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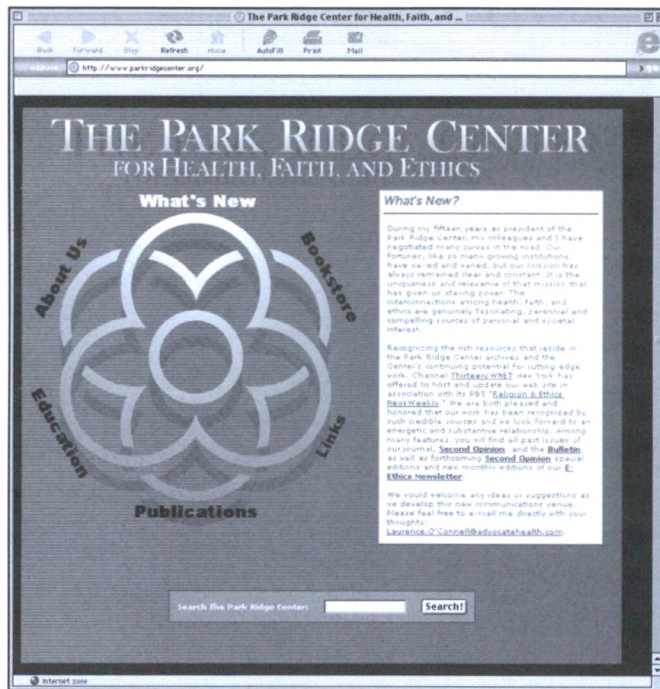
HEALTH | FAITH | ETHICS

SECOND O P I N I O N



THE PARK RIDGE CENTER

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Dear *Second Opinion* Reader,

During my fifteen years as president of the Park Ridge Center, my colleagues and I have negotiated many curves in the road. Our fortunes, like those of so many growing institutions, have waxed and waned, but our mission has always remained clear and constant. It is the uniqueness and relevance of that mission that has given us staying power. The interconnections among health, faith, and ethics are genuinely fascinating, perennial, and compelling sources of personal and societal interest.

Recognizing the rich resources that reside in the Park Ridge Center archives and the Center's continuing potential for cutting-edge work, Channel Thirteen/WNET New York has offered to host and update our web site (pictured on the facing page) in association with its PBS *Religion & Ethics NewsWeekly*. We are both pleased and honored that our work has been recognized by such credible sources, and we look forward to an energetic and substantive relationship. Among many features, you will find all past issues of *Second Opinion* and *The Park Ridge Center Bulletin*, as well as forthcoming *Second Opinion* special editions and new editions of our newsletter, *e-Ethics*.

We would welcome any ideas or suggestions as we continue to develop this new communication venue. Please feel free to e-mail me directly with your thoughts: Laurence.O'Connell@advocatehealth.com.

And one final note: We would very much appreciate your returning the enclosed envelope with a contribution. We continue to depend upon the generosity of our friends to support much of our work.

Sincerely,
Laurence O'Connell

HEALTH | FAITH | ETHICS

SECOND O P I N I O N

SECOND OPINION

NUMBER 11 | APRIL 2004

Publisher	Laurence J. O'Connell
Editor	Martin E. Marty
Senior Editor	David B. McCurdy
Managing Editor	Therese Samodral
Production Editor	Ben McDonald Coltvet
Associate Editor	Kirston Fortune
Design	Haru Furuya
Technical Assistance	Al Hurd Bryan Coyle
Editorial Committee	Philip J. Boyle Edwin R. DuBose Martha B. Holstein

The mission of the Park Ridge Center is to explore and enhance the interaction of health, faith, and ethics through research, education, and consultation to improve the lives of individuals and communities.



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Phone (847) 384-3504 or fax (847) 384-3557.

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Darrel Amundsen
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Peter J. Whitehouse
Quentin Young
Laurie Zoloth

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CONTRIBUTORS

Helmut David Baer, Ph.D., is Assistant Professor of Theology and Philosophy at Texas Lutheran University. He received his Ph.D. from the University of Notre Dame.

Philip J. Boyle, Ph.D., is Corporate Vice President, Ethics, for Catholic Health East, a multi-institution Catholic health system in the eastern United States. He previously served as Chief Operating Officer at the Park Ridge Center for the Study of Health, Faith, and Ethics.

Mary Ann Clemens, Ed.D., is Vice President, Medical Education and Research, Advocate Health Care, Oak Brook, Ill. She was previously Senior Ethics Consultant and Director of Education at the Park Ridge Center for Health, Faith, and Ethics.

David B. McCurdy, D. Min., is Senior Ethics Consultant and Director of Organizational Ethics at the Park Ridge Center for Health, Faith, and Ethics. He is Senior Editor of *Second Opinion*.

Arthur W. Frank, Ph.D., is Professor of Sociology at the University of Calgary. He is author of *At the Will of the Body* (1991) and *The Wounded Storyteller: Body, Illness, and Ethics* (1995).

Cheryl A. Kirk-Duggan, Ph.D., is Director of the Center for Women and Religion; Assistant Professor of Theology and Womanist Studies in the Graduate Theological Union; and an ordained minister in the Christian Methodist Episcopal Church.

Stephen B. Levine, M.D., is Clinical Professor of Psychiatry at Case Western Reserve University and Codirector of the Center for Marital and Sexual Health, Beachwood, Ohio.

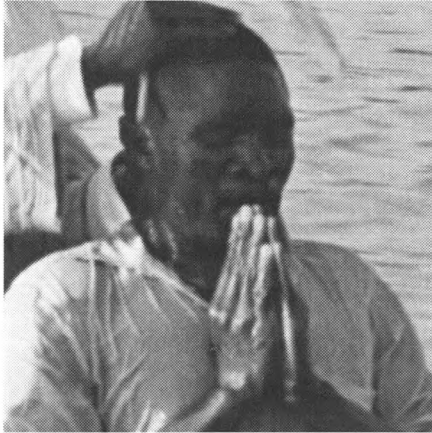
Abby Lippman, Ph.D., is a Professor at McGill University. She is on the Advisory Committee of DES Action Canada and is cochair of the Canadian Women's Health Network.

Ana Smith Iltis, M.A., is currently finishing her Ph.D. in philosophy at Rice University. She is managing editor of *Christian Bioethics* and co-managing editor of *The Journal of Medicine and Philosophy*.

