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# S E C O N D O P I N I O N

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HEALTH • FAITH • ETHICS

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Anger and Healing • Home Care • Public Health, Poverty, and Racism • Theological Ethicists



COVER

*Death of the First Born.* Oil on canvas by Robert Reid, 1888.

Collection of the Brooklyn Museum, Brooklyn, New York.

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HEALTH • FAITH • ETHICS

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The Park Ridge Center exists to explore the relationships among health, faith, and ethics. In its programs of research, publishing, and education, the Center gives special attention to the bearing of religious beliefs on questions that confront people as they search for health and encounter illness. It also seeks to contribute to ethical reflection on a wide range of health-related issues. In this work the Center collaborates with representatives from diverse cultures, religious communities, health care fields, and academic disciplines and disseminates its findings to professionals and others interested in health, religion, and ethics.



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*Second Opinion*, as its name implies, recognizes that the complexities of modern health care make it increasingly difficult to find the single “correct” action, thought, or method. Each situation is open to a variety of apparently legitimate and appropriate interpretations and applications. But such confrontations with ambiguity need not lead to discouragement. They can instead elicit greater research, discussion, and thought.

By inviting contributions from a wide range of perspectives, *Second Opinion* stimulates interdisciplinary conversations between members of fields relating to health, faith, and ethics. While other publications deal with one or two of these concerns, *Second Opinion* distinctively seeks to address all three. The Park Ridge Center created this publication in the hope that it will help form one public out of a number of related constituencies. This public will not only wish to relate ethics and faith to health issues, but should also, through lively and enlightened interchange, be better equipped to do so.

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## SECOND OPINION

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\* *The first 16 volumes consisted of one issue each and were published every four months beginning in March 1986.*

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# INITIAL COMMENT

## If Only . . .

ONLY A FEW THOUSAND PAIRS OF EYES WILL get to see this issue, in libraries, waiting rooms, parishes, and private homes. As I reread the articles before we went to press, the eager small boy surviving in me kept wishing: "If only the hundreds of thousands of medical professionals, clerics, professors, and patients knew about *Second Opinion* and could start reading . . ." and "If only they knew how much enjoyment and help they could gain . . ." While we try to realize those wishes, let me say why we care and then play the role of the responding reader.

Why we care. When the Lutheran General Health Care System helped make possible the Park Ridge Center, which publishes *Second Opinion*, I asked why. The best answer I got: "Because people in the clinics and churches and universities are hurting. Caregivers and thinkers about care have to make hard decisions. They need help." We like to think that we provide some help on the health-faith-ethics front. To illustrate, let me suggest what help a responding reader might get from this issue.

I need help, says a caregiver, in understanding the despised themes of anger and suffering. No, this is not the time for faddish comment about why I should have more anger than I have or about why and how suffering is not so bad and how creative it can be. I need philosophers—like Arthur W. Frank and Jerome A. Miller—who can

speak from the heart, write with style, draw on profound reading and experience, and aim for the real world where the angry and the suffering live. Both of them draw, if critically, on specific faith traditions, and they speak to the general human condition.

This reader in need of help will get help from the story of Cardinal Jackson and the responses to her physician, David Schiedermayer, who writes so movingly about her. He or she, or I, needs help understanding house calls and human personality, care and context. As an editor, I had earlier read this narrative three or four times, but even on a final reading it brought a tear or two. Not a tear of sentimentality but one of empathy and hope that there be other families like hers, other physicians like her house-caller.

Then this reader needed comment, lest the story by its emotional power and narrative nuance carry one away. Stanley Hauerwas is characteristically bold in his celebration of the Cardinal Jackson instance and in his criticism of the medical profession where it fails to be alert or where it remains academically remote in its devotion to principles. And Elizabeth M. Johnson keeps our feet on the ground and our eyes on reality with her observations about certain limits revealed in the account.

Also in these pages, Mark Siegler revisits the modern classic case of Karen Ann Quinlan,



providing a parallel reading to the Cardinal Jackson version. His article raises questions about how the Quinlan story is usually analyzed and says some good words for the hurting caregivers who get overlooked in most tellings.

Readers will benefit, too, from acquaintance with the personality, achievements, and outlook of Reed Tuckson. Several times since we first contacted Dr. Tuckson for this interview, I have had the experience of hearing someone comment, after attending a conference or watching a televised panel, on the freshness and memorability of his voice. Tuckson discusses here the effects of complex, entrenched social problems on health care. His stories persuade us that fixing blame and admonishing people to "behave" will yield negligible results and are symptomatic of "magical thinking."

Madeleine Leininger is a veteran caregiver whose word is welcome for those of us who are often too much at home in too narrow a cultural

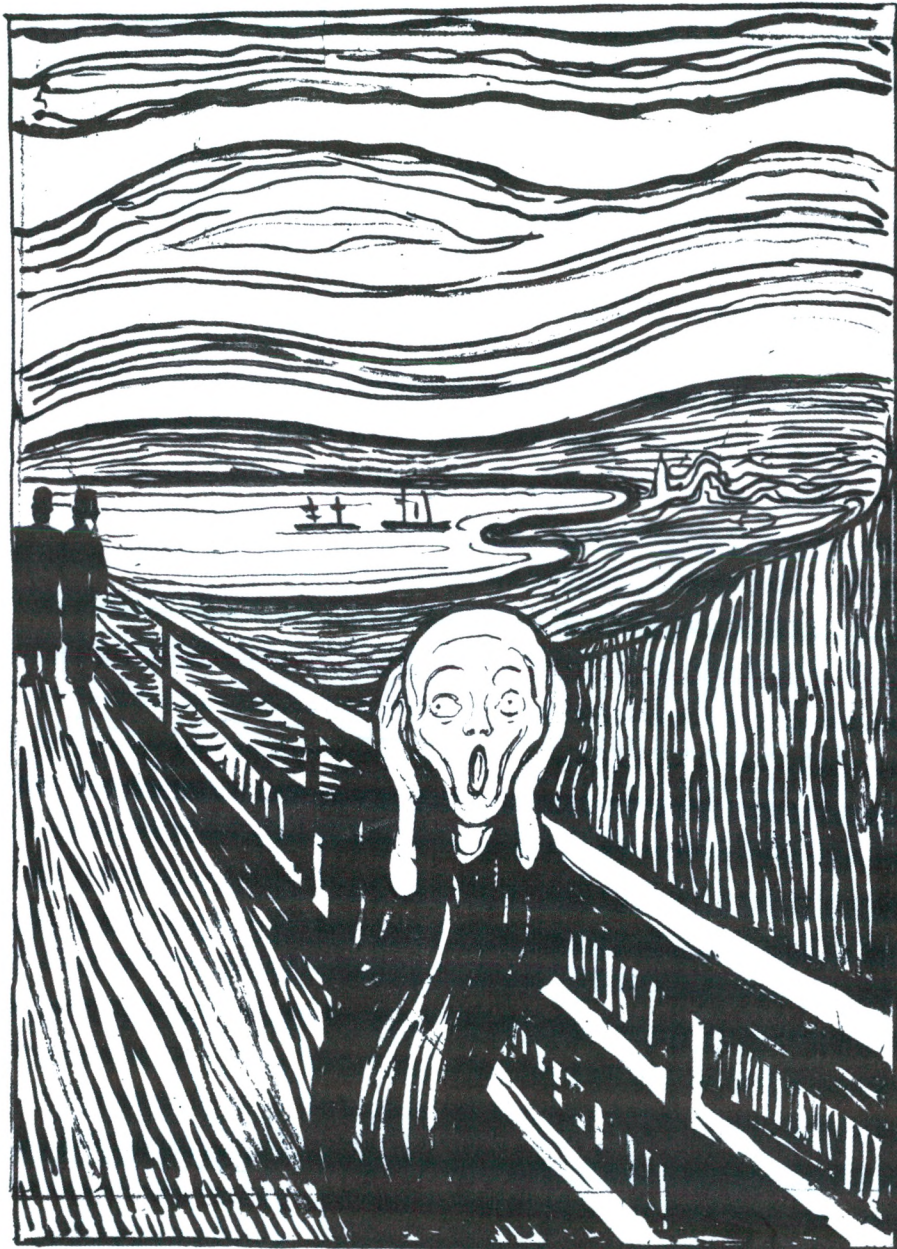
slot in respect to matters of health, faith, and ethics. Drawing on her considerable experience, she speaks up for transcultural nursing and, along the way, gives implicit lessons to all of us in our many professions.

My own article is in a way itself a response—to nine essays on theological ethicists that have appeared in *Second Opinion* over the last five years. The people about whom I write show how important it is to keep together both story and principle, narrative and reflection, cases and concepts. We need not find the concrete and the abstract to be in conflict. They meet at the focused points of all our work: in the persons of dignity and worth who suffer and would find meaning, who give care and receive it.

Pass it on.

A handwritten signature in dark ink, appearing to read "M. E. Marty". The letters are fluid and connected, with a stylized flourish at the end.

*Martin E. Marty*



*The Scream.* Lithograph by Edvard Munch, 1895.



# Anger, Illness, and Healing

Arthur W. Frank

Unless you go through all the genuine angers you feel, both justified and unjustified, the feelings of love that you do have will not have any legitimate base and will be at least partially false. Plus, eventually you will go crazy.

—Christopher Durang, Author's Notes on *The Marriage of Bette and Boo*

I READ THE ABOVE QUOTATION ONE EVENING in the half-light of a theater. I was distracted, waiting for the play to begin, skimming the program. Durang's notes gave me a sudden liberation. What he told me—what he authorized—was that I no longer needed to sort out my “justified” angers from those that were “unjustified.” All my angers were genuine. Not only did I have a right to express them, I had a positive responsibility.

That night I was more than a year out of treatment for cancer and was starting to write a book about my experiences. The Durang quotation eventually became one of the epigraphs of the book, *At the Will of the Body*. There I wrote about various angers: my anger at how badly persons with cancer

are often treated by others, and my anger at society's cancerphobia, which invents theories about a “cancer personality” in order to isolate the risk of cancer in the behavior of those who “have” it and thus to blame them.

I also wrote about my anger at not being allowed to be angry. The anger of the ill has many dimensions, but society has just as many ways to tell people *not* to express their angers. One way is to perpetuate a distinction between angers that are justified and unjustified. Because some angers are “unjustified” and therefore not legitimate to express, the ill person is constantly guessing: is this anger justified or not? Am I justified if I express it?

Anger is one of the most difficult emotions for ill persons to deal with, because our society authorizes anger least. At a recent community seminar on health care I heard a participant discussing Elisabeth Kübler-Ross's stages of dying. Her opinion was that people should spend more time

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experiencing the depression stage but less time being angry. This comment struck me as strange from several perspectives, but at present it can stand for the general unwillingness among those who would be caregivers to have ill persons act angry.

Would-be caregivers deny anger in many ways, but I'll suggest only one. I was talking to a nurse about a hospital, not the one where she herself works.

It's a modern, well-decorated facility, but I was objecting that the coolness of the decor functions to suppress any displays of emotion; what may be calming from one perspective can be restraining from another. I love post-Impressionism too, but I could trust only a hospital that put Edvard Munch's *The*

*Scream* up on the walls. That bald skull with its huge mouth sucking all the world into its silent scream is an emblematic expression of the suffering that cancer brings. A cancer center that hung such a picture would be telling its patients clearly: here your suffering will be seen for what it is, not glossed over. I was trying to explain all this when she interrupted, but my argument was less interesting than her reply: "Maybe that's just your perception."

Of course it is just my perception, and probably an eccentric one. But the point of care is that it's never anything but "my perception." Care consists in affecting the perception of the person being cared for. Rather than understanding my perception, this would-be caregiver dismissed it as "only" mine. I was angry—justified or not—and she resisted my anger by relegating it to being "just my perception." Even if anger is only mine, and even if it's unjustified, I have no less need to express it.

If anger goes unexpressed, Durang is right: you will go crazy. Or with regard to illness, you will remain unhealed. Healing, not necessarily of the body but certainly of the spirit, requires feelings of love. As Durang says, these feelings must have a legitimate base for their expression. Love and anger

are often conceived as antithetical, but Durang's point, and mine, is the contrary: the expression of anger is necessary as the legitimate base of feelings of love. I often wonder why I never felt much love toward the professionals who took care of me while I had cancer—respect, certainly; appreciation on many occasions, sometimes even affection, but almost never love. Perhaps one reason is that in their

questionnaires and their conversation and their hospital decorations, they shut out my anger.

The first liberation I felt on reading Durang was that *both* my justified and unjustified angers were genuine and worthy of expression. Realizing that by itself would be only half an in-

sight, and possibly a dangerous half. The second liberation, more difficult to understand but perhaps more important, was that anger is part of love.

## The Angers of the Ill

Ill persons tell me of many angers. When a friend who has a terminal lymphoma first saw a doctor about his "bumps," he was told (after no physical examination) that at his age he was a "low risk." When the lymphoma was diagnosed months later, that physician was angry at him, angry that *he* had "let his condition go so long" without medical attention. Stories of such nondiagnoses are common among cancer patients: an older woman told me how her cancer was first written off as an effect of menopause.

Then there are angers at family. A young woman tells of how her family's taboo on speaking of cancer incapacitated her ability to respond to her diagnosis and treatment. When she offered to talk to her nieces about what had happened to her, their mother, her sister, told her she preferred that the girls not know why their aunt had been in the hospital. The woman

**Having a heart attack at age 39  
and cancer a year later, I felt  
that all I had prepared myself  
to be was on the verge of being  
destroyed, for no good reason.**



ended her story sadly, even bitterly: “there goes another generation.”

And anger can be directed at institutions. Several patient support groups were given permission to set up information booths in a hospital, but the staff then posted no notices telling patients and visitors where the booths were. A large group of physicians was attending rounds in a lecture hall next to the booths. When they came out for coffee, none of them came over to the booths or acknowledged their presence. Those physicians who had worked specifically with people in the booths avoided eye contact.

These anecdotes are chosen arbitrarily, and readers can add their own. Each is, of course, only a story—“just one person’s perception” of what happened. But what *is* life except many stories, happening to many people, and what are these stories but individuals’ perceptions of what has happened to them? Who is to say which of the angers expressed in these stories is justified? The only reason to sort out angers as justified or not is to make moral judgments on the validity of those angers, to weigh fault and assess blame—and to what end? Suffering is reduced not by people placing blame but by people acting differently.

Telling these angers is a necessary part of healing. Some may get well and others may not, but the healing of the spirit can come only through expressions of love, which often if not always require expressions of anger. To render this relation of anger to love less strange, we need a paradigmatic act of anger that is, in its unjustified expression, utterly pure.

## A Perfect Anger

For our healing, we need to get over the characterization of anger as a “negative” emotion requiring justification. We want to find an anger that is beyond justification and thus intimately connected to suffering and to love. I find such an act in the

history of someone we may be reluctant to think of as angry, Jesus.

On the following day, as they left Bethany, he felt hungry, and, noticing in the distance a fig tree in leaf, he went to see if he could find anything on it. But when he reached it he found nothing but leaves; for it was not the season for figs. He said to the tree, “May no one ever again eat fruit from you!” And his disciples were listening.

So they came to Jerusalem, and he went into the temple and began to drive out those who bought and sold there. He upset the tables of the money-changers and the seats of the dealers in pigeons; and he would not allow anyone to carry goods through the temple court. (Mark 11:12–16, Revised English Version)

The passage tells of two acts of anger, one involving the fig tree and the other, the money-lenders. Jesus’ anger at the money-lenders is easily justified by our current morality, but this anger is not what draws me back to the passage. The verses have always engaged me because in the cursing of the fig tree, Jesus seems to be acting out an anger that I can only read as unjustified.

The fig tree no more determines when it will produce figs than an ill person determines the onset of disease; each has its season. Jesus is angry at the lack of fruit, although he would have known the tree’s proper season. If Jesus had the power to cause the tree to wither prematurely, he presumably could have caused it to bring forth figs prematurely. But he chooses to destroy. His lack of concern with eating suggests he is acting out an anger that comes from elsewhere, not from the tree’s lack of fruit.

Biblical scholars interpreting the fig tree verses usually turn the story into an allegory. My healing requires a literal reading of a story about a man who is not actually ill but whose imminent suffering and death give him affinities to the critically ill. As a story about a fully human person anticipating pain greater than what most illnesses bring, the verses have several morals.





*Tormented Man.* Ink on paper by Leonard Baskin, 1956.

Collection of the Whitney Museum of American Art, New York.



The first returns us to Durang. The Gospel account does not make much distinction between the *unjustified* anger against the fig tree and the *justified* anger against the money-lenders. The two acts are placed side by side in the text and given equal weight. The point would seem to be that both angers are genuine and worthy of expression, in the original actions and in the Gospel retelling.

The second moral has more to do with illness and how its suffering affects us, *us* including any human being, especially Jesus. Few of us experience illness, pain, and loss without moments of confusion that express themselves in anger. Few can endure the suffering of bodily failure and the indignities that attend even the best treatment without developing resentments and frustrations that eventually turn into anger. Jesus is anticipating the degradation of desertion by his friends and assault by his enemies. His expressions of anger, especially the *unjustified* anger, convince me that his is fully human suffering, in which lesser mortals can see themselves and learn.

In holding up this biblical story as a paradigm for the ill, I hope I will not be read as recapitulating the theodicy of earlier centuries that tried to justify the place of illness in God's creation by seeing illness as each person's opportunity to emulate the sufferings of Christ (see Porter and Porter 1988 for examples). Such attitudes persist in our time, but I put them on the side of cant, not spirituality. I try instead to reclaim a spiritual dimension of illness experience without bringing in theodicy.

## Turning Anger into Action

Christopher Durang was obviously angry when he wrote his autobiographical play, *The Marriage of Bette and Boo*. The expressions of anger in the play need no other function than to express anger; that is enough. But Durang's achievement is to express his angers in a form that can change other people's lives. The expression of anger may be an imperative in itself, but if there were no element of responsibility in these expressions, life would be, in Hobbes's

famous phrase, nasty, brutish, and short. When the television character Basil Fawlty rips a branch off a tree and gives his stalled car a sound thrashing, that is certainly an expression of anger, but it's ridiculous. To be responsible, an expression of anger should have some capacity to change the cause of the anger.

We can act to change ourselves, to change others immediately around us, or to change the larger systems in which we all exist. These can be called the personal, interpersonal, and political levels of change. If all angers deserve to be acted upon, action is more or less responsible depending on whether it is directed at the appropriate level.

When ill persons express frustration and anger over the waiting times for appointments with specialists and for test results, change must be political. The economy of medicine is allocating too few resources, and the result is needless suffering. Changing one's personal outlook will not help, nor will it usually help to assail those representatives of the system who end up fronting the institutional inadequacies. Patient support groups must develop political action wings. These groups are being formed, and their reception by those in power shows why they are necessary.

Women with breast cancer have recently become militantly political. The response to their activism is expressed by a health care bureaucrat who was reported as "uncomfortable with a single cancer being singled out, because advocacy groups for every type of cancer could follow." What if all cancer groups—and all illness groups—started demanding better treatment? "Where does it end?" was the bureaucrat's rhetorical question about such advocacy groups ("Anger Sparks Activist" 1991). Those of us who have had, or might in the future have, critical and chronic illnesses can only hope for such an end.

Expressing anger to achieve political change is difficult because it yields so few results; organizational establishments seem impermeable. Expressing anger to achieve interpersonal change has a different difficulty: it requires confronting with our anger those we need and love. For someone who is



seriously ill, weakened, and afraid, even mild confrontation can be too much. But avoiding confrontation when there has been an insult can be equally weakening.

In all the stories of anger told above, an interpersonal response was possible. Patients wrongly diagnosed could go back to their physicians and demand to know what they were thinking of and how they intended to avoid future mistakes; these would be interesting interviews. The woman who wanted to tell her nieces about cancer could have told her sister about the suffering she was setting in place for her daughters by denying them access to what really happens in cancer treatment, leaving them to fantasize about what goes on in the hospital. And the people in the patient support booths could have gone to the physicians and refused to be avoided.

Custom and decorum, "manners," weigh against such displays of anger in response to the behavior of others. Even when we are healthy, it is no easy thing to confront another person with a demand for personal change. A hospital nurse recently gave me an informed consent form for a diagnostic procedure which is standard but has some invasive aspects and risks. "You have to sign this first" was the sum of the "informed" consent. I know what energy I had to muster to ask her for the full explanation to which I was entitled. Much more energy is needed to confront a family member, and that energy costs more for someone who is ill, as I was not. And then there is the ill person's fear that however insulting others may be, they are still needed, and accepting insult may seem preferable to being abandoned.

Given the difficulties of political and interpersonal change, it is certainly easiest to respond to anger by seeking to change ourselves. In fact it may be too easy: changing ourselves, if that is all we

change, is a limited response. If we need to change ourselves, this change should be a preface to engaging in interpersonal and political change.

The part of the self that often does need to change is the attitude toward anger. Ill persons who tell me their angers often seem to seek affirmation that they had a right to be angry. Their stories are

told in a neutral tone, without commitment about what was felt; but when I respond by saying how angry the person must have been, a flood of feelings comes out. People who tell their stories in such a neutral way have been too well socialized by society's denial and deprecation of anger; they have not yet learned Durang's lesson.

Some day in anyone's future it may be worthwhile to

pass judgment on an anger, but first any of us needs to be angry without evaluating that anger or resisting it or hurrying through it. Thus ill persons need caregivers who will engage their angers without evaluating, resisting, or hurrying. People who talk about their angers relax visibly in the course of the telling. But we should not tell our own angers, or elicit others' tellings, as some therapeutic sleight of hand to make these angers go away. The point of telling is to refine the capacity to act in the most responsible way.

The Gospel story seems to chart a refinement in Jesus' capacity to act in response to anger. Perhaps it is consequential that the anger against the fig tree precedes the more clearly directed anger against the money-lenders. And both angers form a prelude to that most consequential act of suffering, the crucifixion.

**I no longer needed to sort out  
my "justified" angers from  
those that were "unjustified."  
All my angers were genuine.  
Not only did I have a right to  
express them, I had a positive  
responsibility.**



## Anger as Openness

Every religion contains its stories of suffering; the crucifixion is the story told in Christianity, and it has special resonance for me given my cultural upbringing. I read it as a particularly useful story but not a privileged one. What *is* necessary is to link anger, suffering, and spirituality. The three are inextricably intertwined, and the crucifixion of Jesus is one of many stories, going back to the descent of the goddess Inanna<sup>1</sup> and certainly earlier, that express this linkage.

I need the fig tree story before I can understand the crucifixion. As embellished by an artistic tradition in a society that sustained a pleasure in cruelty, the crucifixion has an element of sadomasochism that I, like many others, find repellent. Making the fig tree a station of the cross helps me recover the story as one of suffering that relates to the shared human vulnerability to illness. Jesus' anger, especially his unjustified anger, is necessary to keep his story from turning into one of mere resignation.

Jesus' anger at the fig tree shows he is hardly resigned to the suffering he anticipates. He is angry, but he does not remain in a state of rage. The passage from Mark, begun above, ends this way.

Early next morning, as they passed by, they saw that the fig tree had withered from the roots up; and Peter, recalling what had happened, said to him, "Rabbi, look, the fig tree which you cursed has withered." Jesus answered them, "Have faith in God. Truly I tell you: if anyone says to this mountain, 'Be lifted from your place and hurled into the sea,' and has no inward doubts, but believes that what he says will happen, it will be done for him. I tell you, then, whatever you ask for in prayer, believe that you have received it and it will be yours." (Mark 11:20–24, REV)

Jesus' response to Peter surprises me. I would have expected Jesus to apologize for having withered the fig tree, but that expectation is because I still make moral judgments about whether or not an

anger is justified. Jesus is beyond such judgment, much as the God of the Hebrew Bible is beyond apologizing to Job. Instead, Jesus describes his withering of the fig tree as an act of prayer. The lesson is counterintuitive to our conventional sense of manners: the Gospel seems to be saying that even an act performed in "unjustified" anger can be an expression of prayer.

Prayer arises out of a life of generalized openness to creation and all its possibilities, and it then intensifies this openness. Within such a life, prayer is a concentrated attitude of wonder. Given the volumes that have been written on prayer,<sup>2</sup> this is little enough to say, but it may be just enough to help us understand how, in the last chapters of the Gospels, acts that we would often call destructive are transformed into attitudes of prayer. This assimilation of destruction to prayer is, I believe, one of the most important lessons that the fig tree story offers the ill. In illness a body that is otherwise vigorous can be destroyed because of the failure of one part, and a promising life wiped out; how can we experience such destructions as prayer? How can we live through such destruction in an attitude of prayer?

Consider another "destructive" act. In Matthew's Gospel (26:6–13), the chapter in which Jesus is arrested begins with a woman pouring "a bottle of very costly perfume" over his head. The disciples criticize the waste, but Jesus affirms her action. The incident provides a significant framing for what follows. In the same sense that the disciples consider the perfume to be wasted, Jesus' premature death on the cross could be considered a waste. Understanding why the perfume is not wasted opens an understanding of why the self-sacrifice on the cross is not a waste either; if one act does not make sense, neither does the other.

To understand either act as "waste" is wrong, because both are performed in an attitude of prayer. The woman pours the perfume in an act of full openness, with concentrated wonder at the mystery that has brought her together with this extraordinary man. The perfume is the response she offers up



to creation for what creation has offered her. Jesus will die as his own offering to creation. His death is not a waste, but a final, full entry into the mystery of his being. When things—perfume or bodies—return as offerings to the source of their creation, this is not waste but praise, and prayer is an essential form of praise.

Connecting destruction to prayer, rather than understanding it only as waste, can do much to diminish the suffering of illness. Part of the anger I experienced during my illnesses was a sense that I was being wasted. Having a heart attack at age 39 and cancer a year later, I felt that all I had prepared myself to be was on the verge of being destroyed, for no good reason. What I continue to fear about illness has much to do with what would be “wasted” if I became ill again, before my season. This fear inhibits my attempts to heal.

The perfume-pouring occurs in Matthew’s Gospel at about the same place in the sequence of events that the fig tree occurs in Mark. I read the stories as parallel. Jesus’ anger at the fig tree is part of his opening himself to understanding his death not as a waste, which is surely one sensible way to interpret it, but as the fulfillment of living in an attitude of prayer. The anger, far from being the expression of a “negative emotion,” is a necessary stage in his full opening of himself to the spiritual. And the spiritual has, as at least one of its dimensions, the agony of the flesh.

Again, I read the fig tree story literally. Jesus does not set out to “do a lesson” using the tree. He really is hungry, and the minor discomfort of that hunger is magnified by his anguish at what lies before him. The frustration of his attempt to satisfy his hunger takes on the weight of the suffering to follow, and in a moment of pure anger he withers the tree, just as he might like to do away with the cross that waits for him.

Jesus’ enlightenment is his recognition, at the same moment, that his capacity to wither the tree is a wonder. In *destroying* some bit of creation, he also *affirms* deeper powers within creation. The creative power that put the fig tree there is equally expressed

in his withering of it. Of course the withering is, in itself, a petulant act. But then enlightenment is not freedom from human petulance but the capacity to turn that petulance into prayer. Anger is the moment of that turning, the razor’s edge between the human and the divine, the mundane and the mysterious. Anger is a door between one dimension and another, and Jesus has the power to walk through it. That walking through is the perfection of his anger.

Jesus’ anger at what will happen to him reclaims the crucifixion from its sadomasochistic overlay, but it still has to be read as a sacrifice. The idea of sacrifice accepts dying as an active participation in creation, and this acceptance comes hard today. Perhaps we are able to think of illness only in terms of prevention and cure because we resist placing ourselves within intergenerational cycles of death and rebirth. The crucifixion is the final answer to Job, in which Jesus willingly takes on himself the sufferings that were inflicted on Job. The vulnerability to suffering and the inevitability of death are affirmed, not merely accepted, as part of *embodied* creation, and the full mystery of creation is thus grasped.

Sacrifice is not a waste. Nothing is wasted when it is offered in an attitude of prayer; perhaps, on the contrary, things are being wasted until they are offered in an attitude of prayer. But there is no cause to rush the season in which the literal sacrifice is fulfilled; winter will come soon enough. The brilliance of the crucifixion is that it could be the last such sacrifice. The crucifixion is a sacrifice that does not demand a continuing tradition of more sacrifices. That such sacrifices did follow, and still do, represents the refusal of humanity to grasp the “good news” of the crucifixion.



## Healing and Stories

As I think of my own illnesses and talk to others about theirs, I see that our healing begins in mundane stories, like the angers of the ill told above. These stories are complete in themselves, but they gain additional weight when put in relation to eternal stories, like those in the Gospels but hardly restricted to those.

These stories tell of angers caused by individuals and institutions that acted badly. If we fail to hold on to the demand these stories make for immediate change, the anger will have been wasted. The angers of the ill are in no sense allegories of “deeper psychological tensions.” To hear them as symbolic diffuses their anger and its demand, just as reading the fig tree story as allegorical takes out the anger. For the story to remain human, it must retain the petulant, bitter anger at the minor hurt that anticipates a much greater hurt. Unless this anger is accepted just as it is, it cannot be turned to something else. Until anger is turned to something else, it is not entirely responsible.

What anger becomes is both prayer and action. Prayer is not a turning away from the anger but a

turning through it, to act on it. Precisely because the withering of the fig tree *is* destructive, it expresses Jesus’ relation to the deepest forces of creation. He must affirm this relation as he prepares for his own destruction, with no expectation that the universe will apologize for his suffering.

Healing occurs when, in the midst of our own destruction, we find an opening in which to experience a relation to the source of our own creation. Anger is one privileged moment of opening. What I call the deepest forces of creation are what Durang calls “the feelings of love that you do have.” When we can turn our angers into moments of prayer, that is love, and healing.

But turning anger to prayer does not mean “getting over” the insults and injustices that made us angry. This turning to prayer is not inward. Jesus’ message is that prayer must turn outward, to others. Jesus expresses his anger toward the money-lenders in a fully political act that is still a prayerful one. The crucifixion is a prayerful turning outward that will have the most far-reaching interpersonal and political consequences. Turning anger into prayer means preparing to act on that anger in the most powerful way. In such an anger we change the world, and we heal. ☸

## NOTES

1. In the Sumerian Cycle of Inanna, the goddess willingly descends to the underworld, where she is flayed and her skin hung on a peg. After she has been gone three days, her earthly helpers travel to the underworld, cause her rebirth, and return her to the earth (see Wolkstein and Kramer 1983). The Inanna story has achieved particular prominence among feminists involved with the goddess movement.
2. Among these volumes, the one I had read most recently when I wrote this article was Fox 1976, for which I am grateful.

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*Grief.* Bronze sculpture by Marie Apel, ca. 1940.

Collection of the National Museum of Women in the Arts. Gift of Wallace and Wilhelmina Holladay.



# The Way of Suffering

## *A Reasoning of the Heart*

Jerome A. Miller

IT IS IMPORTANT TO MAKE CLEAR at the beginning the perspective from which I will be trying to explore the question of God's existence. I think we approach this question most appropriately when we understand that it has to do with the least accessible regions of the human heart. The French philosopher Pascal claimed that "the heart has its reasons, which reason does not know," but perhaps he underestimated the capacity of reason to take the heart seriously and reflect on the insights that might lie concealed in our most heartfelt realizations. The word *heart*, as it comes to us from the Hebraic tradition,<sup>1</sup> does not refer exclusively to our emotions but rather to the very core of the self, that mysterious center of our being that is so inexplicably opaque and distant from ourselves.

When the very center of the self is deeply affected, as happens for instance to a young person when he or she falls deeply in love for the first time, one's whole way of thinking about the world, as well as one's whole way of feeling it, is profoundly and

permanently altered. No part of the self is exempt from such an experience. One is touched in depths one did not know one had but whose reality one cannot possibly doubt. That is why falling in love can be so devastating to us in our youth and why the upheaval it causes has always been symbolized by a wound. The person one was before has, to some degree, ceased to exist—and so has the world one used to live in.

Any experience that affects one in the core of one's being, like being in love or being in intimate proximity to death, enables one to realize things one had never truly recognized before. For example, the youthful longing to be with the beloved (described so well by Plato)<sup>2</sup> simply makes it impossible for the person experiencing it to take very seriously many matters that up till then seemed to be of paramount importance. When you are being affected in the core by something, you realize that your whole life is at stake and that in some very profound sense nothing else matters. Such an experience enables you to see the superficiality and unimportance of your ordinary worries. This is why Plato considered being in love a profoundly religious experience (see Pieper 1964). He thought it could help transport a young person to a new level of being from which she could begin

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to realize that selling a lot of insurance premiums is not the most important thing in life.

But if this is true, it means that such an experience, precisely because it affects the whole of the self, should not be treated as if it were nothing more than an emotional episode. To *realize* that the person one loves is much more, infinitely more important than insurance premiums requires an *insight*, a recognition of a profound truth that might very well lead to a radical change in one's whole way of living. I do not think it is preposterous to suggest that human beings can learn something from their deepest wounds and exultations if they take the time to reflect deeply on them.

It seems to me that suffering of the kind undergone in a profound experience of love or death is full of intimations. Is it not possible for reason to follow these intimations rather than to silence them? If such experiences enable us to realize things in our heart of hearts, are not these the lessons we should study long and hard in the hope that they might begin to make us wise? The core of the self in the Hebraic sense is only capable of weeping and rejoicing because it harbors the deepest realizations we come to in this mortal life. Perhaps, contrary to Pascal's epigram, one of the great tasks of reason is precisely to mine this precious ore, not leave it buried. The heart has its reasons which reason can begin to plumb, even if it can never finish fathoming them.

