENTS AND THEIR FAMILIES

In this technological day and age, the consumers of healthcare are much more sophisticated and computer savvy, investigating and researching all aspects of their disease or illness. Patients expect to be partners in planning their healthcare and are much more assertive in communicating their needs to members of the healthcare delivery team. All patients should have a right to call for an ethics consult. Hospitals should readily supply information both verbally and in writing, via brochures and fliers posted in highly visible areas. Patients are in vulnerable positions when they enter an organizational system where some aspects of their care will not be under their direct control. Patients count on doctors, nurses, and other caregivers to provide them with information so that they can make well-informed decisions about what happens to their body. No system process should hinder the ability of the nurse, physician, or any other caregiver from advocating on behalf of the patient.

RESEARCH

The Gordon and Hamric research study, somewhat limited by its scope, has implications for further study within the realm of nursing. Nurses play a key role in caring for and bonding with patients and should definitely be included as part of the team that has the responsibility and accountability for calling an ethics consult.

The study could be replicated in other types of healthcare organizations, such as rural versus suburban versus inner-city urban. How would geographical considerations affect the outcomes of the study? Is there a difference in how nurses in the Midwest would respond, compared to nurses in the East or the West? Does education play a role?

Another consideration is to look at and analyze the ethics consults done within a specified time period, looking at who actually called the consult within the hospital. Does this differ from what was found on the self-report surveys?

Lastly, doctors could be surveyed and interviewed to compare and contrast their perceptions with those reported by the nurses.

CONCLUSION

As the healthcare environment is increasingly challenged with ethical dilemmas, the role of all caregivers becomes critically important in ensuring that the wishes of patients and/or their surrogates are respected and that outcomes of the highest quality are achieved. Hospital and healthcare facilities should remove barriers and create an environment such that it is clear that nurses' input in resolving ethical dilemmas is valued. In addition, opportunities for ethics education should be provided, as described.

Nurses themselves have a professional responsibility to take advantage of these opportunities, and, when they are not provided, they have an obligation to seek ethics training.

Physician-Nurse Relationships and their Effect on Ethical Nursing Practice

Teresa A. Savage

In this issue of *The Journal of Clinical Ethics*, Gordon and Hamric conducted an elegant study exploring why nurses do not use ethics consultation (EC) more frequently. They identify power inequities in terms of nurses' access to EC and describe discouragement by physicians. Nurses in their study reported experiencing moral distress, but the distress needed to rise to the level of moral outrage before nurses could summon the moral courage to request a consultation. They reported that the nurses' concerns were dismissed as emotional responses to a situation, or were not seen as an "ethics" concern. Their findings resonated with my many years of nursing practice, my years as an ethics consultant, and with findings in my own research. I believe the underuse of EC services by nurses rests on nurse-physician relation-

ships. For my dissertation, I conducted in-depth and multiple interviews with 18 nurses (all female, hence the use of the "she" pronoun exclusively) at an academic, tertiary medical center.¹ I began with an open-ended question, "How do you get things done for your patients?" The stories unfolded to reveal that nurses act to "prevent the preventable" from happening (nonmaleficence) and their actions are dependent upon the nurse-physician relationships within their organizations.

ADVOCACY

I agree with the authors that nurses are taught to be patients' advocates, and the *Code of Ethics for Nurses* expects nurses to be advocates.² Advocacy often requires nurses to interact with physicians, either to seek clarification for and/or the rationale for an order or plan of care. As Gerald Winslow pointed out, advocacy requires courage, and nurses may not feel secure enough to demonstrate their courage and exercise their advocacy role.³ I recall being disappointed when I analyzed my dissertation data and realized that nurses often avoided a direct approach in resolving ethical issues for their patients. They vigorously pursued an issue, going through the medical hierarchy of intern,

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resident, fellow, up to the attending physician, *only* if they had been socialized to do so. If they observed that a fellow nurse suffered repercussions from advocating for their patients, they were reluctant to take the risk of advocating. Instead, they found other less direct ways, such as playing the “doctor-nurse game,”⁴ working through their nurse manager, or bullying a resident. Below are some excerpts from their interviews.

This nurse was unaware that she played the “doctor-nurse game” until a social worker who observed her interaction with a physician pointed it out to her.

RN: I usually say . . . this person’s potassium is low, should we treat them for this? I always put it so they’ll answer yes to what I want them to do . . . I lead them. I’ve been a nurse 11 years and I think now, you can call it collaboration, but when I . . . what do I want to say? I don’t consider it collaboration. I just consider it politics that this is the way you have to say it to get things done for your patient, so your patient gets what he needs. And a woman who’s too pushy or knows too much or tries to tell the doctors what to do doesn’t get very far. A woman who’s tactful and polite, phrases things appropriately gets a lot further . . . make them think, yeah, I should have thought of that, or, oh yeah, I meant to do that . . . you have to talk to them in a certain way, because you know what you want to get done, and you’re trying to do it in the most effective way. Sometimes you can’t just be real straightforward about it, saying, we have a low potassium, I’d like to hang potassium, they feel like you’re telling them what to do, you want to handle it in whatever way to get it done.⁵

Another nurse described how she was socialized to work through the housestaff or her nurse manager; she was discouraged from contacting surgeons directly. She said:

RN: You’re dealing with surgeons. You find a real different relationship between specialties and general practice who are not surgeons as opposed to surgeons, because surgeons are very elitist and I think from what I’ve seen on other floors or heard nurses talk about, there is a much more collegial relationship between internists or family practice, pediatricians, or even some of the specialty groups than there is between

nurses and surgeons. If I went up the ladder, even up to the senior resident, much less to the attending, I was likely to get progressively more hell as opposed to be appreciated for questioning what’s going on. So that was a very real consequence to have to consider. And granted, that compared to if I thought the patient was really in danger, I think I would make that decision, but most of the time I could squeeze by until 6 in the morning, until somebody else came around, either the attending on rounds or somebody that could give me a hand to straighten the situation out. I would probably have called my head nurse at home in the middle of the night before I would have called an attending because you just can’t imagine the havoc that could be wreaked on you by some of those people.⁶

Another nurse relates an example of her interactions with a second-year surgical resident. This narrative illustrates the unpleasant interactions nurses wish to avoid with physicians:

RN: I get a phone call from an irate surgeon screaming at me, saying, you idiot, do you know how hard I worked to get this [X-ray] set up stat? I said, but the [jejunos-tomy] tube’s working. He said, of course it is, I changed the tube. I was up there and I put in a new tube. And this was a J-tube we’re talking about. And I said, excuse me? He said I put in a new tube, how dare you cancel this X-ray? I said, well you didn’t tell any of us. You didn’t tell the resident, you didn’t tell me, I’ve been on the floor within 30 feet of the room this whole evening. I’ve been running around like [a] crazy person, but I’ve been here. You could have paged me. There’s a clerk at that desk all the time I’ve been here. He just continued to yell at me. This was actually a resident on the surgical staff who had changed the tube and not told anybody. I guess he had gotten the order right at change of shift and had come right up and done it which is highly unusual, and he goes, what was very frustrating to me, he said, this is your fault because you didn’t read my note. It’s in the chart. There’s an order there for that patient to come down and have the tube checked to make sure it’s working fine. And my impulse is to scream and yell, and I said, excuse me, but right at change of shift, I’m very busy. I have not had time to go and just look through my six patients’ charts to see if any notes have been written. He absolutely would not do anything but blame me for this situation. And he said I want your name. I want

it spelled, and I want your license number. Excuse me, you want my what? He wanted my ID number and he was going to report me to hell and back. I've got visions of my job being yanked away, and I was very polite and I said what would you like me to do with this patient? He said, you get her on that cart down to radiology right this minute, don't you dare go against any order I say ever again. So I said, thank you very much, be glad to, I hung up the phone. I went and checked the chart and sure enough, there's an order for the patient to be sent to radiology [that] I did not see which had been written right before 3 o'clock, which is not a time I'm usually sitting reading charts. I went immediately to the charge nurse, here's the situation, here's what is going on, where we left it, and about 10 minutes later the surgeon was up looking for me in person to yell at me some more and make sure I got that patient on the cart, to make sure the tube was working and, um, it was just horrible, but, so the charge nurse called, made all the arrangements to get the patient down to . . . because the surgeon had also asked me that could I also call and get transport all set up for the patient to go down there, and I told him, no, I said actually now, I can't. I was in a patient's room and had things going on that I could not leave. And I can't remember exactly the things I was in the middle of, but I vaguely remember wishing I had six other arms and there were two other nurses on staff that night . . . the surgeon came up on the floor to find me and was following me into patient rooms as I was giving pain medication and turning people and cleaning up diarrhea, and would berate me while I was in the room. It was one of those things where I felt, this guy is just not going to let me off of this. He's not. I turned to him and I was kind of proud of myself because I was thinking this was one of those things maybe two years ago right out of school I would have been a little more freaked out about it. I said, I talked to my charge nurse, the charge nurse took care of getting transport up for me, and was very pleasant and the transporters were all upset that that stupid nurse up there cancelled the transporter, and done all this. She was very good, was very diplomatic in handling that so I could take care of patients, when the surgeon came up I said it had all been taken care of and if he had any further questions he could talk to my charge nurse. And he said, no I'm just up here to see that you get that patient on the cart . . . the patient

was not alert in any way at all, but that was one of those situations where I felt like I could not handle the situation, and I don't know, maybe somebody with a lot more years would be able to field this thing. . . . It was really upsetting to me . . . this was one of those situations where I felt like even if I had jumped through hoops, I wouldn't have really been handling this doctor very well.⁷

This is another example of how a nurse manages the relationship with housestaff.