CONTRIBUTORS

Charles Villa-Vicencio, S.T.M., Ph.D., is Executive Director of the Institute for Justice and Reconciliation, Cape Town, South Africa. He served as Research Director of the South African Truth and Reconciliation Commission. Before that he was Professor of Religion and Society at the University of Cape Town.

Leonard J. Weber, Ph.D., is Professor of Ethics at the University of Detroit Mercy and the author of *Business Ethics in Healthcare: Beyond Compliance*.



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*A Bantu Christian is baptized near
Johannesburg, South Africa.*

EDITOR'S NOTE

BY MARTIN E. MARTY

The Final *Second Opinion*, Not the Final Opinion

Some day archivists digging into the relics of our years may come across two sets of the journal *Second Opinion*. This publication has in the last score of years had two incarnations, two formats, two sets of editors with me serving as continuity between them, but one mission.

Before I revisit that mission, I should insert a paragraph dealing with the sad news that has reached many of

you through other Park Ridge Center publications or through cyberspace. This will be the last issue of this series of *Second Opinions*. Laurence O'Connell, the chief executive officer of the Center, has explained that the Advocate Health Care system, which has been so generous with the Center through two decades, is unable to sustain some of the Center's ventures. Any-

one who follows economic trends in health care will understand. Yet understanding does not lessen the shock or the sadness for us who edit it—and, I hope, for you who have been reading it. Still, we say thanks to Advocate for what it helped sustain, just as we “roll with the punch” as this venture ends.

Back to the mission. I was “present at the creation” of the journal both times, so let me reflect on what we intended and, I hope, at least partially achieved.

I want to say we detected a void, but “detecting” usually involves using fine instruments to discern subtle gaps. No, we were aware of a chasm separating “secular” talk about health and ethics from religious, spiritual, or faith-inspired talk. This chasm opened on an abyss of indifference, ignorance, neglect, and lack of discernment concerning the lives of patients and caregivers as they cope with crisis, disease, matters of justice, and ethical dilemmas, and plan for better delivery of care.

Into that scene of health and ethics, we inserted the word “faith,” and our mission came to be finding talent who would discover ways of forming that three-way link. To our modest surprise, first-rate talent responded to our invitations to write. Others found

Second Opinion to be a creative outlet and its readership one they wanted to reach. I recall instances where I would read articles having to do with ethics or the understanding of suffering by recognized authorities. I would write these authors and say something like: “It seems to me that you are on tip-toe at the edge of informing your writing with an explicitly religious outlook. Would you consider doing that here?” They would often confess to having had an itch to write in that vein but had felt or been inhibited by academic convention. So they wrote for us, found a readership, started conversations, and, to our knowledge, did not suffer for having called the convention into question.

Instead, they turned out to be in an advance guard. What was once in the footnotes or left behind is now up front in much writing on these subjects. We have found much company, some that we stimulated and some that exemplifies the fact that the health-faith-ethics nexus shows promise and attracts energies in many ways and places.

We won’t be on the scene in the revised Park Ridge Center. Relocated, it will continue, with a smaller staff, to connect the three terms and seek to fulfill the mission. The accent, at least at first, will be on serving the Advocate

Health Care system, which is a large, strategic, and influential deliverer of care, and then, through it, setting out to reach larger publics again. “Research” and “publication” are not as large a part of this revised entity as they were in the Park Ridge Center you have known as publisher of *Second Opinion*.

There is no need to end on a note of diminishment or with an announcement of denouement. Conferees who found each other and quickened each other's interests through the Center, and writers who read and stimulated each other through this journal and its predecessor will, we trust, keep furthering the cause.

Most of the work lies ahead. The topics only grow in importance. We have long felt that “mere” ethical talk, impressive as it can be, often lacks the contexts that the faith dimension provides. So we have argued that, alongside ethics and undergirding it at its best, is the ageless search for meaning, especially in the face of suffering or injustice. This means that something like theology, philosophy of religion, the language of the believing community, and pastoral care enhances the ethical search and addresses more human needs than does academic or clinical ethics in isolation.

Getting professionals in medicine, religion, and the academy to find common language and to see that their worlds intersect has always been an editorial challenge that we welcomed. Such language does not come easily in the era of necessary specialization. Yet we believed and have found evidence that there are circumstances and settings wherein the common concerns produce enough common discourse to encourage others to carry on.

You are likely to read elsewhere many of the authors you have come to know from these pages. I cannot sign off without saying that if they are to be discovered, corralled, edited, and promoted by the colleagues with whom it has been my pleasure to work, you will be well-served. You can have confidence in what you read if members of this team have been agents in the task of getting good writing to you.

When you close this issue after reading it, I hope you'll file it with other saved copies of *Second Opinion*, and will find that it stimulates some third and fourth opinions as you set out to discover more ways than one to talk about “health, faith, and ethics.” ■

GENETICS AND PASTORAL COUNSELING

BY PHILIP J. BOYLE

A Special Report

OVERVIEW

INTRODUCTION

I had a case where I was called to the pediatric intensive care unit and greeted by a dad who said, “Our baby of nine months died of a genetic health problem in a Boston hospital and I turned my back on G-d.” And before the child died the mother was pregnant with twins. Now they are in the pediatric intensive care unit because one of the twins has the same genetic heart defect. So the parents

did not find out about the genetic heart conditions until after the death of the first child and she was already pregnant. And he said to me, “I went through the death of one child without G-d and I don’t want to go through the death of another child without G-d and I don’t know how I am going to find G-d and reconnect with G-d, but I am going to need a lot of help.” I have dealt with similar parents who reject G-d saying, “If G-d is going to cause this much suf-

fering in death, then I am just going to reject G-d." As a chaplain you never know what will turn them one way or the other, but it has to be addressed as part of their healing.

—An interviewed chaplain

With the first draft of the map of the human genome complete, forecasters predict that during the next decade hundreds of genetic tests and therapies will be available, will be integrated into the healthcare delivery system, and will have a cascading effect. The increase of genetic diagnosis will bring with it a host of medical and moral options, all of which will carry serious social and religious implications, as the chaplain's story illustrates. Today's thousand-plus clinical

geneticists and two thousand genetic counselors will barely be able to keep up with medical aspects of genetic counseling, and they will probably be unable to meet the religious and spiritual needs evoked by the new technology. Patients, families, and genetics professionals will turn to pastoral counselors (a term used here to encompass a broad range of persons providing pastoral or spiritual care and counseling, e.g., Christian clergy, imams, rabbis, deacons, chaplains, and nonordained lay ministers); they will also wonder whether these pastoral counselors have the education and skills to meet the growing need. The study discussed in this article explored the kinds of pastoral counseling currently offered and asked what needs to be done to

This report was prepared for the Park Ridge Center project, *Genetics and Pastoral Counseling*, which was funded by the National Center for Human Genome Research of the National Institutes of Health grant 1R01HG02172-01.