The question of God's existence is, I think, a matter that is capable of affecting us in our heart of hearts. It is one of those ultimate matters, like love and death, that can come to matter ultimately to us in the center of our selves. This is because what we mean by the word *God* is a being that deserves to be worshipped, and the one thing worship cannot be is

half-hearted. Worship has to be extravagant (see Pieper 1963:58–59). In the end, the martyrs and mystics are right at least about this: To love God, if God exists, requires one to spend one's self completely and without reservation. This is why the philosopher Bernard Lonergan (1972:104–7) describes religion as falling in love with God. One

cannot worship and hold the core of one's being in reserve. It is true, of course, that apparent acts of worship are performed all the time that do not in fact represent such a complete donation of self on the part of the worshipper. But in such acts there is a double-heartedness that is contrary to the very essence of what is being vowed. In bowing down before something, one is trying to convey that even the gift of one's whole self is insignificant compared to

what the object of one's worship deserves. Seen from this perspective, the question of whether God exists can be translated to read: Is there a reality that deserves to be loved with such extravagance?

Let me say first as frankly and delicately as I can that for most of us, in our heart of hearts, God does not exist. Or, if God does exist there, it has little effect on us: we keep our hearts as buried as we can so that they will not interfere with the ordinary business of living. In the one case, God has never become real for us, has never ceased to be an abstraction; God is something we talk about because we have learned the word. In the other case, something has happened to us at some point that broke through the surface and penetrated the most secret, intimate part of the self. Some agony, some joy, some terrible suffering, or some transporting ecstasy made us think, at least while it was happening, that we were in the presence of something of absolutely transcendent importance. We may not remember with any

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clarity what brought on this experience. We may not know how to retrieve it or repeat it. It may have left no discernible effect on our lives precisely because it happened at so deep a level, and we do not ordinarily live at the depth of our selves. We do not know our own hearts.

And now, perhaps, we begin to glimpse the real issue. We hide our hearts from ourselves. We do not want to know the wisdom we could learn from the heart; we would like to mind our own business and have nothing to do with it. The wounds love has inflicted are too deep, the dread the heart harbors is too perilous, for us to want to think about what it might teach us. We know just enough about the heart's core to keep as much distance from it as possible. Its joy, just as much as its weeping, is too overwhelming for us to bear. That is why we do not often talk to each other in the deepest way. Perhaps twice or three times in our lives we break through and acknowledge to one another the truths we have kept hidden from even ourselves. Sometimes this happens on one's deathbed, sometimes not even there. One might conclude that the heart must be a profoundly fragile thing if we take such pains to keep it concealed from even our own awareness. But in fact it is not its fragility that terrifies us but its power—the piercing truth of its deepest wounds, the unbearable weight of its regrets and longings, the terrible import of its darknesses and silences. It is all of this we want to be ignorant of, at almost any cost. We do not want the deepest truths within us known to us.

But, try as we might, we cannot help being haunted by them. In the darkest, truest hours of our lives, the things we keep secret from ourselves catch up with us. One of the implacable laws of the universe is that the deepest things are our masters. We try to protect our hearts from them, but we would have to cut our hearts out to free ourselves from their haunting intimations. We want, more than anything else, to be in control of our lives, but being in control requires that there be nothing deeper in us than what we can cope with. And what, in the end, does this will to control accomplish—

except to make those most obsessed by it the most deeply haunted of all souls?

Suffering, Aeschylus says in *Agamemnon*, is the greatest spiritual teacher. It is through suffering that one learns whether God exists. It is no academic matter. I do not mean that one can learn nothing from the philosophical arguments, but that to do so one has to find, deep in the heart's core, the terrible realizations of which these arguments are a faint and not always reliable echo.

## I

THE WAY TO FIND OUR HEART IS TO RETURN TO our most haunting moments, those times when all the things we have kept hidden from ourselves seem on the verge of breaking through our long, laborious avoidance of them. How close we come then to a moment of truth—and how quickly we usually recoil from it.

What would one have to do to cross that borderline instead of moving away from it? Shrouded as these matters are, the answer is all too concrete and obvious. One must allow oneself to be alone, even to the point of being physically solitary. But it is precisely when what haunts us presses in on us most intimately that we flee solitude most quickly. We do so with a special desperation whenever something happens in our lives that makes death real to us.<sup>3</sup> I am not thinking here only of the physical death of someone we have deeply loved, but of what happens to us when something we have centered our lives on, something infinitely precious to us, is irremediably lost.

In many cases, this infinitely precious thing is a relationship with another person. But it can also be the failure of a project that had become one's life work. In any of these cases, one is losing something that meant more to one than the whole world. When someone or something becomes the center of one's life—the reality in relation to which everything else is viewed and evaluated—then, in one's heart of hearts, nothing else matters. One would rather lose



*everything* than this reality that is not just one being among others in one's world but something like the radiating center that makes one's whole world possible. Romantic love of the type Plato described is not the only kind of affection that causes such a profound attachment. It can also exist between parent and child, as is made clear when the child who sees her parents as the center of her world does something terribly wrong and so feels she has forfeited forever the love that made all her confidence in herself possible. It is also clear from the kind of unspeakable grief parents suffer when the child in whom they see the perfect reflection of their love for each other dies before their eyes without having even reached the age when she could put her suffering into words.

There are those of us to whom none of those things have happened—the child who is the light of our lives has not died, the person we first gave our hearts to in our youth remains beside us even now. Our worlds are still intact; the thing at their center that all else depends on still gives off its life-sustaining radiance. We have never been brought face to face with the utter emptiness that would be left by its absence. Yet however reluctant we might be to acknowledge it, none of us in the end will be able to find a way around this emptiness. Whatever the object of our love, we will have to suffer the mortal wound of its loss. That is why death is not just one example among others of what it means to suffer. For suffering, as distinguished from simple physical pain, means the convulsion of grief the heart undergoes when it is bereft of everything. And what does it mean to lose the thing that meant more than everything and made the world possible, if it does not mean to undergo a death?

We are accustomed to thinking that death, which we identify with physical extinction, is completely inaccessible to us, since we have not literally undergone it yet. We are, we think, too far this side of it to know anything of what death is really like. And yet even those who have not yet suffered deeply the irreparable loss of what we most love have been close enough to the experience of death to be

haunted by it. What keeps us from knowing more of it is not the impossibility of being acquainted with it until literal death comes to us but rather our recoiling from the intimations we already have of its dreadfulness. Death is all too real to us—right underneath the surface of all the avoidances we use to keep from realizing it.

To see that this is so, I would not have you think of the kind of radical rupture I have been discussing, the kind that tears your heart right out of you. I would have you think of those moments that only you can pinpoint, the moments that catch you unaware as you brush your teeth or wait to make a left-hand turn, the moment you pause on the landing on your way to bed, or when you read the last scene of a tragic story, when perhaps for no discernible reason you have an irrefutable intimation of your own nothingness. Such intimations come to us unexpectedly and inexplicably.

Nothingness, it seems, does not need a crisis to make itself felt. It takes advantage of the smallest, least noticed openings in our everyday lives. What could be more innocuous, more serenely refreshing, than a brief walk down one's own tree-lined street in the evening twilight? And then, as if from nowhere, one feels a speechless dread rubbing itself against one's heart—and it seems then that it somehow comes *from* the heart, like the deeply buried secret that is at the root of everything. For a moment one knows that one's whole life is not what it seems and that underneath it all is a deeper truth too devastating to know. And so we come home sooner than we intended from our evening walks and resume our domestic routines without even realizing we have had a disquieting inkling of our own deaths.

The desire to recoil from proximity to death and to resume our ordinary habits becomes, of course, much more compelling when one has undergone the kind of radical disruption that causes the end of one's world. We know how eager friends are in such situations to relieve the terrible sense of being bereft, of being left with nothing, which must follow upon the loss of what one had loved more than everything. Friends fear most the dangers of a long, despairing





*Too Late.* Oil on canvas by Charles Arthur Fries, 1896.

Collection of the Corcoran Gallery of Art, Washington, D.C. Gift of Mrs. Alice Fries King in memory of her father.

withdrawal from the ordinary routines that up to now gave order and purpose to the bereft person's everyday life. Their solicitude is understandable. By virtue of their own intimations of it, they have an inkling of how harrowing an ordeal it would be to be utterly alone with one's own nothingness. And who could be more horrified than the bereft person himself who knows, as his friends do not, that the experience of nothingness comes not from the outside like a trespassing stranger but from the fissure in his own heart?

It is possible to seal that fissure and consider it healed. One can resume ordinary life even after the

terrible loss of what had up to then been its center. Something else can take its place fairly quickly. There are, after all, other people to be in love with, other children one can bear and nurture to fill the gap left by one who is lost. But must we not admit that this way of healing the heart is also a betrayal of it? For what does it mean to make something the radiating center of one's life if it does not mean experiencing the unrelieved darkness caused by the loss of it? The only way to avoid that darkness is to suppress the anguish that is finally inseparable from love (see Lewis 1960:167–70). Love always asks in the end that you be willing to let it turn to sorrow



and that you let that sorrow bear you all the way down to the very bottom of its poverty. To lose what meant more than everything, to allow that loss to devastate you in the very center of your being, is to become destitute. To have nothing. To have nothingness itself as the sole companion of your solitude.

Because it removes one from the distractions and diversions of everydayness, some degree of physical solitude constitutes a precondition for this companionship with nothingness. But a more essential condition is the willingness to be devastated, to let the mortal wounds penetrate one's heart so deeply that it is broken completely open. The deepest lessons the heart has to deliver to us become accessible only when it is ruptured. These are terrible lessons, the kind that fill one with nausea. We like to think our lives would be happier if we could find a way to avoid learning them; but the only way to do that is to close one's heart and keep it closed, so that nothing gets in or out of it. It is terrible to put into words the one real alternative to this avoidance. But I see no way to get around what seems to be the harshest, most merciless truth about the human heart—the fact that, to keep it open, once it has been pierced, one must allow it to remain an open wound.

## II

*DEPRESSION* IS THE WORD WE HAVE COME TO USE for the kind of withdrawal into oneself that grief can cause. It is symptomatic of our culture's attitude toward suffering in general that it tends to view this deepest, most intimate suffering as a psychological disorder. From a therapeutic point of view, at least as it is popularly conceived,<sup>4</sup> no reaction in the face of crisis is more harmful than an introspective self-

absorption that detaches one further and further from the routines that the crisis interrupted. On this account, the longer one sits brooding about one's loss, the more paralyzed one becomes. The alternative is to get on with one's life.

But what does real living consist of? Evidently, to really live, one must learn to treat the most radical

rupture of one's life as no more than an interruption. Our therapeutic culture has taught us the ideal response to even the most intimately personal crisis: one must be strong enough to "handle" it, to "manage" it, to "come to grips" with it, to "deal" with it. Being able to "deal with death," for instance, is now supposed to be part of our repertoire of techniques for "coping" with life.<sup>5</sup> And

to cope with death—someone else's or even my own—means precisely not to be devastated by it.

The underlying motive for therapy as so conceived is to seal the fissure in the heart so that it can return to normal life intact. And this means that, though it tries its best to unravel the knots that paralyze the heart, it does so to prevent the unraveling of normal life itself. Such recoveries can be achieved, of course—but only by again closing up the heart that, in the time of crisis, lies open to its deepest truths. If we are hopeful of such recoveries, and drawn to those who promise them, it is because we want, more than anything else, to be in control of our lives, and never more urgently than when the very center that makes them whole is lost.

The anguish lies within, not without. It wells up in us without words, without hope of solace or remedy, without being able to give us any clear reasons or explanations for itself, as if it were the terrible cry of nothingness itself. We have seen it reflected perhaps once or twice in each other's eyes. It is the most terrible thing in human life to look at because we know in our heart of hearts it is the echo

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of what we have heard in ourselves. As long as that cry lasts and our ears are open to it, we know we have broken through the artifices and pretensions of our even-keeled lives to something that is not of this world and has to do with our own deaths. These are the most real moments of our lives.

To remain real, the full length and breadth and depth of anguish they reveal has to be suffered. And suffering is the exact opposite of being in control. It means opening oneself to what is horrifying, instead of recoiling from it. In trying to manage grief, or suffering in general, one is trying to get rid of the very thing that makes grief grievous—its capacity to upset one in the core of one's being. To be stricken by grief means precisely to have one's managerial control over one's life incapacitated by it. The therapeutic effort to bring grief into the open, to talk about death without our old hesitations and reluctances, is often motivated by a desire so to transform the experience of death that we can undergo it without being ultimately upset by it. But the sufferer may be close to discovering a truth that the therapeutic way of thinking never leads us to suspect—that our whole ordinary way of life, with all its evasions and avoidances, is in some profound sense unreal. Suffering has a way of turning everything upside down. And from that overturned perspective, it makes no sense to resume one's ordinary life—because one knows now the truths it was designed to keep hidden. In that sense, someone who truly encounters death can never recover, for she cannot resume the way of life that sheltered her from every intimation of it.

If my criticism of the therapeutic attitude toward the experience of death seems harsh, I would mitigate it by emphasizing its terrible irony. This attitude wishes, more almost than anything else, to take the reasons of the heart seriously and to mend its deepest wounds. But more than anything else, it wishes there were no wounds. And so it fails to uncover the truth we now suspect—that our deepest wounds are not the problem but the answer, that they can teach us things not to be learned through any easier pedagogy, and that the key to wisdom is

not at all to recover from them but to let them speak even if at first they do so in the inarticulate tongue of anguish.

### III

IT IS IN ANGUISH THAT THE WORD *GOD* CEASES TO be an abstraction. Few if any of us come to God completely firsthand, through the untutored promptings of the heart or the unaided exercise of the mind. From sermons half-heard, from clichés repeated too often, from Christmas melodies and good-night prayers, from radio preachers passed by while we search for a music station, but most of all from the brief words we hear even as children over the bodies of the dead, we glean a picture of this provident Father figure who will not fail us because he protects every falling sparrow. He will be there, we are told, in the center of whatever crisis the future holds in store, to prevent it from devastating us.

The promise of that presence is the promise that our world will never be broken, that the garden of our innocence will be guarded and tended even in the worst of weathers. For some this is the deepest, most cherished of all beliefs. For many of us, it is something we believe halfheartedly, absorb almost unconsciously; we give it, as we get older, hardly a second thought. It does not become real to us until something happens that renders us as helpless, as incompetent as children.

It is then, I think, that the child in us begins to realize for the first time that this God of our childhood does not exist, though we clutch desperately to any uplifting hope or saving belief. As Freud (1961:15–24) has pointed out, the belief in a paternal God who will protect us from upsetting events seems to have been especially designed for healing the deepest hemorrhages in our lives. We reach for God when we know all our own therapies are of no avail. Although this is no argument against God's existence, it does unravel the logic in our hearts that gives rise to a therapeutic belief in him.



God is the last thing we can grasp to shield us from an experience of nothingness.

Those who have suffered a mortal loss, those who have allowed it to shatter them, know that God does not prevent it from happening. Our lives do not turn out as we hope and expect them to, in our innocence. Our deepest loves are shattered; the things we love most of all are taken away from us. And the deeper our belief in God before this happens, the more shattered that belief is afterward. The God we would like to have, the God who would prevent our undergoing the deepest anguishes, does not exist.

One who has suffered such anguish may still believe in the God of her childhood who was expected to protect her from being devastated. But she believes in him bitterly, as the God who failed. And what smolders in most of us, to the degree that we are no longer children and yet believe in our childhood God, is an unspoken accusation of this God who has allowed us to be mortally wounded by allowing our world, in one way or another, to be shattered. Every once in a while, when our tenderest spot is rubbed the wrong way, this resentment surfaces in a brief, unguarded outburst. One feels guilty for allowing it to escape; one knows one ought not feel contempt for God. In this secret resentment, however, we take the God of our childhood seriously for the last time.

But deeper than any belief in that God, deeper than the bitter resentment such belief turns into, is the shivering horror of nothingness itself which undermines our whole world, God and all. Underneath our therapeutic beliefs, however fondly we hold onto them, lies concealed the dreadful intimation that nothingness really is the final word and all else just an avoidance of it. It is despair that has the deepest ring of truth. Ordinarily we allow ourselves to hear only its faintest echoes. But it waits there inside us like an unanswerable retort, like a feeling of nausea we keep down. The God we would like to believe in does not make it go away. The protecting promises God is said to have made have turned, each one of them, into a betrayal. The very void he was supposed to fill swallows him up.

When God is taken away, one has nothing left. One assumed one's life made sense, that it held together as an intelligible whole, like a garden watched over by a reliable overseer. Now one knows it is not like that at all. For at the bottom of it all is my nothingness, my terminal incompetence, my humiliating inability, on my deathbed, to control even my own bowels. We who ought to be superior to nothingness are never more than sufferers of it.

I do not think such despair is something we should be ashamed of. Perhaps what we should be ashamed of is our attempts to deny its presence in us, in that silence that we use our radios, our Walkmen, our televisions, but most of all our own chatter, to block out. We do not know, until such silence falls, how much we have lied to ourselves. How can we spend our lives avoiding nothingness unless we secretly know it is there, silent, unanswerable, impossible to expunge, like an inoperable tumor in the heart of being itself? We try our best to pretend, when it catches us unaware, that we do not recognize it. But during the long, long silence of our dying, nothingness will perhaps wring from us the horrifying admission that it has been our intimate all along. And then the humiliating emptiness of our ordinary world will finally be too obvious to deny and too upsetting to ignore. That, and not our literal death, is what we live in horror of.

To give up in despair all one's attempts to avoid nothingness is not, as we ordinarily suppose, a cowardly surrender. It is rather the courageous act that facing our nothingness requires of us. Does this mean despair is the deepest human experience? Is there nothing beyond it—or is there, perhaps, a deeper experience of nothingness which despair itself does not enable us to reach?

## IV

DESPAIR IS NECESSARY, I HAVE ARGUED, IF WE ARE not to backtrack from the void in ourselves. But even though it makes one give up all hope in the ordinary world, despair still remains bound in a paradoxical



way to that world and wedded to its presuppositions. It brings one to the edge of a final precipice, but it does not allow one to fall over.

It is true that, in despairing, I give up all the sustaining hopes and uplifting beliefs that up to now have given me control of my life. But despair also counsels that without these hopes and beliefs, life must be absurd. It brings me to the edge of an abyss and makes me look straight down at my own nothingness. But if I despair because of this nothingness, it is because I am still viewing it from the vantage point of my ordinary life which is shattered by it. And this means that I have still not opened myself fully to it, or to the possibility that a real acceptance of it might alter my whole understanding of my life. In despairing because my ordinary world has been irreparably shattered, I am still paradoxically holding onto this world—and avoiding nothingness. My moments of despair teach me that my life, as I have conceived it, is absurd. But what is beyond despair's ken is the possibility that it is not life itself but my whole ordinary way of living it that is absurd.

What if the answers to our deepest questions, the mysteries at the bottom of all our most heartfelt intimations, are to be found only *down there*, where we have never thought to look for them, *down there*, in the very nothingness from which even despair pulls back in horror? Haven't we known all along that this ordinary world of ours, with its loves and anxieties, its amusements and worries, however whole it ever was, was never all there is? And the things we loved most deeply, the loss of which has brought us to this precipice of despair, did we not love them precisely because they gave us such infinitely precious intimations of something we could

not see or name and yet were beckoned by?

Where else do we have to look, now that we have lost those intimations, in all their preciousness, except as deeply as we can into our very loss of them? We loved them so because we felt, when we were in the presence of the child who is now gone from us, the beloved who is now numbered among the dead, that we were as close as we could ever come in this

life to what is truly, fully, unmistakably *real*. We felt, when in their presence, that nothing else mattered except their reality. How can we now get closer to what is ultimately and finally real except by opening ourselves as deeply as we can to whatever truth is hidden in their loss? If nothingness is the final reality, this is the time to find it out and to be faithful in that way to what we have loved, if that is the only fidelity left us. Our hearts have never truly belonged to the world we

ordinarily live in. They belong to another universe, which becomes real in our ultimate moments.

So the question must be broached—what does one realize when one removes even the final guardrail, the barrier of despair, that protects one from fully experiencing one's own nothingness? Simply that this nothingness which has haunted me at the most unexpected moments, and broken through to me in moments of crisis, this nothingness which I have done my best to keep hidden and separate from me—this nothingness is I myself.<sup>6</sup> I have always wanted to treat nothingness as a trespasser sneaking up on me unfairly or to look down on it from a position superior to it. I have never wanted to see in it the mirror image of my own poverty and destitution. But, in and of myself, I have never been anything but this simple nothingness lacking all worth and importance. And into this

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wrests from the deepest part  
of the self a confession of our  
poverty, our utter  
unworthiness to be at all, our  
nothingness, in and of  
ourselves, before God  
created us.**





*Before the Black Sun of Melancholy.* Lithograph by Odilon Redon (French, 1840–1916), 1882.

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nothingness that I have always been and am now and will always be, into this abyss that is my original and permanent condition, has been poured the gift of existing which I did nothing to earn or deserve. What can this mean, then, but that this nothingness which I have spent my life avoiding is the most priceless of gems because, when I finally accept my identity with it, it enables me to experience existence itself as an unspeakable grace.

I hope the metaphysical language in which I have cast this realization does not obscure the profound simplicity of its import: it is the realization that God creates us and that this is the most unimaginable act of generosity because it is directed toward us in our nothingness. In traditional philosophical descriptions of the creative act it is explained that God creates from *nothing*. But only in a personal realization of the kind I have tried to describe does that philosophical abstraction acquire its mortal and mortifying impact. It is not that we find God and then realize that God created us from nothing. Rather, it is only in finding our own nothingness and embracing it that we realize God exists. For only an encounter with nothingness takes us far enough outside our world for us to realize that there is a giver of being who does not belong to it.

One finds God by dying. And what dies last and most reluctantly is our longing to be important, to be *beings in our own right*, our not wanting to have the mortally embarrassing realization that we are nothing and have done nothing to be worthy of existence (see Burke 1969:68). But only someone suffering that sense of unworthiness, of not deserving to exist, is in a position to know what it means to be loved into being by God. For it is precisely in our nothingness, and nowhere else, that God loves us. To be loved, we said, is to be wounded, and no love hurts more, pierces more deeply, than the kind we are completely undeserving to receive.

Understood in this light, the avoidances of our ordinary lives take on what I think is their true meaning. What we cannot bear, what we want most to undo, if only we could, is the fact that God created us from nothing—because that makes us, however

great the radiance he gives us, nothing more, in and of ourselves, than the undeserving recipients of divine generosity. We would like to be in a position to *look down* at nothingness as if we were superior to it; but, in fact, we have to *look up* from nothingness to the God who embarrasses us because he sees us naked in all our poverty. It is our nakedness we try to cover up. Everything in our ordinary life makes us want to avoid the embarrassment of it—and yet is there not something deeper in us that longs to confess it? Every once in a while, in our most intimate talks with each other, we come close to the most embarrassing revelation—and then pull back from it in terror. It is our deepest weaknesses we don't want known, and the deepest of all our weaknesses is our poverty before God, our having to be nothing, our having to be nothingness itself in God's presence. But this nothingness we have so dreaded to face or have seen is our only self. Because of our avoiding it, we have never been at home, have never known, even with all our comforts, the kind of serenity that comes only by being completely at peace with oneself.

It is, I think, God's love we have dreaded to find because it wrests from the deepest part of the self a confession of our poverty, our utter unworthiness to be at all, our nothingness, in and of ourselves, before God created us. The God who was supposed to save us from having to acknowledge our nothingness does not exist because the real God is found only by experiencing it. It is the very grievousness of our griefs that brings us to God, not because God relieves us of them but because, if we allow them to, they can teach us that our whole world is not as truly, fully, unmistakably real as our own nothingness, nor as real as the God who, knowing us in our nothingness, loves us into being. The real God, the God who evokes such extravagant gestures of worship from the martyrs and mystics, is not to be found in any way except through suffering. For worship, whatever its outward form, always requires one to say, in one's heart of hearts, "Thou art all, I am nothing."

From this perspective, which suffering makes possible, one realizes the truth of what the argu-



ments for God can only abstractly affirm—that the universe as a whole, and everything in it, is capable of not existing, that the possibility of not existing lies concealed, like an unnameable dread, at the heart of its being. As long as we resent the fact or find it nauseating, we stop one step short of being fully devastated by it. One's heart is only fully broken open when one realizes that this vulnerability in the heart of the universe testifies to its utter poverty, its utter dependence on a being who so loves the universe in its nothingness that he beckons it into existence.

And this brings us, I think, to the final twist in the bend of our reflections. The experience of nothingness is, as we have seen, an excruciating ordeal which we ordinarily spend our lives avoiding. But for someone who undergoes it, a miracle does happen, although it is not at all the miracle we have wanted and hoped for. The moment in which a human being accepts fully and without evasion the dreadful poverty of his own nothingness, and, with it, the horrifying poverty of everything that exists, that very moment is like the birth of a new universe. It is something like being present at creation. It is hard for us who live most of our lives on this side of suffering to have any more than an inkling of how it could possibly turn not just into joy but into ecstasy. But we love the things we love most deeply because they give us an intimation of something absolutely radiant, something infinitely lovable, infinitely precious, infinitely beyond our poetry to praise, something that we sense could satisfy that deep unnameable longing that even the most lovable things in the universe ignite but do not satisfy. When we lose the thing that gives us so clear, so perfect an intimation of something infinitely precious, the loss seems the most deadly of wounds, dashing everything we have longed for. But what we

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never suspect, what we never in a million years would have thought to anticipate, is the simple truth that the only way we can ever find that infinitely lovable reality we have always looked for is by losing the very thing that has given us the most perfect intimation of it. It is *in* the very loss of one's child, in the very death of one's beloved, that one finds the God they were a reflection of. For only in suffering fully its loss do I let go of the intimation

and so allow it to reveal for the first time the God of whom it was an intimation.

We may want here an image of someone who does not just have an inkling of this God but lives every day in that upended universe, so different from our own, where nothingness is more real than the things we use to avoid it, and God more real than our intimations of God. It is the saints we understand least of all. We

think, from our perspective, only of how close they are to God. But what makes them different from us is how close they are to their own nothingness. That is why in most stories, in most religious traditions, the saints are drawn to beggars, to homeless derelicts, to lepers, to AIDS victims, to the dying who are too incompetent to control their own bowels. The leper, like the AIDS victim, suffers from a highly communicable and mortal disease. If the saint dares to come close to him, dares to embrace him, it is because she is not afraid of catching nothingness. It is already her own. We should not imagine kissing the AIDS victim as a sign of her willingness to risk her own life. It is, from her perspective, more like participating in the only life that really matters.

By reflecting on that image one can begin to appreciate what T. S. Eliot means in *The Four Quartets* when he says "humility is endless" (1952). It runs infinitely deeper, and so requires infinitely more



courage, than the most unflinching despair. Despair goes far beyond the kind of therapeutic belief that uses God as a shield against the experience of nothingness. Such despair brings one to the edge of an abyss. It takes only one short step to fall from that position into the abyss itself, but taking it costs not less than everything (Eliot 1952:145). We cannot get to the bottom of our nothingness. But one can become intimate enough with it to recognize it as one's self and so look up from its bottomless depths to recognize the radiance of one who does not belong to our universe but is the Creator of it. From that recognition issues an inarticulate cry of praise that to our unaccustomed ears might sound indistinguishable from the cry of anguish. What we do not realize is that a mortal wound can become an endless fountain.

However well we hide it from ourselves, I think we all have in our heart of hearts an inkling of this humility, an intimation of this cry of anguish and praise. It is the part of us that is capable of embracing lepers. I have suggested that such humility is the deepest part of ourselves, the part that harbors the deepest truths. But it is only our griefs, our wounds, that can bring us to listen to them. A saying attributed to the poet Claudel captures this paradox: God writes straight with crooked lines. The most crooked path conceivable is the one that leads us up to God by inviting us to follow the intimations that lead us straight down into our own nothingness. That is the last place we would have ever thought to look for God. But it is there, and nowhere in our ordinary world, that we will know we have found our way home. ☸

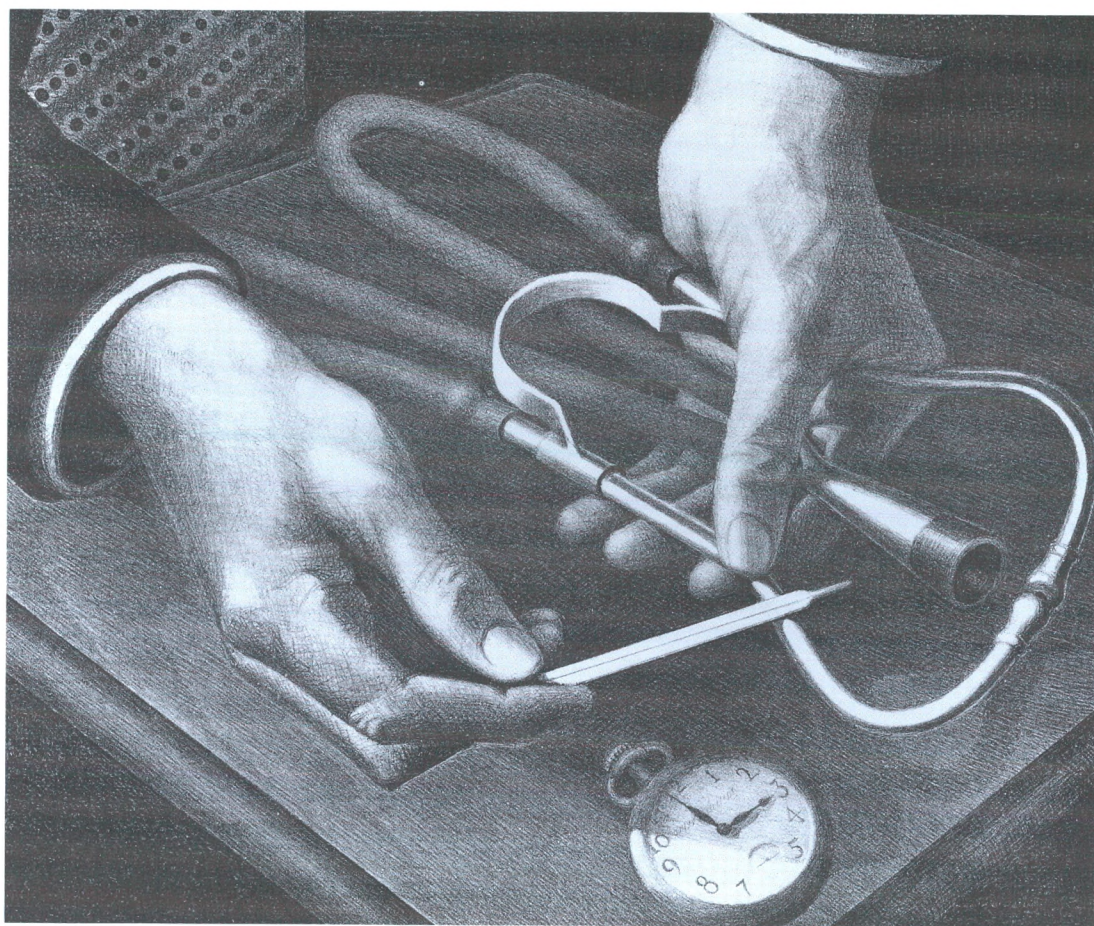
## NOTES

1. See *The Jewish Encyclopedia*, s.v. "heart." I am grateful to Stephanie Fridle for this reference.
2. I am thinking, of course, of the *Symposium* and the *Phaedrus*.
3. Here and throughout, I am influenced by Martin Heidegger's discussion of the encounter with death in *Being and Time* (1962).
4. There is, of course, a kind of therapy which *helps* one address one's most upsetting experiences and questions, instead of avoiding them. Therapy in *this* sense moves in the opposite direction from the kind I am describing here.
5. I am thinking here of the vast new literature on death for which Elisabeth Kübler-Ross's *On Death and Dying* (1969) served as the catalyst.
6. See the fourteenth-century mystical treatise *The Cloud of Unknowing* (Johnstone 1973) and also Maritain 1954:18–20.

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*Family Doctor.* Lithograph by Grant Wood, 1941.

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*Sixth in a series edited by Steven H. Miles  
and Kathryn Montgomery Hunter*

## *The Case* House Calls to Cardinal Jackson

David Schiedermayer

HOUSE CALLS ARE EASILY SCHEDULED. You look on your pocket calendar for a time when you are not in meetings or in clinic. Over the lunch hour, maybe. Then you call the person you are going to see, tell them of your plans, and see if they agree. You don't need a secretary to make the arrangements for you. Like a visit to a friend's place, a house call is something you'd best plan yourself. And don't forget to ask for directions.

I began making house calls to Cardinal Jackson when she was 73. Now she's 79. She lives on 35th Street in the nicest part of the central city of Milwaukee. If you take 27th Street north from Wisconsin Avenue, you pass Central Hospital, now out of business. You pass the businessmen cruising for prostitutes on 29th and State. You pass the porn shops, the pawn shops, the checks-cashed shops, and you finally come to a neighborhood where a large factory provides several hundred decent jobs. Around this factory, where heavy metal parts for engines are made, small, neat green-lawned homes prove that jobs mean life and love.

Some of the homes have chain-link fences with gates in front of them. Cardinal's home has such a fence, with a little latch on the gate that you have to lift up. No drug houses on her street, but more people hanging around the corners than a suburban doc is used to, so I fumble quickly at the latch.

My '78 Dodge Colt, golden and rusted, sits by the curb; no one ever bothers to steal it or anything in it. But even if I owned a nicer car—a Toyota, say—I don't think I'd be afraid to drive it in Cardinal's neighborhood. Cardinal's daughter married a hardworking man. He can afford to live in this part of town.

His name is Joe Brown. I've only met him once, but I always feel his presence in the house. He is big, strong, and very black. When I thought during one of Cardinal's hospitalizations that she was going to die, I spoke to Joe, who ran the family meeting.

"I'm sorry, really sorry to tell you all this. But we think that Cardinal is now dying. Her temperature has been over 105 for more than a day, in spite of very strong antibiotics. We're doing all we can to keep her comfortable. She's getting Tylenol and pain medicines, and she doesn't seem to be suffering from the fever."

"Doctor, when will it be? Do you know?"