RN: What we're here for is to prevent the preventable things. If there is a piece of data or something we can do to prevent a bad outcome, it should be done . . . if you as somebody who comes here for a diagnostic test and runs a V-tach [ventricular tachycardia] and there's no 'lytes [electrolytes] sent from yesterday, then I think it's only reasonable you should get electrolytes drawn. So that we know your potassium, then your potassium comes back, then I'll say [to the physician], so-and-so just had a run of V-tach, I looked up her potassium, and we don't have one from the last 24 hours, so I think we need one. So why don't you draw it? Or maybe I'd just leave it that we don't have a potassium. So I guess, I'd lead him. . . . and if they don't get up (laughs), say they go "Uh huh," and I'll say, "Are you going to draw the potassium?" and then they'll say, "We don't need it" and I'll say "You know, we do need it because she doesn't usually have these symptoms, this is atypical of her . . . if they say "No" then I'll say "Then I'll call your resident."⁸

Another tactic she would use when an intern would not do as she asked was to embarrass the intern during rounds:

RN: I have said . . . to interns . . . that I don't think you know what you're doing and there's nothing wrong with that, but there is a problem with your making decisions not knowing what you should . . . they stomp off usually, sometimes we get into a heated debate . . . you go to off-shifts [evening and nights] and that's where you can really get into bigger fights so you've got to really be assertive and go up the chain of command where on days [day shift] people are there. A real passive-aggressive trick to avoid all this is when you could wait for rounds, 'cause you have the whole chain of command there, and just talk about, so this is what's happening . . . what do you want to do? And then they

tell the intern what to do, so you've sort of avoided that whole confrontation.⁹

TRUSTING NURSES' KNOWLEDGE

These nurses said that physicians often dismiss their concerns because the nurses are acting on subjective data — the patient just doesn't "look right," the nurse has a "funny feeling," a "gut instinct." The objective data do not support the nurse's sense of dread. In my own experience, and as nurses in my study agreed, attending physicians have learned to rely on the experienced nurses' clinical insight, even if there are no supporting objective data.¹⁰ Because of the medical hierarchy, though, nurses must first interact with the most junior person in the hierarchy, the intern (and occasionally the medical student). Interns may not appreciate or trust nurses' insight, may want to wait for more objective data, and nurses must "go over their heads" to prevent potential harm from coming to the patient. Depending upon how nurses have been socialized on that particular unit in the hospital, they may or may not pursue their concerns. Nurses may alert the nurse manager and have the nurse manager pursue the concern, or they may doubt their own assessments, defer to an intern's judgment, and wait to see what happens.

THE ATTRACTION OF ETHICS CONSULTATION

The cumulative effect of communication games, moral distress, and fear of repercussions make ethical consultation an attractive avenue for resolving ethical issues. However, barriers to access or lack of available services can stifle that route as well. In my experience as an ethics consultant, nurses often wish to "sound out" their concerns before making any kind of formal request for consultation, and often I encourage them to coordinate a patient care conference, to seek to clarify the goals for the patient. (Hospital policy at the time required that the attending physician be notified that an ethics consultation was requested, and that the attend-

ing had to agree to the consult before a note could be entered in the medical record. The consult could be done, but a note could not be entered in the chart without the permission of the attending physician.)

It often surprised me that nurses needed encouragement and support to take what seemed to me to be an obvious and appropriate step to facilitate communication with all of the persons involved in a patient's care. The nurses had access to my informal ethics consultation because I was a nursing instructor in that department, with clinical students on their unit between three and four days a week. (When I worked as a clinical nurse specialist in the same institution, and my office was located in a suite of subspecialty physicians' offices, I had physicians "drop by" to informally discuss ethical issues that they were currently facing.)

Proximity and open accessibility seemed to facilitate nurses' requests for ethics discussions; occasionally informal discussion would lead to a more formal request for an ethics consultation and documentation in the medical record. Whether or not a formal consultation evolved from these discussions, nurses were able to strategize with me on how they could address the ethical issues that were bothering them.

RECOMMENDATIONS

I wholeheartedly support Gordon and Hamric's recommendation that nurses should be made aware of EC services. I also agree that nurses do not always identify an issue as an "ethical" concern, but, if asked to describe their concern, they use language of "right and wrong," "harm," and "acting on the patient's behalf." Nurses' clinical concerns are rooted in the nurses' ethical obligations to the patient. But as Gordon and Hamric found, having access to an EC does not mean the nurses will feel safe in using one. Interdisciplinary ethics education, as suggested by Gordon and Hamric and others, may hold the key to empowering nurses.¹¹

Finding a common point for interdisciplinary ethics education is challenging. Usually undergraduate nursing students do not take any

course work with medical students. Graduate nursing students may take ethics courses with medical students, but medical students are just beginning to get a sense of the clinical arena, so having graduate nursing students and medical students together makes for an uneven foundation on which to analyze clinical ethical issues. However, interdisciplinary education at this point would be a start.

At my current institution, we have an 11-month program in which employees (and a limited number of professionals who are not employees, usually MD or PhD faculty from other institutions) apply to be accepted in our ethics scholars program.¹² Their application includes a letter of support from their supervisor indicating that efforts will be made in scheduling to facilitate their attendance; the day and time of the weekly tutorial is negotiated with all of the scholars once selected. The scholars meet weekly for 90 minutes for guided discussion on assigned readings and work toward completion of a focus project. The focus projects vary between studies approved by the institutional review board (IRB) to literature reviews, posters, quality improvement projects, graduate-level course development, or in-services on their units, for example. For the tutorials, the four part-time faculty (physician, social worker, psychologist, and myself) in the ethics program take turns in leading discussion, and guests are often slated to make presentations and join in the discussion. Since employees from all departments are eligible to apply, we have had diverse groups, ranging in size from three to 10 scholars, including nurses, therapists, administrators, technicians, physicians, social workers, security guards, administrative assistants, pharmacists, chaplains, vocational rehabilitation counselors, public relation and development associates, volunteer directors, and researchers. There is a collegial atmosphere, and, although there are passionate disagreements, the discourse remains civil and respectful. We have "graduated" 55 scholars in 10 years and most of them have remained at our institution. The "ripple effect" of having a critical mass of employees with eth-

ics education is felt throughout the institution. Scholars have stated that they feel better prepared to facilitate discussion of ethical issues in their units and more likely to contact us or refer others to us in the ethics program. Scholars who have left our institution serve as ethics resources for their new institutions.

Our scholars program is one way to provide ethics education. We also have monthly ethics seminars planned and conducted on the units with input from the unit staff regarding the topic; quarterly ethics grand rounds that are usually attended by physicians, medical students, and nurse practitioners; a monthly film series focusing on a brief (60 minutes or less) video to stimulate discussion; a newsletter highlighting an activity or topic; and invited community round tables that function as "mini-think tanks," devoted to a particular topic that is relevant to our patient population or a disability community. These various avenues provide forums for ethics education, and permit more employees and community members to learn who we are and what we do. We hypothesize that this type of education and open accessibility to our program will improve our visibility, and, over time, build trust in our capacity to address ethical issues and empower our employees to take steps to prevent or reduce moral distress.

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Autonomy

Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta

Marilyn E. Coors and Susan F. Townsend

Obstetrical healthcare professionals strive to promote shared decision making with patients during pregnancy and delivery. In most cases professionals provide comprehensive information that promotes collaborative patient decision making and enhances overall well-being. Prenatal testing sometimes reveals information that effects the decision. The testing can lead to situations of substantial uncertainty in which the values of pregnant women are overwhelmed by the influence of healthcare professionals.

CASE PRESENTATION

A routine ultrasound at 21 weeks of gestation had shown evidence of a fetus with multiple congenital fractures, resulting in a diagnosis of Osteogenesis Imperfecta Type II (OI). OI is a potentially lethal genetic condition associated with defective maturation of collagen. The expression of the disease varies from mild osteoporosis to brittle bones, blue sclera,

deafness, and early death.¹ Some forms of OI have recently been treated experimentally with pamidronate to increase bone density, symptomatically resulting in fewer fractures and more comfort.² Life expectancy and quality of life vary depending on the severity of the condition. There is no definitive antenatal genetic marker(s) to predict severity of OI, and some infants who are diagnosed prenatally with the most severe forms turn out to be more mildly affected and survive.³ Type II OI is the most severe form, with perinatal death caused by respiratory failure.

When faced with the early diagnosis of OI in her fetus, the pregnant woman in the case under discussion chose to continue her pregnancy with the understanding that her child might be compromised or live only a short time after birth, depending on the severity of the disorder. The prognosis for this particular fetus was uncertain, even among the physicians and staff who had seen the ultrasound. The decision to continue the pregnancy was not challenged by the healthcare team, even though it may not have been the course of action that they would have recommended.