How might pastoral counselors help individuals cope with ethical and religious issues in genetic diagnosis?

enhance the role of pastoral counseling in responding to genetics issues.

The goal of this project was to identify the nature and extent of the pastoral counselor's role in dealing with the range of genetics issues. Specifically, this research examined

- Whether and how pastoral counselors might help individuals cope with the ethical and religious issues that arise in genetic diagnosis and treatment
- The knowledge and skills necessary for pastoral counselors to serve effectively in genetics cases
- The institutional and professional factors that hinder or facilitate pastoral counselors' involvement in genetics issues

The initial method for achieving the goal was to have geneticists, genet-

ic counselors, and social workers who work with persons with genetic conditions articulate what role they thought pastoral counselors could helpfully play. The study was expanded to have pastoral counselors who work with genetics cases articulate what they found helpful, harmful, and unique in working with genetics issues. With the use of national telephone focus groups, 17 in all, more than 140 professionals (including geneticists, genetic counselors, social workers, and pastoral counselors) were interviewed about the questions listed above. Interviewees were asked to talk about pastoral counselors, a group that in their experience included clergy, pastors, rabbis, imams, chaplains, deacons, spiritual counselors, and nonordained lay ministers. Consequently, this study uses the term "pastoral counselors" in a generic sense to designate a range of religious professionals who serve the religious needs of all faiths. Most interviewees were unaware that the term pastoral counselor can refer to a specific group of professionals with distinct credentials and competencies.

FINDINGS

The range of professionals who study the social, ethical, and religious implications of the human genome

project lacks evidence about the nature of pastoral counselors' involvement in genetics counseling, healthcare professionals' expectations of pastoral counselors and their roles, and the types of obstacles and opportunities that pastoral counselors encounter. This study adds qualitative evidence to fill in these gaps in understanding, and provides baseline data for reconceptualizing policies and practices that address pastoral counseling in relation to genetics.

Problems Identified

Those interviewed recounted an array of problems and obstacles, most notably:

- Uncertainty about the identity and nature of pastoral counseling and who is qualified to provide the service
- Conflicting expectations about the level of understanding in genetics that a pastoral counselor needs, and variation in the level of skills and experience deemed necessary for practice in pastoral counseling
- Turf wars over the extent and limits of pastoral counseling practices in genetics-related cases
- Patterns of practice by clinical genetics professionals that reduce the likelihood of involving pastoral

Those interviewed recounted an array of problems and obstacles

counselors in genetics cases

- Unhelpful stereotypes in which clinical genetics professionals are perceived as nondirective in counseling and pastoral counselors as always directive. Other stereotypes frame religion as simplistic and monolithic in its approach to ethical norms and religious responses, and assume that religious traditions share a single, extensive view about how to address the religious and spiritual issues raised by genetic diagnoses.
- Interprofessional relations that are sometimes fueled by mistrust, based, for example, on long-standing suspicions between science and religion
- Institutional barriers in the form of suboptimal hiring practices and inadequate funding for pastoral care services

Recommendations

Among their more salient recommen-

Genetics professionals need to consider their deficiencies in understanding pastoral counseling.

dations, the interviewees highlighted the following:

- Healthcare institutions ought to utilize only pastoral counselors who have the professional education, skills, and competencies recommended by professional associations involved with pastoral counseling. Clinical genetics professionals ought to refer only to pastoral counselors who are known to have the requisite qualifications.
- Pastoral counselors need to consider what education and skills are needed for dealing with genetics, and clinical genetics professionals need to consider their own educational deficiencies in understanding the nature and content of pastoral counseling and its relationship to genetics questions.
- Professional associations of pastoral counselors should reexamine whether existing credentialing pro-

cesses will adequately address the spiritual and religious issues occasioned by the increasing number of genetic diagnoses.

- Clinical genetics professionals should develop a rudimentary understanding of issues associated with religious coping, including a capacity to assess patients' needs for pastoral counseling and determine how and to whom such patients should be referred.
- Schools offering theological and pastoral education, and national and regional denominational organizations (e.g., dioceses), should consider providing continuing education programs on pastoral counseling skills, and should collaborate with clinical genetics professional organizations, medical schools, or healthcare institutions to provide education in clinical genetics.

THE STUDY

BACKGROUND

In the past ten years, the use of genetic screening and diagnostic testing has grown exponentially. The completion of the Human Genome Project (HGP) will, according to the Institute of Medicine's Committee on Assessing Genetic Risks¹ (hereinafter "the Com-

mittee”), increase even further our ability to conduct predictive testing for monogenic, late-onset disorders such as Huntington’s disease, and susceptibility testing for late-onset disorders involving complex genetic-environmental interactions, such as breast cancer. Society can also expect more testing of embryos, fetuses, newborns, and prospective parents. As a result of the HGP, the next decade will see testing to identify the genetic components of disease and will see a rapid increase in the number of tests available to detect a growing number of illnesses. Test kits and diagnostic products will become readily available to the public. The Committee notes that commercial and academic “genetic testing services” will probably offer their products without approval from the Food and Drug Administration (FDA). “Multiplex” tests that can detect simultaneously the presence of numerous genetic markers for disease, carrier status, and susceptibility have already emerged. In the face of this explosion of knowledge and capacity, there has long been a question whether there will be enough trained individuals to provide education and counseling.²

The number of trained genetic specialists is still relatively small. The Directory of Board Certified Medical