"I don't know. But she can't go on like this. The fever is too high. It takes too much out of her,

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especially at her age. And then there's the pneumonia. It's not much better, and it may be getting worse."

"Thanks for calling us all here. The whole family in town is here. We'll just wait. Does anyone have any questions?"

Of course I was wrong about Cardinal. After another day or two, she opened her eyes again. The fever resolved. She went home. Joe was puzzled by my deathbed predictions, I heard later from his wife. Cardinal had looked worse before.

I WALK UP THE STEPS—PAST NEATLY TRIMMED grass, yellow marigolds, a couple of Japanese yews—and knock on the door. It is always Cardinal's daughter who answers. Mrs. Brown was a nurse at Central Hospital when I first met her. I agreed to come see her mother at home. Six years have passed, six years of turning and wiping and washing Cardinal Jackson. Six years of house calls every month or two or three, and six or seven hospitalizations for pneumonias that didn't respond to antibiotics. Always the nurse-daughter answers the door.

"Good morning, Mrs. Brown. How are you today? How is Mrs. Jackson? I haven't talked to you since our phone conversation a while back."

"Good morning, doctor. How are you?"

"OK, really OK. What a hot summer, eh? I think maybe I'm not dressed for it, and I don't have air conditioning in my car."

"Oh yes, it's hot. And mother feels it. Her skin always seems to stay so cool, but during the summer she heats up to about right."

"Is she still having a fever?"

"Well, only about 101 axillary." [They measure her temperature in her armpit because Cardinal won't hold a thermometer in her mouth.]

I go to the bedside, pulling out my stethoscope. "Let's listen. Hello, Mrs. Jackson. Dr. Schiedermayer. I'm just going to listen to your lungs. Look at those braids! Who did those?"

"The kids do that, or sometimes I do," Mrs. Brown answers. "Does she sound OK?"

"She sounds all right. But she does have the gurgles."

"Same?"

"Same, yeah. But her skin looks good. Let's look at the urine in the catheter. It's pretty clear, don't you think?"

Always, when I see Cardinal Jackson, I am obsessed with her eyes. They are green as a Georgia hill, humid, warm and smoky. Her freckles, her tiny gray braids, her smooth skin. She doesn't look a day over 60. She has been mindless, lights-are-on-but-nobody's-home, for over 10 years, but her eyes are as wild as a girl's. They cannot say all they have seen, but that is the wonder and the mystery of Cardinal Jackson's eyes.

When she was born they named girls after birds and boys after old men. She grew up down South, knew her portion of hell well enough. That is why her eyes surprise even more. You would think they would be small and cold and stony from all they had seen. But they are full as the moon, luminous and sweet.

Cardinal Jackson is always in the end of the living room. The room is set up especially for her. Her bed and medical supplies have been right where they are now for nearly a decade. Occasionally the TV and sofa are moved, but the bed remains fixed. I suppose there's no other way to turn it, and if it was in the other part of the room there wouldn't be room for the sofa and the TV. I turn and speak again to Mrs. Jackson's daughter.

"The urine looks as if it is flowing all right. I don't think the fever is from a urine infection, but if we need to use antibiotics we should probably use strong ones to cover urine germs also. Do you have enough potassium?"

"Yes, I think so, but I'm going to need more Tylenol. Will you send the copy of the order to the home health care office?"

"Sure. I'll check. Now, what's happening with her skin here?"

"A little breakdown on mother's heel. I have an op-site [bandage] on it and we are using the heel protector pad."



"Good, it looks like it's healing. Let me know if it opens up. Is she having good bowel movements?"

"Oh, yes. This new tube feeding is good for that. Real good."

"Good. Cardinal. Cardinal! I'm going to look at your hands."

"She holds them so tight. We've got that new pad in there. If we don't use it sometimes she'll scratch herself bad right on the inside of the hand there."

"It works. This kind of protector works."

"Yeah. I keep her nails short, too, so she won't dig them in so much like before."

"Good. I'm sorry I can't remember—have we given her a flu shot every year? This year?"

"Yes, the nurse came last fall."

"OK, we'll do it again in about two months. October. Remind me. I'll try to write it down, too. Anything else?"

"Doctor, look at this. What is it?"

"Hmmm. Well, I think just a skin growth. A skin growth, but not cancer. It comes on with aging. Has it always been that big?"

"Yes, lately."

"We'll keep an eye on it. She looks good. You have been doing a good job with her. Goodbye, Cardinal! Goodbye, Mrs. Brown."

"Goodbye, Dr. S. I'll let you out. Thank you so much for coming."

"Sure. Thank you. Call me if the fever comes back. Bye!"

The door is doubly unlocked and then doubly locked again after I leave. It's hot and miserably humid outside. A central air conditioner is humming at the side of the house. I'm glad they have air conditioning for Cardinal's sake.

I turn on the radio as I'm driving back to the hospital. I like Wisconsin Public Radio, but today they're talking about all the drive-by shootings in the inner city. The Dodge feels a bit less invincible. So I just switch over to country music. The song is about somebody's grandmother's eyes.

I drive by the factory. It's the change of shift. They still wear those blue-gray working shirts that

my grandpa wore when he worked as a foreman in the paper mill. They still carry lunches in steel buckets, probably with a small thermos tucked in the upper cover. Saves the price of a cup of coffee. I drive by the girls, the porn, the booze. I think of Cardinal's green eyes.

WHEN YOU MAKE HOUSE CALLS, an old Wisconsin doc once told me, you should somehow find your way back to the kitchen. The kitchen is where you learn about a patient's personality and interests and religion. Kitchens are much better than most rooms, especially for learning about religion. (I've had coffee in Cardinal Jackson's kitchen; it is small but clean.)

One long glance in the fridge can be worth more than months of futile questioning about dietary compliance in the clinic. If a diabetic has high blood sugars, look at what they eat.

Dress modestly. Carry a black bag if you have one, a stethoscope if you don't. When you examine the patient, if dignity permits, have a family member present. Always look at the patient's hands and ask about their bowels. Talk to both the patient and the family members.

Keep your eyes open, but don't snoop. Don't open any drawers, but check for pets and insects and look at the art. Remember the smell of a patient's house; let it register deep in your brain, and you may be able to recall it when you talk to the patient on the phone or see the patient in the office.

Maybe keep some notes. Linger just a little longer than you really have to. People can tell.

After making house calls to a patient, you naturally want to go to the funeral if he or she dies. In fact, when you make house calls you are kind of expected at the funeral. Don't miss a one, especially in churches where the people are so used to singing that they don't use hymns.

The old doc told me that the way things are going in medicine, doctors should make house calls whenever they can find an excuse. I have found at least three or four.



ONCE YOU HAVE DEMENTIA OR SOME OTHER serious mind-destroying illness, your family usually doesn't take any more pictures of you. Even though Cardinal is beloved, this is true for her. Her last picture was taken when she was 55, maybe 60. Her smile is dignified. She is erect. She looks right at you. Her hair is a bit less gray, her eyes look the same as always, but the smile says she sees the camera and knows the photographer. She doesn't know the photographer anymore. No use taking pictures. The lights, oh the green lights are on, but nobody's home, nobody's home.

When I get back to the medical school I go to my office, which is near the anatomy lab. Sometimes I go over and sign out the large bucket with the preserved brains in it. I give talks at my children's school about the brain. The most striking thing about the preserved brain is the heaviness. It is all dead weight, more like an amputated limb than a brain. Lifting it is like picking up an unexpectedly heavy stone.

The children sit enthralled at the sight and the smell of the brain. They want me to put the brain back in the skull I bring, but I explain that the brain is not the skull's own brain. I see them struggle with the concept of human dissection and disembodiment. I am sympathetic; I struggle, too. What kind of person was that skull, they ask. Was it a boy or a girl?

I can only tell them that it is good for them to take both their brains and skulls to school. Learn while you can, I tell them. Soon enough, the brain turns to mush. And I think of Cardinal Jackson.

Cardinal was the old Southern kind of nonsense, have-fun, sing-like-an-angel Christian. Her family has been objectively blessed because of that, but now Cardinal is blessed. She is rocked like a baby by her daughter as if that was the normal thing to do. She is cradled, blissfully ignorant, through her slow dying and all of her leakiness. Sing it for me, the blind preacher says, when the soloist finishes the song. Sing the old song about the amazing grace of God. Please sing.

ON THE PHONE WITH MRS. BROWN. "Does Cardinal still have the fever?"

"Yes, it's up to around 103, 104. The only time it goes down is right after the Tylenol."

"Well, I guess we'll have to go with antibiotics again. Did she have diarrhea with the Keflex last time?"

"Yes, quite a bit."

"Well, let's try Cipro. Didn't that work before?"

"Yes, it knocked the fever out in two or three days. And you know, doctor, the fever didn't come back after that one for quite a while."

"Let's try it. I'll call it in to the pharmacy. Is she breathing pretty fast with the fever?"

"Yes, pretty fast, and even grunting a little bit. But thanks for calling me back. Can you plan a visit a bit sooner than usual?"

"Sure. I'll be there tomorrow over the noon hour. Or let's make it in the morning, around 11:00."

"OK. And can you call in some more potassium and Tylenol, too?"

"Sure I can. I don't like the rapid breathing. Keep in touch. Bye."

"Goodbye."

WHEN I LECTURE IN THE ETHICS CLASS, the medical students ask me why I keep treating her. Why not just stop treating, they ask.

Why not? Six years of knowing her. A dozen life-threatening infections. Already a no-code, already no-ICU. That's why not. I asked the daughter five times to stop tube feeding, shocked her each time, and she said definitely no each time. That's why not.

A socioeconomic history of discrimination and mistreatment. A tradition of poor health care and nontreatment. The need to show her somehow we're not abandoning her. That's why not. Because her daughter's a nurse, because her daughter loves her and thinks it's best to keep doing things just as we are. That's why not. And because I can't stand to think of the fire dying in those green eyes.

But why not just let her die, they ask.



I try, but I really can't explain. It just doesn't make sense to them. Their parents probably have living wills. They just don't understand yet, but they will understand when they have a Cardinal of their own.

Dying, you want dying, I guess I should say to them. I know how to stop treatment and let dying happen. I have stood by the bedsides of plenty of patients. I have seen long, slow dying. I have witnessed the leaving, the parting, the closing.

For example, one patient has cancer of the lung but is dying of the union of the tumor's appetite with his fatigue and pain and depression. I have given him pain medication and done what I could, but he has been going downhill for the last several days, blood pressure drifting lower, pulse thready, breathing irregular. Now as I stand in his room I think that death has moved in before me, slipping in the door ahead of me. The man's eyes are already distant. The room is cold and humming. Death has been a whispering wind in his sleep, sweeping away.

So then, I should ask the students, so then are we children of the sun or of the earth? If the students will answer this question, then I will tell them why I don't just let Cardinal Jackson die.

What is it that gives a person dignity? What is that inner grace that projects out toward the doctor, so that he, despite his intellect and education and training and skills, is taken aback? Whatever it is, Cardinal has it. And she has passed it on to her daughter. It manifests itself as inner ability, as a palpable sense of self. The dignified are above reproach. You can't take dignity away from the dignified. They wear it lightly.

Once, Cardinal became critically ill in the middle of the night, and the paramedics took her to the

nearest hospital, not mine. Another physician took care of her, and when he called to tell me of his treatment plans, I realized that Cardinal's disease was ordinary. To him, she looked like an old demented patient with recurrent pneumonias. He just hadn't ever seen her picture. He hadn't seen her eyes.

They always close when she gets very sick. It wasn't his fault, but he took care of her like she was a vegetable. And her family knew it. After she was discharged from the hospital, her daughter called me.

"Doctor?"

"Yes, Mrs. Brown. I heard she was in the hospital. How is she doing now? How is her breathing now?"

"She's got a bit of diarrhea from what's left of the antibiotic from the hospital. But her breathing is a lot better."

"Good. But let's try stopping the antibiotic and backing down on her tube feeding a bit. Is she still at a total of five cans a day?"

"Yes. But I've been giving her a lot of water too, because I was worried about the diarrhea."

"Well, let's back down to two cans a day, just for a day or two. But keep going with the water."

"All right."

"Is it real loose?"

"Yes, pretty much. But it's brown, and I don't see any blood."

"Good. Good. Any bedsores on her rear?"

"No, we keep her pretty well turned."

ONE TIME, WHEN I MADE A HOUSE CALL, Cardinal was so sick we had to hospitalize her immediately. I drove her daughter to the hospital. I asked her whether she ever thought about Cardinal's dying.

"Oh, yes, I think about it sometimes."

"This may be the time. She's breathing 50 times



a minute, and I know you don't want the respirator."

"No, no respirator. Still, God will take her when He's good and ready."

"You think soon?" I asked. "You mean, you think He's not going to take her this time . . ."

"Well, not yet. I think she'll go more quietly, at home some night."

"Hmmm. Yes."

Even though now I make mostly house calls to see Cardinal, I keep some notes on her chart in my office. Her problems are noted as follows: Dementia, Alzheimer's, negative reversible causes. History of colon cancer, treated by surgery, 1963. Multiple infections, pneumonias, urinary tract infections.

A few other items cover her feeding, medications, and allergies, and it's also noted that she's cared for at home by her daughter, with a Visiting Nurses aide coming three times a week. The ethics orders read: "Do-Not-Resuscitate, no ICU treatment, consult with family."

Cardinal does not survive because of my care. She is alive because her daughter is a nurse. You can't buy hired love like hers. Cardinal would have been slain by a bed sore years ago if she lived in most nursing homes. I don't know the exact cost of her care, but it's probably a lot and would be a lot more if her daughter weren't her main nurse.

THE WEATHER WAS TURNING COLDER. To be more specific, 12 inches of snow had fallen, and a cold sun was shining. The temperature was way below zero. I slipped through the chain-link fence and rang the doorbell.

"Hello, Mrs. Brown. What a cold day!"

"Hello, Dr. S. How are you?"

"OK, how are you? How's Cardinal? Looks like she's resting well. And look at her hair this time!"

"Oh, she's doing pretty well, doctor. She's had a temperature of about 101, but her cough is pretty clear."

"Good. Let's see how she's doing. Her lungs sound about the same. Do you need more Tylenol?"

"Yes, I think it would be good to have some more."

"Good. Hi, Cardinal. She's really awake today. Look at these beads! How do you do this?"

"Oh yes, my daughter did her hair."

"She looks like a little girl today."

"Yes, she does." Turning to a young woman who comes through the kitchen door, she says, "Doctor S., this is my daughter, Alicia."

"Hello, Alicia. I don't think I've met you before."

"I've been away in the army, and in school."

"Oh, what school? Far away?"

"The U."

"That's a good school. Good. What are you studying?"

"Biology."

"Oh yeah? I studied that once or twice myself. They can make it hard."

Mrs. Brown says proudly, "She wants to be a doctor. A pediatrician."

"Great. But it's hard. The studying is hard. They work hard. Lots of phone calls."

"I know it. But I'm doing pretty well in school."

"Well, good. I'm sure you are. Good luck. You've had plenty of practice taking care of your grandmother, here."

Both of them laugh. "Yes. We sure have. Yes."

Cardinal's eyes are on the ceiling. She doesn't see me when I say goodbye. But her daughter and granddaughter walk me toward the door. We talk some more about medical school. I smell Lubriderm cream. New rug. The television is on, a talk show. No change in the plaques or pictures on the walls. Something good is cooking in the kitchen. I remember that smell from before: greens. Mrs. Brown unlocks the door for me, and I have time to glance back toward the bed. Cardinal Jackson is breathing slowly and steadily. ☉

## NOTE

The medical story of the patient is true, but certain details have been changed to protect patient confidentiality. The family of Cardinal Jackson has read this story and given their consent for its publication.

## *Commentary*

# The Eyes Have It

Stanley Hauerwas

TRUTH LIES HIDDEN IN THE DETAILS.

That is not quite right. Truth is revealed in the details. But insofar as truth is revealed, of course, it is also hidden.

The story that Dr. Schiedermayer tells of Cardinal Jackson is familiar to those of us in medical ethics. We know how to cut through the details to get to the heart of the matter: Should people like Cardinal Jackson continue to be cared for? Such a question, we say, turns on whether she is still a “person.” Or even if she is a person, we can still ask if we must do all we can do. After all, there is a difference, we say, between putting to death and letting die.

We know how to analyze this story. We have the principles and distinctions that can make the story of Cardinal just another example. But for Dr. Schiedermayer, Cardinal’s green eyes will not let him use the abstract tools we call ethics. Thank God somehow in some way he has learned to resist the “ethics” we taught him.

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It is tempting to suggest that Schiedermayer’s story is but another reminder of the contrast between a narrative-based ethic and an ethic based on principle. Thus the suggestion is made by some that we must supplement ethical analysis based upon principles like autonomy and benevolence with narrative. But narrative as narrative will not save us from our analytic abstractions. Appeals to narrative in and of itself after all are as abstract as principles like patient autonomy.

Narrative in itself serves no purpose without the details. We need to know that Cardinal lives in Milwaukee. We need to know that her daughter is a nurse and that her son-in-law is named Joe Brown and is a very strong and very black hardworking man. We need to know that the lawn is trimmed, that yellow marigolds have been planted. We need to know that someone has taken the time to braid Cardinal’s gray hair. We need to know about her temperature and her urine. We need to know that her daughter knows how to care for the wound on her heel. We need to know that the family is from the South and is Christian. Without such details we cannot know why Dr. Schiedermayer knows he must continue to make house calls to care for Cardinal Jackson even though he believes she is “no longer home.”

For the mystery of Cardinal Jackson, the self of



Cardinal Jackson, is contained in those details. That is why her green eyes are so wild even though Schiedermayer may think “nobody’s home” behind them.

The dignity that Dr. Schiedermayer connects with Cardinal is there in the details. One need not invoke postmodern understandings of the de-centered self to appreciate the fact that Schiedermayer’s care of Cardinal is part of a network of relationships that makes Cardinal Cardinal. There are no hard lines of difference between Cardinal and her nurse-daughter and the grandchild preparing to be a doctor. There were no hard lines when Cardinal “was home,” and there are no hard lines now that she is not “at home.” Through the details Schiedermayer helps us realize that Cardinal has never been more at home than in the 10 years she has lain in that “fixed bed” where her daughter has patiently cared for her.

Schiedermayer provides us with the details, but he wisely does not try to explain them. Rather he rightly expects us to help constitute the narrative. I see him torn between the medicine he has learned from the experienced Wisconsin doctor who can teach him how to make a house call by smelling the kitchen and the medicine embodied in brains in jars and the impersonality of Cardinal’s chart. He knows that Cardinal’s brain could be exhibited before a class of children, but they could never see Cardinal.

Schiedermayer, after all, knows that Cardinal and her family’s story is inseparable from that larger narrative of being black and from the South. These hardworking people have managed a life of decency against a racist society. How hard it must have been for a young black daughter from the South to work to become a nurse. How hard it must be to carry the cost for Cardinal. How hard it all seems to be, yet no one in Schiedermayer’s story complains.

I am a white Southerner, but I know the family of Joe Brown. White Southerners and black Southerners in the North discover they are Southern. The heart of that discovery is that, unlike Yankees, we believe for good or ill we were fated to be what we are—Southerners. In like manner we assume we exist only as we are part of a family. That is why the details about Cardinal are also the details about her family.

But their being a black family is not enough to explain the care of Cardinal. The uncomplaining care the Browns provide is the common habit of people who have had to struggle against all odds to survive. Not just to survive, but to survive as a family that cares for those who have made them what

they are. The Browns do not seek to keep Cardinal alive for no reason, but neither do they seek her death for no reason. To continue hoping that Cardinal will live is as natural for them as hoping to survive as a family.

Being Southern and being black usually also means being Christian. No abstract Christianity here but rather flesh and blood that rocks to hymns and then rocks the dying. Of course, Christianity has taught us to care for the sick, but without the Cardinals and the Browns we have no idea what that means. We have no idea what that means even if we are doctors with great technical power. Without the Cardinals and the Browns we have no idea how to live or how to die, and as a result we have no idea how to care for those who in their living are dying.

If the truth is in the details, then what are those of us who supposedly do medical ethics to do? What good are principles of autonomy and benevolence, what good is our analysis of the preconditions for personhood, what good are our distinctions between letting die and putting to death if they make us overlook Cardinal’s green eyes?

**What good are principles of  
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Of course I ask such questions polemically. I confess that I did not like medical ethics of principles even before I read Schiedermayer's story. Yet the point I argue remains unimportant without the details, details like those about Cardinal Jackson.

There are good reasons that the medical ethics we generate is centered on principles like autonomy and benevolence. Medicine in our day in our kind of society is practiced by strangers for strangers. Modern bureaucratic medicine, therefore, can care only for the patient who can be "charted." For medical care must be routinized in such a way that the bureaucrat, now in the form of the physician, is at home in a way the patient is not (as moral philosopher Alasdair MacIntyre has observed).

The bureaucratic character of medical care cannot help being replicated in the formal character of our reflection about medical ethics. Yet against the

bureaucracy comes someone like Schiedermayer testifying to lives like that of Cardinal. He knows he cannot make clear what he has learned from Cardinal if he uses the terms of bureaucratic ethics. So he unashamedly confesses that he refuses to stop treating her because of the six years he has already treated her. It is *his* knowing that matters. That is why he cannot explain: "the knowing" is in the details. All he can do is call our attention to the details and hope we'll understand.

The question remains, however, how to teach a new generation what Schiedermayer has learned from Cardinal Jackson and the Browns. Clearly bureaucracy has won, and we will increasingly lose our ability to relate the details. We will all become "case studies." Our only hope is that some doctors will be taught, probably by some nurses, to appreciate the smell of greens as they cook in the kitchen. ☉



*Commentary*

# How Does Ideal Care Really Work?

Elizabeth M. Johnson

IF EVER I AM BEDRIDDEN AND DEMENTED, if ever my mother is bedridden and demented and I am the nurse-daughter responsible for her care, surely the physician I want is Cardinal Jackson's physician. Here is a caring man who sees the whole patient, not just the limb or lab tests. That first sentence—"House calls are easily scheduled"—have I ever heard it before? I am hooked immediately, knowing I will read about health care as it ought to be. And yet . . . As the story evolves, troubling issues come to the surface: issues of pragmatism; of family dynamics and resources; of race, class, and gender; of values, choices, and decision making in long-term care. These issues and how they impinge on this case are what interest me. I want to know how such ideal care can be made to work.

If we take the page at face value, "House Calls" is the doctor's story. As narrator he gives us only his thoughts and feelings, not those of the other characters. We learn that he has a special relationship to Cardinal Jackson, and we get some clues about why. From an older doctor he has absorbed the value of

house calls, has made them to "at least three or four" of his patients. Not a lot, but 300 or 400 percent more than most. He teaches ethics and insists in the face of student inexperience that determining who gets what level of care is part of the physician's work. He is hooked by Cardinal's eyes, "green as a Georgia hill, humid, warm and smoky," a description that signals an attachment greater than duty or interest. This patient has touched something in him that not all patients do, and she gets better care because of it. I wonder if there is something in Cardinal's family history that connects the doctor to his own background. Did he come from this neighborhood or one like it? Did his grandmother live in his childhood home? But then I am wandering from the page, and if I am going to do that, there are far more important questions to ask. For this is not just the doctor's story. It is the story of Cardinal Jackson and her family. About them we know very little.

What happens in the family determines what happens to the patient. We are told about Joe, the son-in-law whose presence fills the house; about the nurse-daughter who is the primary caregiver; about Alicia, Cardinal's granddaughter, who has been away in the army and at the university. We know there are children—we don't know their age or sex—who sometimes do Cardinal's hair. I assume they are the children of Mr. and Mrs. Brown. These

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are the lives most involved with and affected by Cardinal Jackson's home care. We know very little about what it is like for them to live in relationship to her in her present dependent state. As much as I am wooed by the idealism of this portrayal, I am uneasy about what it costs in human terms and who pays.

I want to know what it costs this nurse-daughter to take such beautiful care of her mother. We know that she once worked at Central Hospital, which is now closed. Does she still go to a paying job? How many hours a week? Who takes care of her mother while she is gone? Perhaps she had to give up her job in order to take care of her mother. Does she miss her co-workers, their personal and professional interactions, the variety of patients? What does she do when her mother doesn't need something? Are the children young enough that her presence at home is a blessing? How did the loss of her income affect the family? Do they eat the same, dress the children the same? Can they go to the movies? I wonder about Alicia. Why did she go into the army? Is she interested in the military or in patriotic service, or is that how she is financing her education? Did she go to Lebanon, Panama, the Persian Gulf?

These questions lead us into the realities of home care. "Cardinal does not survive because of my care," the doctor says. "She is alive because her daughter is a nurse." Very true, but even that is no guarantee. It is the practical realities of home care that make it or break it. In this case it works for the patient and, we hope, for the family, but we don't know how.

Cardinal Jackson is a completely dependent patient. Although the doctor describes her as "mindless" and says of her that "the lights are on but nobody's home," her eyes are "wild" and she requires a great deal of Tylenol. This may mean that she is responding to pain. Though she may not be able to

communicate, we are not sure that she cannot think and feel. Cardinal cannot feed, wash, dress, or turn herself. She does not control her bladder and bowels. A catheter has been in place for some time. There is no indication that she can signal the onset of a bowel movement, and we know she has had loose stools. Is there a smell? How many times per day must her pads or linen be changed? How is the soiled material disposed of? Who washes the linen? Is there a washing machine in the house? A dryer? Are they in the

basement? Does Mrs. Brown do all the laundry? Do the children help? Do the children know how to turn their grandmother, wash her back, prop her on pillows, protect the bony prominences from excessive rubbing on the sheets? Is Mrs. Brown in good health? What happens if she gets

sick? Can the children or Mr. Brown mix and give a tube feeding? Do they know about wrapping her fingers around a rolled washcloth or a pad to minimize the contractures in her hands? About propping each foot in its normal right angle to the leg to prevent the foot-drop contracture? Does anyone else bathe her? Does the catheter require irrigation? The gastrostomy tube? The success of home care depends not just on one person but on a plan that includes all the needs of all the people affected. To view this situation in its most positive light, we need to see that plan.

How do the family members act toward Cardinal? We see twice that the kids have done her hair in a way that catches the doctor's eye. I deduce from that that these children are comfortable touching her. I can imagine them involved in her care, being taught by Mrs. Brown to hold, turn, pull the sheet, tuck the pad and pillow, stir the tube feeding, drip it carefully into the tube. Where do these kids bring their friends? The television is right there; does it have to be kept at low volume? Can they play the radio? Loud? How much does Cardinal moan? Do

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their friends like to come to the Browns' house? Do they get together elsewhere instead? Do the Browns want their children to gather at home? What about Mr. and Mrs. Brown? Do they have any private time together? Can Mrs. Brown go visit a friend? These latter questions lead us into the dynamics of this particular family and how Ms. Jackson's presence alters those dynamics. I do not mean to suggest that the family is changed for the worse if the children can't play the radio in the living room. In fact, if they are involved in her care, they are having an intensely enriching human experience. You cannot put your hands on another's flesh over and over again and not make deep personal connections to her. I want to know what is happening to them.

When the doctor visits, he controls the conversation, even though the daughter knows much more about the patient and the family. "How are you?" he asks as she opens the door. "Good morning, doctor. How are you?" she defers. He then talks about the weather and himself. We never hear him go past the perfunctory greeting and ask, "Really, how *are* you?" He asks questions about facts; she answers. Fever, stools, skin, medications. In their five recorded conversations, he asks nothing about the family environment, asks "Anything else?" only once. Only once does he ask a truly open-ended question. He is driving Mrs. Brown to the hospital when he asks whether she has thought about her mother's eventual death. The patient is not there to focus on, but the road is, and he can ask this feeling-level question in the safety of the enclosed space in which they both sit facing straight ahead. Mrs. Brown gives a cautious response: "Sometimes." I think surely this time he will encourage her to open up to him. I yearn for him to say, "I wonder how that will be for you." He doesn't. He says this-could-be-it and talks about her respirations. Mrs. Brown comes

back anyway, says God will know the time and it will probably be "at home some night." (I imagine her waking up every morning wondering if her mother is alive.) I want this moment to be one in which she can articulate her fears. The doctor merely says, "Hmmm. Yes." Ideal care includes attention to social and psychological needs as well.

When a family makes a long-term care decision, some of the factors are emotional, some practical.

One of the biggest is money. Attendant on Ms. Jackson's home care are the costs of the equipment, supplies, medications, tube feedings, the Visiting Nurses Association, and the house calls, as well as the loss of Mrs. Brown's income if she had to quit her job. Because these expenses occur over time, the family may not be aware of their full impact at the time of decision making

unless the health care team presents the information. Chux pads go quickly with an incontinent patient.

Those families who decide against home care are often faced with a large up-front expense, as well as considerable monthly charges, when they admit their relative to a long-term care facility. This choice is therefore restricted to people who have that money to spend or whose relative has insurance or qualifies for Medicare or Medicaid. Other families who choose home care purchase nursing care, from round-the-clock nurses to night nurses only to nurses for one or more days a week. These, too, require significant financial resources. I wonder what part money played in the decision to keep Cardinal at home.

As I read Cardinal Jackson's story, another factor becomes acutely clear to me. From the very beginning of the story the narrator takes pains to place us in a specific socioeconomic niche. "You pass the . . . prostitutes, the porn shops, the pawn shops" on the way to "the nicest part of the central city" where, though the hospital has closed, a factory provides the

**As if it were "the normal thing to do," Cardinal Jackson is "cradled . . . through her slow dying and all of her leakiness." We believe it can be done. We need to know how.**



## CASE STORIES

jobs that “mean life and love.” Jobs mean income; income means possibilities. Cardinal’s home with its neat lawn (and marigolds) is protected by a chain-link fence. Although the “suburban doc” feels his old car is safe from theft, he is a little uneasy in the neighborhood. Yet he seems to admire the “very black” Joe Brown, the “hardworking man [who] can afford to live in this part of town.” As the story goes on, I sense the doctor’s deep respect for the family’s values and the fine care they provide, so I feel no disparaging of them on the basis of class or race, though I wish he smelled meatloaf instead of greens cooking. Yet these careful details call such attention to the fact that this is a lower-middle-class family that we must pay attention to it. The class lines are drawn between doctor and patient as clearly as if he were driving a BMW. Though he undercuts an interest in wealth and possessions, he is a doctor. This home care decision is not being made in the doctor’s family. Though his grandfather was a factory worker, he is not.

What difference does socioeconomic class make? Would the doctor take care of his mother in his home? How would he handle his job? Would he have to give it up? Or would he put her in a nursing home where she would be “slain by a bedsore”? I don’t want to consider class differences in this heartwarming story, but the author insists. I want to think that the Browns care for Cardinal because they are wonderful people with great reservoirs of human caring, and that they represent the possibilities in all of us. They accept the very tactile work of washing and soothing their mother’s slowly deteriorating body. This is what families miss who send their relatives to nursing homes. As others take over the daily care, it is the family members who literally lose touch. The author seems to be saying

not only “You can’t buy hired love like hers” but that such love is a virtue of the lower class, perhaps even their privilege, rather than their burden.

Gender issues also echo in the text. It is not unusual that the primary caregiver is a woman. It troubles me, however, that the daughter has a title, Mrs. Brown, and a function, nurse, but no name. She is the pivotal person. We do not see whether Joe participates in the care, only that he ran the family meeting, even though the person in question is not his mother. One of the last things we are told is that Alicia wants to be a doctor. Although Dr. S. does give her some encouragement, he repeatedly emphasizes how hard it is. True, but is this how he would respond to a young man? Or to his own neighbor’s daughter? Expectations of this family seem to be underscored by stereotypical attitudes of race, class, and gender.

In “House Calls” the long-term home care plan works because a professional woman makes it work. She chooses to continue the life-sustaining tube feedings and accepts the responsibility for her choice. Not everyone has the competence or the “inner grace” she has inherited from her mother, which has attracted the doctor and makes the house call like “a visit to a friend’s place.” What about difficult patients? Recalcitrant families? If they lack the dignity that reaches him “despite” his scientific education, what kind of care can they get?

No case is easy, no story simple. Gritty factors from daily life always enter in. This story pulses with unanswered questions and unspoken assumptions. As if it were “the normal thing to do,” Cardinal Jackson is “cradled . . . through her slow dying and all of her leakiness.” We believe it can be done. We need to know how. ☸



“Those of us who are trying to solve difficult health problems have really been trying to grow crops by planting seeds in the middle of concrete. Why aren’t these things taking root and becoming beautiful flowers? We need the soil to be tilled first, and I think the church can do that.”



# A Question of Survival

## *An Interview with Reed Tuckson*

*The most common causes of illness and death—heart disease and cancer, chemical dependency, HIV diseases, homicide, suicide, and accidents—all have their origin in this society, says Reed Tuckson. Discussing his earlier work as commissioner of public health in Washington, D.C., and with the March of Dimes, Tuckson decries the growing tendency to blame the poor for their plight even as the public health system is being dismantled. Observing how the disintegration of society's infrastructure has fostered hopelessness and contributed to people's choosing unhealthy life-styles, Tuckson notes that churches—as institutions that transmit values and ideals, give mutual aid, and furnish a safe meeting place—have a central role in building a healthier society.*

*In his current position as president of Charles R. Drew University of Medicine and Science in Los Angeles, Tuckson has an opportunity to help lay the foundations—in research and in education—necessary to the work of those in the front lines of health care.*

**Second Opinion:** We've heard a lot about changes in the American climate beginning in the early nineties—the age of greed is supposed to be passing and the age of volunteering dawning. Do you find that to be true?

**Tuckson:** America is a very diverse place, and some segments of America are doing just what

you've suggested. I think it's an important trend that's gathering momentum. A growing number of people *are* becoming a little more involved in issues outside themselves, like issues pertaining to childbearing and family development. That's unmistakable. Unfortunately, many, many Americans are finding it increasingly difficult to focus on family

or to devote their resources to family. Significant and probably increasing numbers of poor Americans are struggling with tremendous obstacles just trying to live their daily lives. That is also a reality.