At 34 weeks, this case was the focus of ethics rounds in a tertiary care hospital because it was time to consider the mode of delivery. The obstetrician strongly recommended a vaginal delivery because she felt that the infant would not survive more than a few hours or days, as ultrasound findings in this fetus suggested the most severe form of OI. Data from a regional study of the medical records of 55 deliveries of infants with the most severe form of OI revealed 24 of 31 babies delivered by cesarean section and 21 of 24 delivered

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vaginally died within two weeks of birth.⁴ Given these observations, the obstetrician did not want to jeopardize the future reproductive health of the pregnant woman with what the doctor considered “an unnecessary, potentially risky and expensive surgery” for the mother. As an alternative, one of the staff suggested that a cesarean section might be an option that would increase the chance of a live birth without additional fractures. It is not unusual to recommend a cesarean delivery for a fetus with evidence of fractures or deformities,⁵ although this is debated.⁶ As the case discussion continued, it became clear that the primary obstetrician was not open to further consideration of a cesarean for the reasons stated above.

A clinical geneticist who was present emphasized the difficulty of determining the actual severity of OI or the length of time the infant would survive based on an ultrasound diagnosis.⁷ She stated that even with biochemical testing and x-rays after birth, it is difficult to predict the phenotype of an individual infant; the infant’s clinical course and evidence of respiratory failure are more relevant than laboratory or imaging studies. The geneticist was currently treating several patients with severe forms of OI who were 19 and 20 years of age.

PRENATAL DIAGNOSIS WITH ULTRASOUND

Ultrasound screening is routinely performed during the first and second trimesters to provide information that professionals and families use to guide care throughout pregnancy. It often permits pregnant women to know whether an anomaly is present in their fetus and increases the information available to guide various courses of action.⁸ Ultrasound may be the initial indicator of anomalies in a pre-viable fetus, and it is often followed by more extensive testing to clarify diagnosis and/or prognosis, including karyotyping and searches for additional anomalies. Occasionally, fetal ultrasound surveillance can be misleading, or misinterpreted, causing stress and anxiety for women whose fetuses turn out to be normal or mildly affected.⁹

As clinical information is gathered, the weighty decisions of whether or not to terminate a pregnancy, attempt intrauterine therapy, or support a pregnancy to term must be addressed. Some women, when confronted with

the diagnosis of a pregnancy complicated by severe fetal anomalies detected by ultrasound, opt for termination of pregnancy.¹⁰ Professionals typically honor this decision for a pre-viable fetus with severe anomalies.¹¹ In third trimester pregnancies, others choose non-aggressive obstetric management when there is little benefit for the fetus.¹² A number of women use the information to prepare for a difficult pregnancy outcome and choose treatment or delivery options with the potential to benefit their fetus. When a pregnant woman’s choice gravitates towards fetal over maternal benefit, professionals sometimes find it more difficult to support decisions to continue a pregnancy with severe and potentially life-limiting fetal anomalies.¹³ This may be explained by evidence that some families do not perceive severely compromised health status to be as concerning as healthcare professionals and typically prefer more aggressive support than their providers would.¹⁴ Many families embrace the challenges of caring for an impaired infant. For other families, the birth of an impaired infant is too economically or emotionally onerous or may dash their hopes and dreams for a “perfect” child who would meet certain predetermined criteria.¹⁵ Professionals should respect both perspectives as long as the treatment decisions are medically and ethically appropriate.¹⁶

In addition to the above options (termination or continuation of a pregnancy), a pregnant woman can decide not to screen her fetus for many reasons including the perception of overmedicalization of her pregnancy. This third option avoids anxiety-generating elements that a potential diagnosis of fetal anomaly can entail, but, likewise, a decision not to screen deprives her of potentially valuable information. False-positive and false-negative obstetrical ultrasound exams, the uncertainty of prenatal testing and diagnosis, and the risk of depression following the termination of a pregnancy are all possible risks of routine obstetrical screening.¹⁷

MODE OF DELIVERY

During the third trimester, new issues emerge because the fetus now is potentially vi-

able. Care decisions address alternate modes of delivery and the option of a tertiary or quaternary care hospital to give birth. At this point physicians and patients begin to discuss the benefits of cesarean versus vaginal delivery and aggressive versus palliative care for an infant with severe anomalies, or some level of care in between. In our experience, opinions frequently vary about the appropriate route of delivery and elements of perinatal care. There is a range of reasonable values that can inform treatment options in a fetus with severe anomalies, some of which result in increased risk to the mother for the benefit of the baby; maternal autonomy should govern within this range. Fetal anomalies and genetic disorders vary greatly in severity and availability of effective treatments. The more severe the anomaly, the more important it is that the decision-making process and the language used in counseling be ethically sound.¹⁸

It is important to acknowledge the tensions between the goals of professionals and those of families. Most families are able to articulate a reasonable decision, but their preferences, values, and beliefs are sometimes discounted. Medical professionals occasionally fail to recognize extra-medical factors that include family context, physical and emotional support systems, and financial factors. Instead, professionals may prefer a more straightforward course, based upon medical indicators, or sometimes their own unrecognized personal beliefs and values.¹⁹ Some physicians exert not-so-subtle pressure on women regarding the mode of delivery and care options for an infant diagnosed with anomalies such as OI and other skeletal dysplasias, aneuploidy, spina bifida, certain renal anomalies, and cardiac disorders.²⁰ The tension around these decisions may stem from the different perspectives of obstetrical careproviders and patients, as providers may focus prudently on the woman as a patient, and the woman may focus altruistically on the duality of mother and infant as patients. For example, the option to deliver in a manner that potentially minimized risk to the fetus was not acceptable to the obstetrician in this OI case.

It is possible that the unequal power/knowledge base of professionals may overwhelm the

values of a woman who opts to assume the risks that a cesarean entails. Knowledge creates great power, and the increased medical and genetic complexities of delivery and care decisions may exacerbate the physician/patient imbalance.²¹ In this construct, it is especially important that physicians acknowledge this imbalance and strive to emphasize a pregnant woman's autonomy in "life-and-death decisions" regarding her fetus. New mothers have inadequate understanding regarding the benefits and burdens of caring for an infant with severe anomalies, but, in most instances, they are in a better position than the medical community to make that assessment in their particular circumstances. Professionals may have their own opinions about the course of treatment; however, they are obligated to provide information and expertise to assist patient-centered decision making, based on the woman's own religious, ethical, and cultural values, acknowledging the completeness as well as deficits in available medical information.²²

PERINATAL CARE

Decisions about perinatal care for an infant with a severe or life-limiting anomaly can cause conflict between careproviders and families, because of some degree of uncertainty about the diagnosis and prognosis that is always present. Because medical knowledge is imperfect, choices in neonatal care are, optimally longitudinal, that is, made over time, with multiple opportunities to reassess the care plan based on new information. Therefore, professionals frequently adopt a "wait and see" approach when the viability of a fetus is difficult to predict, because even the best care plan can disintegrate when an infant's condition at birth is different from what was expected. For example, if a decision were made prior to delivery to provide only palliative care after birth, difficult questions such as feeding, providing intravenous fluids, and medications must be addressed if the baby lives days instead of hours. Such a course of action may be difficult for families and staff if palliative care training is inadequate, and care issues are not addressed prior to delivery.

The mode of delivery should not predetermine the nature of care provided after the birth of an infant with severe anomalies. A decision to offer a neonate some level of support until an assessment of his or her medical condition can be made does not necessarily mean that aggressive support or unnecessary treatment will follow. Rather, the goal may be to support the infant's life for a short time to gather more medical information after birth and enable effective grieving for the family if the infant will not ultimately survive. These reasons are sometimes unrecognized or undervalued, even when they are medically and ethically appropriate. Alternatively, on the basis of compassion, a family can decide to forego aggressive treatment because the suffering involved is too grave a burden for the infant without hope of benefit. The obligation for pregnant women and their physicians is to balance the potential benefit versus the suffering for the infant in choosing a course of treatment or palliative care. In the OI case under discussion, intervention would be indicated when it would be beneficial, useful, and not disproportionately burdensome for the infant. It would be a mistake to extrapolate this discussion to presume that aggressive treatment is always indicated; refusal of aggressive treatment in cases involving severe anomalies is often an ethical option.

ETHICAL IMPLICATIONS

In assessing the ethical implications of this case, two medical ethics principles predominate: autonomy and beneficence. These principles are relevant based upon an accurate evaluation of the clinical facts with regard to the mode of delivery and plans for perinatal care, together with the goals of the patient. The principles of beneficence and autonomy are *prima facie* principles, which mean that they hold as long as there are no overriding considerations to the contrary.²³

BENEFICENCE

The principle of beneficence in clinical practice obligates physicians to strive to maximize benefit and minimize harm for their patients.²⁴

Benefit should be defined expansively to include the protection and promotion of the health-related interests of the pregnant woman and her fetus as well as extra-medical benefits.²⁵ In contrast, harm is disregard for her health-related interests and well-being. The prospective assessment of benefit is especially complex in this case due to the difficulty of making accurate predictions of good and harmful outcomes and assessing which consequences have greater weight.²⁶ According to the historical view, beneficence was characterized from the physician's perspective.²⁷ In recent times, patient-oriented theorists have reconstructed beneficence from the patient's perspective, averting the potential conflict between beneficence and autonomy.²⁸ In most clinical situations, a collaborative approach to the characterization of beneficence that takes into account the medical knowledge of the physician and the goals of the patient is most advantageous, even though this practice may need to include a way to resolve the differing perspectives.