The number of trained genetic specialists is still relatively small

Specialists lists some 1,000 medical geneticists in the United States.³ In addition, approximately 1,800 professional genetic counselors practice in the United States, with about 145 new counselors graduating each year.⁴ It is widely recognized that this number is insufficient to meet the increased demand for genetics education and counseling that increased numbers of genetic tests, screens, and interventions will generate. A 1998 report shows the following regional distribution of genetic counselors in the U.S.: 7 percent are in New England; 29 percent in the Mid-Atlantic States; 10 percent in the Southeast; 20 percent in the Midwest; 9 percent in the Mountain/Southwest region; and 20 percent on the West Coast.⁵ The combination of the increased availability of genetic services, lack of genetic counselors, and uneven distribution of genetic counselors nationally, supports the call for new models of counseling service delivery.⁶ If, for example, there will indeed be genetic tests for an increasing variety of monogenic and complex dis-

eases, and for susceptibility to more common disorders such as breast, colon, and other cancers, who will provide the counseling that those undergoing these tests—and receiving the results—will need? The Committee concludes that these developments will require the design of other models of service delivery beyond those that have until now provided genetic testing and screening. Convinced that the point of genetic services delivery will increasingly be primary care practice, the Committee envisions the growing involvement of pediatrics, obstetrics, internal medicine, and family practice in providing genetic testing, screening, education, and counseling in a variety of individual and group practice settings.⁷

As the number of physicians involved in genetic testing and screening expands, their professional inclination to advise and treat may compromise autonomous, well-informed decision making by patients, particularly when the disorder being tested for has no immediately available treatment.⁸ To counterbalance this tendency, a broader array of counseling and educational services, made available through less traditional models of service delivery, is essential to meet the needs of a wider spectrum of the population.⁹ As the

Genetic counseling should respect the culture and convictions of the client

Committee observed, “The social and cultural meaning of class, race, ethnicity, and religion all impact on genetic testing and reproductive decision making.”¹⁰ For these reasons, genetic counseling should respect the culture and convictions of the client. The involvement of the client’s faith community, possibly through the presence of a pastoral counselor such as a Christian clergy person, rabbi, imam, or nonordained chaplain, is one way to achieve this end.

Given the revolution already under way in the delivery of genetic services, there are compelling reasons to consider why and how pastoral counselors can be significantly involved. As the number of available genetic tests increases, so will the number of those who receive the test information and wonder about its religious and ethical meaning.

The potential number of pastoral counselors who could address issues related to genetics is remarkable. The number of ordained clergy in the United States alone exceeds one half million: 45,000 are Roman Catholic,¹¹

488,000 are Protestant and Orthodox Christian,¹² 4,600 are rabbis for the four major branches of Judaism,¹³ and approximately 980 are imams.¹⁴ Hundreds of clergy and other spiritual leaders serve Buddhist, Hindu, Sikh, and other immigrant religious groups, although figures are not readily available. More important in North America, nearly 10,000 of the professionals listed above identify themselves as working in health care as they participate in five of the largest organizations of chaplains and pastoral educators: the Association for Clinical Pastoral Education (approximately 1,000 members), the Association of Professional Chaplains (approximately 3,000 members), the Canadian Association for Pastoral Practice and Education (approximately 1,000 members), the National Association of Catholic Chaplains (approximately 4,000 members), and the National Association of Jewish Chaplains (approximately 400 members).¹⁵

Beyond the remarkable size of this potential work force, other factors suggest why and how pastoral counselors might be able to assist persons with genetic conditions. First, as the number of cases grows, more patients and health professionals are likely to involve pastoral counselors. Recent research indi-

The potential number of pastoral counselors who could address genetics-related issues is remarkable

cates that pastoral counselors are increasingly being called upon to advise patients and professionals in health-related areas. Thus they have the potential to affect knowledge, attitudes, and behavior related to health and its religious and spiritual implications.¹⁶ Moreover, a review of the literature shows that pastoral counselors are in a strategic position to offer health-related information and counseling.¹⁷ Rabbis, priests, imams, and ministers enjoy a natural entree in the genetics-related context when they counsel couples who intend to marry, have given birth to an impaired child, or have a genetic illness.¹⁸ In addition, the research shows that congregants have come to expect help in health-related problems from their clergy, particularly when there has been a prenatal diagnosis of abnormality.¹⁹ Research indicates that congregants can benefit from and, increasingly, are looking for spiritual and moral assistance to help them apply knowledge of human

genetics and employ reproductive technologies in their own situations.²⁰

Pastoral counselors offer several important benefits to patients and families who struggle with genetic diagnoses and conditions. First, pastoral counselors provide the opportunity and the religious resources that permit individuals and their families to seek answers to moral and spiritual questions raised by genetic testing and illness. The questions vary, depending on the severity of the genetic condition and when during the life span it affects the patient or family. Couples contemplating marriage and starting families might reconsider marrying if one or both of the partners carry a lethal or debilitating gene, or one that could be passed on to the next generation. If they marry and conceive, they may consider prenatal diagnosis and face questions about abortion; they may also consider alternative means of conceiving, such as in vitro fertilization. A couple giving birth to a child afflicted with a lethal or debilitating genetic illness might have to struggle with termination of life-sustaining treatment or caring for a disabled infant.

Children and young adults with genetic disabilities, some of which stem from lethal conditions, will have to face eclipsed futures. Couples might face

Genetic conditions afflict patients and families across the life span

marital problems occasioned by genetics-related issues.²¹ Older adults with late-onset genetic disorders will struggle with infirmity and sometimes with end-of-life decisions. Therefore, genetic conditions will afflict patients and families across the life span and will pose unique moral and religious questions, depending, for example, on the time in life when the affliction emerges, on spiritual maturity, and on life circumstances (such as being married or not). Pastoral counselors can help patients and families integrate their religious worldview with the implications of the genetic condition.

Second, pastoral counselors can support and complement the work of genetic counselors. While both professions help patients and families cope with grief, a pastoral counselor engages patients and families in conversation about the moral, religious, and spiritual meaning of the grief and can help them find support from their religious tradition. Pastoral counseling can also

Pastoral counseling can integrate the patient's religious priorities with the medical treatment plan

integrate the patient's or family's religious priorities with the medical treatment plan and thus lessen the potential for conflict and stress. In some cases information provided by genetic counselors for purposes of informed consent will differ from religious information that a pastoral counselor might offer and a patient might want to consider.

Third, pastoral counselors help connect individuals and their families to larger faith communities that can provide support.²² While genetic diagnoses are made within hospitals, clinics, and physicians' offices, patients and families return to local communities, where they spend the majority of their time, to find resources for coping and making meaning. Pastoral counselors help patients and families draw on the resources of their local congregations and support networks.