It may be true that we have moved from being preoccupied with self and with acquiring resources for their own sake to



being a little more grounded in enduring values like respect for our relationships, respect for monogamy and honesty, respect for our children and the imperative to make the world better for our children than for ourselves, to be more concerned about their development than about our own gratification. But we are also seeing a hardness, a toughness of spirit when it comes to helping others outside our family and immediate environment. Much of the discussion about individual responsibility maintains that because people don't always act in their own best interest, they are somehow responsible for their illness and disease and perhaps not worthy of society's resources. An undercurrent of blame runs through all this.

So yes, we are seeing some people becoming more interested in family values, being more responsible about their own behavior and in particular about their relationship with those in their family network, and that is a turning away from narcissism and greed. But for a large number of Americans, it is very difficult to maintain those stable family relationships and make the best personal choices because the obstacles, the stresses they're trying to overcome in their world are so difficult. And there is often tension in public policy debates between those who are doing fairly well and are able to make wise

**"If we are going to lament the social pathology around us, those of us who have access to society's resources have some responsibility to do something about it."**



choices and those who are not doing well. The words *responsibility*, *blame*, and *guilt* surface often in those debates.

**Second Opinion:** You talk a lot about responsibility, and I'd like to follow up on that. Elsewhere you've talked about the problems of violence, drug use, the use of drugs by women during pregnancy, and you've related them to issues of personal responsibility and self-esteem. You've also talked about how a corporate raider becomes enormously wealthy although his business doesn't provide anything for the community, doesn't provide jobs, doesn't create a product. Are you saying that the charge of irresponsibility should be leveled at the corporate raider as well?

**Tuckson:** Yes. If we are going to lament the social pathology around us, those of us who have access to society's resources have some responsibility to do something about it. So yes, I think it does become a responsibility of those who, like the corporate raiders, are rewarded for their work with almost unimaginable amounts of money. This work, in many cases, is not associated with the building of a community, the building of a society; it provides no opportunity for unemployed people to find employment or for untrained people to receive training. There are two dangers in this discrepancy of opportunity. One is that as people lose jobs, the tensions and frustrations in their

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lives manifest themselves in behaviors that lead to disease and death. The other danger is that society creates a warped sense of expectations.

We glorify phenomenal economic achievement and acquisition. A poor person may think, "Let me try to approximate, with my limited resources, the experiences that I see celebrated and glorified every day." The images of fabulous, unbelievable life-styles, incredible amounts of money, and the associated rewards are not lost on people from impoverished backgrounds. So of course they approximate and try to do the same sorts of things.

It is our responsibility as a society to do everything we can to hold all individuals accountable for their actions. We ask people to meet certain standards in order to participate as members of a civilized society, and it's important for those standards to be very clearly articulated and understood. But people behave in inappropriate ways *for reasons*. When people have a difficult time meeting those standards—acting in their own best interest and in the interest of those around them, living a principled and rational life—we as a society have the responsibility at least not to make it more difficult by laying more pressure on them and then, when they can't hold up under it, blaming them, scorning them, and denying them assistance.

I'm interested in how we solve these problems, but the answers

aren't simple. They're complex and multidimensional, and they require the involvement of everyone. We must find a way to train and employ people who live in the inner city, in rural areas, on reservations. We have to encourage their belief in the concept of a future and get them involved in the process of progress. If you don't believe in the possibility of a meaningful future, you're not going to take the behavioral steps consistent with trying to achieve that future. You're going to smoke cigarettes, and you're not going to be worried about diet. If you don't believe there's anything out there for you, if you have no expectations, why act?

*Second Opinion:* You talked earlier about a toughening of the spirit in our responses and a tendency to blame.

**Tuckson:** We see that attitude most vividly, for example, in the federal government's response to infant mortality through the Healthy Start Initiative. I have great respect for Secretary of Health Louis Sullivan and what he's doing. He's a teacher of mine. I like him a lot. He and President Bush are making a very strong argument about the issue of character in our culture. They talk a lot about it because so much of the pathology that we see expressed in disease is the result of behavior. They say that people need to take responsibility for their lives and, of course, no one in his right mind would ever disagree with that.

But then they stop rather dramatically at that point and begin to engage in magical thinking. Magical thinking goes like this: Now that we've reminded you that you've acted in inappropriate ways, you should start acting in appropriate ways; disregard the fact that there are drug dealers on the corner, that people are getting murdered every day in your neighborhood, that you don't have a job. If we just say, "do right and behave," then everyone will stop, do right, and behave. I think that's a little simplistic.

But how do the nation's leaders create an opportunity to solve fundamental structural problems and thereby give folks the chance to make decisions consistent with their best interests? That's the hard part. I'm concerned about the reluctance to mobilize and organize the various resources necessary to give individuals a chance to do the things we want them to do, to create the space and the incentive and the encouragement and the nurturing and the support for individuals to be able to actually change their life, change their world. We are not seeing this as a priority. Given the problems of the federal budget and the state and local budgets, we're not going to see expenditure of resources to accomplish this. There's a tacit acceptance that we don't have more money to spend. We don't seem really energetic or passionate about finding ways to solve this problem, whether those things take money or not. That's what I mean by the toughening of



the spirit. In the end we say what's left to say: It's your fault, you shouldn't have done it, you deserve what happened to you, and don't expect too much help from us because we can't give it to you.

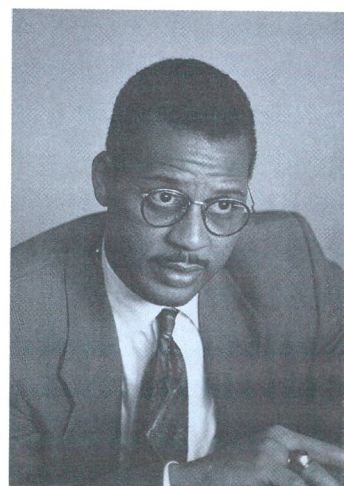
**Second Opinion:** If someone asked you for an agenda, how would you rank the issues before us? Which would you address first?

**Tuckson:** The first item on the agenda is whether or not people will survive and what the quality of their survival will be. For me as a physician, that has to do with prevention, treatment, and cure of disease. The specific diseases are the most common ones: heart disease and cancer, chemical dependency, homicide, suicide, and violence, accidents and trauma, HIV diseases. To accomplish anything, Americans first have to care about whether their countrymen and women are living or dying; we have to care that every year 40,000 babies die in the first year of life; we have to care that the life expectancy of black males is still decreasing each year; we have to care about the 250,000 babies born with birth defects every year. I look at the common diseases that are out there, and I'm struck by the fact that all those diseases have their origin in this society and that they have their treatment, their solutions, and their management in this society. So first, the nation has to care; it has to want to make a difference.

Second, we have to do the fundamental work that gives us a chance to prevent those diseases. That involves what we talked about earlier—giving all Americans the opportunity to believe there's a future for them. To do that, we have to deal with education, housing, employment, the basic infrastructures. We have to give people a functional education so that they can get jobs. There have to be jobs to get, and there has to be great attention paid to developing the community infrastructure. We need institutions that are able to transmit and organize the values of the community, that can communicate the sense that we are building something together under rational, collectively held principles and ideals and dreams. I'm thinking of institutions like churches, civic associations, fraternities and sororities, boys' clubs and girls' clubs, Boy Scouts and Girl Scouts—these are the places where we support each other and nurture each other, where we transmit values and give mutual aid.

In approaching this question, I don't look first at what's most important on the agenda—preventing crime, stopping cigarette smoking, helping education. My agenda is to look at the most important outcome—do you live or die? And then I try to deal with all the issues where people have choices to make. If I do an anti-cancer program or an anti-heart disease program or an anti-drug program or an anti-

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violence program, they're all the same program. Ultimately, the message is similar to this: I don't want you to smoke cigarettes, and therefore you need a different set of images in your mind—not the Marlboro man or the guy on the Newport commercial riding off into the sunset on a motorcycle. Each program involves having a different idea in your mind about wanting to live and thereby not killing yourself prematurely. It's having a different idea about the nature of your life and what's important in life, as opposed to trying to model yourself on the images brought to you by the makers of death and disease, which are based on silliness and narcissism and which exploit your sense of powerlessness and hopelessness. So it has to do with whether or not you are educated well enough to read the label, educated enough to participate in other experiences that give you a fuller and richer life, as opposed to the life of the limited set of choices you now have. It's all those things together.

Violence can be prevented if young people believe that they have worth and opportunities. If they don't, then the smallest incident like being called a name or hearing something disrespectful said to a girlfriend is going to call their entire ego into question. That person will feel compelled to defend himself even if it means risking his survival or the survival of the person who was disrespectful. Being respected is critical when you have so little else. You

have to fight because you can't define yourself; you can't go to another arena and say, "Well, you may have said something mean to me, but I control resources and I'll get back at you that way, or I have value, I see my value in the quality of the work I did today and what I built today, in the way I changed or influenced the world today. I define myself in many different ways." You define yourself only in terms of whether or not somebody showed you disrespect. Then your reactions, of course, are very different. That's why all those problems are the same problem, and that's why they need to be worked on together.

***Second Opinion:*** What allies would you look for? If you were addressing a church or a synagogue and people asked how they could begin to do their part, what would you say?

**Tuckson:** Our most important ally is, in fact, the religious community. It's such an absolutely vital institution for the transmission of values and ideas, hope and purpose. But the church is not only a place where there is hope and optimism, the chance to teach and to pass on a sense of history and a connection to issues and ideas in an institution larger than ourselves; it's also a place with resources—money, expertise, talent, and volunteers. Finally, the church is a place where people can gather, where people can be protected from the elements, where they can sit and be safe. The

church is all of those things at once, which is very important. Those of us who are trying to solve difficult health problems have really been trying to grow crops by planting seeds in the middle of concrete. What we need is for the soil to be tilled first, so that when we plant the seed called "prevention of disease" or "health-promoting behavior," it has a chance to grow. Right now, our seeds are being planted in concrete, and we're being held accountable: Why aren't these things taking root and becoming beautiful flowers? We need the soil to be tilled first, and I think the church can do that.

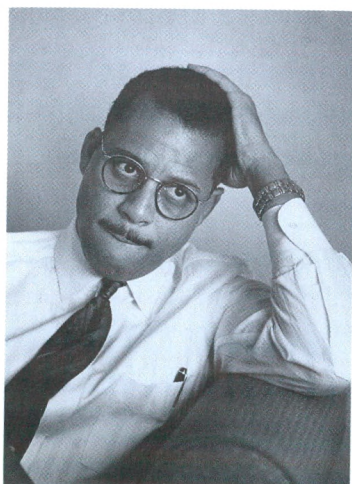
From my travels around the country, I have the impression that church, synagogue, and temple attendance is going up. I'm beginning to see a sense of energy and rejuvenation. My generation made some very bad mistakes in this country during the sixties and seventies when we turned away from the traditional institutions of our community. Those institutions nourished and protected and cared for us. This generation is now turning back to those institutions and rebuilding them.

For example, some 130 churches in the District of Columbia, with all the difficult problems they're trying to face, are opening their doors in the afternoon and evening so that when the children leave school at three o'clock there's a safe haven for them to go to. Teachers come from school to help tutor and nurture the



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children so that they can do homework in a quiet, safe environment. And then adults come to be a part of that experience after they finish their jobs. What needs to happen now, in an organized way, is that the civic associations that might ordinarily meet in a different structure or building be encouraged to meet at the church where these kids and volunteers are, so we have another critical mass of responsible, caring adults gathering at this church site. Then the health people can come, and they can now give the message to everyone at this one place. I'm encouraged to see the numbers of churches that offer things like Alcoholics Anonymous sessions for people suffering from substance abuse, and even more encouraged when those people are welcomed from the basement class into the congregation on Sunday and then integrated into the family of the church. Instead of shunning people because they are struggling with difficulties, we should, out of Christian love and caring, be bringing people to our bosom. People with HIV disease should be brought into the bosom of the church and hear the words, "We love and care about you. If there was ever a time you needed us and we needed you, it's now." Many of our young women abuse drugs because of their sense of isolation from the world around them. How do we get the church to open its doors and reach out and bring in people that have not been coming? How do we find ways of making the church more respon-

sive? It's certainly much easier for the health department to bring the examining room to the church and do the health screening program there than to attempt to get it done in the shadowy world of the streets, where people are not connected to anything.

Many of us in the health professions would like to see the bringing together of the various groups. Then we have a chance to connect and use the expertise of congregational members: people who have many different kinds of jobs, who know how to market an activity, who know how to organize, who know how to decorate a room in a way that causes people to want to come and be in that room for the purposes of survival. Churches also collect enormous amounts of money. It must be uncomfortable and frustrating for seriously religious people to have resources at their fingertips and not see the world changed or shaped in ways consistent with the ideas that are talked about in church. Those who care about these issues need to find ways to help each other so we don't feel as frustrated.

**Second Opinion:** As you deal with these many intractable problems, you seem to have energy and spirit to keep going. What sustains you? Which authors do you read? Who are your heroes?

**Tuckson:** I first am sustained by my parents whose example inspires me constantly. My father and mother have devoted them-



selves to the issues of survival, the prevention of disease, the treatment of disease; they have been part of institution building to create the infrastructure that supports their professional endeavors. So I'm inspired there. I am inspired also by a profound belief in the human spirit. So many people around me are suffering and struggling with such difficult circumstances, but they refuse to become bitter and give up; despite great obstacles, they really do try to overcome. I'm also sustained by my conviction that we can't give up. Thousands of deaths each day are unnecessary deaths, and the dimensions of this tragedy consume me and force me to be energetic.

I was one of those young people in America who was nurtured on the ideals of the nation and the responsibilities of individuals to change the world. When I got to medical school I became incensed at the needlessness of much of the pain and suffering I saw. My internal medicine training at the University of Pennsylvania caused me to become the kind of physician that I am, concerned about the larger issues.

What do I read? I read a lot of things by young people. I read and listen very carefully to youth. When I speak, I often use a poem about a young man who was suffering from all the burdens that a society can place on a young black male's back. This young man responded to love and care by adults who voluntarily mentored,

nurtured, and reached out to involve him in their world instead of fearing him and shunning him. In the poem he talks about what is now possible for him—he's able to speak and able to express: "I cling to handfuls of love and support, love and support that others give to me, but I now know I can give them even to myself."

I am inspired in great measure by a theater company in Washington, D.C., called the Living Stage Theater. The Living Stage Theater is a group of artists who have translated their creativity and their talent in ways that change the world by confronting the difficult realities and exploring them to find the pathways to hope—both for the individual and for us collectively. I've worked with this group by taking kids who are in substance abuse treatment programs and involving them in the discipline of acting so that they get a chance to realize the possibilities inherent in themselves: they can fully imagine themselves as people, in roles that are natural, as opposed to having to turn to a chemical drug to be able to achieve that same imagination. These kids inspire me more than anybody. They give me my sense that it can work! The other day they sent me something they had written—the 10 commandments for parents. Parents should not beat children like animals; parents ought not to molest; parents ought to let children dream their dreams all the way through; parents shouldn't knock down somebody

else's dream. If we saw these same kids walk across the street at dusk, we'd grab our pocketbook and clutch it to our chest. These are the kids that we forget to care about. But if you give them a camera and ask them to take a picture of hope, they'll go out into their world and take a picture of hope that will astound you. If you ask them to take a picture of anger, they'll show you a picture that will astound you. But we don't give them the chance to express that genius. We limit them and burden them, they get frustrated and angry, and they do things that cause death and disease for themselves and for others. But when you give them the chance, these kids grow and blossom. So I am inspired by the Living Stage Theater—that's the best example I can give.

I also listen to the rap music of the kids. These kids are extremely innovative, and they have a lot to say about their world. They comment on, and observe their world much more than most adults do. They're much more involved in critiquing, analyzing, and dealing with the social issues that are affecting them than most adults about the issues concerning them. There's a lot of love and beauty in some of them. True, some are negative and dangerous and damaging, but still, they're very important. So I listen.

I've been reading a book, *Pale View of Hills*, by a Japanese writer who lives in England, Kazuo Ishiguro. He's writing wonderful things about responsibility. His



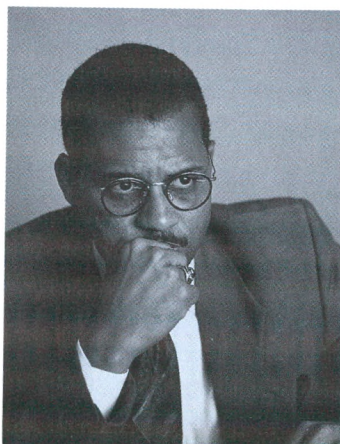
book is gentle, subtle, extremely well-crafted, and it deals with how people's actions advance or do not advance the common good. He reminds us that we have responsibility, that what we do with our lives matters.

My chief role models and mentors are my father and mother, and my brother who is a surgeon. Of course I've learned from the masters that came before, like Martin Luther King, Malcolm X—certainly I've been inspired by them. But I think we have a responsibility to be our own heroes.

**Second Opinion:** Has being an African-American given you special credentials or created special barriers in your work or vision?

**Tuckson:** There's no question that being an African-American in the U.S. presents a unique set of issues. Racism remains a lamentable part of the American experience and has a profound effect on those who practice it and on the millions who must live with that reality. I believe in the ideals of the nation. And to the extent that the realities don't consistently match those ideals, I am given passion, energy, and enthusiasm. I feel rage when I realize that 60,000 more black, brown, red, and yellow Americans died prematurely than would have died if their health status had been the same as that of white Americans. I am consumed and outraged by the realization that America isn't concerned about that. I am fearful

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that the country does not see this as a fundamental priority, that America is not mobilized to act aggressively on the fact that black babies die twice as often as white babies. Being a person of color also, I think, gives me a very real solidarity with all Americans who are poor and Americans who are brown, red, and yellow as well. When you add together the people in these groups, you've got the majority of Americans, and the number is increasing.

At the March of Dimes, I was in daily contact with Americans of goodwill who were white, and so I am somewhat encouraged that this polarity does not necessarily have to exist. I am also completely convinced that the problems confronting people of color and people who are poor inevitably will determine the character and the quality of life for the entire nation. We are all in it together, and though many may think that they can postpone these problems or wall them off—put a police corridor or criminal justice fence between themselves and society's problems—the issues confronting those who are struggling in this country are the issues that will define the country.

I have been very proud to be an African-American. I'm very proud of the African-American communities and institutions I've been associated with. One frustrating thing about being a person of color is that so often we forget or do not acknowledge the extraordinary vibrancy of life in the African-American com-



munity, the extraordinary contributions that have been made and continue to be made. So often when we think of people of color, we think only of difficult, troublesome realities. We should never forget those realities, but we should likewise not forget the legacy of African-Americans in this country. The black church, for example, helped shape who I am. I was an altar boy in the Episcopal church. I was a Boy Scout. The Cub Scout groups met in the church. I had to go every Saturday to St. Luke's and practice to be an altar boy, I was there for Cub Scouts, and then on Sunday I came back and participated in the services. So I have tremendous respect for the black church and what it's able to accomplish. I'm sure that much of my thinking about the role of the church in health care has been shaped by my experiences there.

**Second Opinion:** From your position as commissioner of public health in Washington, D.C., you moved to the March of Dimes. What led you to that decision?

**Tuckson:** I enjoyed my experience in government. It was a very important experience, but it also became frustrating. Health commissioners are trying to solve problems that they really can't solve alone. There needs to be a wide range of support to help commissioners. At the March of Dimes I wanted to be a part of trying to get some of those other supports, and there were also op-

portunities for my own development. Some things that I needed to learn I couldn't learn while doing the health commissioner's job.

Health commissioners are not going to be successful unless there are volunteers out in the community who are tilling the soil. The March of Dimes is an organization of 135 chapters around the country filled with volunteers who are from the community infrastructure, and often the leaders of the community. Networks like that give us a chance to get the health message across. Also, health commissioners need access to better scientific and health policy information. The March of Dimes has such a progressive and thoughtful research program. To be able to give that research to health commissioners and others on the front lines makes their jobs a little easier. That job allowed me to be involved in basic research, clinical research, the applications of research, and I liked that. It allowed me to be involved in advocacy in legislative bodies, in efforts to provide the necessary resources so the people in the front lines can do their jobs, particularly as they affect survival. In my new job as president of Charles R. Drew University of Medicine and Science in south central Los Angeles, I continue to work on these same problems.

Health is the place where all the social forces converge to express themselves with the greatest clarity. It's where you face the crucial issue of whether you live or die.

**Second Opinion:** When you focus on infant mortality, the problems of fetal alcohol syndrome, low-birth-weight babies, and HIV-infected women who've become pregnant must be of special concern to you. You've remarked elsewhere that certain attempts to protect the infant through law enforcement can be counterproductive. Do you see a potential conflict between the goal of ensuring the healthiest infants possible and the civil liberties of the women involved?

**Tuckson:** The rights of the child are ultimately not in conflict with the rights of the mother; they are together, they are uniquely together. We have to appreciate that and try to deal with that. Second, we have to care genuinely about protecting the mother's life and giving her the chance to survive; she needs relief from pain and suffering and disease. But we have to care passionately also about the child. Both are our responsibility as a society. They are of and among us. So we have to make available the opportunities and support, first, for women of childbearing age to fulfill their natural inclination to lead healthy lives. We ought to create the climate that gives them a chance to be who they need to be, not who they settled for being because of drugs or alcohol or tobacco. Why do 5 million women of childbearing age abuse one drug or another? Are there just 5 million "bad" women? Why do 1 million women of



childbearing age abuse cocaine? Is this just an unusual sample of 1 million "bad" people? Why did 350,000 women last year give birth to babies who were exposed to a drug in utero? Why were an estimated 100,000 babies last year born exposed to cocaine? Are all these just discrete populations of "bad" people? I don't think so. Of course there are all kinds of people, but I am not prepared to begin my understanding of which of these are bad people. The issue is, how does this occur?

Second, if we legitimately cared about both the women and the children, we would make available treatment resources for people. As a nation we need to become a little more sophisticated. The problem will not go away with magical thinking like "Just say no." Magical thinking, while appropriate to children, is not appropriate for solving the problems of children. Let us figure out now how to give people the chance to overcome their addictions. We know that people care about their addictions and that, given the right set of circumstances, they can overcome them. So we need to make that possible. If we approach the problem from the other direction, we end by blaming the victims for their own victimization: "It's your fault; therefore you don't deserve the resources of the society, and we're going to use a hammer to change your behavior." We know that's not going to work. People don't change just because you threaten them. Addiction is a difficult

problem to overcome. It requires something more than saying, "I'm going to lock you up, and that's the end of it."

If it was that simple, the problem would have gone away a long time ago. I think we have to be concerned about the criminal justice approach which says, "We will threaten you by taking your child away," because many people will then see the health care system not as a place to go for help but as a place to put themselves at risk for adverse outcomes. There are already enough barriers: the drug addiction itself, financial limits, the unavailability of treatment centers. To put up extra barriers by telling people that if they come here and are caught, they're in danger of going to jail or being prosecuted or losing the children they already have—that doesn't help very much. The maternal instinct is still there, and it's very strong.

I've talked to a lot of women who are suffering from addiction and who are pregnant or have recently delivered a child. They are a very diverse group. I'm amazed and impressed by the fact that they are American women, our countrywomen. Some women were employed, some unemployed; some were white, some black, some Hispanic, some Native American. The majority had suffered extraordinary insults as they were growing up. Many had been abused sexually and physically as children; many had been treated in terrible ways. Their coming to this disease of addic-

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tion was a complex process. It is naive and simplistic to write them off as bad people who made stupid decisions and now have to live with the consequences.

So I came to realize the diversity of the population. I came to realize how much suffering they were enduring, how much they need us to care about them and do something for them. I also learned that the fear of losing their children can sometimes help get their attention and overcome some of the denial that accompanies the disease. Perhaps there is a responsible role for the court system or the social service system acting as agents of the state. Maybe there are appropriate roles, but we have to continue to develop those in a spirit of compassion for mother and child, not as an expression of our frustration and outrage at their behavior. Those ways of looking at the issue are incompatible. They are diametrically opposed. One is helpful and life-sustaining. The other is irresponsible, short-sighted, and doomed to fail.

**Second Opinion:** I want to pursue this question from a different tack. In a recent speech you urged that *parents* have to be accountable for raising their children. But in many cases, as you know, it's the *mother* who raises the children. How can we get the fathers involved?

**Tuckson:** It's normal for society to demand and encourage parents to accept their responsibilities. It

is impossible for the state to raise the children of the society. I felt tremendous pressure and frustration when I was the health commissioner. I had to make decisions with profound religious and ethical implications for parents because they were not making them for their children. It was an unfair position to be placed in, although it came with the territory. I felt very uncomfortable in that role, and I wanted to support programs that, to the greatest extent, forced parents to confront the issues and be involved.

For example, you could locate a comprehensive health center in a school, but it would be important to involve parents in the discussions that subsequently occurred on issues like sexual activity and substance abuse. The parents would need to make the decision to talk to their children about the difficult issues. The children are sexually active in extraordinary numbers, and we have to talk to them about that. We have to talk to them about substance abuse. I want parents to be involved in helping us to learn how to talk to them. Some parents, of course, might become involved in *preventing* any discussion from occurring, and that would be difficult. But parents must be accountable for raising their children.

We then need to go to the next step—giving parents the support they need to fulfill their fundamental responsibility. Given the reality of so many single female-headed households, we

have to find ways to encourage meaningful participation by fathers. We need to encourage the functioning of the extended family and the community family. I come back to those same memories from my childhood. Anybody in our church could correct my behavior. I may have been Evelyn and Coleman's son, but if I acted like a fool Mrs. Smith would discipline me just as quickly as my parents would. Now, of course, we are so afraid. We wouldn't begin to talk to somebody else's child.

My point is that there is a role for other adults. We may lament the absence of a father or mother, the traditional concept of family; we may lament that that's not as common a phenomenon as we wish. But while encouraging that to occur, we also have to deal with the reality of the situation. We need to work collaboratively to provide the extended family support that allows children to be raised with all the benefits of adult supervision and experience and wisdom. I'm encouraged by the mentoring programs that are springing up, but they're more successful reaching out to young kids in collaboration with their parents. We perhaps have to rethink our definition of *family*.

I am inspired by the work of a man named Kent Amos in the District of Columbia. Kent is a successful businessman who leaves his office every day to be home by 5:30. There he meets a van that he purchased and that is driven by the high school football



coach. In the van are 10 boys and girls, along with food prepared by the home economics department as part of their curriculum (Kent contributes the grocery money). The students bring the food, and they eat dinner with Kent and his wife as an extended family around the table, discussing what happened that day. After eating, they study, with girls in one room, boys in the other, and no televisions on. At 10:30 or so Kent and his wife drive these kids home, and then they come back and finish their day. It's a different sense of family, but an essential family experience is being recreated, and this is happening with the endorsement and cooperation of their parents. It's not the government doing it. It's a member of the community making a decision to put the children first. I think we all have to do that.

**Second Opinion:** In the background of much that you talk about is the issue of television, advertising, mass media, and mass marketing, which distract us from these crucial issues. What would you like to see done in respect to those influences?

**Tuckson:** I would like us to be able to celebrate and give value to those Americans who are about the business of building our communities, our cities, our states, and our nation. I would like us to give value to people for the quality of their contributions, not for where they go for vacation, what

clothes they wear, what car they drive. It frustrates me that carpenters are not celebrated: the people who use their hands and their creativity to create the space we live in. Such people are not stars, but a silly person who makes a record and wears strange clothes can be.

Michael Jordan, the most popular athlete of our time, has now been enlisted to use his fame and popularity to influence children: his picture is being put on a pack of bubble gum designed to look exactly like a pack of chewing tobacco. Inside, the bubble gum is shredded into pieces just like chewing tobacco. This popular man, who is paid handsomely, lends his name and his face and his image and his mythology to try to get kids to chew bubble gum that looks like chewing tobacco—and we still celebrate him. Of course that leads inevitably to having more kids chewing tobacco and getting cancer of the lip. Why can't we find a way to celebrate the carpenter and communicate the message that a reasonable aspiration in life can be to work with your hands and to make a good living doing that? And that you don't have to believe that the only valued occupations are those that bring in enormous amounts of money and get you in *People* magazine, "Lifestyles of the Rich and Famous," and "Dynasty."

Why don't the media celebrate and give value to those things that build and move life forward? Why aren't teachers

celebrated for what they do, and why aren't we made aware of those teachers as being superstars, as opposed to somebody who can dribble a basketball? Why is it that the only time an inner-city black male ever gets on television is either when he is lying in the street bleeding or when he has been the perpetrator of such a tragedy, as opposed to when he gets an "A" in school?

When drugs get talked about, it's almost always a face of a person of color, which then allows Americans to believe this is a problem only of African-Americans. It allows Americans who are mean-spirited to say, "It's not important for me to be involved because it's not my life and my world. It's those people over there, and they deserve what happens to them anyway." That's the perception that gets played out in the media because of how editorial decisions are made, how pictures and imagery are selected. These issues are complex, but the media could at least not be a *negative* influence. Choices are made about who's going to be important, and I would like to see us be able to make the people important who are working on opportunities for survival, not destruction.

**Second Opinion:** Could you tell us a story from your past work experiences that will make vivid what you do and what motivates you?

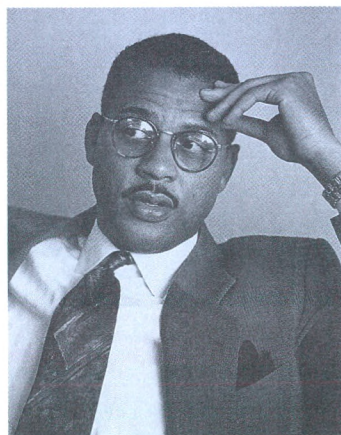
**Tuckson:** I remember taking care of a woman in a clinic that we ran



on Wednesday nights in the poor section of D.C. The leadership of the health commission ran the clinic because we believed that health services had to be available when people needed them. Many working poor Americans are without insurance, but they can't get to the doctor because the clinics for the poor are closed at 4:45 P.M., just when the working poor get off from work. Such people often go to emergency rooms. So we opened up two clinics in the poor sections of town and did it with overtime.

The budget problems that confront D.C. are like those of every big city, every state, the whole nation at every level. They are short of money, but what resources there are increasingly go toward the use of force, for example, to police departments. The police departments get their money, do a great job, and lock up all the people, and then the corrections department and the criminal justice system expenditures go up. But we have fixed amounts of money. It's got to come from somewhere. So it comes from health. That's happening right now. In D.C. we had been told to close our clinic. The leadership was so frustrated, so angry, that we decided to donate half an evening a week to running our clinic in the poor section. I was the doc, my deputy commissioner of health—a social worker—took the position of social worker, and the chief nurse became the clinic nurse. We filled every position. Those who didn't

**“Why do  
5 million women  
of childbearing age  
abuse one drug  
or another?  
Are there just  
5 million  
'bad' women?”**



have health or professional experience acted as our budget analysts or the receptionist and the intake workers. We had a clinic that we were really proud of.

One evening a woman got off the bus and came in. “I can’t believe you’re open,” she said. “The lights are on. It’s eight o’clock at night. I just got off work. I need some help.” When I asked her what the problem was, she said, “I’m six months pregnant and I’m addicted to cocaine and I need help.” And we decided to love her, care about her, and work with her, instead of threatening to lock her up. We asked her, in the course of things, why she did drugs: “Didn’t you see the commercials we put on television? Didn’t you read the literature we kept giving out? Why didn’t you just say no?” She answered, “I don’t want to make an excuse or justify it. I’ll just tell you what happened to me. Life is very hard for me. I am abused by the people in my house and outside of my house. I am so tired of waking up in the morning to the daily death count and so tired at night of hearing the bullets go whizzing past my window. I’m tired of seeing the syringes and needles all around. I’m tired of the confusion, the chaos. I’m working, and I’m hardly making anything. I can’t get out of this environment and I’m tired. I’m alone and I watch TV and there are these commercials. I read the magazines with ads for alcohol, cigarettes. I should look like I’m on the beach in Bermuda smoking

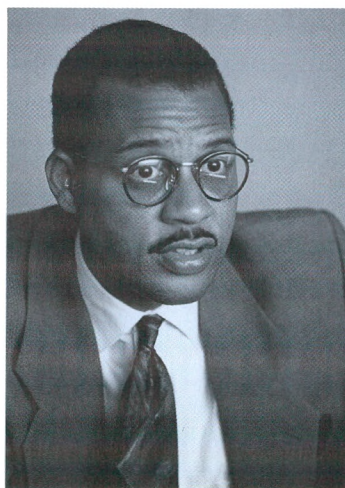


a cigarette. I can't go to Bermuda, but I could go to the corner and buy a \$5.00 piece of crack and escape, and I did. I know I shouldn't have, but I did. And once I started, the way the drug works, I got addicted. It's just hard to break it. It's so deep within me. I'm not having fun. I don't like it. I don't want to feel this way. I don't want to do this. I want to stop. I don't like it, but it's just hard. I can't do it by myself. There's no place to go."

For me, this woman epitomized the whole set of issues. We gave her drug treatment in the clinic. The guy that ran our drug treatment program volunteered. He was the drug counselor, and we gave everything there on site. We worked with her. We encouraged her to bring her boyfriend. He came in. We worked with them as a couple, as a family group, and she came regularly. She delivered a baby, right before I left, a normal, healthy, good baby. It was a success. We were happy.

I took that experience to the March of Dimes. I was very worried that many of these babies were going to be born with a birth defect and many would not survive. I knew that to help this woman and women like her I needed to be involved in the scientific thinking, in the research, in the sophisticated exploration of what is going on from a human development perspective. We should be interested in the issue on that level. We should be interested, for example, in what al-

**"We need institutions that are able to transmit and organize the values of the community, that can communicate the sense that we are building something together under rational, collectively held principles and ideals and dreams."**



cohol is doing to that developing fetus. We know that alcohol and birth defects are related now, but understanding exactly what happens can help us figure out preventive measures. So the March of Dimes is studying that issue in some detail through its research.