Based on medical factors and the principle of beneficence, an urgent cesarean section is routinely advised in the case of fetal distress to benefit the fetus, even though there is some risk of harm to the woman. Likewise, an urgent cesarean section is routinely advised to benefit a pregnant woman, in instances such as severe preeclampsia, even if this would result in some harm to the fetus. When cesarean delivery poses potential risk to a woman, and the impact of mode of delivery for the fetus is neutral, vaginal delivery is recommended. In the case of a pregnancy that is complicated by severe fetal anomaly, a woman may be advised against cesarean delivery because of potential harm to her and the possible subsequent demise of the baby. Nevertheless, maternal autonomy sometimes expresses choices that may result in increased risk to self for the sake of the infant. Therefore, if cesarean delivery entails minimal risk to the woman, while the impact on the fetus is potentially beneficial, the woman's wishes regarding the mode of delivery should be respected, even if the newborn may subsequently die.

Ample data show that decision making about cesarean delivery is complex, and is in-

fluenced by a patient's preference as well as non-obstetrical factors and physicians' preferences.²⁹ The percentage of all births by cesarean section was 27.1 percent in 2003, and has been increasing over the past decade, as indications for cesarean section appear to be changing.³⁰ The physician in the OI case advised against cesarean section for a fetus with severe anomalies; other obstetricians may support cesarean delivery to potentially benefit the fetus or simply on maternal request.³¹ For example, in the past, similar arguments were made with regard to cesarean section for myelomeningocele, a spinal defect conferring risks of paraplegia and other disability. It is now the standard recommended practice to deliver infants with myelomeningocele by cesarean section, as this is now known to provide some benefit to affected infants. Thus, as medical science progresses, recommendations regarding the mode of delivery can change.

AUTONOMY

The ethical principle of autonomy obligates healthcare professionals to respect a patient's decisions regarding which clinical strategies she will authorize based on an evaluation of the medical indications and her values and beliefs. One important way that respect for autonomy is implemented clinically is the process of informed consent for treatment decisions. Informed consent requires a professional to disclose information in simple language, assess a patient's capacity, appraise a patient's understanding, and ensure that the decisions made are voluntary. The purpose of informed consent is to assure educated, uncoerced choice on the part of the patient. Attention to this process fulfills the ethical mandate to treat "all others never merely as a means, but always at the same time as an end in himself."³² By that is meant, respect others as persons who choose their own goals, rather than merely as a means to another's end.

In contrast, a failure to provide information that a patient can understand or the exercise of undue influence from professionals or others undermines a pregnant woman's autonomy, because it thwarts her freedom to make deci-

sions about treatment for herself and her fetus during pregnancy and delivery. Sometimes physicians truncate the norms of disclosure and respectful discussion in the process of informed consent when the prognosis is uncertain, despite evidence that patients want information even if it causes anxiety or distress. In cases such as this one, professionals may avoid adequate disclosure because they fear it could cause mistrust and confusion for the patient and the staff. Moreover, the unknowns surrounding the actual severity of the OI diagnosis and the prognosis for viability in this case made the requirements of disclosure in the informed consent process particularly challenging. However, it was precisely because the outcome was so uncertain that the physician's obligation to present information in a relevant and understandable manner was of heightened importance.³³

By virtue of her condition, a pregnant woman is typically not a model of an autonomous patient (a self-governing agent/decision maker who is unencumbered by outside influences). She faces the usual impediments to the strict notion of autonomy that can include the web of interpersonal relationships, the role of community values, financial issues, legal precedents, the imbalance of knowledge and power, and other personal considerations. As a pregnant woman, she faces the additional consideration of the existence of her fetus as a second patient, who experiences the unavoidable effects of her decisions.³⁴ In this case, there were two patients, the pregnant woman and the fetus, both of whom had health-related interests and elicit ethical obligations. However, only the pregnant woman had autonomy-based obligations, and she made decisions for herself and the fetus.³⁵ Access to the fetus was only through her, and her autonomy would prevail, with limited medical or legal exceptions, as discussed below, or unless she was compromised in a way that undermined her autonomy. Professionals should assume that adult pregnant women have decision-making capacity to choose the clinical strategies that correspond to their well-being, unless there is reliable evidence to the contrary. Given this woman's situation, one would

expect the healthcare professionals would work to underscore her autonomy, rather than challenge it.

The four main normative principles of bioethics (autonomy, beneficence, nonmaleficence, and justice) are intentionally unranked. Even though the principles have no assigned weight, autonomy often outweighs the others.³⁶ The frequent predominance of autonomy is relatively recent; its emergence as “first among equals” tempers the age-old belief that a doctor’s primary obligation is to the principles of nonmaleficence and beneficence, and the pursuit of those principles should supersede patient’s preferences and decision-making rights when the doctor and the patient disagree.³⁷ Given the current lofty ethical and legal emphasis on patients’ autonomy, it is curious that in this case the pregnant woman, who wanted to put herself at risk to potentially benefit her fetus with a severe anomaly, was questioned. The reluctance to respect autonomy is particularly remarkable in this case because such a decision was within the realm of standard of care, and there was evidence that it was well-supported by obstetrical codes of ethics and legal precedent.³⁸ Why did autonomy not rule here?

The ethical considerations in this case were seemingly broader than the principle of respect for the pregnant woman’s autonomy to decide what health risk was reasonable for her to assume, to potentially benefit her fetus who had severe anomalies. In addition, this case likely entailed a patient-physician discrepancy of perspective on the value of the fetus. The physician apparently felt that the status of the fetus didn’t warrant the risk of a cesarean section, and the woman disagreed. Other healthcare professionals involved in the case were uncomfortable considering quality of life issues, given the uncertainty of the severity of the OI in the prenatal diagnosis and the discrepancy of the physician’s and patient’s views. The pregnant woman’s beliefs concerning the moral value of her fetus could not be discounted. Many pregnant women believe that their fetus possesses moral worth, regardless of a diagnosis of disability, and they make choices accordingly.³⁹

The bond that develops between a pregnant woman and her unborn child during the course of gestation is often unrelated to the medical status of the fetus. In contrast, obstetricians may hold different beliefs from patients, and focus primarily on the health of the pregnant woman and pay less attention to the potential for fetal benefit, particularly if they anticipate the fetus will die during or after birth. Ultimately, the definitive decisions regarding outcome and management of the pregnancy are the responsibility of the pregnant woman. If a physician opposes a care plan based on his or her own values and beliefs, the physician may withdraw from the case as long as the patient is not abandoned.

LEGAL IMPLICATIONS

A review of the legal actions that address pregnant women’s choices at the time of delivery are beyond the purview of this article. However, we will digress briefly to consider one recent case as an example of the potential for legal action by the state to affect maternal autonomy. Ethically, a woman can refuse a cesarean section for fetal benefit or for her own health-related interests on the basis of autonomy and clinical uncertainty.⁴⁰ In 2004, Utah challenged the legal right of a pregnant woman to make decisions on behalf of herself and her unborn children. The Utah court charged a woman with the death of her stillborn fetus when she declined the advice of her physicians to undergo a cesarean section to optimize the outcome for her twins.⁴¹ Even though she subsequently agreed to the surgery, only one twin survived, and the prosecution alleged that the demise of the second resulted from the delay. The woman avoided a homicide charge by pleading guilty to child endangerment charges. The Utah case ignored an earlier ruling by the District of Columbia Court of Appeals, with the American College of Obstetrics and Gynecology as *amicus curiae*, that held, “in virtually all cases the question of what is to be done is to be decided by the patient — the pregnant woman — on behalf of herself and her fetus,” and in

the case of incompetency, the decision is to be made on the basis of substituted judgment.⁴²

Several other states have extended their child welfare laws to address prenatal abuse or neglect. The laws vary considerably in their scope and approach, but they all mainly focus on substance abuse in pregnant women. Moreover, the fundamental nature of these legislative attempts is the same. Policy makers and law makers are endeavoring to weigh the autonomy and bodily integrity of pregnant women with society's interest in promoting the birth of healthy children.⁴³ In each instance, the legislation raises ethical questions whether: (1) the state is warranted in intervening in the private autonomous choices of pregnant woman in order to generate healthy outcomes for women and children; and (2) if punitive approaches generally foster or hinder those outcomes. In addition, the abuse and neglect language in these laws is potentially applicable to decision making in pregnancies that involve lethal anomalies, and the ensuing clinical and ethical implications for maternal choices involving life-and-death decisions could be significant.

CONCLUSION

The woman delivered her baby via cesarean section at 38 weeks, and the baby survived for several days. During that period, additional x-rays confirmed the severity of the OI and palliative care was recommended. After the infant died, the woman reported that the opportunity to resolve the uncertainty of the diagnosis and have time to hold her baby and say good-bye was valuable. Even though the surgery likely relegated her to future cesarean sections, that didn't negate the benefit for the woman of closure and, also, the feeling that she had done everything appropriate for her infant.

By virtue of their specialized role in health-care, obstetricians and neonatologists regularly participate in complex and difficult decisions that address issues of life and death. These decisions are complicated by the preferences of patients or their families who may have dissimilar values and different levels of understanding

of what congenital anomalies can mean for themselves and their infant.⁴⁴ Medical decision making in pregnancies that are complicated by severe fetal anomaly requires comprehensive assessment of the quality of medical information available about the anomaly as well as the uncertainties and ambiguities in the diagnosis. In seeking a collaborative approach about pregnancy and delivery options, physicians have an obligation to foster patients' autonomy and respect reasonable maternal choices and goals that are within appropriate standards of medical care. In some circumstances, a pregnant woman's choice may include interventions that have potential benefit for the fetus, despite some negative health consequences for the mother, so that a decision may be made over time, including postnatal assessment of the baby's medical condition. A comprehensive approach to obstetrical counseling, including addressing elements of perinatal care and personal values, should be an integral part of the patient/professional relationship.