Fourth, as patients and families return to their communities, pastoral counselors associated with congrega-

tions are more available and accessible than healthcare professionals. Pastoral counselors can help congregants appreciate how their religious faith, of whatever depth, can influence decisions they might make under stress. It is important not to underestimate the significance for a person of religious faith that the birth of a child with Down's syndrome or Tay-Sachs disease may have. Also, it is important not to overlook the anxiety of the expectant mother whose decision to undergo amniocentesis may have created doubts in her own mind about her fidelity to her religious beliefs. After genetic counseling, pastoral counselors play a positive role by supporting the work of the genetics counselor, thereby securing the religious well-being of congregants who find themselves dealing with genetics-related issues in their personal and family life.²³

Fifth, research shows that ethical and religious counseling by an informed pastoral counselor can add a dimension to the genetic counseling process that genetic counselors and members of the medical community alone cannot provide.²⁴ This dimension is counseling that moves beyond the medical discussion of *what* happened, to a religious and spiritual discussion of *why* it happened. For example, genetic counselors

Although patients know what has happened, they do not know why it has happened

explain birth defects at a chromosomal or metabolic level. But explanations of this sort can leave patients looking for more because, although they know *what* has happened, they do not know *why* it has happened in the larger, possibly transcendent, sense of “why.”

This sense of dissatisfaction may not disappear when the genetic counselor reassures parents that nothing they did contributed to the genetic problem: it was “just one of those things.” When parents find no comfort in a random statistical process as the explanation for the genetic problem of their child, they frequently resort to religious explanations.²⁵

The case of a couple who lost a child to anencephaly illustrates the critical difference. The genetic counselor, by way of explanation, had described the fetal development of the brain and spinal cord, explained how the level of alpha-fetal protein was increased in the amniotic fluid and maternal blood, and pointed to this process to indicate what

had caused the child’s abnormality. That the physiological explanation was less than satisfying is apparent in the comment of the mother who, when asked subsequently what had caused the anencephaly, replied that God had. By allowing the death of her child, the mother explained, God had taken care of the mistake.²⁶ Religious explanations of this kind are quite common.²⁷ For instance, parents who deal with a prenatal genetic problem frequently ask questions that imply God’s involvement as a cause of the problem and a source of its solution. They ask questions with the understanding that God expects the parents to do something, even though what to do may not be clear at the moment.²⁸

One can explain the difference between what genetic counselors say and what parents say about the same genetic anomaly as a matter of seeing from differing perspectives and finding different meanings in the same event. Operating out of a self-perceived nondirective role, genetic counselors are inclined to omit discussion of “final” causes of genetic disorders as professionally inappropriate. In contrast, many parents trying to live their lives in the presence of genetic anomalies and their implications seem compelled to

search for ultimate answers.

Parents frequently consider their children affected by a genetic condition as tests set before them by God; they do not view the child in the same light as genetic counselors do. Ultimately, genetic disorders are not, for many parents, the result of impersonal, probabilistic forces. They are neither arbitrary nor anonymous; rather, they are specific problems affecting particular families, and they require particular explanations.

From the perspective of faith, genetic diagnoses and conditions press patients and families at a fundamental level to consider their role and participation in creation.²⁹ And it is in this context that people facing choices about things that earlier were assumed to belong exclusively to God will confront the theological and moral dilemmas posed by genetics.³⁰ If they are people of faith, a fundamental question for them may be how they should conceive and bear children. Should they test the fetus? Depending upon what the tests reveal, should they terminate the pregnancy? Is it still possible for people of faith to see fetal development as a sacred mystery, and childbirth ultimately as a gift of God's creation?³¹

Behind these questions lies a ten-

Parents' questions frequently imply God's involvement as a cause of the problem and a source of its solution

sion between seeing themselves as made in the image of God and as merely the sum of their genes. There is also the tension between wanting only the best for their children and the disposition to accept them as they are, with whatever abilities and disabilities they may have.³² While genetic counselors may recognize such distress and sympathize with their patients, they may not view sympathy as something to account for in their professional capacity as counselors.³³

Pastoral counselors are often uniquely qualified to help individuals and their families resolve these tensions and answer questions of ultimate meaning. In general, genetic counselors, medical geneticists, and physicians do not have the professional training to help answer questions that link one's genetic decisions to one's religious faith. But since the desire for a broader-than-medical context is com-

mon among those who confront genetic anomalies, it would greatly assist them if some component of the counseling process recognized and responded to that desire.

Sixth, as genetic testing becomes more commonplace, healthcare professionals and organizations would be wise to consider what may happen to patients if pastoral counseling is not provided. Will individuals who might otherwise benefit from genetic testing stay away from it on religious grounds? What are the long-term psychosocial consequences for individuals when they undergo genetic testing but are denied the opportunity to engage in guided reflection with a pastoral counselor on the religious meaning of the medical intervention? While this research did not answer these questions directly, it did provide a sense of the dimension that pastoral counseling brings to the care of patients and families with genetic disease.

A Snapshot of Current Practice

If pastoral counselors are a potential source of service in the rapidly expanding genetics field, interview data from our study and others suggest varied expectations and practices on the part of pastoral counselors and of clinicians who might refer patients to them. A

snapshot that the 140 interviewees provided of their activities depicts no uniform practice or expectation regarding the nature and extent of pastoral counseling services in genetics. Wide variability exists in how pastoral counselors become involved and how they subsequently participate.

How pastoral counselors become involved

Pastoral counselors' opportunities to participate in genetics-related cases arise in four ways: they are expected to participate as staff members of healthcare institutions; they are invited by healthcare professionals; they proactively intervene with the patient and/or family; or they are sought out by the patient or family. When they are members of an institution's staff, pastoral counselors experience the fewest barriers, since in institutions that employ them there are standing expectations that patients will receive spiritual and religious care. Nevertheless, while an institution may employ a pastoral counselor, there is no guarantee that the clinical staff will recognize a patient's or family's need for pastoral counseling in genetics-related situations. Some interviewees reported that pastoral care was included as a participating discipline

during daily rounds within teaching hospitals. Some hospitals with large pastoral care staffs expect that chaplains will visit all inpatients, a fact that makes it more likely that inpatients suffering from a genetic condition will receive pastoral care.

However, the inpatient focus of pastoral care, which is normally short term, reduces the likelihood of contact with outpatients who are seen in clinics or in physicians' offices. Patients with chronic genetic conditions treated in outpatient settings will likely have little contact with pastoral counselors. Patients and families who receive genetic testing as part of prenatal testing will rarely have access to the institution's chaplains.