There I could be involved by helping through our advocacy and our volunteers to get Americans to care about this woman and her baby. Such women are our countrywomen; we need to care about them, do things on their behalf. We can then get Americans to look at why she did these things. We can examine the relationship between violence, poverty, confusion, eroded social structure, isolation, and victimization. Then we can be involved in helping to design a model drug treatment program. Nobody knows nearly enough about what a drug treatment program for this woman should look like. Inpatient? Outpatient? How long should she stay? How many health professionals and what kind should be there?

The example of this woman helped me to look at my duties as the senior vice president of programs at the March of Dimes: to be responsible for research, for community services, for model education and service delivery programs, for professional education activities, for advocacy at the state and local governments. I have a political opportunity to advocate a point of view. I want to give these women the best chance

not to have babies be born with birth defects or die in infancy.

Whether our babies live or die has to be the most important indicator of what's happening in this society and what the quality

of life is in our society. And by focusing on advocacy issues linked with infant mortality I'm also focusing on the larger issues of the health and survival of the American people in general. We

have babies. We allow those babies to live and to be the best that they can be. What else is more important than that? 🌐



# A Medicine of Strangers or a Medicine of Intimates

## *The Two Legacies of Karen Ann Quinlan*

Mark Siegler

IN 1563, WHEN HE WAS 88 YEARS OLD, just a year before his death, Michelangelo wrote to Vasari, a fellow artist: "I have reached the twenty-fourth hour of my day, and . . . no project arises in my brain which hath not the figure of death engraved upon it."

"The figure of death" was engraved on Michelangelo's last work, the powerful and mysterious *Rondinini Pietà*. Michelangelo's correspondence documents that he was still working on this *Pietà* six days before his death. This last work stands in dramatic contrast to an earlier *Pietà* (at St. Peter's in the Vatican) that Michelangelo had completed 60 years before.

The early *Pietà* is a marvelous but somewhat traditional rendering of the theme. It depicts the individual figures conventionally, albeit sensuously. Mary, a monumental figure, supports the dead body of Jesus. Her closed eyes, but even more, her left hand signal acceptance and resignation. The two figures are separated and isolated, and Christ's head

and eyes are tilted away from Mary. By contrast, when Michelangelo returned to the same subject more than 60 years later, his image of the relationship of the living to the dead had changed. In the *Rondinini Pietà*, one sees the two bodies supporting each other in mysterious ways that defy the laws of physics. As the figures emerge from the marble block, it is Mary who is leaning for support on the dead body of Jesus, while at the same time holding up and supporting her dead son. Christ's right hand and arm partly merge into Mary's body. The two figures are united, almost inseparable. In contrast to the early *Pietà*, there is a sense here of mutual support, almost a union of the living and the dead, that brings to mind notions of the social, personal, and religious contexts in which dying and support for the dying occur. There is a sense of intimacy and connectedness in the late *Pietà* that is not captured in the earlier work.

These sculptures provide two strikingly different images of the relationship of the living to the dead and dying. And these images, in turn, provide insights into two radically different conceptions of medical practice and of patient-physician interactions. One is a legalistic perspective appropriate to strangers, and the other is a caring perspective ap-

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appropriate to relationships between intimates. I wish to explore these two different conceptions of medicine by examining perhaps the most well-known case in American medical ethics, the case of Karen Ann Quinlan.

## Stories and Moral Reflection

THE TRAGIC EVENTS THAT LED TO Karen Ann Quinlan's coma, the legal drama that followed, and then the extraordinary supportive care Ms. Quinlan received for 10 years while in a coma were a moving story, now part of the collective American experience. But the legacy of Karen Ann Quinlan will depend on how we choose to tell her story or stories, which lessons we choose to extract, and how we elect to use the story in the future. Which events in the story will be regarded as central and which as peripheral?

The stories used to describe the practice of medicine and the metaphors used to depict the relationship of patient to physician affect the practice itself. Ethicist James Gustafson once made this point in a lecture: "How we describe persons and their relationships to each other—whether as individual contractors or as persons in patterns and processes of interdependence—is a matter of critical judgment. The alternative descriptions back alternative ways of construing the moral situation. How that situation is construed confines or enlarges the morally relevant features taken into account in patient care." Thus, depending upon which parts of the story we choose to focus on, different meanings may be extracted. I can see two alternative ways of telling the story of Karen Ann Quinlan, and depending upon which story one tells, the legacies derived from the case of Karen Ann Quinlan will be different.

ONE DRAMATIC ASPECT OF THE QUINLAN STORY resembles Gustafson's notion of "individual contractors" and has to do with the court cases and the important precedents established by the intellectual force of the New Jersey Supreme Court decision. The legal roots of the Quinlan case reach back hundreds of years to the framers of the United States Constitution, but Quinlan's legal legacy extends to current medical practice.

The court held that a patient's constitutionally protected right to privacy includes the right to decline medical treatment under certain circumstances. Such circumstances are determined by balancing the patient's individual right to privacy against competing state interests in the preservation of life, protection of third parties, and maintenance of the ethical integrity of the medical profession. The court concluded that in the circumstances presented in the Quinlan case, the state's interest should yield to those of the patient.

The court further held that the right of privacy could be exercised on behalf of an incompetent patient by a guardian who used "substituted judgment," a judgment of what the patient herself would have wanted if she were able to speak in her interest. The court empowered Mr. Quinlan to make decisions for his incompetent daughter. The court concluded that health care decisions should be controlled primarily within the patient-doctor-family relationship and should generally be free of unwarranted judicial intervention.

Thus one important part of the Quinlan story has to do with judicial procedures and even with some nonjudicial practices of clinical decision making. Focusing on this aspect of the story, we can learn about patients' rights to privacy, about the use of substituted judgment for incompetent patients, about the importance of living wills and other advance directives, and about decision procedures regarding the withholding and withdrawing of medical treatments.

In this regard, the Quinlan case was a watershed in the ethical and legal debates about the treatment of permanently unconscious patients and about the



rights of proxies to make decisions for incompetents. The Quinlan case produced the first judicial ruling in the U.S. to permit the removal of life-sustaining medical treatment from a permanently incompetent adult. Prior to the Quinlan case, these discussions were carried on in clinical and academic settings; since 1976, they have become part of public discourse.

THE LEGAL SIDE IS AN IMPORTANT PART of the Quinlan story and legacy, but it is not the whole story.

The other part of the story is not well known. For understandable reasons, the Quinlan family and their physicians, nurses, and counselors have chosen to keep private much of this other story. As far as I know, it has never been the subject of medical, legal, or ethical analysis. I refer here to the events that followed Mr. Quinlan's decision to have Karen Quinlan's respirator discontinued. Quinlan survived for almost 10 more years. During that time she must have received extraordinary nursing and supportive care, and as far as I know, she continued to be attended by her family.

If the first story of legal procedures emphasizes individual rights, then the untold story of 10 years of support should teach us lessons about the medical and nursing functions of caring for individuals who are handicapped, chronically ill, disabled, retarded, cognitively impaired, and at an extreme, per-

manently unconscious like Karen Ann Quinlan. Even though cure or functional improvement was never possible for Quinlan, the supportive care and compassion she received reflects some of the traditional goals and ideals of medicine.

What are some of the lessons to be learned from this other side of the story, the story of 10 years of care?

First, we learn something about standards of care for neurologically impaired individuals. Many in-

dividuals in our society, presumably including the Quinlan family and Quinlan's physicians and nurses, are not yet ready to consider permanent neurologic dysfunction or cognitive impairment—for example, Alzheimer's disease—as equivalent to death. The Karen Quinlan case is a vivid reminder of this fact. The case alerted the public and the medical profession to the difficult problem of people who are permanently unconscious or who are conscious but severely impaired neurologically. Some ethicists have responded by proposing rules that might free them from legal respon-

sibility and moral anguish by considering the profoundly neurologically disabled person as if they were dead. But there is every reason to worry and agonize over these difficult life-and-death decisions. As a society and as a profession, we must continue discussions about what our obligations are to neurologically disabled individuals and to other handicapped members of society. The Quinlan case



*Pietà*. Sculpture by Michelangelo, 1497–1500.



showed that those who make difficult and wrenching proxy decisions for incompetent loved ones—including even the withdrawal of potentially life-prolonging interventions like the respirator—can remain committed to the impaired person and can refrain from abandoning them.

The case also showed that guardians and family can be selective in which treatments they wish to withdraw and withhold. Even if they feel it acceptable to withdraw a complex technology like a respirator or dialysis, families and guardians may draw the lines at not withdrawing or withholding simpler care measures like nursing support, the provision of fluids, and the use of tube feedings. This last point suggests that proxy decision makers can withhold or withdraw treatment while not intending or even desiring that such withholding directly cause the patient's death.

Finally, the case of Karen Ann Quinlan seems to challenge the utilitarian calculus that would have us reach life-and-death decisions based on a benefit-burden formula. For a neurologically disabled individual who is not experiencing pain or suffering, life itself must be the burden, and the benefit being sought, supposedly in the patient's best interest, is the person's death. It is understandable that such a death could provide benefits to third parties, including the society that ultimate-

ly pays for the support of such individuals or the family who must grieve and suffer for their loved one who is now permanently unconscious. But what benefit is derived by the unconscious person who is being made dead? The best-interest claim from the patient's perspective seems a dubious one—medically and legally—since in the American context both the

medical and legal systems have usually regarded the maintaining of life (particularly when it can be done without pain and suffering) as a core component of the patient's best interest.

Of course, it would be desirable to recount and learn from both sides of the Quinlan story and to integrate both sides into our clinical practices. My great fear is that we already have trivialized the legacy of Karen Ann Quinlan by focusing primarily on the judicial events of 15 years ago. Unquestionably, these events are vitally important; they were legal milestones. But they are not the whole story, only the prologue. The body of the story, largely untold, turned out to be the care of the body of Karen Ann

Quinlan along with the responses of family members, health professionals, and health care institutions. That story lasted 10 years, not one, and represented another aspect of the legacy of Ms. Quinlan.

The two legacies of Karen Ann Quinlan resemble the two Michelangelo conceptions of the



*Rondinini Pietà*. Sculpture by Michelangelo, 1555–64.



*Pietà*: one legacy and vision relates to ordering and representing the relationships of isolated strangers while the other legacy speaks to providing medical care within the intimacy of a family and community structure where the involved parties know each other and are close to each other.

Some years ago, when ethicist James Childress and I examined various models and metaphors of the doctor-patient relationship, we offered some preliminary thoughts contrasting a medicine of strangers with a medicine of intimates (Childress and Siegler 1984). We noted that in relations among strangers, rules and procedures become very important, and control rather than trust is dominant. Strangers do not know each other well enough to have mutual trust. Thus, in the absence of intimate knowledge or of shared values, strangers resort to rules and procedures to establish control. By contrast, in relations of intimacy, all the parties know each other very well and often share values, or at least know which values they do not share. In such relations, formal rules and procedures, backed by sanctions, may not be necessary; they may even be detrimental to the relationships. In relations of intimacy, trust rather than control is dominant. Trust means confidence in and reliance upon the other party to act in accord with moral principles and rules.

I fear that too much of what we call medical ethics has been focused on the stranger model in which it is never assumed that patients, families, and health professionals share common goals. Further, I fear that the way we conceive of a practice—the way we tell its stories—may determine how that practice evolves. That has surely been the case in American medicine. Because we have conceived of medicine as a practice of strangers, or of those who are estranged, we have chosen to control and regulate it through legal and ethical rules that attempt to provide at least minimal standards. These have substituted for the trust and confidence that previously guided medical relationships. The principal legacy of cases like Karen Ann Quinlan's has been a long line of precedents aimed at defining legally acceptable

standards of medical practice. Predictably, this legalization of medicine has created a downward spiral in the relationship between patients and professionals. The process goes as follows: mistrust encourages rules and regulations, which instead of inspiring more trust tend to result in mutual suspicion and recriminations between doctor and patient. It would be preferable to bring back to medicine a different set of stories, particularly stories that revealed the intimate and covenantal relationships of doctors and patients, relationships premised on promise keeping, justice, fidelity, and responsibility.

ON HIS DEATHBED, MICHELANGELO SAID: "I regret that I have not done enough and that I am dying just as I am trying to learn the alphabet of my profession."

We in medicine are just learning the alphabet of our profession, particularly with respect to the new and awesome technology we have at our disposal. The story of Karen Ann Quinlan provides us with many lessons, not least among them the extraordinary sense of how medicine frequently involves communal concerns of caring and nurturing and supporting, how often it involves "persons in patterns and processes of interdependence," the image revealed in Michelangelo's late *Rondinini Pietà*.

I suggest the shift in perspective from Michelangelo's early to late *Pietà* could serve as an analogy to the other legacy, the untold story of Karen Ann Quinlan. This is the legacy that we the living learn from the dying because it is the dying and the handicapped and the disabled who teach us about caring and about comforting and respecting the body.

The movement for "death with dignity" arose in response to concerns of the public that medicine was paying inadequate attention to caring for dying patients. It would be sadly ironic if the legacy of Karen Ann Quinlan was limited to establishing legal precedents or ethical rules by which supportive care for the profoundly disabled could be

withdrawn. Rather, the complete legacy of Karen Ann Quinlan would include procedural standards for withdrawing treatment but would also include family, community, religious, and medical standards through which simple care and support could continue to be provided to disabled but living per-

sons. The decision to continue care like that provided to Karen Ann Quinlan would reflect deep human and social values and would repudiate the notion that decisions for the profoundly disabled should be based either on quality of life standards or on so-called objective best-interest standards.⊗

## REFERENCE

Childress, James F., and Mark Siegler. 1984. "Metaphors and Models of Doctor-Patient Relationships: Their Implications for Autonomy." *Theoretical Medicine* 101:268–74.



# Medical Ethics and Theology

## *The Accounting of the Generations*

Martin E. Marty

*As the field of modern medical ethics took shape two generations ago, its articulators were at ease with theology and often even at home in theological seminaries. A generation later they and their colleagues had "moved out," to clinics and universities, where religious questions were often alien and theology was excluded. Today both the public and academic and medical professionals are raising religious questions again. In a series of nine articles, Second Opinion has taken a look at these turns of the generations. Editor Martin Marty here synthesizes the themes of these articles to provide a background for the current scene.*

"On James F. Childress: Answering Every Person," by Courtney S. Campbell

"On Germain Grisez: Can Christian Ethics Give Answers?" by James G. Hanink

"On James M. Gustafson: Can Medical Ethics Be Christian?" by Allen D. Verhey

"On Bernard Häring: Construing Medical Ethics Theologically," by Ron P. Hamel

"On Stanley Hauerwas: Theology, Medical Ethics, and the Church," by Stephen E. Lammers

"On Immanuel Jakobovits: Bringing the Ancient Word to the Modern World," by Marc Gellman

"On William F. May: Corrected Vision for Medical Ethics," by Gilbert Meilaender

"On Richard McCormick: Reason and Faith in Post-Vatican II Catholic Ethics," by Lisa Sowle Cahill

"On Paul Ramsey: A Covenant-Centered Ethic for Medicine," by David H. Smith

NINE YOUNGER EXPERTS WHO BRING THEOLOGY to bear in the field of medical ethics have written in *Second Opinion* on the work of nine of their predecessors from the two previous generations. These were mentors who began to be active after mid-century and who have made their mark during the most recent third of this century. (The dividing line between such generations, of course, is never neat, so there is some overlap.) Assuming that these writers have done a reasonably accurate job of condensing, presenting, and criticizing the thought of the modern shapers of their discipline—most of whom drew upon and reworked ancient traditions of moral and religious discourse—we can use their essays as a valuable and revealing body of thought for appraising the enterprise as a whole.

One way to grasp something of this whole is to picture some archaeologists, centuries from now, unearthing this collection. Suppose they found no other traces of such lore as this surviving from our time, no other documents to probe. If they could work only with this sort of Dead Sea Scrolls of theologically informed medical ethics, what would they conclude?

To make the game of appraisal worthwhile, we have to hypothesize that the choice of figures for analysis was representative. It would be impossible, of course, to get complete agreement among everyone about who should be in this canon. The most obvious missing candidate would be the recently deceased Joseph Fletcher, who many would say was the pathbreaker in the 1950s and who lived on to continue his radical love-centered (and eventually post-theological or nontheological, agnostic) probing. Likewise, a footnote in the essay on Immanuel Jakobovits mentions numerous candidates in the second generation of Jewish medical ethicists, peers of some of the Christians in this collection, who

might well have been included: for example, J. David Bleich and Moshe Tendler from Orthodoxy, or David Feldman and Seymour Siegel from Conservatism (Gellman 1991:115). Were there space for more, certainly Charles Curran at least would be a credible Roman Catholic nominee. All such additional choices would have provided important exceptions to some of the generalizations that follow, just as much of their work would complement what these nine writers have analyzed. It is hard to say who *else* might belong, but there is no question that these nine *do*.

The company of these thinkers would provide a clue about vocations to archaeologists of the future: for instance, that theologically informed medical ethics might have been pursued in the rabbinate—no parish priests or ministers happen to be here—but that the conventional abode for such inquiry was the university or the graduate theological school connected with universities.

If the archaeologists were to find a comparable collection from the subsequent and thus current generation, they would find women represented as decisive thinkers. Women were not so active between the 1950s and the 1970s; only one is among the authors of this collection. Why? Legal scholar Dena Davis (1991) has shown why it was difficult for women to master the vastnesses of rabbinic texts without which one could not “do” Jewish medical ethics: they were not in the rabbinate, where acquaintanceship with the documentary tradition and habituation to the ethos of these studies occurred. One generation later, women had joined the rabbinic ranks or had found ways to join the company of lay scholars in universities.

Similarly, archaeologists of the future would have to imagine their way back into our times to understand another distortion in the collection: since Catholicism did not ordain women as priests, American Catholic women, though they had access to the documentary tradition out of which Catholic ethics emerges and also had some precedents, especially in religious orders of times past, had less chance to make their way in the theological

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academy. Even without their ordination, however, Catholicism in the subsequent generation produced numerous leaders among women who would be candidates for inclusion in a future round.

As for Protestants, where the ordination of women became common during the part of the century under scrutiny, it is hard to remember that at mid-century only two or three women held tenured chairs in notable Protestant theological schools. The development of religious studies in universities and the diffusion of women's presence in all the theological disciplines meant that the period from 1950 to 1970 was the last from which women would have been excluded in a representative collection.

One could point to other scholarly cohorts that had less chance than others to leave their mark: Eastern Orthodox Christianity was only coming to be a sufficient cultural presence in North America. Scholars in African-American Christianity, Islam, or Asian religion rarely branched into medical ethics. What we have, then, is a portrait not only of a company of scholars but a glimpse of the culture in the academy, church, and clinic after the middle of the twentieth century.

The lore and ethos on which these scholars drew came to be denominated, somewhat artificially, as *Judeo-Christian*, and it would be this tradition alone that the diggers in some remote future would uncover. Given the great differences in philosophies of history subscribed to by Jews and Christians, the naming of this tradition appeared to some to have been a political invention designed to suit the situation of American pluralism and also to do justice to a strong Jewish cultural presence.

In Marc Gellman's (1991) tracing on these pages, it would become obvious to the future scholars that Rabbi Immanuel Jakobovits did not draw on Christian sources; neither, in these condensed presentations of their thought, did the Christian eight make any references to the rabbinical tradition. When Americans speak of any common tradition, they are usually talking about the use Christians make of the Hebrew Scriptures, which

they call the Old Testament. Christians interpret these scriptures in vastly different ways than do the Jews, but their reliance on them is genuine and profound.

In passing, one might note that if Christian readers found the writings of Rabbi Jakobovits to be somewhat remote, arcane, and not easily accessible, so Christian exposition similarly would not check out as the linguistic or conceptual "coin of the realm" to most intellectuals in the generally secular culture of America, whose published works would no doubt be available to tomorrow's archaeologists. At the same time, the discourse of these Christian ethicists would be remote from that of most Christian believers, who were not, for the most part, theologically informed in any technical sense. That is, an archaeologist pondering the pop and folk literature of Christianity in these times would find that the ethicists necessarily drew on specialized language to communicate.

Could the archaeologists in a remote tomorrow rely on these writings, then, as having been addressed to or having issued from the communities of substantial numbers of Americans? The answer has to be an emphatic yes. These future archaeologists may not stumble upon parched opinion polls—though, given the prevalence of polls and the relative scarcity of theological ethics writings, they stand a good chance of coming across some—but they would find that as late as 1990, polls that relied on large or small samples of the citizenry found 85 percent of the population considering themselves to be Christian. Another 3 percent of the public considered themselves to be Jewish. Six out of ten Americans considered themselves Protestant; one out of four, Catholic. The main sources of modern theological ethics are the texts on which the faith communities of a significant majority of Americans were founded.

The probing archaeologists who looked beyond denominational identifications to find the sites of theological work would find that it occurred chiefly in the academy. The newer field of "clinical ethics," in which medical doctors predominated, also



developed during this period, but no one who possessed an M.D. and a Ph.D. had yet become a pace-setting writer (as opposed to practitioner) in this field, at least not where theological concerns were present.

The university location was an important element in the scholars' work. Some of them may have been responsible to ecclesiastical bodies, but their credentialing came chiefly from fellow academics, from professors, not from higher clergy. When their work was analyzed, it was by other professors. In the case of some of the Catholics, their church body might monitor or criticize their work, but the academy was free to prize what the current church leadership censored or treated warily. The rules of the game in theological ethics were chiefly set by the academy.

Medical ethics in the decades after mid-century was in the hands of philosophers and theologians. Other seminary disciplines, like practical theology or clinical pastoral care, underwent considerable development after mid-century, but their articulators did not specialize in ethics, and they addressed other elements of the human condition. The concerns in these disciplines often complemented those of the ethicists, as in the case of the overlapping approaches to themes like suffering. But differentiation and specialization dictated that the credible voices in theological ethics undergo technical training developed through a lifelong familiarity with a particular set of texts and approaches.

If one had asked the nine ethicists "back in the twentieth century" to write ordinary job descriptions for themselves, how would they read? It is always a bit startling to think of one- or two-word descriptions; "Martin Luther, Professor of Old Tes-

tament," for example, sounds different from "Martin Luther, Reformer," the latter a title that would not have been appropriate for *Who's Who in Germany*, 1517.

In the present sequence, Rabbi Jakobovits would be described no doubt simply as rabbi, the others as professors. Only one or two would say they were professors of medical ethics. The rest were self-described as theological ethicists who had something important to say about medical ethics or who sometimes even made it their chief field of application. But none of them sought "instant relevance" as commentators on the hard cases they all had to take up. They exercised

more durable influence because they gave most attention to the matrix and context of theology and ethics as background to the medical ethics world. None would have chosen the term *bioethicist*, a coinage of the period, as a self-description.

For William F. May, the task of academic theologians was to "clarify, interpret, and criticize" the abundant religious realities surrounding them (Meilaender 1989:107). Allen D. Verhey (1988) saw James M. Gustafson pursuing Christian theology as "an intellectual discipline undertaken within the context of the faith and tradition of the Christian community, where the experience of an ultimate power is nurtured and informed by the memory of certain religiously significant events, concepts, and symbols." Meanwhile, ethics is "an intellectual discipline that reflects upon a dimension of human experience, . . . denoted 'moral'" (Verhey 1988:105). Ron P. Hamel (1991:116) wrote of Bernard Häring that this priest saw the ethicist as "one who brings moral and religious sensibilities to a broad-based discussion seeking ethical insights and judgments in cooperation with others."

**How could these ethicists get a hearing for religion, theology, and church in a culture where academic and medical professional elites had no patience for and often showed disdain for all three?**



Ethicists in those years did find zones where practice counted in their work. Illustrative were the involvements of Richard McCormick on an array of panels such as those of the American Hospital Association, American Fertility Society, National Hospice Organization, the Ethics Advisory Board of the Department of Health, Education and Welfare, and the President's Commission on Bioethics (Cahill 1988:109). The citation of the writings of James F. Childress in landmark instances (Campbell 1989:131) showed that these professors by no means led sequestered lives doing work with high levels of abstraction and remoteness. Anything but that. Still, the university disciplines to which they contributed helped define them and shape their work.

The various essayists treated these nine thinkers as members of a generation and a half. They could not have produced a collection such as this back in 1950. Bernard Häring first published his landmark work *The Law of Christ* in English in 1961 (Hamel 1991:110). The other senior figure, Rabbi Jakobovits, had produced *Jewish Medical Ethics* in 1959, but Marc Gellman (1991:97, 115) thinks it inappropriate to speak of the new era in medical ethics before 1967, when the Harvard Medical School advanced new criteria for brain death. The pioneer of Protestantism (in this company), Paul Ramsey, brought focus to his work with *The Patient as Person* in 1970. The timing is important: it was during the 1960s, a period of tumult in churches—the Vatican Council (1962–65) in Catholicism and various versions of “radical” and “secular” theology predominating in Protestantism were highlights—that theological interest in medical ethics grew. This was a time when there were cultural indications that America was turning radically secular, rejecting Jewish and Christian traditions, making it harder than before to apply biblical and ecclesiastical norms to the fields of medicine and well-being.

The cultural situation may have occasioned what almost all the essays suggest: that the ethicists regarded their work as fundamentally problematic. How could they get a hearing for religion, theology, and church in a culture where religion was pervasive,

theology vital, and the church strong, but where academic and medical professional elites had no patience for and often showed disdain for all three? Conversely, how could they get religious bodies to overcome their suspicion of so much in medicine, technology, and philosophy, so that their resources could be brought to bear on people who faced illness and sought health? How could they speak the theological word in the medical world?

Given their interpretations of their environment as being uncaring and sometimes hostile, it is a marvel that these theological ethicists persevered and made any mark. At times, some of them wavered and adopted the “ordinary secular” language of philosophical ethics in many settings; one might even say that the isolation of theological motifs in these nine thinkers when appraised for the journal *Second Opinion*, which paid special attention to such motifs, may make them sound more explicitly theological than they tended to be when they spoke up in clinics or universities.

Allen D. Verhey (1988:104) tells of James M. Gustafson's poise: “He acknowledged that there were sometimes good reasons for silence about theological convictions” in commentaries on medical ethics, but, Verhey went on, Gustafson “more vigorously pointed out good reasons to lament this silence. Chief among these was the simple truth that faithful members of religious communities want to live and die and work and care with faithful integrity, not just with impartial rationality.”

American culture of the time, in a term William May once used, “reeked of religion,” but it was also secular in many dimensions, and that created problems. So did pluralism, as all these thinkers recognized. Stanley Hauerwas, citing Alasdair MacIntyre's *After Virtue*, made that particularly clear. “MacIntyre holds that people today live in a morally fragmented world, that there is no coherent morality” (Lammers 1988:131). Hauerwas and others asked why, in the midst of all the fragmentation, one mode—the one based on secular rationality alone—should be privileged and have hegemony, if not monopoly.



The society had made one form of discourse apparently easy for itself by conventionally turning religion into “a private affair.” Yet religion clearly had public consequences. Patients brought their private meanings into the pluralist setting of the hospital, where they often reasoned about morality in ways that did not match those of the philosophical ethicists, especially whenever they were attentive to religious norms, the ones with which theologians worked. This secular-pluralist concept of the times conditioned and colored everything that this band of theological ethicists analyzed and proposed. Yet, as presented here, they did not gripe or sulk; they set out to do something about the situation. It would be absurd to say that they or anyone else had won their way and become privileged. But as the second half of the century unfolded, the voice of religion and theology was increasingly heard in sectors of the academic and clinical ethics world, thanks in no small measure to thinkers like the 18 (counting both the subjects and the authors) in this collection.

Lest it appear to the archaeologists centuries from now that a hostile world around them simply united this band of theological ethicists, let it be noted that they in various ways also had adopted modes of thinking which their own spiritual and theological ancestors would have called *secular*. While numbers of them stressed that death did not have the last word with human existence, they found talk of *transcendence* more congenial than the language of supernatural *otherworldliness*.

Pluralism is indeed represented among them; there were vast differences not only between Jakobovits and the Christians, or between the three Catholics and the five Protestants, but also among

those in each camp: James Childress and Stanley Hauerwas represented opposite poles on most vital positions, including their originating points, the communities they would address, and many of their intentions and goals.

**Hauerwas and others asked why, in the midst of all the fragmentation in American culture, one mode—the one based on secular rationality alone—should be privileged and have hegemony, if not monopoly.**

One thing the archaeologists would discover is that these thinkers all *did* have in common a resistance to the trendy “more secular than thou” theology of many radical Jewish and Christian thinkers of their period. Only two or three of them (perhaps Jakobovits, Grisez, and Ramsey) would have been considered conservative by their ecclesiastical colleagues, but they were all traditional in the sense that they engaged in *ressourcement*, a profound revisiting of and drawing upon their traditions, and they were

more ready to reinterpret than to reject classic symbols and statements.

This tendency shows up most in their frank and up-front stress on God. Were they Buddhist or Confucian thinkers they might be religious but not theistic, God not being the subject of religious thought or the object of faith in such traditions. Ron Hamel quoted an important positioning statement by James Gustafson in which he criticized religious ethicists working in medical ethics—sometimes including thinkers in this collection—for too frequently abandoning their responsibility to do Christian ethics theologically. “The relation of their moral discourse to any specific theological principles or even to a definable religious outlook is opaque,” he complained. Hamel also cited physician-philosopher Leon Kass: “Perhaps for the sake of getting a broader hearing, perhaps not to profane sacred teachings or to preserve a separation between the things of God and the things of Caesar, most religious ethicists entering the public practice of



ethics leave their special insights at the door and talk about 'deontological vs. consequentialist,' 'autonomy vs. paternalism,' 'justice vs. utility,' just like everybody else." At least in the presentations here, which focused on the theological dimension, the thinkers made some effort not to be "just like everybody else" (Hamel 1991:111).

Rabbi Jakobovits, insistent that he should speak only out of Jewish texts to the Jewish community, made no compromises in efforts to write with immediate relevance for the general medical and ethical communities that he professed he intended to reach. The Roman Catholics, on the other hand, had the easiest time showing that their tradition at least *intended* to aspire to the universal, through the time-honored concept of *natural law*. Yet there were open disagreements between a neoscholastic Catholic like Germain Grisez, who relied strongly on a kind of unreconstructed usage, and Richard McCormick, whom Grisez criticized for reinterpreting natural law teaching too much. For Grisez, "a moral philosophy within the natural law tradition sees actions as right insofar as they help to realize the full potential of human nature and wrong insofar as they frustrate the full realization of that potential." But he then fleshed out natural law in such a way that it ruled out all "artificial" birth control. His fellow Catholic Richard McCormick and many other Catholic thinkers of the times did not concur with him, an indication that natural law was itself a divisive issue that settled little and a problematic tie on the part of some religions to secular ethics in American culture (Hanink 1990:87). On the basis of his version of natural law thinking, Grisez could say with comfort that there were moral absolutes and could spell them out (Hanink 1990:93), something that other natural law thinkers were less ready to do and that the general ethicists' community dismissed as being confessionally Catholic.

Richard McCormick used Catholic natural law thinking as a bridge to other approaches, but he also wrote that "there are factors at work in moral convictions that are reasonable but not always reducible to the clear and distinct ideas that the term 'human

reason' can mistakenly suggest." McCormick also used a frankly hermeneutical approach that Grisez would reject. That is, for him there is no stable meaning to a text; what the interpreter brings to it affects the interpretation. Thus: "the Catholic church *interprets natural law*; it *does not simply transmit revelation*," and that fact produced problems for Catholic and non-Catholic alike (Cahill 1988:112). McCormick, on the other hand, drew fire from Hauerwas and his kind for contending that the substance or content of Christian moral thinking was not different from what one could deduce from natural law reasoning. The priest's six main themes were designed to suggest this: "the value of life as a basic but not absolute good; the inclusion of 'nascent' life in the good of human life; the definition of the highest and only absolute good in human life in terms of love of God and neighbor; the essential sociality of persons; the unity of the 'spheres' of life giving and love making; and the normative value of heterosexual, permanent marriage" (Cahill 1988:116).

Not only Catholics aspired to address the universal situation with a translatable ethic; James Childress among the Protestants leaned furthest toward the "universal"—to some of his critics he looked quite like a secular rationalist with a reminiscent Quaker piety. This did not mean that he was not theologically informed or given to what James M. Gustafson called "natural piety," or even Quaker piety! Explicitly, Childress's Quaker impulse asked him to be preoccupied with "answering that of God in every person," an approach indicating "a universalistic impulse" that required the ethicist "to take account of and be accountable to non-theologically informed positions."

Childress, as an author of medical ethics textbooks, had considerable influence beyond theological circles and became one of the prime keepers of the secular philosophical canon and code. In his outline, medical ethics was devoted simply to *nonmaleficence, beneficence, utility, justice, and respect for persons* (sometimes spelled out as *autonomy*). In all cases he connected these themes with divine *agape*,



or love. But Childress's critics questioned whether the theological connection was anything but merely an evidence of nostalgia or arbitrariness (Campbell 1989:121–23).

Hauerwas, as already noted, spoke from the opposite pole, from which vantage Childress's thought would be called liberal. "Liberalism as an approach to morality is flawed because it presupposes a universal morality. For Hauerwas, there were moralities only of particular communities; a universal morality is an illusion," even, Hauerwas insisted, when it came through Catholic natural law reasoning (Lammers 1988:131). Yet, said Stephen E. Lammers, "Hauerwas thinks that he is advancing a 'natural theology' when he discusses medicine," and did not want to be dismissed as merely confessional or sectarian. He simply saw "no way to speak except within the confines of a particular language, devoted to a peculiar story of a special, e.g., Christian, community" (Lammers 1988:138).