ACKNOWLEDGMENTS

The authors would like to acknowledge the thoughtful contributions of Jacqueline Glover, PhD, Sterling McColgin, MD, and Jean Abbott, MD, in the development of this article.

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Medical Education

Individuals, Systems, and Professional Behavior

Evan G. DeRenzo

INTRODUCTION

The Outcome Project of the Accreditation Council for Graduate Medical Education (ACGME) has set a difficult and important goal for residency programs.¹ Of its six general competencies, the inclusion of an explicit focus on systems-based practice is recognition of the radical changes needed to achieve excellence in medicine. Although the consideration of systems-based organization has been gaining credibility for many years across a variety of fields, it has yet to be embraced in medicine.

Systems thinking represents a profound shift in understanding organizations and processes. Systems thinking rejects a mechanistic, reductionist understanding of organizations and processes in which the whole is thought to be merely the sum of the parts; in which the primary focus is on the nature of the part rather than the interactions between and across parts.

Rather, systems thinking understands organizations and processes as interactive, with the parts as subsystems and the system itself as a part of a larger suprasystem. Systems thinking understands that the parts are not merely additive, but that they affect each other. The whole is now understood to be far more than the sum of the parts.² Today, systems theories dominate the field of organizational science. One can even see systems thinking creeping into medicine. Healthcare organizations, such as Intermountain Health Care, apply systems-based practices to their healthcare delivery processes, resulting in excellence in patient outcomes.³ Juxtaposing systems thinking with traditional medical practice, however, is difficult for many. This may be because applying a systems approach can seem almost heretical to medicine's moral traditions.

At its heart, medicine is about the relationship of an individual physician to an individual patient. To be a physician, or at least a good one, is to take on the persona of healer, caregiver to the sick and the needy. To be a patient is to suffer, to feel pain and fear, to experience loss, to face death. To be a patient is to give up equality and to be forced to trust. These complex

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human experiences make the patient dependent on the skill, competence, compassion, and professionalism of his or her physician.

A contemporary perspective on the traditional doctor-patient relationship, however, encourages thinking of patients as customers or consumers, individuals entering into a contractual relationship for medical services. Thinking of patients this way is appealing. It is far less complex to construct morally acceptable roles in a relationship of equals than in one in which the weak is dependent on the stronger. But patients, especially the sick, frail, or frightened, will never be equal partners entering into an exchange of goods and services such as one does when buying a loaf of bread or a new car. The conditions of need that bring a patient to a doctor are inequality in health, knowledge, and power.

Appreciation of the dangers for abuse from the unequal power distribution of this relationship has produced centuries of scholarship and professional attention to building protections for patients into the doctor-patient relationship. Now, into the ancient and unchanging moral core of the doctor-patient relationship, comes an awareness of the multiple systems that influence this primary dyad, and an appreciation of just how profoundly influencing these systems are. This awareness is exemplified by the ACGME's competency in systems-based practice. Centuries of attention on protecting patients from potential abuse by physicians has expanded to include attention to protecting patients from the potential abuse of today's healthcare delivery systems.

THE TASK

The ACGME has set a difficult task for residents and resident education program directors and supervisors. The ACGME General Competency states, "The residency program must require its residents to develop the competencies in the 6 levels below to the level expected of a new practitioner. Toward this end, programs must define the specific knowledge, skills, and attitudes required and provide educational ex-

periences as needed in order for their residents to demonstrate the competencies." Specific to the competency on systems-based practice, it states:

Residents must demonstrate an awareness of and responsiveness to the larger context and system of health care and the ability to effectively call on system resources to provide care that is of optimal value. Residents are expected to:

- understand how their patient care and other professional practices affect other health care professionals, the health care organization, and the larger society and how these elements of the system affect their own practice
- know how types of medical practice and delivery systems differ from one another, including methods controlling health care costs and allocating resources
- practice cost-effective health care and resource allocation that does not compromise quality of care
- advocate for quality patient care and assist patients in dealing with system complexities
- know how to partner with health care managers and health care providers to assess, coordinate, and improve health care and know how these activities can affect system performance.⁴

Acquiring the requisite knowledge, skills, and attitudes will be challenging for residents. But what is interesting, and perhaps more pronounced for this competency than for any of the other five, is that assuring that residents have the educational experiences necessary to develop the knowledge, skills, and attitudes to demonstrate competency in systems-based practice will require that everyone throughout the systems in which the residents train and work model the practice of medicine with a systems-based approach. Anything less won't work.

Resident training programs are subsystems within the suprasystems in which residents work and train. No training program, whether it is of residents or any other category of trainee,

will ever be successful if those who train do not model the behaviors desired of trainees. When instructors and supervisors espouse one kind of behavior but model something much less, the integrity gap is clear. This disconnection between word and deed produces cynicism in trainees, a grave outcome in young physicians. Almost 20 years ago, Donald Kanter and Philip Mervis, in their research on cynicism, found,

Cynical tendencies are growing into a consensus world view with implications for society, commerce, and the workplace . . . the cynic . . . sees selfishness and fakery at the core of human nature. . . . Cynics mistrust . . . most authority figures, regard the average person as false-faced and uncaring, and conclude that you should basically look out for yourself. . . . Cynics at work deeply doubt the truth of what their managements tell them and believe that . . . given a chance, will take advantage of them.⁵

This sorry trend has only continued to deepen within medicine and society over the past 20 years.

That the ACGME now requires resident training that includes systems-based competencies promises that this trend may be reversed. We have the knowledge to make our healthcare systems patient-centered environments in which personnel can work together in personally and professionally rewarding ways, while, simultaneously, providing healthcare services at the highest levels of professionalism. But to achieve this possibility means our healthcare delivery operations must be totally re-engineered.

The new century has seen systems thinking move to center stage in healthcare. The Institute of Medicine (IOM) has made clear that healthcare systems must move from a self-identity as mechanical organizations to networks of complex adaptive systems (CAS).⁶ This transformation requires that healthcare organizations must shift from outmoded mechanical behaviors to current systems processes. Mechanical systems are predictable and program-

mable; complex adaptive systems are not. Mechanical systems are composed of standardized and replicable parts; complex adaptive systems are not. Mechanical systems are characterized by ever-increasing levels of specification. Intense levels of specification will strangle and paralyze a CAS. A complex adaptive system is one that flourishes under conditions of fluid exchange of information, transparency of process and decision making, elimination of counterproductive routines, and a gentle regulatory yoke.

For residents to learn to demonstrate systems-based practice, the practices of the institutions in which they work and train must be systems-based. Because residents cannot be responsible for altering their institutional environments, it will be up to the resident education program chiefs to assure that the environment changes so that the needed educational experiences can be provided. In sum, to teach systems-based practice, a healthcare organization must become a systems-based organization. Personnel at all levels, especially those in leadership positions, must incorporate the characteristics of a CAS into their normal work patterns. That means everyone in the organization must become comfortable with change. Rules need to be simplified and their ubiquity pruned. Personnel at all systems levels need to take responsibility for actions in an environment of fewer rules and less behavioral specification. Everyone must learn to celebrate and reward novel thinking, creative problem solving, and the discussion and disagreement required to achieve these ends. Personnel must embrace the difference between order and control, developing confidence that order, where and when needed, will emerge so that outmoded attempts at centralized, bureaucratic control can be jettisoned.

These activities are ordinarily anathema to an organization. Organizational psychology teaches that organizations, like individuals, seek stability, will squeeze out disruptive influences, and will endeavor mightily to retain the status quo. Routines are comforting to individuals and institutions. Change-agents are upsetting. But

if the IOM and progressive business pundits are correct, it is just these tendencies that must be overcome if we are to train residents to become physicians practicing at the highest levels of excellence and professionalism.

Impeding this process is that the qualities of a change-agent — that is, being a collaborative questioner and someone who disagrees agreeably — are not primarily the kinds of skill for which physicians, especially medical students and physicians in training, have been rewarded. Rather, knowledge-based skills have been emphasized. Mastering scientific and clinical knowledge, the core skills of the medically competent physician, are not the skills considered primary for mastery of systems-based practice. Skill in systems-based practice requires mastery of complex psychological responses and the ability to engage in refined yet vigorous ethical debate. Consider the following case.

North Central Hospital's ethics committee includes two third-year residents. During an ethics committee discussion of a particularly complicated case, one of the residents disagrees with the position taken by the new chief of medicine. The chief of medicine dismisses the resident's comments, with an edge in his voice, saying that the resident is too inexperienced to understand the ethics of the case. The chairperson of the ethics committee says nothing. Nobody else gives the resident's position fair consideration. For the rest of both residents' terms on the committee, they no longer offer their opinions. Having heard the story many times over, future residents do not offer comments when the chief of medicine is present, nor do many residents call the ethics committee chairperson for consultations. The inability of the hospital's leaders to master their psychological defenses and fears will have been a toxic lesson for the residents.

Learning to be comfortable with, or at least to tolerate, the vigorous debate called for by the medico-moral decisions clinicians and health-care administrators make daily is a psychological skill. Regular and searing self-examination, at the individual and systems level, requires control of one's emotional defenses. Learning to challenge each other across peer groups and up, down, and across the various chains of command in ways that produce learning and collegiality takes emotional maturity. The quality of

decisions that physicians make in treatment recommendations, advocacy, and resource allocation policy is based on skill in managing their own psychological responses and refinement in ethical analysis. In sum, demonstration of the ACGME systems-based practice competency outcomes will spring less from knowledge and more from mastery of ego challenge and refinement of moral judgment and debate skills.