A consensus paper issued by five leading professional groups of pastoral counselors suggests that there is a greater likelihood that patients with genetics-related conditions will rely on healthcare institutions' pastoral counselors than on other religious leaders who might provide counseling:

Many religiously active persons do not notify their local clergy of their hospitalization Additionally, many patients do not have a religious community to which they can look

Patients who receive prenatal genetic testing rarely have access to the institution's chaplains

in healthcare crises. In one study, only 42 percent of hospital patients could identify a spiritual counselor to whom they could turn, and many of them had not talked to their religious leader about their situation For others, attention from their spiritual counselor is limited by being in a hospital far from home . . . , by patient concerns about privacy or confidentiality, or [by] a fear that their own religious leader would not understand or be supportive.³⁴

A less common but extremely effective means of a pastoral counselor's entry into genetics-related cases is through clinical genetics professionals who refer patients and families to pastoral counselors, either as a standing practice or on an as-needed basis. A few of the interviewed geneticists, genetic counselors, and social workers made it a practice to inquire about patients' religious involvement and, if the patients

expressed interest, to refer them to pastoral counselors. Clinical genetics professionals normally refer to pastoral counselors within the healthcare institution whom they know personally or who have a reputation for competent pastoral care. If the clinical genetics professional does not know the pastoral counselor, he or she utilizes different strategies. Clinicians ask patients if they have a good relationship with their congregational pastoral care person and then refer to that person. Alternatively, they contact clinical colleagues for referrals to pastoral care people who have experience in dealing with genetics issues. Sometimes they tell a patient of their willingness to speak directly to a pastoral care professional, if the patient gives permission. In sum, availability and positive prior experience of pastoral counselors increases the probability that clinicians will refer.

Only in a few cases did interviewees report that pastoral counselors proactively inserted themselves into a situation when the patient had a genetic condition. This practice was most evident with pastoral counselors who provided education. For example, some congregational pastoral counselors educate congregants about genetics issues, especially genetic testing. In some reli-

gious communities, for example, among Orthodox Jews in New York and in areas with a high concentration of Muslims, religious leaders commonly address genetics-related religious issues. In some cases pastoral counselors help couples respond to prenatal diagnoses of genetic abnormalities or assist in arranging marriages. Interviewees noted that in these same communities, some patients and families seek pastoral support from local pastoral counselors while considering genetic testing or after receiving a genetic diagnosis. One respondent, who identified himself as a rabbi, recounted that Jewish women with breast cancer who wanted mastectomies frequently involved the rabbi because under Jewish law self-mutilation is forbidden unless it can save a life. Several pastoral care respondents noted that the most frequent psychological reason they are sought out by patients is the issue of guilt, especially before or after the termination of pregnancy. However pastoral counselors become involved in genetics cases, interviewees perceived that pastoral counselors are most involved with genetic issues at the beginning and end of life. Problem pregnancies are laden with religious and ethical value conflicts, especially if abortion is a possibility.

Pastoral counselors are most involved with genetic issues at the beginning and end of life

Why pastoral counselors do not participate

Interviewees were clear about why pastoral counselors do not participate in genetics-related cases. A significant number of genetics professionals reported negative experiences with pastoral counselors, particularly pastoral care professionals who were judgmental or who undermined the genetic professional's counsel. Some cited these experiences to explain their reluctance to mention pastoral counseling as an option. They believed that they were "protecting" their clients from further suffering that "hard-line" clergy might impose.

Other Studies

The current study was supported by two earlier studies (a study of clergy in Indiana and a study of rabbis) that provided snapshots of pastoral counselors' knowledge and practice in relation to genetics. This research makes it clear that the majority of clergy have not been pre-

pared to assist congregants with their genetics-related problems. In the study of Indiana clergy, 77 percent of the responding clergy indicated that they spent up to 5 percent of their counseling time dealing with problems related to genetics. None of the respondents claimed to spend more than 20 percent of their counseling time on genetics-related matters. According to the authors, these findings have at least three possible causes: 1) neither clergy nor their congregants recognize the genetic component of many physical and mental conditions; 2) congregants fail to recognize underlying moral/ethical issues in genetics, which they perceive as largely medical and for which, as a result, they look to physicians for counseling; 3) congregants do not view their clergy as having professional training to deal with problems in human genetics. The study also found that 83 percent of the respondents indicated that they had not offered their congregations educational programs on the moral dimensions of making decisions related to genetic disorders. These figures are understandable in light of a central finding of this study, namely, that 68 percent of the respondents had no formal education in genetics, genetic disorders, or reproductive technolo-

The majority of clergy have not been prepared to assist congregants with genetics-related problems

gies. Of the 32 percent who had some formal education in these areas, only one in three had received it through a college-level course. Moreover, 73 percent of respondents indicated that they had not had any formal education in making ethical decisions relative to problems in human genetics and reproductive technologies.³⁶

In addition to this lack of genetics education, the study found that 44 percent of respondents were unsure whether their denomination had issued a formal statement on human genetics and reproductive technologies; 30 percent indicated that their denomination had not issued such a statement, while 24 percent were certain their denomination had done so. Finally, only 8 percent of respondents claimed to know the location of centers in their state that provided counseling and diagnostic services in human genetics.

In summarizing the findings of their 1993 study of the involvement of rabbis in genetic counseling and referral, Steiner-Grossman and David reported that 56 percent of respondents indicated they discussed health issues as a routine part of premarital counseling. In addition, 22.3 percent indicated they had counseled a couple after prenatal diagnosis of an abnormal fetus. The study found that Orthodox rabbis were more likely to distribute pertinent literature to their congregants, and more likely than rabbis from the other branches of Judaism to have contacted medical personnel in these circumstances. Orthodox rabbis also reported more involvement in assisting families after the birth of a child with a hereditary condition or birth defect. At the same time, 90.9 percent of respondents from all branches indicated they would refer families in this situation for genetic counseling. Ninety-four (53.7%) of the 181 respondent rabbis indicated they discussed Tay-Sachs carrier testing with their congregants. These rabbis tended to be Reform, to be younger, and to be more recently ordained. Reform rabbis also demonstrated significantly more knowledge than Orthodox or Conservative rabbis about Jewish genetic diseases.