However much the thinkers might have disagreed with each other on how the talk about God connected with "natural," "universal," or "other" languages and concerns, their own talk about God was open, persistent, and focal. Gustafson would have found few reasons to accuse these colleagues, as here represented, of muting or muffling their witness to God at the grounding of theological ethics, including in its medical applications. For theologians *not* to talk centrally about *theos* might seem oxymoronic, but there was a good deal of oxymoronism running around in the decades when these thinkers made their statements.

One wonders, however, whether it was not precisely the frankness of their God-talk that secular colleagues found impressive even as it raised

problems. The theologically informed ethicists who fled for cover, lost nerve, covered up their tracks, or found no ways to focus on God seemed to have less influence than did their expressive co-believers (though Daniel Callahan, who began as a lay Catholic theologian, moved clearly and cleanly out of the orbit of faith and theology and yet had profound influence). The lesson that might be taken from these theo-centered if not necessarily "God-intoxicated" reasoners is that one cannot have it both ways: to establish one's credentials as a theologian and then be embarrassed about one's chief subject.

Rabbi Jakobovits, as presented by Marc Gellman, did not talk so much about God as about the Law given through Moses and ex-

pounded by the prophets and rabbis, but there was no question at all about the rabbi's theocentrism. The God to whom such as the rabbi testified and whose bearing they would see in relation to human persons and in ethical discourse is rather consistently the One described by Gustafson as "Creator, Sustainer, Judge, and Redeemer" (Verhey 1988:106). None of the nine were pragmatists, cocksure elaborators on the ways of God as if they could know this God in exhaustive ways. Yet they were also not agnostic; whether through experience, revelation, apprehension of divine self-disclosure, reckoning with classic texts, being moved by stories, or by reason, they spoke of some measure of knowability directed to the divine.

On these terms, Gustafson issued a "call for piety to form the intention to relate to all things in ways appropriate to their relation to God." This formation, he argued, could happen only when "the transcendent God cannot be altogether unknowable, an empty cipher behind or beyond all human attempts to describe God." So, in Verhey's reticent

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description of a diffident Gustafson, “the character and purposes of the transcendent God are not unknowable, even if they are not fully and exhaustively knowable. The transcendent God is not a totally unknown God, even if God can be known only by analogy” (Verhey 1988:111). Readers who a priori ruled out the possibility of intelligible discourse by reference to a symbol of the Other (“God”) to which over 90 percent of their fellow citizens somehow related positively would find little point in pursuing the thought of these theological ethicists except as a curiosity.

Eight of the nine thinkers, as already observed, were Christian. “Can medical ethics be Christian?” Gustafson once asked (Verhey 1988:111), and he answered his question affirmatively, if with many qualifications and complications. Admittedly, when theological ethics turned Christocentric, as it did with Stanley Hauerwas and Bernard Häring, more qualifications and complexifications appeared. Childress spoke of God’s activity “expressed theologically as creating, ordering, and redeeming,” and linked this with anthropological corollaries in the human situation “being understood as created, fallen, and redeemed” (Campbell 1989:125). He may have spoken positively of Jesus Christ, but Christ was not integral to his ethics.

Häring, on the other hand, made much of “discipleship” (Hamel 1991:111) without trying to separate himself from the larger ethical and medical communities. Hamel summarized his accents: “Häring’s ethics is religious in structure (word-response), biblically and theologically influenced in conception and content (an ethics of discipleship and of Christian freedom), person-centered rather than principle-centered, and more concerned with good character than with right action.” All of these accents separated him from traditional, pre-World

War II, pre-Vatican II ethics (Hamel 1991:115). It was the “Christian freedom” motif, tied to the figure of Jesus Christ, that was least immediately translatable to the larger community.

Hauerwas expressed little interest in anything but the story of Israel and the Christian church, as focused in Jesus Christ. Stephen E. Lammers summarized: “Christians must give primary witness to the person of Jesus, Jesus as he is presented in the

Gospels. . . . [Hauerwas recognized] that the Jesus presented [in the scriptural texts] is not the ‘historical’ Jesus but Jesus as he was understood by those whose lives he had transformed. This . . . is all that we have and all we can know.” In Jesus came witness to the kingdom of God—theocentrism therefore triumphed—and to discipleship.

The Christian community, Hauerwas argued, must reflect and embody the commands, obedience, and example of Jesus in dealing with the subjects of medical ethics (and all other subjects). Here, as so often, the meaning of Jesus Christ divided not only Jew from Christian but also Christian from Christian (Lammers 1988).

The scholars who would study what future archaeologists dug up when they found this series in *Second Opinion* would deduce the central issue when a medical ethicist began with or brought up *theos*: What is the character of this Other? All the thinkers recognized that the human situation needed divine address; there is a “fault” (Verhey 1988:107), a flaw, a need for sustenance and redemption. But the main assertion about God is that God is creator of all people and all things.

If people asserted something like that, as most people in this culture did, there had to be consequences in ethics. For Ramsey, “the world is God’s creation, dependent on God for its being, order, and future,” and hence, he went on, it served as a base

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for “establishing the equal worth of all people, whatever their social status.” For Ramsey and others, this also meant that the case method was an excellent way of discerning need, for one should make crucial determinants of ethical action on the basis of study “of the historical world, rather than from revelation” (Smith 1987:112). Gustafson and all the others reasoned that medical ethics acquired a special character when all that is, is perceived as “gift” (Verhey 1988:118). For all, as with Bernard Häring, the response to creation and gift implies “stewardship,” a sense that exacts care and carefulness. Creation is unfinished, and the human—including the researcher, the physician, the cooperating patient, the ethicist—all become “cocreators” (Hamel 1991:118). Such is the testimony of these unearthed texts.

While all the thinkers set the human in a natural context and cared about the whole created environment, they were especially attentive to humans themselves and, with Häring, could be described in general, though not as members of a technically defined school, as *personalists*. Care for the person, for each person, in generally nonpaternalistic ways, came close to being an obsessive theme in these essays. For Häring, the person outranked even the application of divine law and certainly of human law (Hamel 1991:112). There must, he argued, be a “resacralization” of the person if the gift of creation was to be properly stewarded.

Grisez, using natural law and Catholic doctrine as his basis for reasoning, was explicit and firm about his point of view: basic goods and human beings “are both incommensurable and nonfungible,” that is, “they admit of no common measure enabling us to say that one is more valuable than another. Nor without loss could we replace one basic good with another, or even with another instance of the same sort of good.” Commodities like soy beans “are fungible, exchangeable. Babies are not. Nor are friendships or any other of the basic goods.” Not all of Grisez’s colleagues found the notion of nonexchangeability and nonfungibility to be quite so determinative, but they matched him in concern for

the distinctiveness and value of all humans (Hanink 1990:89–90).

With surprising frequency these thinkers relied on the concept of “covenant,” so familiar in Hebrew Scriptures and Reformed Protestant (Calvinist, Puritan) treatises and hence in many American Protestant spheres but less widely used in some other Christian communions. David H. Smith sent up an alert: “The first step in understanding Paul Ramsey’s moral theory is to recognize that it is controlled and informed by prior faith commitments: it is covenant-centered. Its basis is the assumption that God has made a covenant with people and that people therefore have an obligation to be faithful to that covenant” (Smith 1987:108). This covenantal thinking in many of the figures—less so in Childress than in the others—qualified their talk about the “autonomy” of individuals. Here Gustafson was most explicit, as Verhey condensed his position: “‘Certainly it is correct to respect [persons’] capacity for agency,’ Gustafson says, ‘but persons are more than their capacity for agency. . . . We are to respect persons not merely as individuals but as “members one of another” in their communities’” (Verhey 1988:108). Germain Grisez, less predictably a covenantal thinker, notes that “all our moral insights are deepened by our covenant relationship with God” (Hanink 1990:92). William F. May developed the notion most decisively, having written extensively on covenant in the professions and at book length on the physician’s covenant (Meilaender 1989:105). It may impress the future reader that one could write the story of theological ethics in this period as an elaboration of the concepts of divine creation and divine-human relations based on covenant. This combination separated theological ethics from the “contractual” thinking that dominated desacralized and secularized medical ethics.

Another way to put the case for the human side of the covenant is this: Whether through obedience to divine law (Gellman 1991:100), involvement with the Christian “story” (Lammers 1988:133), or attention to “deontology,” that is, ethics based on duty



(Smith 1987:108), a key characteristic was always “response.” Ordinary medical ethics was responsive to the needs of a patient, but theological ethics perceived all creativity, stewardship, care, research, and provision of resources to be part of a response to the divine “Thou” who demanded response—and graciously made it possible, even in a broken world where all actions are partial.

One peculiar stress of a number of these thinkers was on the theme of justice. Who merited care when not all could have care, as in the case of kidney dialysis or heart transplants? Paul Ramsey and James Childress, starting from somewhat different bases, both employed an inelegant but easy to understand coinage: to use Ramsey’s term, one “randomized,”

either through lottery or by priority in line—but not by measuring who merited attention because she or he was of higher value (Smith 1987:116). And according to Courtney Campbell, “Childress reflects the views of Paul Ramsey in holding that the experience of God’s indiscriminate love for human beings provides a morally significant analogy that favors equality in rationing decisions and rules out social worth assessments” (Campbell 1989:135).

The fact that different thinkers began at different points did not mean that they never converged on their themes and conclusions. For an example of convergence: *community*, in the responsive context of covenantal thinking, was a prime element for most. Hauerwas, naturally, made it central. For him, the community was the church. “Hauerwas thus explicitly counters the individualistic understanding of the person that he finds in modern society. He counters with the church, which for him stands against not only this society but any political society. Unlike modern society, the church is formed by the conviction that God rules the world, and it bears

witness to this fact” (Lammers 1988:137). So persistent and dominant was this theme that Hauerwas’s critics claimed that he had little to say about the ethical possibilities of non-Christians. “His response is quite simple: the church is his social ethic” (Lammers 1988:137).

This is not the place to follow these case-minded

personalists through the sample “hard cases” to which almost all of them attended consistently and exemplarily. Not all of them would be relevant in the time of the future archaeologists, thanks to anticipated technological changes that would occasion fresh framing of issues. Few writers in this series could avoid the topic of abortion, perhaps the most controversial issue that emerged in their time. The spectrum of

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positions was wide, beginning with Grisez on one end, in what might be called a “pure prolife” situation—in code language, not exactly theirs, “better two deaths than one murder”—and moving to much more qualified and tempered treatments across the range of possibilities. Given their presuppositions, including the pervasive wariness most of them showed toward individualism and autonomy, none of them would be on the “pure prochoice” end, which would have meant that nothing but the decision of the isolated woman mattered, that no life issue was at stake. No, for these writers fetal life was also a divine creation, a gift, which demanded response and stewardship in the context of covenant and community.

Similarly, at the other end of the life span, all nine were attentive to issues associated with death. There were distinctives here, too, born of religious faith. As preoccupied with persons as they all were, they did not see the mere extension of biological existence as the only and highest good. Whatever their (generally cautious) stands on euthanasia,



many of them stressed that the community-based character of theological ethics made “walking with” the patient the urgent ethical theme. Thus, for Ramsey, when the patient started to die, the talk of *cure* became irrelevant. “Now the most serious problems are discomfort and loneliness. Medical care for the dying instead requires providing *comfort*, that is, symptom control and company” (Smith 1987:123).

Similarly, for May, “death is not only a crisis of the flesh. It is . . . a crisis of community. . . . Death will also reveal—starkly and unmistakably—something about the communities in which the dying person lives,” just as it brings another crisis, of separation from God. May’s approach to all this was to give explicit witness to the fact of “death’s powerlessness over against the love of God [which] has been revealed and enacted in Jesus. This frees us from the power of death as a sacral reality, frees us from either preoccupation with or avoidance of death” (Meilaender 1989:111). An ethic of Christian address to Christian was particular here.

In earlier ages the intrusion of God-language into ethical situations usually came down from a human hierarchy and was asserted dogmatically and repressively. Modern medical ethics was born in a time when religious triumphalism had come to be seen as a foolish expression. The address of most of these nine thinkers and their nine expositors tended to be quite modest. May spoke of theological ethics as offering a “corrective view” more than as having all the answers (Meilaender 1989:112). Regarding what the theological ethicist had to offer, almost all the thinkers shared Gustafson’s word: *limited*. As Verhey condensed Gustafson’s position, “Theology qualifies the fundamental orientation of a person’s life, . . . but it can qualify judgments about conduct only indirectly, only through the process of discernment used to reach them. ‘From the standpoint of immediate practicality, the contribution of theology is not great’” (Verhey 1988:116).

Such a sense of finitude, ignorance, and limitation was appropriate, given the complexities, but all the thinkers acknowledged that issues beyond “im-

mediate practicality” went into the personal relations of the patients’ world and that of those who seek well-being. *Discernment* was an often-used term in the calls of these responsive thinkers (Verhey 1988:108; Hamel 1991:124; Meilaender 1989:116). The important issues tended to be settled not only as prime-time and page-one addresses to crises and dilemmas. They had to do with understandings of creation as gift, evoking stewardship; of covenant, involving response; of community, countering autonomous individualism and loneliness. Through all the writings there was evident an awareness that the human condition is, in its own terms, a tragedy (Lammers 1988:180) not to be overcome by casual or brusque and oversure ethical comment, including or especially by theologians.

At times as one reviews these essays a temptation comes to the reader to ask for less of the “relentless consistency” with which people like Ramsey pursued uncomfortable themes. Here and there one looks for a lighter moment, a grace note to go with the witness to grace, the gift of relief to go with the perduring testimony to gravity. Yet the seriousness of these thinkers, who—as the archaeologists would have found had they had a chance to know them in personal encounter—by and large were good company, *bon vivant* types who loved life as they loved theology and ethics as these related to life, is apparent.

In their seriousness they kept demonstrating a kind of “go slow” approach to ethics when the character and quality of human life were concerned. It has been said that once upon a time when the theologian was too obtrusive and obstructive, the scientist had to serve as the guardian of human freedom. In the period of modern medical ethics, science and technology, even in the most ethical and discerning hands, could be the limiters of human freedom and barriers to community. In such a situation the concerns manifest in the work of these 18 thinkers might well have performed humanizing and personalizing functions both in the communities that shared something of their theistic faiths and those that rejected such faiths outright.



The archaeologists of the future who came across these writings would be struck by the authors' genuine interest in seeing the details of bodily and social existence thrown against the background that offered the largest scope. That meant a resort to the concept of God, of *Theos*, as in *theology*. They were ready to speak and write in this manner fully aware

of the difficulty induced by God-talk in a society that describes itself as secular and pluralist. The prospect for yield, in their eyes, is too great for them to be content with lesser concepts. They leave a rich legacy for the generations which, though they use different terms, also speak of ethics, the good, and God. ☸

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# REFLECTION

## The Need for Transcultural Nursing

*Madeleine Leininger*

WHEN I ENTERED NURSING IN THE EARLY 1940s, there were very few patients one would consider as "foreigners" in the hospitals. Today, however, it is common for the nurse to have patients from Pakistan, Tehran, Kiev, Palestine, Bolivia, El Salvador, Haiti, Pretoria, Tokyo, the Yukon, Melbourne, or the Philippines on any given day. Moreover, whatever the cultural differences, it is the nurse who is expected to provide the most direct and continuous care to patients in acute or chronic illness states. It is therefore imperative that nurses be prepared through educational programs to learn about, understand, and respect the cultural beliefs and religious values of their patients.

The transcultural nurse specialist is a relatively new practitioner in health care. As the founder, in the early 1960s, of this new field, I am pleased to know that today a cadre of such specialists works in a variety of health care settings and also as international consultants. The transcultural nurse specialist is one who has the knowledge, sensitivity, and skill to care for people of diverse cultural backgrounds. Today these practitioners are in great demand, and the field has helped increase patient cooperation, promote well-being, and prevent lawsuits. A few illustrations help to show why.

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I WELL RECALL WHEN NURSE JONES CALLED ME on the afternoon shift, annoyed because Mr. C was refusing to drink the fluids offered to him following his major bladder surgery. He was supposed to "force fluids" and drink at least six glasses of water that day. Mr. C was a recent immigrant from China, but he spoke some English and had told the nurse, "I cannot drink that water." Ms. Jones, a nurse of European-American heritage and a very persuasive and assertive person, was trying every possible professional strategy she had learned in fundamentals of nursing to get Mr. C to drink water. She had even warned him that he *must* drink fluids, or the physician would give him fluids in his veins. I saw right away that the problem was a transcultural one: Mr. C had firmly refused the water because it was full of ice. After talking with Mr. C about his homeland, I made him a warm cup of tea. He immediately drank the tea and said, "This is exactly what I needed, not that ice water." I explained to the nurse that Mr. C, along with other Chinese patients accustomed to the practices of traditional Chinese medicine, would consider major surgery to be a "hot condition with a hot procedure." Drinking ice water after such a hot procedure, they believe, would cause an imbalance in body temperature, which could make them ill and greatly handicap their recovery. The "hot-cold" theory of how to maintain wellness and prevent illness was very much on the mind of Mr. C. A thermos of warm herbal tea with a cup and saucer was placed at Mr. C's bedside. He was very happy and made an uneventful recovery.

In another encounter I found a staff nurse trying to convince a patient to accept pills, but he was flatly refusing them. The nurse was annoyed with Mr. G,



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but she was also baffled. After none of her persuasive strategies worked, she resorted to a firm threat: "Your physician wants you to take these pills now, and if you don't you could get sicker." The nurse did not know that Mr. G was an Arab Muslim with special beliefs and religious rituals, and she did not recognize that he was refusing to take the pills in his *left* hand. Exasperated, the nurse turned to me and said, "I have all these medications to give this morning, and I cannot spend any more time with him. Can you get him to take his medicine?" I talked with Mr. G and then offered him the pills in his *right* hand. He quickly accepted them, saying "Thank

you. You seem to understand me." He seemed greatly relieved. Mr. G had important religious reasons for not taking pills or food in his left hand. For a devout Arab Muslim the left hand is used for unclean tasks like cleansing one's body or genitals before praying to honor Allah, whereas the right hand is used for clean duties like preparing food or receiving pills. Mr. G's behavior was firmly guided by his belief in the Qur'an, the sacred book of the Muslims. Neither the nurse giving the medication nor the other staff nurses on the unit were aware of this Lebanese Muslim's beliefs, and they judged his behavior to be uncooperative and suspicious. After this incident, however, Mr. G was given medications in his right hand, and he washed himself with his left hand five times a day before praying to Allah.

On another occasion I was working with Mrs. Smith, the staff nurse who for several weeks had been

caring for Mary, a 12-year-old Mexican-American girl with terminal cancer. During this time Mrs. Smith had become much attached to the girl, spending time with her and giving her tender, loving care. Mrs. Smith, however, could not understand why the parents and many other family members would pray so fervently at Mary's bedside. Mary always seemed

relaxed and consoled when the family prayed with her, but the nurse also noticed that the parents seemed to accept Mary's illness without raising nursing or medical questions. They expressed appreciation to the nurse for giving their daughter good care but would always end by say-

ing, "Mary's life is now in the hands of God, and we accept whatever God wills." This statement annoyed Mrs. Smith, who would respond, "But Mary is going to get well because today we have powerful new medicines, effective treatments, and good nursing care for cancer patients. Please don't place everything in God's hands, for we will get her well." The parents listened to Mrs. Smith but would shake their heads in disbelief. It was clear that the nurse was uncomfortable about leaving Mary's life completely in the hands of God; she wanted modern nursing and medicine to be in control and to help Mary recover.

When Mary died soon thereafter, the nurse openly cried for her and said to the parents, "I am sorry this happened. Mary was to live. I liked her so much." Mary's parents attempted to console the nurse: "Don't cry so hard. We are very pleased that God chose our daughter to be with him in heaven. She is in good



Martha Tabor/Impact Visuals



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hands forever." This view troubled the nurse—it seemed too fatalistic and unreal. At the parents' invitation, however, Mrs. Smith attended the Catholic funeral mass for Mary—called the "Mass for Celebration of Life." Afterward she observed, "I gained a new perspective on living and dying, even though I lost a very precious child I loved." The strong faith in God exhibited by Mary's Mexican-American family shaped their supportive care of the sick and dying, and the nurse saw dying in a new light: as a returning to God. This new perspective helped Mrs. Smith and other staff nurses in their care of similar children and their extended families who brought a strong faith to their nursing encounters.

In still another encounter, I recall stopping briefly to see Mrs. T, a patient from the Philippines who was experiencing her first stay in an American hospital. When I walked into her room, I found her tense and pulling on blankets to cover her body while the nurse was trying to give her a morning bath. The nurse had removed the blankets and was using only a small towel to cover the woman's breasts as she washed the rest of her body. Mrs. T was most uncomfortable and told the nurse firmly, "I am clean and do *not* need this bath. Please leave me alone." The nurse was annoyed but said, "All right." Called to the nurses' station for another matter, she left the patient. Later in the afternoon, when the patient's daughter came to visit, Mrs. T asked for a basin of water so she could bathe herself with her daughter's help. From this situation, the nurses learned the tremendous importance of maintaining modesty for Philippine female patients and not overexposing their bodies. The values of modesty and privacy meant much to Mrs. T, who had only been in the U.S. for a short while. In addition, Mrs. T wanted her daughter to bathe her because this was a daughter's obligation. The nurse was unaware of these cultural values and so had interpreted Mrs. T to be resistant, uncooperative, and unappreciative of her nursing care. Viewing the situation differently, she could be more sensitive to the need of her Philippine patient for privacy, modesty, and respect and could include the daughter in her mother's care.

The final incident I recall concerns a head nurse in the labor and delivery room who was trying to get a Lebanese Muslim father to "bond" with his newborn

child. The father was disturbed about such an idea and refused to stay in the delivery room. I was called to help the father stay with his wife and newborn child. After recognizing the cultural background of the father and mother, I discouraged the nursing staff from holding to this practice because it was offensive, unethical, and inappropriate for them. In fact, it was a violation of Arab Muslim beliefs and practices. According to modern Anglo-American medical practice, it is highly desirable that husbands remain in the birthing room during delivery and "bond" immediately with their infants after birth. For Arab Muslims, however, it is culturally taboo for males to be present during childbirth and to see a woman's genital organs exposed. Childbirth is viewed as a *woman's* special experience and not a man's. Thus the nurses learned that various cultural expectations concerning sex roles must be honored by nurses and physicians during pregnancy and delivery. In this case the father was very upset with the staff. He left the delivery room and went home, later warning other Arab Muslim males about this strange practice in the American hospital.

FROM THESE FEW NURSE-PATIENT ENCOUNTERS, one realizes that seemingly minor nursing or medical practices can become major factors in gaining patient and family cooperation. Transcultural understanding can prevent major clashes or conflicts and lessen the fears of patients who enter a strange hospital culture. Indeed, not only do cultural factors make a big difference in health care and treatment practices; they can determine whether patients will even come to the hospital.

In any culture, the patient brings his or her religious, spiritual, moral, and ethical values to the hospital, and these values are closely linked to well-being, health, sickness, and death. But many cultural values tend to be covert; people may not readily discuss or share them with professional strangers, unless the strangers are trusted. Cultural care—which consciously integrates sensitivity to patients' religious, philosophic, ethical, kinship, and social values—enables nurses and other health care providers to enter the cultural world of their patients. When this is achieved, many rewards and positive outcomes are forthcoming.



# ON THE BIOETHICS FRONT

*In this issue, "On the Bioethics Front" takes up a topic that naturally concerns each of us—ourselves. Ruth Purtilo focuses on an aspect of self that has fallen somewhat out of favor recently in bioethics, the notion of autonomy. There remains a pressing practical need to refine what self-determination is all about, and the first three articles reviewed here attempt just that. Stanley Samuel Harakas then looks at the idea of self from a different angle, examining the notion of embodiment. Two articles are considered, each probing in interesting ways the relationship between "biological truth" and "ethical truth." All five articles underscore the importance of the abiding questions, "Who are we?" and "How are we to be?"—questions as much of faith as of fact.*

— John F. Kilner

## Patient Autonomy: Revisiting a Concept

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**Ruth B. Purtilo**

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Marion Danis and Larry R. Churchill. 1991. "Autonomy and the Common Weal." *Hastings Center Report* 21:25–31.

C. Cohen and M. Benjamin. 1991. "Alcoholics and Liver Transplantation." *Journal of the American Medical Association* 265:1299–1301.

Matthew Robert Gregory. 1990. "Hard Choices: Patient Autonomy in an Era of Health Care Cost Containment." *Jurimetrics Journal: Journal of Law, Science and Technology* 30:483–500.

PATIENT AUTONOMY IN HEALTH CARE HAS FALLEN on hard times in the bioethics literature. A decade or

so ago, bioethicists heralded this concept as one of the governing ideals of the patient-physician relationship. Today it is sometimes blamed for creating an overly individualistic ethos and generating selfish expectations in patients or else ridiculed as part of an outmoded mantra of medical ethics that older ethicists learned to chant at a young age and somehow can't grind out of their psyches (or writings). Very few recent articles in the bioethics literature take up the issue of autonomy.

Meanwhile, society at large seems not to have noticed that autonomy, or self-determination, may be passé in the health care setting. In December 1991 the Patient Self-Determination Act went into effect, causing clinicians and hospital administrators to link arms to meet this challenge. Furthermore, case law and legislation provide support for the patient's "voice" to be not only heard but listened to in health care situations. Health professionals themselves continue to practice as if the patient's dignity and respect are at least partially realized by enabling the patient to be treated in accord with his or her informed preferences.

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In the midst of this foment, fortunately, thoughtful treatments of the concept occasionally still emerge in the bioethics and other professional literature. Rather than concluding that autonomy is an emperor with no clothes, these articles attempt to revisit the concept and place it in proper perspective as the context of providing and receiving health care changes and our insights evolve.

In "Autonomy and the Common Weal" physician Marion Danis and bioethicist Larry Churchill offer one such treatment of autonomy. As in several other recent bioethics writings, the authors attempt to bring into focus two tasks of the physician seemingly in competition: honoring patient autonomy and protecting social equity. The authors observe correctly that ethicists often apply the concept of autonomy to justify the patient's wishes alone, placing the physician in the untenable position of having to ignore the impact of that choice upon the common weal. They note that a dilemma has emerged because the meaning of patient self-determination has changed—from the right to refuse treatment to the right to very costly but potentially beneficial interventions if the patient wishes them. Not surprisingly, the authors use as a test case choices about medical care toward the end of life. Their major contribution is to propose an analogy between patienthood and citizenship.

According to the authors, *citizenship* embraces two identities: the "liberal, personal" identity and the "moral, social, and communitarian" identity. In her personal identity the citizen as autonomous decision-maker or agent has legal standing defined by rights and duties. In her communitarian identity the citizen shares purposes and vulnerabilities with everyone else. The latter understanding views selfhood as essentially social and the individual as a steward of communal resources. Within this dual identity a person should not view himself or herself as an absolute without a context but as a being bounded by the limited resources of society and the competing rights of others. In short, the authors conclude that conceptualizing the patient as citizen brings to light the necessity that individual decisions be balanced with "duties to make judicious and proportionate choices." Individual autonomy may be exercised only within the context of responsibility and a sense of stewardship.

This approach succeeds in keeping the concept of autonomy intact as an ideal while attempting to place

reasonable limits on an individual's exercise of it. Most readers would agree with the authors that the pivotal idea of citizen as steward is "usually associated with religious traditions rather than civic ones" and emphasizes the communal aspects of identity. Herein lies an important critique of their approach, because concerns about stewardship are neither logically nor pragmatically a necessary component of autonomous decisions (though these concerns may be taken into account if the agent so chooses). The authors' acknowledgment that their schema works best in societies guaranteeing the fundamental right to basic health care for everyone points to a weakness in their approach to the function of autonomy. In such a society an individual's stewardship of shared resources would be easily exercised in most health care decisions: a person would not have to make a choice that would cheat himself or his loved ones. Under those societal conditions, the exercise of individual autonomy in the direction of considered constraint would present little peril in mundane health care decisions. But what about life-and-death decisions? There the communal self might well lose the battle with the individual self's fear of death and wish to survive. In the life-and-death moment one might just as likely judge that one had rendered unto Caesar that which was Caesar's and hope that the lifesaving intervention be applied.

IN THE SECOND ARTICLE, AS ABOVE, AUTONOMY IS seen as a concept pertaining to individual choice, and the autonomous person is one who makes choices in isolation. But the focus here turns to choices made *before* the life-and-death moment. The position that previous life-style choices influence—and may even determine—a patient's opportunity to exercise informed preferences in life-and-death decisions is addressed in "Alcoholics and Liver Transplantation," a document promulgated by the Ethics and Social Impact Committee of the Transplant and Health Policy Center at Ann Arbor, Michigan (hereafter referred to as the Ann Arbor Committee). The reader should recall, as background, that in the early days of organ transplants, subjective judgments about patients' situations were sometimes part of the decision about who should receive the scarce and precious lifesaving resource. Parenthood, a high status or high level of responsibility in the workplace, and age were among



the determining factors. When the moral underpinnings of this new decision-making process were later scrutinized, however, questions were raised about such considerations. A new twist has arisen in the case of alcoholism and liver transplants, and the discussion has serious implications for the allocation of future scarce resources, for example, in the distribution of a possibly scarce supply of any curative medicine for AIDS that is developed.

The Ann Arbor Committee gets right to the heart of the matter: "A widespread condemnation of drunkenness and a revulsion for drunks lie at the heart of this public policy issue. Alcoholic cirrhosis—unlike other causes of end-stage liver disease—is brought on by a person's conduct, by heavy drinking. . . . Even if it is true that alcoholics suffer from a somatic disorder, many people will argue that this disorder results in deadly liver disease only when coupled with a weakness of will." The committee observes that the alcohol abuser is condemned not on the basis of failing to exercise autonomy or even of being deemed incompetent to do so. She is excluded from receiving an organ transplant because she made the wrong choices before arriving at the negotiating table where scarce resources are allocated. In other words, it is not the patient's awareness of the context in which autonomy should be exercised (that is, the societal context with its need for good stewards of scarce resources) that will govern but rather her choices predating the life-threatening situation in which she now finds herself. For all practical purposes, the alcoholic patient's previous choice removes her right to self-determination at the crucial life-and-death moment, even if a successful medical outcome is probable.

Cohen and Benjamin, the lead authors of the Ann Arbor Committee document, try to show why this line of reasoning is not morally justifiable. First, they maintain, one can question the degree of volition in the decision to drink to excess. Substantial evidence indicates that some who use alcohol have a greater predisposition for abuse than others. And for some who do, the predisposition to cirrhosis also is greater. Second, and more important, even if we could assess volition, we cannot reasonably decide what penalties different wrong choices deserve. In fact, other previous life choices (a history of abuse of one's children, cheating on one's income taxes or spouse, lying to protect one's interests) are not deemed sufficient to preclude

a patient's making life-and-death choices. Thus judgments made on the basis of one choice—namely, to use alcohol excessively—do not pass the test of consistency.

The report of the Ann Arbor Committee is especially important because it helps to highlight how a person's choices before he becomes a patient can be imported into health care practice and policy. The role of autonomy in health care decisions usually is treated as if it applies only within the boundaries of an existing relationship between health professional and patient. The authors show that focusing on the autonomy exercised before the relationship was established can remove the potential to exercise it at the most crucial moment.

It follows that the alcoholic must go to extreme measures to have his wishes heard in such a predicament. In this regard the alcoholic person's situation is similar to that of the woman in the Christian Scriptures who had to push through the crowd to touch Jesus' garment. She differs from the alcoholic in that there is no evidence others believed she had brought her hapless state on herself. But her condition did stigmatize her, even beyond the stigma of her being a foreigner in that land. And she, too, knew that she would not receive help through the usual means of access. To reach Jesus, the healing source, she forced her way through the crowd. Her potential for gaining Jesus' attention was less than she realized because Jesus was being rushed to a life-and-death scene involving a small child, the daughter of a community leader. That the woman had gone well beyond the bounds allowed by society is evidenced in the terror and astonishment she expressed when Jesus, understanding her "request," said, "Who touched me?"

Such extreme means should not be required of a person whose choices have placed him in a stigmatized position in society, particularly since the alcoholic patient's efforts are much less likely to obtain the healing that Jesus bestowed on the woman. In short, to allow the life-style choices made by someone before he becomes a patient to preclude that person's further choice is to misuse the concept of autonomy. The same exercise of autonomy that is deemed appropriate for other types of patients should be allowed.



"HARD CHOICES: PATIENT AUTONOMY IN AN ERA OF Health Care Cost Containment" turns the kaleidoscope on the concept of autonomy once again. Speaking primarily from a legal perspective, Matthew Gregory addresses key questions raised by recent legal and policy developments related to cost containment. Central to the discussion is the legal protection of patient choice. Specifically, what moral and legal importance should patient autonomy have when a physician is economically motivated to withhold disclosure of some medically indicated alternatives?

Gregory is aware that physicians concerned about patient choice in an era of cost containment and a prospective reimbursement system of payment may decide to withhold information from patients. Rather than condoning this paternalism which automatically diminishes patient autonomy, he counsels that "the physician should not hide from the patient the fact that, under prospective reimbursement, treatment must be more cost conscious." Yet, for Gregory, even when a decision to perform or omit an intervention is based primarily on cost considerations, the patient theoretically is still best qualified to make the final choice. The patient has never made decisions based strictly on medical facts, and a change in current practice should not be occasioned because cost consciousness is one of the "facts." Granted, patients who traditionally have not been required to consider the cost-benefit ratios of certain procedures may demand

that the more costly procedures be performed. The author concludes that it is better for the physician at that point, if necessary, to refuse to treat the patient further, but not before the patient has been presented with all relevant facts that go into the decision making.

The concept of autonomy remains intact in Gregory's treatment. New types of facts are provided to the patient, but the basic approach to the patient's right to information as an autonomous agent has not changed. The ironic—many would say tragic—twist is Gregory's conclusion that while the patient is best qualified to make the final choice, he or she may have great difficulty in finding a setting where it will be carried out. This disjuncture between process and outcome reminds one of an old adage: "The operation was a success, but the patient died."