To achieve these outcomes, healthcare environments in which residents train and practice will need to be re-engineered into settings that habituate and reward the desired behavioral outcomes. To create such environments at both the sub- and suprasystems levels, we need to turn our healthcare organizations into healthcare delivery CAS. To achieve this transformation, the reward systems in the organization need to reinforce CAS-oriented, rather than mechanical, behavior.

It is this author's hypothesis that the only way to succeed in such organizational transformation is to create morally safe environments. Only morally safe environments will create the context necessary to convert our mechanical systems into the complex adaptive systems that promise greater safety, better care for patients, and the resident competencies called for by the ACGME.

CREATING A CAS-CONDUCTIVE ENVIRONMENT: THE TRICKLE DOWN, UP, ACROSS, AND THROUGH MODEL

Although physicians and others within traditional, mechanical healthcare organizations have been rewarded for adhering to mechanical behavior patterns, it is important to remember that humans can change their behavior. One of the great beauties of being human is that we can change and adapt to new information. Emotional and psychological insights can result in shifts in behavioral patterns. Evolution in ethical thinking can result in changes, for the better, in how humans treat each other, other creatures, and the environment. In short, we are learning animals.

Optimal learning occurs when an environment is designed to allow those in it to maxi-

mize their own tendencies toward critical thinking and mastery of the principles and skills being taught. In healthcare, the appropriate principles and skills are generally consistent across systems, at all sub- and suprasystem levels. These common principles and skills are summarized in the executive summary of the final report of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry. This report states, "The purpose of the health care system must be to continually reduce the burden of illness, injury, and disability, and to improve health and functioning of the people of the United States."⁷ The IOM has translated the President's Advisory Commission's broad mandate into the six specific aims that healthcare should be safe, effective, patient-centered, timely, efficient, and equitable. These aims, however, are not new. They are the same aims that have been at the heart of medicine since time immemorial.⁸

The difficulty is not in setting appropriate goals, but in how to achieve them. Given that our healthcare delivery systems are in crisis, and have been for years, mainstream thinking has just not yet identified the fundamental sources of the problems or the avenues to their solutions. But these answers already exist.

We must recognize that the problems and the solutions, at their core, are not merely technical, economic, regulatory, or informational, but ethical. Lester Thurow had this insight almost 20 years ago when he noted, "Health-care costs are being treated as if they were largely an economic problem, but they are not. To be solved, they will have to be treated as an ethical problem."⁹ What Thurow understood, but what mainstream medicine has yet to appreciate, is that resolution of virtually every issue, question, or situation in medicine, whether ostensibly technical, economic, legal, regulatory, or informational, requires a moral judgment. For example, although there is no debate about whether or not informed consent documents are required for surgical procedures, it is a moral judgment about how much information is the right amount to be included. We must appreciate that decisions about what we do and how we do it always include an ethical component.

It is now time, also, to act on the insight that to solve the crisis in medicine means we must focus on the ethical climates of our healthcare organizations. We must design systems to function in ways that increase the prospect that residents, other clinicians, staff, and administrators can perform at the highest levels of professionalism. Central to the problems, and the solutions, of today's healthcare delivery systems are the ethical climates of these systems. When we take seriously that creating morally safe healthcare environments is necessary, role models can teach residents how to successfully navigate through the technical, economic, legal, regulatory, informational, and other interconnecting and interdependent systems that affect their relationships with their patients. In short, what is required is to assure that the systems in which residents work and train are morally safe environments.

THE MORALLY SAFE ENVIRONMENT

A morally safe environment is one in which all members of the organization feel safe enough to speak up. A morally safe environment is one in which all are encouraged to challenge each other about medical, economic, policy, scientific, administrative, regulatory, and ethical issues, that is, about every aspect of the functioning of all the sub- and suprasystems within and outside the organization. Creative problem solving, willingness to admit error, openness to questioning, and change flourish in environments where these behaviors are rewarded and celebrated. Such behaviors wither away in environments that are overly controlled by hierarchy and regulatory minutia. When personal initiative and responsibility are positively reinforced, these behaviors multiply across the various organizational systems, and residents learn these skills through observation. Personal initiative and responsibility are suffocated by unnecessary lines of authority, lack of support, and heavy-handed interpretation of regulatory guidance. Under such conditions, residents become morally and intellectually paralyzed.

A morally safe environment is one in which all members of the organization feel safe enough to speak up. A training program that can teach

young physicians systems-based practice requires an organization that is unthreatened by residents and others who speak up. To have residents who speak up requires that everyone in the organization feels safe. Speaking up means being comfortable asking a question or disagreeing. A morally safe environment is one in which anyone feels comfortable enough to ask anyone else a question.

Most residents have had the following experience. On rounds, the resident presents his/her patient, having already had a lengthy conversation with fellow residents about the patient's care. The attending orders a test or initiates a treatment that had already been considered and rejected by the residents, yet nobody speaks up. None of the involved residents challenge the attending or even asks why he or she is ordering the test or treatment. Nobody says anything because the moral courage needed is absent.

Direct interchange between residents and more senior physicians, however, is only one subsystem in which the morally safe environment needs to be created. Systems thinking requires that residents and others learn to appreciate how systems are intertwined. The systems of physician and nurse, or physician and social worker, are other examples of where individual behavior will have large spill-over effects on residents' learning. In a CAS, these subsystems will be open to rigorous discussion, hearty disagreement, and transparency in decision making. In so doing, patients' well-being, staff's satisfaction, and respectful clinical relationships can be maximized. Take the following scenario.

Mrs. G is an 85-year-old patient with metastatic colon cancer and multiple co-morbidities, who is minimally responsive. The patient's adult son is questioning the nurses and social worker whether or not his mother has gone through enough curative treatment attempts. Mrs. G's oncologist, however, cuts the son off and won't discuss the matter with the nurses or social worker. Instead, the physician paints a positive picture to the son about the length of potential life left and says that if they insert a feeding tube, Mrs. G can gain strength and live for many more months, if not longer. After several failed attempts to discuss the matter with the

physician, the social worker calls an ethics committee consultation. When the physician hears of the consult he is incensed, threatening to have the social worker fired.

This case is a prime example of everything that is wrong with traditional medical practice. Today, such behavior has a name: rankism, or rank-based abuse. A term recently coined by Robert Fuller, rankism "is the 'cancer' that underlies many of the seemingly disparate maladies that afflict the body politic. The outrage over self-serving corrupt executives is indignation over rankism. Sexual abuse by clergy is rankism. Elder abuse in life care facilities is rankism. Scientists taking credit for their assistants' research is rankism,"¹⁰ and physicians riding roughshod over surrogates, nurses, and social workers is rankism. Although such behavior is obviously unacceptable, it happens all the time. Resident education program directors and supervisors have the obligation to prevent others from polluting the moral climate of the organization. The organization's response will have important implications for systems functioning and will dictate what residents learn.

If this physician admits large numbers of patients, the hospital may be disinclined to rein in his bad behavior. But not doing so will have serious repercussions. Nurses and social workers throughout the organization will be intimidated and angry, psychological states that predispose clinicians to burnout. The residents will learn that, if not acceptable, it is tolerable for at least some physicians, most notably high admitting physicians, to get away with bad behavior. This information is a recipe for cynicism.

If, on the other hand, the ethics committee consultation results in a formal rebuke of the physician and a clear explanation that such behavior will not be tolerated, everyone's inclination to speak up will have been strengthened. Residents will have had the appropriate behaviors modeled for them. Both the requirement to challenge their peers who act badly and proper interactions among physicians, staff, and family members will be clarified. And, consistent with the CAS characteristic of nonlinearity, it would not be surprising to find that the hospi-

tal that responds this way has fewer nursing vacancies than surrounding facilities.

CREATING A MORALLY SAFE ENVIRONMENT

Creating a morally safe environment is a long-term venture. Creating systems in which any relevantly involved individual feels comfortable enough to speak up takes care, time, and attention. Speaking up isn't easy. It takes moral courage. Fortunately, moral courage is a virtue we can learn.

From Aristotle to B.F. Skinner to more contemporary authors, it seems clear that moral courage, and its manifestation of comfort in speaking up, can be learned. What is clear, also, is that conditions need to be right to allow the requisite learning to take place. In Aristotelian terms, the process goes as follows: "of all the things that come to us by nature we first acquire the potentiality and later exhibit the activity (this is plain in the case of the senses . . .) but the virtues we get by first exercising them. . . . For the things we have to learn before we can do them, we learn by doing them, e.g. men become builders by building and lyre players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts."¹¹ The implications for systems-based practice, if true, are substantial. Physicians who threaten social workers produce residents who habituate into senior attendings who threaten social workers. Physicians who respect the views of social workers and see ethics consultations as opportunities for expanded moral analysis produce residents who do as well. This Aristotelian notion that doing the good produces skill in figuring out what the good is and doing it again might seem like philosophical wishful thinking, were it not for modern scientific validation.