While nearly 90 percent of respondents considered counseling on genetic issues to be part of their rabbinical role, most rabbis, including those who actually provided counsel, considered themselves poorly trained for it. For example, 89.1 percent of respondents indicated that they had never taken a course or attended a workshop or lecture on Jewish genetic diseases. Of the 19 rabbis who had taken a course, only 2 had taken it in rabbinical school. The remainder indicated they had gained exposure to this information at rabbinical meetings, lectures, or workshops at medical sites. In contrast, when asked what ought to be done in this area, almost 90 percent of respondents indicated that counseling about Jewish genetic diseases should be part of their role, and more than 90 percent called for educational programs on these diseases as part of rabbinical training. Large majorities from each of the branches recommended programs and courses on Jewish genetic diseases in rabbinical school. This recommendation was accompanied by a consistent request for assistance in improving their counseling skills and building their referral networks.

The studies of Indiana clergy and of rabbis provide a snapshot of practice

The picture of pastoral counselors' involvement in genetics suggests a variety of practice

that may not be representative of all pastoral counselors. The picture of pastoral counselors' involvement in genetics provided by the current study's interviewees suggests a wider variety of practice, depending on geographic location, availability of a pastoral counselor, and familiarity with the counselor.

METHOD

The project on Genetics and Pastoral Counseling conducted a total of 17 computer-assisted telephone focus groups with clinical genetics professionals (clinical geneticists, genetic counselors, and social workers), with pastoral counselors who have case experience with genetic disorders, and with professionals who have expertise in both religious counseling and clinical genetics ("bridge" participants).³⁸

Focus Groups

Focus groups are a cost-effective way to obtain clear, rich, in-depth qualitative

information when one does not know the issues or perspectives of certain populations, such as target audiences, stakeholders, decision makers, end users, intermediaries, and those who produce or provide products or services.³⁹ Studies use focus groups as a source of expert input for planning and improving products, services, research instruments, organizational procedures and practices, interventions, educational programs, and other communications. Focus groups explore *what* people think about and *how* they think about it.⁴⁰ In view of the inherently exploratory nature of research that seeks to identify roles and competencies in an emerging field for which there is a paucity of existing research, focus groups are the most appropriate research method for such studies.

Focus groups allow guided discussions among a small group (6-12 participants), with the interviewer serving as a “moderator.” Participants are the experts on the topic, since the topic is what they think, feel, or do. A discussion guide (i.e., a checklist of topics to be covered in an expected order) is used to direct the discussion. The moderator guides conversation gently through each topic until it appears to have become unproductive, and returns

to it later if it emerges in a different context. This flexibility allows the moderator to probe and clarify implied or unclear meanings and context. It allows participants to raise important issues and consider nuances that researchers do not foresee. Relatively homogeneous groups of participants stimulate, support, and build on each other’s ideas about the topic and clarify areas of disagreement. They discuss the topic in their own framework and terms. As they become more sensitized to the topic and to each other, participants may take the discussion beyond the rhetorical or the habitual. They “open up” and may reveal important material that would not have emerged in direct questioning—but may emerge in natural settings. Similarly, as researchers learn about new issues, they can quickly introduce them into subsequent focus groups for further exploration.

For all of these reasons—group interaction, spontaneity and openness, descriptive depth, qualitative data, opportunity for unanticipated issues to emerge, and flexibility—focus groups seemed well-suited to exploring possible roles of clergy in ethical/religious counseling related to genetic disorders.

Computer Assisted Telephone (CAT) Focus Groups⁴¹

Telephone focus groups have been in use for over 30 years, and have been enhanced by computer technology invented in the past decade. Organizations are finding this technology increasingly valuable for reaching people all over the U.S. Extending beyond the usual less-than-a-handful of major markets, it allows many locations and kinds of participants to be represented when they would not otherwise be considered. It is especially useful when participants are geographically dispersed, relatively few in number, reluctant or unable to travel to a central facility, or in need of anonymity.⁴² For this project, the CAT method made it feasible to include members of relatively small groups of busy, hard-to-access professionals and specialists of different religious backgrounds who were dispersed across the United States and Canada.

People can participate in CAT focus groups from the comfort of their homes or other private places where they have access to a phone. This feature permits equal ease of access across locations. Participants may also be more candid than in face-to-face groups because there is less opportunity for facial “intimidation”: all are equal on the

phone. Telephone focus groups also make it easier for professionals to have ready access to information and materials they consider relevant to the topic, and thus for interviews to yield greater depth and detail.

In these focus groups, everyone can hear everyone else clearly. Interaction starts quickly and is often more natural and intense than in face-to-face groups. The fact that participants cannot see each other is not unusual or problematic. People use the phone to communicate all the time. Participants use complete sentences and auditory cues, such as “uh-huh,” to substitute for nonverbal head nods. They are encouraged to chorus their agreement or disagreement. Pauses become more obvious and meaningful. Many other auditory cues supplement the conversation, as when participants use their name each time they speak. Mutual invisibility also permits more creative and diverse group composition, and permits mixing people from different specialties or professions (who might comprise a de facto health care “team”).

The computer technology provides several unique advantages. By looking at a computer screen, the moderator can identify who is talking. Research observers can call in from anywhere to

listen without being heard, and can pass notes to the moderator by using their telephone touch pad to contact a technical assistant; the notes appear on the moderator's computer screen without interrupting the group.

Compared with face-to-face focus groups, CAT focus groups are more representative, easier to recruit, and more quickly arranged. They eliminate the costs, time, and inconvenience of travel for client observers as well as for focus group participants. They permit involvement by a broader variety of clients (in this case the research team observers) as well as participants.

Participants

In this study, researchers conducted focus groups with several categories of professionals who work with patients and their families to address the medical and psychosocial issues surrounding genetics problems, testing, and treatment: genetic counselors, physicians (medical geneticists and other specialists who treat patients with chronic diseases of genetic origin), social workers who coordinate social services with persons who have genetic conditions, and pastoral counselors (typically hospital chaplains) who have experience in counseling when genetic disorders are

involved. These four professional categories included those most likely to provide counseling to persons with genetic conditions, and they represented three different professional orientations: psychological, medical, and religious. Focus groups with professionals who had expertise in both religion and genetic counseling ("bridge" participants) were also conducted.