THESE ARTICLES HIGHLIGHT THREE WAYS IN WHICH the role of autonomy is being reexamined in health care: the first focuses on the context in which autonomy is exercised; the second, on the times at which autonomy is exercised; and the third, on the necessity of including cost considerations when alternatives are presented to the autonomous patient. In each, it appears that the ideal of autonomy is "alive and well" within the world of health care. Further attempts to clarify and enrich the concept will benefit theorist and practitioner alike.

## Reflecting on the Body . . . and Ethics

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*Stanley Samuel Harakas*

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Leon R. Kass. 1985. "Thinking About the Body." *Hastings Center Report* 15:20–30.

Thomas Shannon and Allan B. Wolter. 1990. "Reflections on the Moral Status of the Pre-Embryo." *Theological Studies* 51:603–26.

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FEW WHO REFLECT ON THE SIGNIFICANCE OF human existence in our day begin with the phenomenon of our embodiment. Fewer still accord to our bodily existence a heuristic value for assessing not only the meaning of human life but the sense of human identity. Rarer yet is the thinker who starts such a process with dead bodies . . . with cadavers.

One who does is Leon R. Kass. "Thinking About the Body" struck me upon my first reading as expressing much wisdom that is directly applicable to contemporary bioethics. Neither a historical study nor a study focused on sexuality (as is Peter Brown's work *The Body and Society* [1988]), this article looks at the issue of our self-understanding by means of thinking



about the body. This "bodily reflection" is critical if we are to understand the contemporary challenges to ethics in the rapidly changing area of biotechnology. Though Kass's article is reviewed here at length, Thomas Shannon and Allan B. Wolter's "Reflections on the Moral Status of the Pre-Embryo" also comes into the discussion because it illustrates the implications and challenges of Kass's approach for bioethics.

Kass chooses to begin and end his discerning reflections by considering the treatment of the dead body, in the first case at the hands of neophyte medical students and in the latter, in the practices of three disparate cultures. Between, he reflects on the reality of somatic existence and its message to us about ourselves.

The article appealed to me because it charts the author's authentic searching. Here is a man of science—a physician—and a man of disciplined reflection—a philosopher—who remains unsatisfied by the materialistic and mechanistic presuppositions of modern science. He asks, not expecting a positive response, "Does modern medicine, grounded in modern reductive and mechanistic science, have an adequate account of the living body—as an organic whole; as 'lively and self-moving' as a personal center of awareness, felt need, and self-concern; as a vehicle of individuated self-presentation and communication?" (p. 21). The "corporealism" that provokes such a question is not adequate as an answer for Kass.

On the other hand, through the vehicle of a moving personal story about the death of a physically frail but brilliant man, Kass articulates the suspicion that "the body may not be more than stuff, but the man seems to be more than his body" (p. 21). Such reflections force thought about the body. And, he eventually reasons, "Questions about the body are tied to questions about life, death, and soul; the whole cosmic picture is soon at issue. . ." (p. 22).

Thought about the body leads Kass to pull his reader away from abstractions. "In its prime usage, body is always body of: body of an animal or human being. The body is always some-body, somebody's body, some body in particular." This reflection leads him to another position, currently not widely held: namely, a rejection of the existentialist view that seeks the whole of human meaning and dignity in conscious decision making and self-affirmation. This mind-set, so dominant in our society, functions materialistically,

yet paradoxically it ignores the body as part of what it means to be human. Kass seriously questions the adequacy of those "theorists of personhood, consciousness, and autonomy, who treat the essential human being as pure will and reason, as if bodily life counted for nothing, or did not even exist" (p. 20).

So, for Kass, our bodies have a message for us about our humanity. But this is no uncritical New Age dreamy-eyed nature-talk. Interestingly enough, Kass finds grounds in evolution for positive assessments about the meaning of the body for understanding the human. What he lifts up from the comparison between animal and human evolution in a section titled "Looking Up to the Body" is its wholeness. "Perhaps the first thing that strikes us in looking at the body—any living body—is that it is a whole, a unity, a one" (p. 26). It is physical human uprightness that creates the conditions for the exercise of rationality and "a consciousness somehow grafted onto or trapped within a blind mechanism that knows only survival" (p. 26). In this sense, human body and reason are not contrasted but treated as co-terminous: "We are rational (i.e. thinking) animals, down to and up from the very tips of our toes." Immediately he adds, "No wonder, then, that even a corpse still shows the marks of our humanity" (p. 26).

But there is a negative side as well. The section "Looking Down on the Body" highlights the message of our isolation, nakedness, and shame and the difficulties of choosing rightly: "our incompleteness, insufficiency, dependence, mortality, and the lack of self-command. Reason's first and painful discovery was of its own poor carcass. . ." (p. 27). All this follows the paradigm of the Old Testament story of creation and fall. Yet the very act of recounting the fall is in itself "a mark of our dignity . . . since much of dignity consists in our thoughtful response to necessity. . . . Man does not take his shame lying down. Aroused from dormant potentiality, human ingenuity and manual dexterity give birth to the arts, at first glance, to cover our shame, but in truth to elevate and humanize the otherwise degradingly necessary" (p. 27).

Kass describes the bodily impetus to social consciousness in terms of "one's place in the line of generations" (p. 28). The body confirms our self-perception as part of an ongoing human tradition; we are finite, yet we make a personal contribution to that tradition and have a responsibility for its perpetuation.



Source of dignity and sign of our abjection, the body's limitedness witnesses to the transcendent, to our interconnectedness with past and present, and to the truth that we are not the sources of either our physical or our mental existence. Embodiment is a "gift to be cherished and respected" (p. 28), and the body is worthy of respect whether alive or dead. So finally, his assessment:

Thinking about the body is both exhilarating and sobering for the thinker: exhilarating because it shows the possibility of a more integrated account of his own psychosomatic being—against the prejudices of corporealists, subjectivists, and dualists—by showing the way in which his body prepares him (or, shall I say, itself) for the active life of thought and communication; sobering because it teaches him his vulnerability, dependence, and connectedness, exploding his illusions of and pretensions to autonomy. Thinking about the body is also constraining and liberating for the thinker: constraining because it shows him the limits on the power of thought to free him from embodiment, setting limits on thought understood as a tool for mastery; liberating because it therefore frees him to wonder about the irreducibly mysterious union and concretion of mind and body that we both are and live. (p. 29)

Kass ends with an interesting exercise, examining the way three cultures of antiquity dealt with their dead. Culture-bound Indians ate the dead, defying death by incorporating their ancestors into their own bodies. The Greeks cremated their dead, thus transferring their dead to memory and record and affirming symbolically the fullness of their identity and integrity as human beings. Kass clearly likes the Greeks better. The Persians, however, obtain his ire. Leaving the body exposed, to be eaten by wild dogs and vultures, they show disrespect for it and a disregard for its meaning and significance for the total person.

While Kass seems to argue that moral judgments ought not to be drawn from the bodily dimensions of our existence in a physicalist fashion, he clearly conveys the impression that our own society, in its cavalier treatment of the human body as a mere means, is cast in a Persian mold. His concluding paragraph is strikingly ethical:

We, on the other hand, with our dissection of cadavers, organ transplantation, cosmetic surgery,

body shops, laboratory fertilization, surrogate wombs, gender-change surgery, "wanted" children, "rights over our bodies," sexual liberation, and other practices and beliefs that insist on our independence and autonomy, live more and more wholly for the here and now, subjugating everything we can to the exercise of our wills, with little respect for the nature and meaning of bodily life. We expend enormous energy and vast sums of money to preserve and prolong bodily life, but, ironically, in the process bodily life is stripped of its gravity and much of its dignity. Rational but without wonder, willful but without reverence, we are on our way to becoming Persians.

Kass's article served to focus my own disquietude about our society's disregard for the somatopsychic unity of human existence. As an ethicist in the Eastern Orthodox tradition I am imbued with the idea of the fundamental and, because of the resurrection, permanent bodily-spiritual identity of the human being. Precisely as an ethicist, I recognize what Kass hesitatingly implies: that the bodily dimension of human existence has, on a certain level, a normative claim on moral decision making. Yet it cannot be so determining that the body overrides more important values that arise from our identity as also spiritual beings. For the ethicist, a difficult and complex problem arises: How much of the bodily should determine ethical decision making? How much the spiritual?

A case in point is Shannon and Wolter's remarkable and illuminating "Reflections on the Moral Status of the Pre-Embryo." The authors begin with a helpful review of the most recent scientific literature on how the first phases in the fertilization process lead to the formation of the individual from a biological perspective. This study of bodily processes is then matched against prevailing Roman Catholic teaching concerning ensoulment and its moral assessment regarding abortion. Here the bodily dimension of human existence takes on the kind of moral significance that Kass seems to want yet cannot bring himself to admit. In their study Shannon and Wolter describe fertilization as a process, noting that up to the third week after implantation in the lining of the uterus, the conceptus is capable of either reproducing a whole new being or of recombining into twins. This entity they designate a *pre-embryo*. These biological phenomena consequently influence moral judgment. Careful not to contradict official Roman Catholic teaching regarding abortion,



the authors, however, show that biological and somatic information cannot help having an impact on moral decision making. The biology that shows the instability of the pre-embryo (from potential twins to a single individual and vice versa) is an argument against the position that the pre-embryo is a person with full human dignity and rights.

I myself have used an approach similar to Shannon and Wolter's in dealing with Clement of Alexandria's arguments against birth control. In "Christian Faith Concerning Creation and Biology" (1984:246-47) I argue that the inadequacy of Clement's understanding of the process of conception gave him erroneous presuppositions for formulating what must be the most unyielding and extreme position on birth control ever articulated in the history of Christianity. Clement held, with most ancients, that the human being was totally present in the sperm of the male and that the woman's role was to nurture it in her womb until term. Clement drew the conclusion that every sperm was a human being. Using an agricultural model, he argued that every sexual union had as its purpose the "sowing" of a seed for the purpose of procreation. Guided by this erroneous biology, he developed an ethic against contraception that subsequent biological knowledge has invalidated. The biological foundation of the argument no longer holds, and therefore the ethical conclusions based on it cannot stand if that is their sole support.

In their own way Shannon and Wolter use the methodology of Clement. But scientific knowledge has advanced, and conception is no longer seen as a single event. It is no longer possible to speak of conception as an instantaneous happening. It is a process whose beginnings precede penetration of the ovum by the sperm because of the chemical activity necessary to prepare the external layers of the ovum for entry by the sperm. It is understood as a process that can last for several weeks after implantation in the uterus, because not until then is the individualization of the pre-embryo fully set. The concept of the *pre-embryo*, in fact, is a direct result of this new biological knowledge.

For ethical judgment regarding abortion, the concept raises new questions. Even the tradition becomes capable of new readings. Once that biological information is absorbed, the biblical phrase "conceived in the womb" (Luke 2:21) can take on new meaning. If

"conception in the womb" is understood as conforming to new biological knowledge, then is the status of the pre-embryo substantially changed from an ethical perspective? Clearly, the argument based on a "moment of conception" used so often by those of us holding the "prolife, antiabortion" position is challenged by this biological information.

At the same time, I am troubled that too great a focus on the bodily side will make ethics into a deterministic discipline. To what point is biology determinative of norms? It seems clear to me that for somatopsychic beings such as we humans are, the body and its organization and functions must have a significant bearing in moral decision making and most certainly in bioethical issues.

But should the bodily dimension of human life be determinative? I think not, for the intellectual-volitional-spiritual dimensions of human existence are what distinguish humans from the rest of the animal world of which human beings are part. Further, how does one determine which among the numerous biological indicators are normative? For example, Shannon and Wolter discount the importance of the unique genetic DNA code in favor of the significance of the developmental process of the pre-embryo. What gives one of these biological factors control over the others? Is not life itself a continuing process of growth toward the fulfillment of our humanity? In what sense is "individualization" relevant, when to be human requires others so that we can realize potentials only implicitly present in our makeup?

In the existentialism-soaked environment of the twentieth century, both of these articles raise an important and necessary counterargument that needs to be heard and affirmed. They help restore a balance in our views of the importance of the body. That, in my judgment, is essential for good bioethical decision making. But it certainly does not resolve all problems for the bioethicist.

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# NOTEBOOK

On a normal day, the National AIDS Hotline receives about 3,800 calls. This number jumped to nearly 40,000 in the first five hours after Magic Johnson announced he had tested positive for HIV. The basketball hero's infection—and the popular reaction—is



likely to raise new calls for more routine testing. Recent studies show that only some 20 percent of the estimated one million people infected with the virus in the United States know it.

(*U.S. News and World Report*, 18 November 1991)



For nearly 20 years, the government has resisted the appeals of cancer patients for legalization of marijuana for therapeutic purposes. Officials have said that the drug has "no currently accepted medical use."

Now the first published survey of cancer specialists on the issue indicates that many *do* believe that marijuana can lessen their patients' suffering.

Policy analysts Mark A. R. Kleiman and Richard Doblin of Harvard's Kennedy School of Government anonymously surveyed 1,035 oncologists about marijuana's usefulness in controlling the nausea and vomiting many cancer patients experience during chemotherapy.

Among the findings:

- 44 percent said they had recommended marijuana to at least one patient;
- 63 percent said pot was effective;
- 48 percent said they would prescribe it if it were legal.

One hundred and fifty-seven doctors also answered a question comparing marijuana with the synthetic THC tablets that can be prescribed legally. (THC is the active ingredient responsible for pot's therapeutic effects.) Seventy-seven percent of that group said they believed smoking marijuana was more



effective. Kleiman says that might be because smoking makes the drug take effect more quickly and because some patients with stomach problems have trouble absorbing the tablets.

Despite the study's results, it doesn't appear that the administration's policy is likely to change. A Drug Enforcement Administration spokesperson says pot's "potential for abuse" far outweighs any medical benefits it might have.

(*In Health*, November 1991)



Drawings by Susan Teumer Marty



Women around the world now live on average longer than men, and that gap is still increasing both in poor lands and in most of the affluent ones. Australian author Penny Kane, in her recent book *Women's Health from Womb to Tomb* (St. Martin's Press, 1991), reports that only in South Asia are matters otherwise: an excess death rate is still seen among women during their reproductive years. Specific local studies clearly link the increased rate of mortality to pregnancy and childbearing in the absence of adequate medical care. In those circumstances, biology is a kind of destiny.

The preference for sons, which remains strong in Hindu, Muslim, and Chinese societies, has resulted in a higher mortality rate among female infants, Kane reports. "Selective neglect" of girls in the earliest years may be as quietly expressed as weaning infant daughters at an earlier age or even trying for the next pregnancy sooner after the birth of a girl. The effects are much the same: less care, affection, and food for infant girls. And when female infants do get sick, parents are more likely to delay visits to the health facility. Here is a toll collected not by nature but by nurture.

Why, then, is life expectancy still greater for women in the long term? Because young men are plainly at much excess risk from accidents and suicide; older men from widespread coronary disease.

(*Scientific American*, February 1992)

There are 2,300 cases of euthanasia annually in the Netherlands, said the Dutch Committee to Investigate the Medical Practice Concerning Euthanasia in its official report released on September 10, 1991. The definition of euthanasia used, however, included only active termination of life at the explicit request of the patient. The report also documents 23,006 additional cases annually that many would identify as euthanasia. These include 400 cases of physician-assisted suicide; 8,100 cases of morphine given in excessive doses with an intent to end life (3,159 with the patient's consent, 4,941 without it); 13,506 cases of life-prolonging treatment withdrawn or withheld with an intent to end life (4,756 with the patient's consent, 8,750 without it); and 1,000 cases of active termination of life without the consent of the patients. In these last 1,000 cases, 45 percent of the families involved were

not informed. Moreover, in those 45 percent, 14 percent of the patients involved were fully competent and 11 percent were partly competent.

(*Issues in Law and Medicine*, Winter 1991)

While the attempt to legalize voluntary euthanasia in Washington State failed last month, a new measure on abortion succeeded by the narrowest of margins—4,000 votes in 1.5 million. The measure enshrines the *Roe v. Wade* decision in state law so that, even if it is overturned by the Supreme Court, abortion will remain legal in the state. Nevada voters took similar action in 1990.

(*USA Today*, 22 November 1991)

The United States is not among the more than 100 countries that mandate maternity leave for working women in line with the International Labor Organization's provisions: time away from the job before and after childbirth, full or partial replacement of wages, and a guaranteed job to return to. Some provide less—and some much more—than the standard 14 weeks. Soviet women (before the breakup of the USSR) were allowed 18 months' paid leave;



Swedes and Austrians get 12 months. Even many poorer countries like Panama, Togo, and Bulgaria offer women three to four months of paid maternity leave. A few nations offer leave to fathers, too.

Twelve weeks (unpaid) leave was specified in the legislation debated this year in the U.S., one of the few industrial nations that has no national policy.

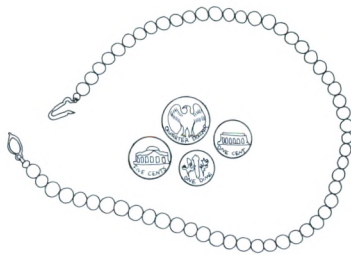
(*World Monitor*, 10 December 1991)



You'd think that people with money in the bank, self-confidence, and a sense of control over their lives would have an easier time coping with the death of a spouse than people with fewer resources.

Not so, according to a study of nearly 100 widowed people by psychologists at the State University of New York. The study is the largest to examine psychological health both before and after the loss of a spouse. The researchers interviewed 2,867 people, first in 1986 and again in 1989. Their analysis focused on 92 people, mostly women, who were widowed during that time.

The researchers found that the greater a person's economic resources, intelligence, and self-confidence,



the more depressed she or he was likely to be after a spouse's death. Strong social support from friends and family, previously thought to help buffer such losses, didn't seem to make any difference. And the findings about money's impact couldn't be attributed to widows worrying about the sudden loss of their husband's income; the higher a woman's own income, the more distressed she became after her partner's death.

The researchers speculate that people with more resources tend to view the world as an orderly, predictable place. Uncontrollable events shatter that view and thus hit these people harder.

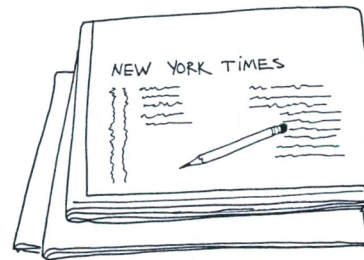
(*In Health*, November 1991)

Health care spending is expected to account for 14 percent of the nation's output of goods and services this year, up a bit from 1991, a Commerce Department report says. Estimated 1991 expenditures jumped 11 percent from 1990 levels, the fifth straight year of double-digit increases. The report predicts that health spending will rise at an average of 12–13 percent annually over the next five years.

(*AMA News*, 13 January 1992)

Nurses' voices are virtually silent in health care news even though nursing is the largest profession in the health care system. So found the Women, Press and Politics Project in a study conducted in the last half of 1990 on behalf of Nurses of America to determine whom journalists used as sources of information for health care coverage. Although nursing care is as crucial as medical intervention with regard to such major health care concerns as maternal and child welfare, aging, chronic illness, AIDS, drug addiction, and disease prevention, nurses were at the bottom of the list of news resources. Out of 295 references, nurses were referred to for information only four times.

One-third of quotes documented were from doctors; and people from 12 other occupational categories (including government officials and business people) were quoted more frequently than nurses. Also near the bottom of the ranking—but still above nurses—were patients, family members, other white-collar



health professionals, and nonprofessional hospital workers.

Female journalists, the WPPP found, seem to adhere to the same definition of expertise held by their male colleagues and virtually never use nurses as a source of news.

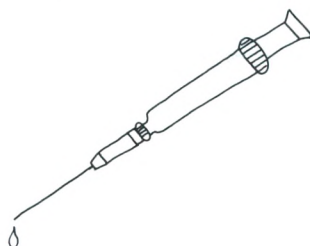
(*Nursing Outlook*, September/October 1991)

It's widely accepted that the use of condoms dramatically reduces the risk of transmitting HIV. There's also an emerging international consensus among doctors (if not yet in the White House) that distributing clean needles significantly curbs new infections of HIV, without increasing the rate of new addiction.

Now one school of epidemiologists is saying that needle exchanges and condoms probably reduce trans-



mission of the most virulent strains of the virus. This is especially true for needle sharing, when the fastest-replicating (and thus most dangerous) strains of the virus are transmitted. When transmission rates drop,



fast replication becomes a liability for the virus: fast replicators again come to dominate but, as a result, die with the host without being transmitted. Under these conditions, slow replicators are more likely to make it into future generations.

These researchers believe that if most major cities were to institute needle-exchange programs, the most debilitating strains of HIV would thus eventually die out.

(*New Republic*, 7 October 1991)

The American Medical Women's Association is backing a new program aimed at allowing physicians to offer women one-stop shopping for health care. The program, designed as continuing medical education (CME), will begin in 1993 and is expected to integrate obstetrics, gynecology, internal medicine, family practice, and psychiatry. It is intended "for women patients who want physicians to treat them as whole people," says Eileen McGrath, executive director of the AMWA.

The course will cover menstrual disorders, menopause, sexual disorders, osteoporosis, sexually transmitted diseases, contraception, infertility, abortion, nutrition, substance abuse, and pregnancy counseling. There will be a focus on preventive medicine; physicians in the program will teach breast self-examination, interpret routine test results, and be trained to recognize signs of domestic violence.

In addition to the CME program, which will also be open to medical students, the AMWA will establish a clearinghouse of information on medical school electives and training programs in women's health.

(*American Medical News*, 2 December 1991)

Nurse Veneta Masson, the director of a family medical and nursing practice that serves a low-income population, reflected with another member of her church on the Supreme Court ban on abortion counseling. "We [the staff of the medical center] really struggled with the subject of abortion and what we would tell pregnant women who asked about it. What none of us had reckoned with in the beginning was the sheer power of Real Life to strip one of illusions, euphemisms, even ideals."

There are no taboos in the clinic. Countless conversations start off with "I'm not gonna lie to you," and move off relentlessly into stories of drugs, sex, suicide, child abuse, murder—and every other form of violence. We don't have the luxury of keeping our focus narrow and our hearts pure. . . . I am thinking back to some pregnancy tests I did last week. . . . There was Lisa. Positive. "I'm tellin' you how I feel," she said, looking away. "I just got a new job and my friend's in jail. I'm going through too many changes. No way can I have it. Is it true that an abortion can mess you up later? How do they do it? Does it hurt bad? I'm really scared."

I did not say to Lisa in that most important and perhaps pivotal moment of her life, "We do not consider abortion an appropriate method of family planning." She hadn't claimed it was. I answered her questions, listened as hard as I could, and helped her make a plan. Because in that moment I was not pro-life or pro-choice. I was pro-Lisa. I wanted to be her midwife in the original sense of "with woman."

(*Nursing Outlook*, September/October 1991)

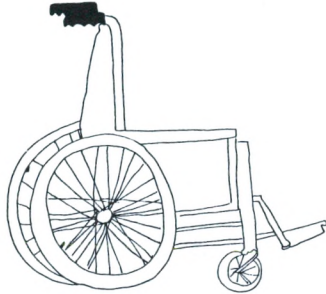
In hopes of giving patients a stronger voice in critical health decisions, New York recently joined the growing list of states that require hospitals to ask patients if they would like to designate a "proxy" decision maker—someone who can make treatment decisions for the patient if he or she becomes mentally incapacitated. To see if the system was working as intended, Mount Sinai Medical Center geriatricians designed a hypothetical test.

They asked 70 physically frail but lucid patients at a geriatric clinic whether they would want to be revived after suffering a sudden heart attack that



stopped the heart and lungs. Nearly all said yes; 67 percent said they would want resuscitation even if they were senile—and no longer able to recognize family and friends—at the time of the attack.

When the researchers separately questioned the doctors and family members listed by the patients as proxies, however, they heard a different story. With regard to resuscitation of senile patients, family mem-



bers were wrong in their predictions of the patients' preferences more than 30 percent of the time. Doctors were even less accurate—they guessed right only half the time.

The disparity came as a shock to everybody, said one researcher, particularly to the patients and families, most of whom had blithely assumed they would be in agreement. "Nobody wants to think about the circumstances of their death," the researcher commented. "But a little heart-to-heart talk now with loved ones and the family doctor may lessen the heart-ache and confusion later on."

(*In Health*, November 1991)



One in ten newborns—375,000 infants each year—are exposed to one or more illicit drugs in utero. While the impact of alcohol and tobacco abuse is by no means inconsequential, crack cocaine poses the most significant threat to the fetus. Crack-exposed infants can suffer from severe deformities of the heart, lungs, or

digestive tract, neurological deficiencies, disfigurement, prematurity, irritability, inability to sleep, muscle rigidity, convulsions, a short attention span, and developmental lags.

"Drug-exposed infants pose a heavy burden in direct and indirect medical costs," says Ronald Tsang, chief of neonatology at Cincinnati Children's Hospital. "And the societal costs as those infants grow into maladjusted, possibly neurologically impaired adolescents remain incalculable." Indeed the economic impact of drug-exposed babies is staggering: Hospitalization of a crack baby in New York City is estimated to cost \$60,000–\$300,000; these figures do not include long-term health care costs, special education expenses, and foster care.

Society has responded to this near-epidemic problem by pushing for the prosecution of mothers and pregnant women who abuse drugs. To date, more than 50 women have been criminally charged for drug use during pregnancy; three have been convicted. Many states have amended their child abuse legislation to include prenatal exposure to controlled substances or to require health professionals to report positive drug tests from mothers or infants. But is criminal prosecution the answer?

While it is true that the behavior of women who abuse drugs and alcohol poses significant potential for fetal harm, there are solid reasons to doubt that a system of legal punishment and intervention would decrease the incidence of this behavior, as it is usually an addiction over which these women have little control. Rather, the threat of criminal prosecution and incarceration might push these women away from the medical help they so desperately need.

A number of physicians have become advocates for national reform of existing prevention and treatment programs. The American Academy of Pediatrics Committee on Substance Abuse, for example, is encouraging multidisciplinary treatment and support for the affected mother, child, and family.

(*Clinical Ethics*, Winter 1992)



# READERS' RESPONSES

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*The Second Opinion staff invited a number of its readers who work in the field of pastoral care to respond to Maxine Glaz's article "Reconstructing the Pastoral Care of Women" (Second Opinion 17, no. 2 {October 1991}). Our thanks to these who shared their reflections, which follow.*

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## To the Editor:

"Reconstructing the Pastoral Care of Women" raised several key issues for me—not only concerning our ministry *to* women, but also *by* women. The opening scenario was indeed painfully shocking and I found myself heatedly asking, Why did the clergyman wait until his eighth "victim" to seek help? What did he do with the pain of his ministry to the previous seven women?

Reflecting on his story, however, made me realize that it could just as readily have been a woman clergyman caught in the dilemma of wanting to be helpful, yet exceeding the bounds of a healthy relationship. It seems to me (as one prone to "rescue" and to empathize to extremes) that one key error was the minister's failure to live out a foundational principle of all counseling: to "affirm the deepest thing in another" (D. Steere).

From the first encounter, it appears, he forgot that his task was to elicit the "Self" of this woman, to affirm her and her ability to survive the trauma perpetrated upon her. Instead, he disregarded the parameters of time, space, and respect that are essential for produc-

tive counselor-counselee relationships. By doing so, he began to exert the same controlling, male-knows-best, domineering attitude that she had experienced with her father—albeit not now involving overt sexual activity. His anxious prolongation of the first meeting and his scheduling of the second meeting the following day so easily conveyed to Carole that she could not be trusted to deal with her pain for even 24 hours.

Instead of allowing the awful reality to surface slowly, the minister instead encouraged (perhaps forced) the rapid exposure of all the sordid details of her molestation. How true it is that humankind "cannot bear very much reality," and how wise it is to allow time in the therapeutic process. This makes two truths evident to the counselee: first, that the experience happened over time and will only be confronted in time, and second, that the counselor trusts him or her to cope in the time between meetings. To say, implicitly or explicitly, that I, as pastoral counselor, do not think that you can handle this alone robs (dare we say rapes) the other of psychospiritual strength that is necessary for wholistic growth and recovery.

By his failure to reverence her as a person ultimately capable of having to grow through this trauma herself, he disempowered her. The strong, supportive, protective, invading attitude, I suspect, began to be perceived by her as another internal violation—not just of her body, but of her psyche and spirit.

In addition, there is no evidence of his anger being dealt with. Where was all that energy going? Surely an empathic minister who had listened to the painful horror of seven women who had been sexually abused felt some anger toward those who caused the molesting.



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However, having said all of the above, I know from my own experience of being wounded by life and also of having walked with others as they faced their scars that the balances are not easy. It is a delicate tightrope to walk between speech and silence, availability and unavailability, walking side-by-side with and carrying, reverencing and ravishing, being open and being prying, empowering and disempowering.

In my own times of enormous pain I have always wanted someone to rescue me, to lift me out of the quagmire, to carry me safely across the chasms of life. A friend in graduate school, however, taught me a very valuable lesson when I was in the depths of self-doubt and depression. He left me alone in my pain for several days and then appeared unexpectedly with a bottle of wine, saying, "I wanted so much to come to you earlier, but I knew that if I did, you would not learn from your experience and tap your own strength to cope with your aloneness and pain."

So many times over the years when I am tempted to "rescue" or smother someone in pain, I think of Joe and the deep care and respect that I learned from him. It was empathy that kept him from rushing to my defense. His reverence for me enabled me to tap the deep inner resources that lay within me but that required (and still call for) hard work and careful tending. By "confirming the deepest thing" in me, he encouraged me to affirm my SELF with all its strengths and weaknesses. That for me became a pivotal experience of finding the "sense in the nonsense," of discovering the God in me waiting to be known and loved.

God's reverence for us is unconditional and cherishing. The Creator's look is always one of care that calls out to us to respond in nurturing, reverencing ways so that we may see God's image in one another. So often and so easily in our pastoral meetings we are seduced into seeing the other with less than Godlike eyes.

That brings me back to my first shock in reading Carole's story. To whom was the minister accountable? With whom was he sharing the painful, difficult struggles in his own life and in his counseling? His experience is a lesson for us all—male and female. That we may be open to a deepening reverence for those who come to us for spiritual counsel and psychological support, it is essential that we have a wise and holy

guide who confirms "the deepest thing" in us as we journey toward the God whose *hesed*, whose compassionate love, sustains us all.

*Colette Hanlon, S.C.*

Director of Pastoral Care  
Saint Thomas Hospital  
Nashville, Tennessee

### To the Editor:

Maxine Glaz's "account of a failed moment in ministry" and her practical application of a feminist psychology of women was persuasive and troubling. In my own work as a Clinical Pastoral Education (CPE) supervisor, pastoral counselor, and counseling center administrator, I have also encountered frequent instances in which students and parish clergy have practiced intrusive and overinvolved pastoral care. The outcomes have not been as catastrophic as in the case presented by Glaz, but troubled persons have suffered.

In some ways it is unfortunate that Glaz chose a case in which the counselor was both grossly incompetent *and* severely character-disordered because the gender issues become obscured, at times, by these glaring faults. While it is unlikely that a woman clergy would have subjected Carole to the invasive and seductive trauma the article describes, a severely character-disordered counselor of either gender who also lacked an awareness of basic counseling protocol would surely have damaged Carole.

Although I am sympathetic with most of what Glaz argues, I think the case actually illustrates two problems with parish-based counseling even larger than the need to "reconstruct the pastoral care of women." These problems are (1) a pervasive incompetence among parish clergy regarding even rudimentary counseling frameworks and guidelines, and (2) the number of clergy who suffer severe personality disorders. Sensitivity to gender issues (for example, the misogynistic nature of many psychological theories) is a part of basic competence for ministry. Similarly, a recognition of boundaries, the dangers of overinvolvement, and an understanding of one's motives are also prerequisites for offering oneself as a



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counselor. In my experience, these aspects of pastoral care and counseling are just recently being emphasized in seminary curricula.

The fact that Carole's pastor continued to work in isolation with sexually abused women after even one suicide suggests the existence of a profound personality disorder. It has been my experience that professional counselors who have a client even attempt suicide characteristically engage in an extensive review of what "went wrong" in *their* efforts to be therapeutic. Parish clergy seem rarely to seek consultation or supervision, but only the most emotionally disturbed would totally ignore their own possible failure after a parishioner under their care committed suicide.

Addressing these problems is the responsibility of both seminaries and denominational bodies responsible for reviewing candidates for ordination. Mandatory CPE, extensive psychological testing, and seminary courses that emphasize the frame of counseling and gender issues are all necessary to protect parishioners from their own pastors. It is more difficult to reach clergy who are already in the parish, but articles such as Glaz's may be helpful. Unfortunately, the clergy most in need of "reconstructing" their pastoral care of women are probably the least likely to read professional journals or pursue continuing education.

**Gene H. Gall, D.Min.**

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Pastoral Care and Counseling  
Memorial Hospital and Medical Center  
of Cumberland, Inc.  
Cumberland, Maryland

### To the Editor:

The Glaz article is quite provocative, and I have a wide variety of reactions. The fundamental point is well-taken, but the intervention described, while typical, would not likely take place with an experienced and clinically trained pastoral counselor. The last few pages of the article are more homiletic, but many good points are made.

As part of my response, I'd like to share an incident from my own experience. Sandy phoned shortly after her abortion; she was frantic and threatening suicide. Would I speak with her, meet with her? After a limited conversation, we scheduled an appointment for the next day. My concern? Why is Sandy feeling so desperate? What is she seeking from our meeting? My task? To understand Sandy's desperation, evaluate her psychological and spiritual strengths and deficits, and assess her lability and ability to "regroup." This process continued on a weekly basis for several months. Did I abuse Sandy because I selected a more removed and structured clinical posture? From one perspective, being more "removed" and "structured" are male-valued characteristics that deny female characteristics of engagement and evolution. I suggest that my latent sexual connections to this model of therapy had little bearing on the requirements of clinical intervention.