Classic Skinnerian theory teaches that individuals are inclined to repeat behaviors for which they have been rewarded. The mountains of data that support this theory show us that if persons are rewarded for doing the good, they are, as Aristotle predicted, inclined toward doing so again and again. Skinner extends this

insight into the realm of group influences on individual behavior: "In a given instance, good behavior on the part of A may be positively reinforced by B because it generates an emotional disposition on the part of B to 'do good' to A . . . it seems clear, simply as a matter of observation, that the behavior of favoring another is modified by appropriate emotional circumstances and that good behavior on the part of another is a case in point."¹²

In turn, Skinner's hypotheses about environmental influences on individual behavior have been supported by more recent research. Synthesizing a body of research studying cognitive bias in human interaction, Robert H. Frank summarizes, "Once the initial valence has been assigned, a biased cognitive filter becomes activated. You still evaluate further aspects of your experience with a new acquaintance, but with a slant. If the initial evaluation was positive, you are much more likely to treat ambiguous signals in a positive light. But if your initial impression was negative, you are more likely to assign negative interpretations to those same signals."¹³ In healthcare, in which the mission is other-oriented, it is critically important that the environmental stimuli produce behaviors that reinforce other-oriented behavior, be it toward patients, surrogates, colleagues, or others.

Let us consider the case in which one of the "others" in a healthcare organization felt safe enough to speak up, to appreciate how important this issue is for systems-based practice.

At a large research center, there was a long-term study of young adult patient-subjects with a chronic pain syndrome. Many of these subjects had been on the study since their early teens. Study procedures required that subjects come into the research facility once a year for a three-week period. Over the years of study participation, the subjects had developed very close relationships with the principle investigator (PI), who, since the beginning of the study many years before, had risen from fellow through the ranks to department chairperson. The PI was a highly private person by temperament and not easily approachable by junior members of the research team.

During the stay of a particular subject, one of the housekeeping staff noticed that the subject was out of his room more often than the other subjects. Paying closer attention, this housekeeper watched the subject enter the elevators with undue frequency. Finally, the housekeeper got on the elevator when the subject and a visitor got on the elevator together. During the elevator ride, the housekeeper observed the friend injecting something into the subject's venous access.

When the housekeeper reported it to one of the research fellows on the protocol, she was told not to get involved, that the fellow would handle it. But the situation continued. Mustering what must have been significant moral courage, she reported the incident to one of the nurses, who then brought the problem to the appropriate staff. It was determined that the subject's friend was injecting illicit drugs into the subject, and a sitter was attached to the subject for the rest of his stay.

In some facilities, a housekeeper might be considered too insignificant to a patient or subject's direct care to have any important information to provide. When such an individual has information that challenges the *status quo*, a traditionally hierarchical, mechanical organization will be prone to dismiss the housekeeper's report. In a CAS, however, one understands that no system is completely detached from any other, and rankism is flattened, when appropriate, to surfacing problems. In a morally safe environment, it is appreciated that nobody in the organization has any greater moral authority than anyone else for illuminating and resolving a problem. Fortunately for subjects' safety, this facility had created an environment in which all individuals felt responsible for the well-being of the subjects.

The following case demonstrates the opposite, that is, how inappropriate application of power withers moral courage.

In a large university medical center, a problem had been identified in the review and oversight of a prominent researcher's work. Briefly, it was alleged that a PI, who was also a department chairperson, had engaged in research on

tissue samples, appropriately obtained for one purpose, without approval by the institutional review board (IRB), for another purpose. In a special meeting of the IRB, a junior investigator challenged the PI about his actions. When the meeting ended, the PI stormed directly into the office of the IRB member's department chairperson, demanding that the junior investigator be removed from the IRB.

The department chairperson had several projects in which his own work, and that of his laboratory, was dependent on the collaboration and good will of the PI. After the PI stormed back out of the office, the department chairperson went to the junior investigator and suggested that perhaps she might have served on the IRB long enough and that she might want to step off the committee. The department chairperson didn't order the junior investigator to step off, nor did he make the suggestion in an angry tone of voice. Neither was necessary to produce a chilling effect on everyone in the department.

BUILDING THE CRITICAL MASS TO SUSTAIN A MORALLY SAFE ENVIRONMENT

As easy as it is to have one or two persons pollute the moral climate, the reverse seems not to apply. It is not enough to have one or even a few individuals within the organization known as wise counselors. The change needed to move an organization from a mechanical system to a CAS, to produce residents skilled at systems-based practice, to create the necessary morally safe environments, requires a critical mass of ethically sensitive persons throughout the organization. As Fuller notes, "Typically, psychological change precedes a political assault on the status quo. Not until a great many individuals conclude that something is wrong and that an alternative exists will they organize politically and try to bring down an existing edifice."¹⁴ A few "high visibility" good souls will never have the influence, energy, authority, and emotional strength needed to change organizational culture.

Rather, what is needed is a critical mass of ethics-focused individuals within and across the

multiple systems of the organization. Starting from the top down, the organization needs persons who are identifiable as ethically thoughtful and interested, throughout all sectors. Such persons initiate discussion about the ethical implications of issues, as they arise, throughout daily work. They encourage and model thoughtful ethical discussion. They are comfortable with, and engage in, disagreements agreeably. Such individuals act as magnets for all of the rest of the persons within their normal daily venues who are also interested in ethical issues, but may not have quite as much psychological strength. These others may not be the ones to expose the ethical aspects of a complex issue, initiate discussions, or openly start a disagreement, but they will join the process if given encouragement by those they know and trust. This is how moral courage is learned and how the necessary critical mass of ethics-focused persons develops. Once there are enough of these persons, when issues have to be handled across multiple other systems, there will be enough persons within all of the systems that the characteristics of a CAS can flourish.

One source for producing this critical mass is through a vibrant and highly functioning ethics committee. Consider a slightly altered version of the first case presented in this article.

North Central Hospital's ethics committee includes two third-year residents. During an ethics committee discussion of a particularly complicated case, one of the residents disagrees with the position taken by the new chief of medicine. The chief of medicine, in a neutral tone of voice, says he really thinks his position is the ethically optimal solution and gives his reasons. The ethics committee chairperson, agreeing that the chief's position is sound, nonetheless takes over the argumentation process from the resident. He then shapes the resident's position into a quite elegant and ethically acceptable option. After that, the chair invites the rest of the committee to think through the two positions as potential boundaries of ethically acceptable possibilities, challenging the other committee members to offer up their own positions, either novel to the two on the table, or elaborations of either one. Lively and substantive ethical analysis ensues. The committee ultimately comes to a consensus that favors the essence of the chief's position, but includes nuances

that only surfaced as a result of the additional considerations raised by the resident and others on the committee.

For the rest of both residents' terms on the committee, they participate thoughtfully in committee discussions and promote the committee to the junior residents who will take their places. The chairperson of the ethics committee begins to notice an increase in "curb-sides" and formal consultations coming from the residents across various units in the hospital.

Word spreads quickly among residents that neither one was "shut down" by the chief of medicine in a meeting, or that, in a disagreement with the chief of medicine, the ethics committee chairperson brought an evenhandedness to the situation that made everyone more comfortable.

The quality of nonlinearity is, as the IOM noted, "Small changes can have large effects; a large program in an organization might have little actual impact, yet a rumor could touch off a union organizing effort."¹⁵ How such a situation is handled will have a ripple effect throughout the organization that can be expected to increase or decrease residents' psychological ability to speak up.

But even having a superior ethics committee is not going to be enough. What is needed is a critical mass of individuals, strategically located across multiple systems, who are committed to focusing on ethics. Further, it is important that these individuals are at the highest levels of leadership across all systems of the organization. As Christopher Meyers states, "Organizational culture is created and maintained by two processes: the top-down establishment of institutional values by owners and managers and the carrying out of those values by in-the-trenches employees."¹⁶ Ethics is the art of persuasion. Moral judgments are only forceful if those who offer them are viewed as wise, respected individuals. Because ethical recommendations lack the force of law, strong intellectual, political, and psychological levers are required to move heavy behavioral objects. That is, when moral judgment faces long-standing practices, it takes great moral force to produce a shift. This moral force is generated by a growing, and highly visible, group of individuals within an organization who actively participate within their

own systems-based practices to advance the creation and maintenance of a morally safe environment. Everyone from the top down encourages and rewards others for speaking up, and takes a firm hand in retraining, or eliminating, those who do not.

REDUCING THE WEIGHT OF REGULATION

Efforts to create and maintain an ethical climate will also require reducing the weight of regulatory and legal ways of thinking. Charity Scott notes, "Law pervades medicine because ethics pervades medicine, and in America, we use the law to resolve ethical dilemmas in health care."¹⁷ But this process stifles ability to engage in ethically sensitive systems behavior and is a threat to the well-being of patients. Psychologically, excessive reliance on regulation and compliance may merely be place markers for fear of litigation. Excessive fear of litigation can obliterate individual common sense, self-reliance, creative problem solving, and ethical behavior, a point already long appreciated.¹⁸ When excessive fear of litigation produces overly legalistic regulatory interpretations and conflates ethics with compliance, the ability of a CAS to overcome mechanical behavior is doomed.

Regulations and compliance are necessary and important. It is, however, the way in which an organization interprets regulations and implements compliance programs that will set the tone for individual and systems behaviors. There can be little that is more mechanical than excessively legalistic thinking. Where it exists, it permeates not merely those who have direct responsibility for regulatory oversight and compliance, but everyone in the organization. Worst of all, such thinking leaves physicians intellectually paralyzed and ethically confused. Modeling such behavior for residents may be lethal to their ability to mature into senior physicians who exemplify the qualities identified by the IOM as critical to improved patient care and safety.¹⁹ This does not suggest that we should deregulate our healthcare organizations or weaken our insistence on legal compliance. What it means is that we must begin to shape

our interpretations of legal and regulatory matters within a framework that focuses on their ethical basis.

To achieve this revolution in legal thinking and regulatory implementation, an ethical approach must be taken in deciding what is necessary. An ethical approach to regulatory compliance and legal interpretation calls on all who must comply with laws and regulations — that is, everyone — to think through how they comply. Asking what the ethically optimal way to interpret and comply with the law or regulation must be the framework for analysis. In a healthcare organization, that means asking such questions as, "What would be in the best interest of this patient?" "What is the organization's obligation to the patient, surrogate, nurse, social worker, et cetera?" "What does justice, fairness, and/or common decency suggest is owed to the patient, surrogate, nurse, social worker, et cetera?" Once consensus around these answers is determined, we can think through how the answers might be consistent or inconsistent with legal and regulatory interpretations.

At their finest, laws and regulations set minimal behavioral standards that are sufficiently elastic to allow for maturing interpretation as the moral norms on which they are based evolve. Such excellence in regulatory guidance is exemplified by the regulations governing the ethical conduct of publicly funded human subjects research in the United States.²⁰ These regulations are brief — barely 20 pages — and have been revised infrequently and minimally since they were promulgated two decades ago. During this period, ethical debate in the professional and lay literature about the ethically appropriate conduct of human subjects research has mushroomed, but these elegantly written regulations continue to be relevant. The regulations have not changed; interpretation of how they should be implemented has changed.

Contrast this example of regulatory excellence with the following.

A patient is brought into an intensive care unit (ICU) in the middle of the night in need of surgery. Upon admission he is still conscious and capacitated, and makes it clear to the medical team that he is a practicing Jehovah's Witness

and does not want any blood. Shortly thereafter, he becomes unresponsive. The family members with him are not Jehovah's Witnesses. Once the patient loses decisional capacity and they are now being asked to provide procedural consents, they tell the medical team that if he needs blood they should go ahead and give it to him.

The next morning on rounds these events are discussed. The bioethicist asked the resident why nobody from the patient's Jehovah's Witness community was called to come and advocate on behalf of the patient. The resident responded that he hadn't thought of it, but wouldn't have done so anyway because it would have been a violation of HIPAA (the Health Insurance Portability and Accountability Act of 1996).²¹

A response of, "Well, let's think this through some more — HIPAA violation or eternal damnation?" resulted in laughter among the team and a look of dismayed shock and unhappy insight on the resident's part that he had made the wrong decision.

A strict HIPAA constructionist might consider contacting a member of the patient's faith community a violation, especially when the patient had caring, if perhaps ethically misguided, family members acting on his behalf. But a loose constructionist might interpret contacting the patient's spiritual leader to be acceptable under the HIPAA allowance for sharing information necessary for patient care. Further confusing the resident, however, was the ubiquitous and misguided legal interpretation about who was the appropriate decision maker. Because traditional medical practice and most surrogacy laws put family members first in line, there was no ethical analysis of whether the family members, in having given permission for a blood transfusion that was refused by the patient, were acting in an ethically, or even legally, appropriate way on the patient's behalf. The resident's fear of litigation by an angry family member inhibited his moral judgment. That nobody else suggested calling a member of the patient's faith community indicates a lack of ethical imagination.

This is a common problem in healthcare facilities in which risk management has the overly anxious and confused view that upholding patients' autonomy and obtaining informed consent means that whatever the patient or family

member wants, goes. Such confusion is less likely in an institution in which risk management's contribution to creating a morally safe environment is supportive. Ethically sound risk managers make explicit that physicians are encouraged to work through the various systems of consensus building and consultation, and once all relevantly involved parties have agreed on the best course of action for the patient, risk management will support their decision, regardless of legal outcome. Legal doctrines, case law, and regulations should provide guidance and wisdom. Becoming slavishly tied to over-interpretation of laws and regulations robs residents of the ability to learn to think ethically. As Scott states,

Law came to the patients' bedside . . . because there was an emerging societal sense that wrong was being done to the patients there. This invitation to get the law involved in ethical conflicts is nothing new. Whenever there is a social sense of wrong, or injustice, or an abuse of power by some people or some institutions . . . those who feel abused often turn to the law for protection . . . a felt need for patient protection from a power imbalance in the doctor-patient relationship has resulted in consent forms, living wills, and other legal documents and rules. That these legal mechanisms frequently provide only minimal protections in practice — that they often fail to achieve the ethical balance that was their goal — does not alter the point that their purpose was to promote an ethical vision of the doctor-patient relationship. . . . And herein lies the pitfall which the very power of the law creates for ethical reflection. . . . Law only sets a floor for ethical behavior. . . . Faced with the power of law, however, we tend to get stuck in our ethical reflections at the ground floor. As is so often true when law packs ethics with a punch, people tend to over-focus on avoiding the punch, and not on the ethical underpinnings of the law.²²

For residents to reach the highest levels of professionalism, they must have models who in-

interpret laws and regulations to maximize patient care, not in ways that some might think will avoid the punch of litigations. Overly legalistic interpretation does not prevent litigation, only the ethical practice of medicine protects against litigation.²³ This is a lesson residents must learn and that can only be taught in healthcare organizations that have adopted an ethical approach to legal and regulatory interpretation.

CONCLUSIONS

Why is the ACGME competency in systems-based practice so important? It originates with the ancient principles that define the ethical conduct of medicine — act in the patient's best interest and protect patients from harm. The ascendancy of the autonomy movement was a way of protecting patients from the tyranny of medical paternalism. Having young physicians learn how to think not only on an individual level, but also at a systems level, is a way to protect patients from the tyranny of systems. Take, for example, advance directives. Advance directives can be thought of as a systems issue. At the suprasystems level, there is a federal law requiring hospitals and other healthcare organizations to find out if patients have advance directives, and, if not, whether patients want information about them. At the subsystems level, healthcare organizations spend inordinate amounts of time figuring out how to implement the federal law, how to demonstrate to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) that the law is implemented, determining which staff will have responsibility for which parts of the process, and designing advance directive information to be provided to patients. All this effort and the following still happens.

Mrs. Jones is going into surgery to repair a broken hip. Her only relative, her granddaughter, has been with her since she arrived at the hospital two days ago. Although Mrs. Jones lives alone, her granddaughter is her only relative. They have always been so close that Mrs. Jones has a durable power of attorney for person and property, including healthcare de-

isions, naming the granddaughter as her agent. In all the commotion, the granddaughter has only now produced the documentation. Mrs. Jones is sedated and prepped for surgery. The nurse looks over the document before putting it on the chart and sees that it says, "... only in the state of Michigan." The patient is in Illinois.

This jurisdictional discrepancy halts the patient's surgery. The nurse calls the resident, who is unwilling to allow the patient to proceed to surgery because now the patient is thought not to have the "right" advance directive. The resident calls the surgeon, who won't operate, because s/he doesn't know if the paperwork is legal in the state of Illinois. The surgeon calls the hospital's risk management department, who then calls hospital counsel. Hospital counsel takes several hours to decide that an advance directive executed in Michigan can be used in Illinois. By this time, the patient's surgery has to be put off until the next day, causing distress to the patient and granddaughter and wasting operating room resources.

If an ethics approach had been taken, the scenario might have gone more like the following. The nurse realizes that the documentation is legally authorized only in Michigan and reports the matter to the resident. The resident, who is comfortable questioning what systems approach might be best implemented to handle this question, decides to check with his/her peer, who sits on the hospital's ethics committee. That resident explains that all that is required to be an ethically and legally valid surrogate is, in the absence of documented agency, that the person acting as surrogate appears to be acting in the best interest of the patient. It doesn't matter whether or not Illinois considers the Michigan document a legal assignment of agency. If the granddaughter is the ethically appropriate surrogate, this meets every ethical and legal principle upon which the suprasystem of advance directives sits. The resident responsible for the patient's care then calls the surgeon, explains the situation, and makes the recommendation that the granddaughter is the appropriate surrogate. The patient then moves on to her surgery as planned.

Wasting resources, provoking anxiety and frustration in patients and surrogates, and putting patients at risk from process errors are

harmful outcomes that can be avoided through skillful systems-based practice. Avoiding such outcomes, however, does not mean that such problems can ever be eradicated completely. The systems in which residents work and train are so complex that errors and problems will always occur. The hope is not for perfection, but rather for the creation of environments that present the greatest opportunities for medical excellence. The promise that such environments will become the norm rather than the exception is on the horizon. Organizations such as the Institute for Health Care Improvement (www.ihc.org) have been created to assist in this process. For resident training, environments are required that reward the psychological responses and ethical discussions necessary for superior patient care. Now it is up to those responsible for resident training programs to create the morally safe environments necessary to assure that the residents they train can demonstrate the ACGME-required performance outcomes in systems-based practice.

ACKNOWLEDGMENTS

The author wishes to thank Jack Lynch, MD, Center for Ethics, Washington Hospital Center, Washington, D.C.; Jonathan Moreno, PhD, Kornfeld Professor of Biomedical Ethics and Director, Center for Biomedical Ethics, University of Virginia, Charlottesville, Virginia; and Jack Schwartz, JD, Assistant Attorney General and Director for Health Policy Development at the Office of the Maryland Attorney General, Baltimore, Maryland, for their review and comments on an early draft of this manuscript, and to Elizabeth Griffin, Falmouth, Massachusetts, for her excellent copy editing.

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