God said to Moses as he approached the burning bush, "Thus far shall you go, but no further" (Exodus 3:5). Questions about modeling and parameters for intervention are old indeed. Similar questions have been raised by all clinical disciplines, particularly the psychotherapeutic professions. Anton T. Boisen's plea to regard troubled souls as living human documents propelled the pastoral care movement into existence, and with it the model of the self-reflective clergy person. Hindsight, however, can characterize these earlier models and methods as masculine, and thus limited. Women's studies have clarified and quantified sexual differences in moral and personality development. This new recognition of sexual differentiation in the realms of social interaction and intellectual achievement are important correctives to the past. Karen Horney, Judith Miller, Nancy Chodorow, Carol Gilligan, and many others have all helped to clarify and to change former assumptions and rules of human interaction and discourse. In any clinical intervention, however, how far need a critique go in order to distinguish between clinically poor judgment and naiveté about sexual differences?

Carole's minister was sensitive, caring, and inept as a clinical counselor. His error lay not in his unintentional sexism but in his hubris. Pastoral care providers and all other clinicians should know and be sensitive to the burgeoning literature about sexual differentiation in personality and moral development.



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Yet clinicians of either sex may at times fail to recognize the implicit expectations placed on those who come for counsel. Transference and countertransference issues are central to the psychotherapeutic enterprise. Anyone engaged in counseling needs to be ever conscious of these parameters. Beyond Glaz's polemics, her underlying theme of being sensitive to the hidden messages we give and receive by virtue of who we are as individuals and as men and women should be foremost in the thoughts and interventions of those who counsel.

**Rabbi Terry R. Bard**

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Department of Psychiatry  
Beth Israel Hospital and Harvard Medical School  
Boston, Massachusetts

**To the Editor:**

What is the "standard of practice" for clergy who offer pastoral care to women, especially women who have experienced deep evil? Glaz's case study riveted my attention on the catastrophic results of one minister's failure to follow an essential component of pastoral care—consultation. Whether or not this caring man understood the dynamics of female development and had the necessary skills to recollect her painful youth with her, he failed by not reaching out to colleagues in ministry and helping professions. That he compounded his failure seven times (dare we forgive "seven times seventy") was inexcusable. "Reconstruction" is undoubtedly needed. Adherence to consultation as a standard practice could have prevented these compounded tragedies.

Glaz's suggestions for reconstruction offer important reminders of ways in which gender differences must be considered in shaping pastoral care. As a Clinical Pastoral Education supervisor I have found my work made both more difficult and more powerful by attending to several of the themes well-summarized by Glaz. I am reminded of a woman I supervised who was coming to ministry as a second career. Although her life journey included relational and vocational failures, she had blossomed in a divinity

school setting and seemed to be participating well in its community and mission. She elected CPE because it was "strongly recommended" for ordination by her ecclesiastical group. While she reluctantly engaged in the group-process aspects of CPE, she experienced overwhelming anxiety in individual supervision. She eventually told me enough that I could hear her history of incest. My consultant helped me plan both a therapeutic referral and a supervisory strategy for reducing her "intrusion anxiety." While CPE was a difficult learning environment, she used it as a bridge toward healing. I learned more about how to let go of some of my own egocentricity in service of an empathic community. My knowledge base has been expanded through Glaz's summary of key themes.

Finally, I strongly affirm Glaz's pastoral theological move to focus pastoral care on exploring and developing meaning. This move is very difficult, especially in the face of senseless evil and violence. Yet if we are to sustain our vocation, we must continually reconstruct a pragmatic theology from human experience. From this foundation we may passionately and pastorally engage those who suffer both tragedy and redemption.

**Steven S. Ivy**

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**To the Editor:**

Maxine Glaz makes several valid points about the nature of pastoral care. What I find puzzling, and have found puzzling since my first encounters with Carol Gilligan's work and all the more so in light of Sidney Callahan's excellent article in the same issue of *Second Opinion*, is that such issues should be restricted to the pastoral care of women. Through my experiences as a rabbi, as a clergy counselor to chemically dependent teenagers, in my work with girl-serving organizations, and as a human being, I have solidified my agreement with Callahan (p. 71) that while gender is part of our being, it is not all of our being. It is odd that Glaz, who understands that "real empathy consists of the



## READERS' RESPONSES

comprehension of the other person's experience" (p. 103), seems to believe that the experiences of men are so different from those of women that men would not be harmed by such inappropriate behavior.

Men, too, may be abused and have their boundaries violated. Most of the teenage women I worked with as a clergy counselor had been sexually or physically abused—and so had most of the teenage men. Most also had lost one or more people important to them—parents, siblings, friends. The example that came to mind when I read Glaz's article about the potential for clergy counselors unwittingly to perpetuate violation of boundaries occurred in the latter context. If a counselor, clergy or otherwise, decided that a patient had not grieved properly, that patient was required to attend "grief group." There the patient was required to share certain information publicly and on a specific timetable. Never mind that the patient might still be in shock and denial from a recent death, might have grieved it adequately despite "expert" opinion, or simply might not be grieving that death in the prescribed manner or length of time. Not to follow the paradigm was to be found guilty of "not working your program," of willfully refusing to be healed. Young people were never pushed to reveal intimate details of abuse for many of the reasons Glaz suggests. But all the pressure of a closed institutional setting was brought to bear to make them grieve according to the rules.

Too strict adherence to the Jewish model of dealing with grieving—limited neither to the Orthodox nor to rabbis—by not speaking until spoken to (p. 105) becomes another burden on the mourners, who feel obliged to draw out and all but entertain those who supposedly have come to comfort them. As Glaz herself says, the best pastoral counselor is "available but not aggressive" (p. 101). Women as well as men can be aggressive and can be false comforters, but men are often taught not to expect comfort at all. Glaz's suggestions for better pastoral care, it seems to me, are needed at least as much for men as for women.

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### To the Editor:

Maxine Glaz presents correctly two specific issues in pastoral counseling: quality of care and the themes of emotional/physical/social developmental experiences that all women deal with.

The incidents Glaz describes illustrate some ministers' lack of adequate training and inability to recognize when to refer. The article makes a strong case for stringent licensure standards for clergy and some form of peer review or supervision (although I doubt the latter will ever happen).

Carole was raped by two men, her father and her pastor; one raped her physically, one emotionally. Her response to both was the same. A properly trained pastoral counselor would be aware of the intensity of care she required. Certainly, such a counselor would not have taken on such a case without having undergone adequate review and perhaps additional training after the first suicide of a patient. A trained counselor would not have accepted seven additional identical cases, each having a similar outcome.

Indeed, pastoral care providers (and other care providers also) must be aware of the power of both words and silence, of the power of an authoritative position, and of the risk of satisfying only personal needs. This is no different from meeting any other professional standard. In the hospital setting, there are standards for all professions. As cases are reviewed in the various quality assurance committees, procedure appropriateness and outcome may be examined. Unfortunately, there is no similar mandated assessment outside the hospital. Other than those few cases that end up in court, a pastoral caregiver will probably never have his or her work evaluated.

Until there are established and upheld professional standards for training, methods, evaluation, and continuing education, pastoral care will not receive proper recognition among other caregivers, nor will patients consistently receive appropriate care. Incompetence has been tolerated far too long. I am especially troubled by Glaz's closing paragraph. Caregivers "whose primary purpose is to maintain control over us" or "whose damaged self-esteem is shored up by the abuse of power" need to be rendered harmless via loss of license or authority until they are able to function safely. We, the professionals, have no excuse for tolerating evil among us.



## READERS' RESPONSES

I thoroughly agree with the premise that the theory and practice of pastoral care have been based primarily upon male experience, and I applaud the efforts of those working to bring an understanding of the female life experience. From here we become able to develop new approaches. But do we stop at this point, formally recognizing that there are gender differences, or will we be wise enough to take the next step to discover the human similarities? Until we are able to satisfy these concerns, maleness or femaleness is irrelevant.

The title of Glaz's article, "Reconstructing the Pastoral Care of Women," is seductive; it is intriguing but not fulfilled by the content. Of the five anecdotes Glaz cites, two deal with her daughter in normal growth situations. These are adequately dealt with. The remaining three incidents all concern women with significant mental health problems originating in sexual abuse, representing a minority of all women. These women have treatment needs ranging from long-term hospitalization to occasional short-term outpatient counseling to no treatment at all.

But what of the needs of the remaining majority of women: is their treatment to be predicated upon the needs of the minority? This hardly seems appropriate.

I am not referring to courtesy or common sense but rather to the assumption that all women have been a victim at some level.

I had hoped for an article that might have helped me in my work with female patients in a wide variety of crises. This is what the title offered. Glaz concentrates on specialized situations that are not the everyday cases for most caregivers. Speak to me about pastoral care for the mother driving the car that killed her children and niece, for the new bride whose husband shot her in the head and then killed himself, for the 28-year-old mother of three who is dying of cancer, for the mother of an anencephalic child.

All four have much to resolve emotionally and theologically, and understanding does not necessarily bring about resolution. Though their needs can be viewed from a female perspective, they are first *human* needs. If these patients had been male, would their situations be significantly different? My experience would say no.

***Paul A. Mathis***

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# LITERATURE DIGEST

## Assisted suicide: a cop-out for physicians?

Richard A. McCormick, "Physician-Assisted Suicide: Flight from Compassion," *Christian Century* 108, no. 35 (4 December 1991): 1132–34.

OPINION POLLS INDICATE THAT MOST AMERICANS approve of physician-assisted suicide. Although the Washington State initiative (Initiative 119) to legalize assisted suicide was defeated, some experts feel that there will be renewed legislative efforts in the years to come. Richard McCormick is one theologian-ethicist who opposes the movement toward legalized assisted suicide.

According to McCormick, Initiative 119 represents the convergence of at least five cultural trends that policymakers must examine thoroughly before moving too quickly to public policy on this issue.

First, McCormick argues, it is now all but universally accepted in Western circles that allowing individual decision making regarding medical treatment is a necessary part of preserving dignity. It is not so well recognized, however, that the heavy emphasis on autonomy accompanying this recognition is an overreaction to medical paternalism and has produced an "absolutization of autonomy" that is driving the movement toward physician-assisted suicide (p. 1132). In the absence of a serious discussion about the difference between good and bad choices, the patient's right to be an autonomous decision maker becomes the sole right-making characteristic of the choice. Autonomy becomes overstated, and the patient's values and wishes are too immediately accommodated. A concomitant effect of absolutized

autonomy is an intolerance of dependence on others. Rejection of our own dependence, McCormick argues, ultimately means rejection of our interdependence. And then we fail to see physician-assisted suicide for what it often is: an act of isolation and abandonment (pp. 1132–33).

Second, our society has secularized medicine, and the medical profession has been divorced from the moral tradition that formerly distinguished medicine as a human service. As a result, medicine becomes preoccupied with factors—insurance premiums, business atmosphere, accountability, and competition, for example—that are peripheral to and distract from giving care (p. 1133). In the process, medical knowledge and skill are construed as commodities belonging to the physician that can be dispensed on his or her own terms in the marketplace.

Third, McCormick argues, an inadequate understanding of pain management underlies the movement toward physician-assisted suicide. McCormick feels that many people don't fear death but rather fear dying—especially a slow, painful dying. It is clear that few physicians receive good training in recognizing or managing pain, and research into pain management is poorly funded. McCormick argues that "if we had better education and better pain control, much of the perceived need for euthanasia would disappear" (p. 1133).

Fourth, the recent and well-publicized cases of Paul Brophy and Nancy Cruzan, among others, have focused attention on issues surrounding persistent vegetative state (PVS). Because people can now be maintained in PVS for years by use of nasogastric or gastrostomy tubes, the debate over nutrition and hydration has propelled the issue of assisted suicide to center stage. Although the debate rages among



physicians and bioethicists, McCormick believes that a majority of people do not want to be maintained indefinitely in PVS and are appalled at the prospect (p. 1134). Many people fear a "needless, heedless, and aimless (as they see it) prolongation" of the dying process.

Finally, the great pressure to cut health care costs is fueling calls for legalized physician-assisted suicide. McCormick believes that these economic pressures create a coercive atmosphere for the debilitated elderly and chronically ill who worry about being a financial drain on their family and on limited resources, or who are perceived as such by their families. This increases pressure to choose assisted suicide (p. 1134).

Unless these five cultural trends are addressed, McCormick argues, the issue of physician-assisted suicide will produce more legislative initiatives.

—Edwin R. DuBose

## The limits of mercy in assisted suicide

Mark A. Duntley, Jr., "Covenantal Ethics and Care for the Dying," *Christian Century* 108, no. 35 (4 December 1991): 1135–37.

AS MEDICAL TECHNOLOGY OFFERS MORE life-prolonging measures, and as more people join the ranks of the elderly, the ultimate issue of individual choice—determining if, when, and how to end one's own life—grows more urgent. Duntley believes that the popularity of Derek Humphry's *Final Exit* and Betty Rollin's *Last Wish* is partly due to the fear many people have about a prolonged and painful death. Because such a death seems anything but good, many have understandably come to believe that there are times when the hopelessly suffering should be allowed to choose a quick and merciful death with the help of a medical professional (p. 1135).

With recent innovations in biotechnological medicine, patients are more dependent than ever upon medical professionals. At the same time, patients have more clout in determining their own treatment. Given the growing moral and legal acceptance of withhold-

ing or withdrawing extraordinary medical treatment (passive euthanasia), many suggest that administering a medication that would precipitate death (active euthanasia) at the patient's request may also be justifiable. Many health care professionals, however, assert that assisting in a patient's suicide betrays their pledge to heal their patients. While physicians have generally accepted forms of passive euthanasia for the terminally ill, most still believe that active euthanasia contradicts their professional responsibilities (p. 1135).

The crux of the matter for Duntley is this: what does it mean to care for another human being? At the heart of caring is the concept of mercy or compassion, which seems central to any philosophy of healing and is most certainly the primary argument for the morality of euthanasia (p. 1136). The key issue is determining the circumstances in which physician-assisted suicide is indeed merciful treatment. An understanding of mercy helps one discern these circumstances.

According to Scriptures, mercy is inextricably tied to relationships, particularly covenantal relationships. One of the central meanings of *covenant* is complete commitment between the parties. The Old Testament, says Duntley, shows how God demonstrated a commitment to the covenant with Israel. Duntley argues that God's mercy is the fulfillment of a covenant based on love for the people. Mercy is available to Israel not because of the people's righteousness but solely because of God's covenantal guarantee of faithfulness to them (p. 1136).

God's mercy becomes a model for humans to follow, and the key to obtaining mercy rests on covenantal relations. The source of human covenants, and thus of mercy, is the covenant with God. Mercy should be most evident within the close ties of the family and, as a sign of devotion, is also part of the covenant relationship between the community and its dependents or the helpless.

The New Testament tells of Jesus showing mercy to those around him, especially the sick and suffering. A recurrent theme of the Christian Scriptures is the communal obligation to love, aid, and comfort each other. If we believe in the biblical standards of mercy, says Duntley, those standards must be practiced in covenant relationships (p. 1136).

Without an appropriate covenantal context for mercy, Duntley argues, assisted suicide lacks moral



force and sanction. Unfortunately, neither our health care system nor our general attitude toward health care providers encourages us to seek such relationships with physicians. The system tends to foster technical specialization and cost management over the physician-patient relationship. At the same time, we tend to think of physicians as omniscient miracle workers who should always be able to cure us. These tendencies lead both patient and physician to view their relationship in merely contractual terms. Such a relationship does not encourage the deep, personal connections of healer and patient that favor mercy and compassion.

Duntley cites two cases to illustrate his point. In the first case—that of Dr. Timothy Quill and his patient Diane—Quill prescribed the barbiturates that allowed Diane to take her life. This decision was based on a long-term relationship and followed treatment for Diane's leukemia and numerous discussions of her options. Duntley characterizes the relationship between Quill and Diane as a covenantal one in which assisted suicide became an experience of mercy and grace.

In the second case, Janet Adkins, diagnosed with early Alzheimer's disease shortly before she first contacted Dr. Jack Kevorkian, died while connected to his "suicide machine." As virtual strangers, Kevorkian and Adkins had a contractual arrangement. As a result, that case of assisted suicide displays a lack of moral force and sanction (p. 1136).

Duntley claims that covenantal relationships go beyond obligation by centering on mutual, enduring responsibilities. Following the work of theologian Karl Barth on covenant, Duntley believes that deep personal relationships lie at the heart of divine and human mercy. As much as we want to codify rules about physician-assisted suicide and either outlaw it or define precisely when it is permissible, such an approach will not fit into a relational matrix. Therefore, assisted suicide cases remain in an ethical gray area. The challenge is to move beyond evaluating individual cases or searching for broad policies to reaffirming the merits of relationships built on trust and mutuality. This movement requires the transformation of a contractual system of health care into one stressing the common good, mutual interest, and "covenantal ethics." While such a system would not remove all ethical dilemmas surrounding physician-

assisted suicide, it would provide a context for showing mercy to the dying (p. 1137).

—E.R.D.

## Thinking again about living wills

John A. Robertson, "Second Thoughts on Living Wills," *Hastings Center Report* 21, no. 6 (November–December 1991): 6–9.

Joanne Lynn, "Why I Don't Have a Living Will," *Law, Medicine and Health Care* 19, no. 1–2 (Spring/Summer 1991): 101–4.

THE ADVENT OF THE PATIENT SELF-DETERMINATION Act, affirming legislative and societal acceptance of living wills, raises fundamental questions and concerns about advance directives. John A. Robertson and Joanne Lynn address some of these issues. Both agree that advance directives for the treatment of incompetent patients do not represent an end to the debate but the beginning of a dialogue. For example, advance directives are most readily accepted in cases of "terminal illness," but these circumstances provoke the least disagreement about treatment or nontreatment. Robertson and Lynn examine the assumptions and oversimplifications that affect the broader application of advance directives for all incompetent patients.

Robertson charges that living wills are inadequate aids in decision making for incompetent patients. He suggests that living wills may, in fact, "threaten the welfare of incompetent patients." He does identify two clear benefits of living wills: (1) they give competent persons a "sense of control" over future decisions if they should become incompetent, and (2) they may serve as a rule for nontreatment decisions that *appear* to maintain the autonomy of individuals without compromising respect for these individuals if they become incompetent patients. But given these benefits, he asks why so few people make living wills, why physicians are reluctant to follow them, and why living will laws traditionally address only the narrow scope of "terminal conditions."

These problems may be rooted in the unclear assumptions underlying the benefits of living wills. A



living will assumes that the competent person is best able to identify his or her future interests. The problem with this assumption in Robertson's view is that "the patient's interests when incompetent—viewed from her perspective—are no longer informed by the interests and values she had when competent." He acknowledges that living wills may reflect the interests of a competent person in determining the future, but imposing a competent person's rationality may "devalue" the more limited interests of an incompetent patient, thus undermining the second benefit of living wills, which depends on respect for incompetent patients.

Thus, according to Robertson, conflicts may arise between an individual's interests while competent and while incompetent. At present, evidence for the conflict in practical situations is purely anecdotal, including cases of patients treated—despite a directive—who recover and are grateful, and times when physicians are reluctant to follow a living will because they feel a patient should be treated. Robertson therefore urges that the possibility of conflicts be considered and a more systematic assessment be made on the frequency of such conflicts.

If conflicts exist and are acknowledged, a more central question may be asked, that is, "whether treatment or nontreatment best serves the interests of the now incompetent patient." Robertson suggests that making difficult quality-of-life decisions will enable discussion to move beyond living wills, which are universally embraced only in cases in which a quality-of-life decision is implicit, that is, in "terminal illness."

Within the current ethical and legislative framework—where living wills may come to be accepted unreservedly—Robertson offers public policymakers four recommendations:

1. Assure that makers of living wills are informed of the potential conflict between their future interests when incompetent and their current interests in achieving certainty about how they will be treated when incompetent.
2. Prepare for more frequent conflicts over whether advance directives should be enforced when they conflict with the incompetent patient's current interests.
3. Begin explicit assessments of the quality of life and best interests of all incompetent patients, not just those who have no advance directives.

4. Do not constitutionalize advance directives.

In conclusion, Robertson recognizes that quality-of-life decisions are fraught with difficulties. As a second best solution he acknowledges advance directives and substituted judgments as preferable to "unrestrained vitalism."

JOANNE LYNN, WRITING FROM THE PERSPECTIVE of a clinician and an ethicist, explains her own hesitation to sign a formal advance directive. Lynn asserts that the text of a "standard" living will rarely gives caregivers any information that would influence their decisions. Most caregivers acknowledge as inappropriate life-sustaining treatment given to an incompetent patient who will die irrespective of treatment. Indirectly, however, the living will may provide more information about the patient. A person who signs and presents a living will communicates the seriousness with which he or she approaches end-of-life decisions. It also opens up communication between caregiver and patient, presenting "an opportunity to explore what he or she really means to avoid, what is really feared and hoped for, and who would be trusted to make decisions."

Lynn makes use of these less formalistic functions of a living will in her practice. She rejects the oversimplifications that writers and interpreters of advance directives may make. First of all, some caregivers may equate a living will with a blanket "Do not resuscitate" order that precludes more thoughtful discussion with the patient or surrogate. Second, writers may decide an advance "yes" or "no" to a procedure (for example, dialysis, ventilator, or feeding tube) without knowing what specific outcome is expected. Third, on a broader level, distinguishing a category of the "dying" from all of us who are mortal does not serve the unique needs of individuals who are imminently facing death, nor does it recognize the needs of those who have not crossed the line to join those who will "die soon irrespective of treatment." Lynn suggests that

Good decision-making rests primarily in pursuing the best possible future, from among those plans of care that can be effectuated, and with the "best possible" being defined from the patient's perspective to the extent possible. Nothing in this model



needs to turn on the proximity to death or the nature of the procedure involved, except as these considerations shape the desirability of various future courses to the patient.

The issues underpinning conventional advance directives may replace the real concerns of very sick patients. In reality, many patients wish to avoid being a burden to their family. Concerns like this may be the very foundation for entrusting another person with decision making. Advance directives, with their emphasis on individual decision making and control of an indeterminate future, may not appeal to all individuals. Lynn suspects that other patients would, as she herself would, "prefer family choice *over* the opportunity to make our own choices," even if the choices were in conflict.

Lynn is wary of any societal mandate that might prevent family input or require a sole decision maker, which seems opposed to conjoint family decisions. In her practice she has identified four situations in which formal advance directives are useful: (1) when a person's surrogate might be contested, (2) when a person has unusually specific or unusual preferences, (3) when they might facilitate discussion about priorities and preferences and allay the anxiety of patients or family members, and (4) when a person lives in legal jurisdictions (outside Virginia and Washington, D.C.) where the next-of-kin is not granted automatic authority. Her own situation falls outside these criteria, and so she has chosen not to sign an advance directive.

—Mary (Daisy) Boehm  
*Research Assistant*

## Sticking to advance directives

Ashwini Sehgal, Alison Galbraith, Margaret Chesney, et al., "How Strictly Do Dialysis Patients Want Their Advance Directives Followed?" *Journal of the American Medical Association* 267, no. 1 (1 January 1992): 59–63.

THE AUTHORS OF THIS INVESTIGATION interviewed 150 mentally competent dialysis patients at seven outpatient chronic dialysis centers to assess how strictly they would want their advance directives followed. They found that only 39 percent of subjects granted

surrogates "no leeway" to override their directives. Sixty-one percent of subjects would allow surrogates to override their specific directives if doing so were in their best interests.

The authors discuss the rejection of best-interest assessments by the courts and some ethicists. These assessments are charged with being poor precedents because no criteria are agreed upon and because surrogates may project their own values onto incompetent patients. However, of these study subjects, 87 percent wanted their quality of life to be considered in the decision-making process. Also in contrast to the law, which gives written directives more weight than oral directives, only a slight majority of subjects agreed that written directives should carry more weight.

The authors encourage physicians to raise the issue of advance directives with their patients and to broaden the discussion to include interpretation of directives. Rather than asking patients to reflect on specific situations and treatment choices, physicians can gather more valuable information by asking patients how strictly they want their advance directives followed and what factors they want considered in decisions made for them.

—D.B.

## The church as a training ground for advance directives

Deborah M. House, "Advance Medical Directives and the Role of the Church," *Christian Century* 108, no. 35 (4 December 1991): 1137–39.

THE CHRISTIAN COMMUNITY IS NOT UNAWARE THAT medical technology often makes the dying process difficult for patients and their families. House notes that the United Methodist Church, the Catholic Hospital Association, the United Church of Christ, and other denominations have all expressed official positions on the right to forgo medical treatment. House's thesis is that medical advance directives confront patients and families with significant issues and that clergy, chaplains, and congregations should be aware of the treatment decisions facing patients. The first half of House's article deals with the legal aspects



of treatment refusal cases. The second half covers the Patient Self-Determination Act (PSDA), its implications for the patient, and suggested responses for churches and clergy.

After reviewing Nancy Cruzan's case, House discusses the important conclusion of the Supreme Court decision: Competent patients have the right to refuse medical treatment, including artificial nutrition and hydration. Before life support measures for an incompetent patient may be removed, a state may request "clear and convincing evidence" that the patient would want the treatment removed.

A person's spoken wishes do not meet the "clear and convincing" standard of proof for patient's wishes required by a court of law. Rather, advance directives—the living will and the Durable Power of Attorney for Health Care (DPHC)—provide a means for individuals to protect their right to terminate treatment. The two documents provide a more formal method of assuring that patient wishes are honored. House outlines the differences between these documents, noting that the DPHC is more legally binding than the living will.

The Patient Self-Determination Act, effective December 1, 1991, requires that facilities receiving federal funds ask new patients whether they have an advance directive, give the patient information on the directives, and educate family and staff about advance directives. Churches, clergy, and chaplains, says House, should be aware that the PSDA means that church members admitted to a hospital or nursing home are faced with profound decisions. The church community must develop ways to assist their members in facing these issues before health crises occur. House provides ideas for ways that churches can respond to these federal regulations:

- Educate clergy about advance directives.
- Foster discussions among church members about the theological, medical, and legal issues of advance directives, including the denomination's position on those issues. Experts on such topics could be found in the church or community.
- Be willing to talk about death and dying within the context of pastoral counseling and be available to patients and families going through the implementation of their directives.

- Take part in the drafting and implementation of a medical facility's response to the PSDA. Encourage a role for the facility chaplain.

—Agnes Coveney  
Research Assistant

## Compassion for the suffering: autonomy is not enough

Eric J. Cassell, "The Importance of Understanding Suffering for Clinical Ethics," *Journal of Clinical Ethics* 2, no. 2 (Summer 1991): 81–82.

ALLEVIATING HUMAN SUFFERING IS THE WARRANT for medicine and the test of its adequacy. When modern medicine and physicians falter, when suffering is not successfully relieved, clinical ethicists may find their usual responses inadequate and their basic concepts challenged. Therefore, understanding the nature of suffering and its impact upon patients is essential to clinical medicine as well as to clinical ethics.

In order for clinical ethics to benefit from the lessons of suffering, it must be aware of suffering's historical development. Cassell notes that the emphasis placed on ethical principles as applied to medicine has resulted in a shifting of focus from diagnosis and treatment of disease toward care that is founded upon "the interests of sick persons *as they define their interests* within the constraints of fate" (p. 81). Because moral philosophy has equated patient self-expression with autonomy, the fields of medicine and clinical ethics have extended this emphasis on patient autonomy into hospitals and medical schools. Thus the operative assumption in medical practice and medical texts is that the patient is completely self-sufficient and self-determining. Neither medicine nor ethics, claims Cassell, has fully considered the impact that the patient's illness has on autonomous choice.

The *person* in much modern philosophy is a completely independent, fully articulate individual, abstracted from his or her past and future (p. 81). But this is not the individual who suffers, so this image provides an inadequate basis for the work of ethicists, particularly as it relates to suffering persons.



Suffering individuals have a past and a future. One must take into account the effects of pain and suffering on autonomous choice, their destructive effect on clear thinking, self-determination, and the maintenance of a person's usual order and stability of purpose. Because of this fundamental disruption of the person and his central purpose, the patient cannot be counted on to express easily and adequately his self-interest. "Suffering persons, alone and unaided, *cannot* articulate their best interests beyond seeking the relief of their suffering and its source" (p. 81). In addition, patients may not be aware that they need assistance in representing themselves.

Caregivers, says Cassell, should help the patient make decisions that are consistent with the unique purpose of his or her life. "This is," he maintains, "the function of medicine—to enable sick persons, within the constraints of fate, to continue to live true to themselves" (p. 82). Using the metaphor of life as a work of art, Cassell says that the suffering person should be helped to see where the next thread in their life-tapestry needs to be placed, according to the pattern or overarching design they have set for themselves.

All of this points to the importance of community in relation to the suffering patient. Though suffering is a private and isolating event, it reminds us that we live in communities. We cannot survive without them. This reality underscores the current mistaken overemphasis on individuality.

The primary community in medicine—that of patient and healer—has largely been ignored by ethics. The doctor-patient relationship should rather be a central concern of ethicists as they examine questions about autonomy, paternalism, and beneficence within varying communities. Do we in fact owe *more* to suffering people because their predicament loosens their ties to the rest of us?

In sum, suffering patients with their compromised autonomy invite clinical ethics and clinical medicine to find better ways to represent their interests within the community of care. The emphasis of bioethics on autonomy poorly serves the suffering patient.

—A.C.

## Respecting religious beliefs in life-and-death decisions

Michael J. Wreen, "Autonomy, Religious Values, and Refusal of Lifesaving Medical Treatment," *Journal of Medical Ethics* 17, no. 3 (September 1991): 124–30.

IN A HYPOTHETICAL CASE POSED BY WREEN, a fully competent adult patient in a nonterminal condition refuses treatment that would extend her relatively pain-free life. The patient is aware that accepting the treatment (a blood transfusion) will almost certainly bring recovery; refusal will almost surely result in death. Because the patient has satisfied the conditions for valid consent, her decision must be honored. This conclusion, Wreen observes, implies that the value of autonomy is greater than the value of the patient's life.

Wreen finds this case troubling because it creates a conflict between respect for personal autonomy and an intuition in favor of overriding the patient's choice in such situations. Is it right to allow so much emphasis on autonomy when the outcome of the autonomous choice is needless death? Can autonomy really carry such moral weight by itself, or are other values needed to ground such refusals of treatment?

Values other than autonomy are often brought up in court cases involving refusal of treatment. They include privacy, bodily integrity, and religious freedom. Privacy, Wreen claims, does not apply to treatment refusal, and bodily integrity is already implied in autonomy. Religious freedom (pursuing religious values freely and acting on them), however, is not usually considered in treatment refusal cases; and when it is—as when a Jehovah's Witness refuses blood—it seems clear that the refusal should be respected. Why is this the case?

Wreen maintains that religious beliefs fit into a rational person's life in a way that other beliefs cannot; religious beliefs make an important difference in the way we regard and treat the one who holds them. Why are religious beliefs so special? Because, claims Wreen, they deal with the meaning of life. They describe and interpret the human condition at the most basic level, provide individuals with a unique concept of self, and attempt to make sense of reality and our place in it. These beliefs originate on a deeper "existential level"



than other values and even influence those other values.

Religious beliefs, Wreen concludes, have a “supremely important integrating and reconciling function” in an individual’s life (p. 128). They are deeply bound up with the patient’s identity. Thus they add weight to the value of autonomy. (The same would be true of “non-religious ideology” that fulfills the same integrating functions as religious belief.) To

override treatment refusal based on religious belief is to dishonor the person at the most fundamental level, the level at which he has tried to reconcile himself to the limitations of his own human existence, the level at which he has made the attempt (even if very misguided) to find out who he is and what his place in the world is (p. 128).

—A.C.



### Erratum

In volume 17, no. 3 (January 1992), the sentence beginning at the bottom of p. 110 should read: "To alleviate the tension in the Nightingale family over Nightingale's desire to do *hospital work, close family friends, Mr. and Mrs. Bracebridge*, took Florence on an extended trip in 1849 and 1850 to Greece and Egypt." The words italicized here were omitted.

Articles are indexed in the following: *Abstracts of Research in Pastoral Care and Counseling*; *Bibliography of Bioethics*; BIOETHICSLINE; *Christian Periodical Index*; *Cumulative Index to Nursing and Allied Health Literature*; *Hospital Literature Index*; *Index to Book Reviews in Religion (IBRR)*; *Religion Index One: Periodicals (RIO)*.



## *Second Opinion* Guidelines for Authors

1. The manuscript should be typed on one side only, on standard white paper, with margins of at least 1 inch. All material, including extracts and references, should be double-spaced. Manuscript length should not exceed 35 double-spaced pages.
2. Style and spelling in the journal are governed by *The Chicago Manual of Style* (13th edition) and *Webster's New International Dictionary*. If you have any questions on style, please consult these sources.
3. Authors are urged to use nonsexist language.
4. Figures, diagrams, tables, and charts, if appropriate, should be submitted on separate pages and keyed to their position in the text. In addition, a list of legends or captions should be typed separately.
5. We welcome suggestions for illustrations. Our criteria for selecting illustrations are relevance to the article and visual interest.
6. Articles should be aimed at a diverse but educated public. Do not write for the six specialists in your field, but rather for the general reader.
7. Notes, citations. Notes are to be reserved for substantive observations, and their use is discouraged. They should be numbered consecutively and placed in a separate section following the text. All notes that consist merely of supporting citations should be placed in parentheses in the text, listing (in order): last name of author, year of publication, and page numbers where appropriate, e.g., (Tillich 1967:353). Subsequent citations of the same source should also follow this model.
8. In a separate section entitled "References" list alphabetically by author (and, within author, by year of publication) all items that are cited in the text. Give complete bibliographical information, including author's first name, publisher, and place of publication. If there is more than one reference to the same author and year, distinguish them by the use of letters (a,b) attached to year of publication, e.g., Smith 1978a.

### *Examples*

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