Specifically, the focus groups included:

- 2 groups of bridge participants
- 3 groups of pastors/chaplains
- 3 groups of clinical geneticists
- 2 groups of chronic care physicians who treat genetic conditions
- 3 groups of genetic counselors
- 3 groups of social workers
- 1 group of mixed professionals (i.e., clinical geneticists, genetic counselors, social workers, and pastoral counselors)

Names of prospective participants to be invited were drawn from national directories of their respective professions, electronic mailing list announcements in professional organizations, web sites for specific genetic disease clinics, and (for the bridge groups) lists that surfaced in networking among members of the research team and Advisory Board.

Prospective participants were contacted by telephone by a professional recruitment service that specializes in recruiting hard-to-get participants for teleconferences, focus groups, and individual interviews for qualitative research. Recruiters screened prospective participants with a brief closed-end questionnaire about their demographics and practice, and offered qualified prospects a summary of the research and \$125 for themselves or as a contribution to a charity of their choice. Participants agreed to share their views on ethical/religious counseling with patients and families about genetics-related disorders in a 90-minute teleconference discussion with other professionals like themselves across the nation. Participants who agreed to be in a focus group session were scheduled according to their availability and their demographic characteristics (to assure that at least two minority groups and both genders, as well as a diversity of faiths among chaplains, were represented).

Participants who agreed to join a focus group were apprised beforehand, in writing, of topics to be covered. The advance notice provided them an opportunity to review documents and to formulate initial thoughts about the topics. They also were offered the opportunity to

Participants shared their views on ethical/religious counseling about genetics-related disorders

review, correct, and amend a summary of their focus group session. This process helped to maximize the accuracy, completeness, and relevance of the research.

To the extent possible, each focus group was screened and selected to assure geographic, ethnic, and religious diversity. The focus group leader and research observers interviewed 145-150 participants. They came from 37 states in the continental U.S. and 2 provinces in Canada. They included representatives of a variety of Christian denominations (mainstream, traditional, fundamentalist, and evangelical Protestants; Catholics; and Seventh-day Adventists) as well as representatives of minority religions (Jewish, Muslim, Hindu, Mormon, Unitarian/Universalist, and Yaqui Indian). Atheists, agnostics, and those who said they were “spiritual” or “searching” were also included. Participants served a variety of religious populations, including 6 mentioned by name (Amish, Hasidic Jews, Mennonites, Muslims,

Mormons, and Ashkenazi Jews), and they served 26 named ethnic, national, or cultural populations (including African, African American, Arab/Middle Eastern, Asian, Caucasian, Pacific Islander, European, Caribbean Islander, Hispanic, Native Alaskan, and Native American populations).

It is important to note that the resulting sample is small, and is not intended for statistical use. Rather, it serves a specific purpose: it provides rich qualitative data about *what* a diverse set of relevant healthcare professionals think about current and possible roles for pastoral counselors in the area of ethical and religious counseling about genetics—and *how* they think about the issues involved.

Discussion Topics

Each focus group covered a series of topics intended to answer the research questions. These topics included: current and expected (or ideal) roles of various pastoral counselors, such as congregational clergy, rabbis, imams, and hospital chaplains; pastoral counselors' actual and expected literacy in genetics; barriers to pastoral counselors' participation (e.g., professional barriers rooted in alternative professional values and beliefs, or in turf issues; institu-

tional barriers ranging from hospital policy about genetics counseling and treatment to practices such as the failure to include pastoral counselors as regular members of a clinical care team); referral practices of clinicians and pastoral counselors; and frequency and range of genetics cases. The specific topics for the focus groups were developed in consultation with the project's Advisory Board.

Analysis of Data

All focus group sessions were audiotaped, observed by investigators and members of the Advisory Board, and transcribed (with participants' informed consent). Immediately after each group, the moderator (George Balch) and observers debriefed on the telephone to review what had been said, what it meant, and what, if anything, might be changed for future focus group sessions. Such changes included adding new topics, dropping unproductive topics, redefining current topics, and changing the order of topics.

The research team prepared written summaries of focus group sessions. After each round of six focus groups, the research team analyzed and summarized the transcript data and debriefing discussions (which were also audio-

taped and transcribed) to identify patterns in the response of genetics professionals to questions about the role of pastoral counselors; the level of genetics literacy necessary for pastoral counselors to counsel competently; rationales for supporting or opposing the participation of pastoral counselors from congregations and/or hospitals in genetics-related counseling; and actual practices regarding the provision of ethical and religious counseling to patients and their families.

The research team and the Advisory Board convened by teleconference twice to review summaries of focus group sessions, as well as to suggest revisions in the data collection procedures for the next round. After completion of the final round of focus groups, the research team prepared a draft report based on thematic analysis of all of the transcripts. Members of the Advisory Board were asked to submit their suggestions for revision and amplification. They also discussed strategies for disseminating the final report and recommendations.

STUDY RESULTS AND RECOMMENDATIONS

BARRIERS

Perceived barriers to effective use

of pastoral counselors can be grouped into two broad categories: first, barriers relating to the nature and practice of pastoral counseling, and to the attitudes of various professionals toward pastoral counselors and their practice; and, second, institutional and systemic barriers. Barriers for professionals constitute the larger category and are related to knowledge, skills, practice patterns, professional self-understanding, interprofessional relations (such as professional turf issues), and professional ideologies and biases.

Who Is a Pastoral Counselor?

The most obvious barrier to increased use of pastoral counselors is confusion in identifying them. No uniform understanding of who is a pastoral counselor exists among the general population or among most of the professionals interviewed. Most interviewees thought pastoral counselors to be chaplains, clergy, pastors, rabbis, imams, spiritual counselors, and religiously educated lay professionals (sometimes called lay ministers) who work in the name of denominations, congregations, and temples. Not surprisingly, seldom did interviewees distinguish ordained from nonordained pastoral counselors, differentiate pastoral counselors who work in congregations

The most obvious barrier to increased use of pastoral counselors is confusion in identifying them

from those who work in health care and other settings, or discriminate among pastoral counselors according to the amount or kind of theological and pastoral education they have. Only a few of those interviewed identified “pastoral counselors” not as a generic designation but as a distinct profession with its own credentials and competencies.

The effect of stereotyping pastoral counselors as a homogeneous group is predictable. Patients’ and healthcare professionals’ positive and negative perceptions of pastoral counselors in one setting, such as a congregation, often color the perception they have in another, such as health care. A remarkable number of interviewed healthcare professionals based their negative perceptions of pastoral counselors who addressed genetics-related concerns on one unhappy episode, such as an experience with a clergy person who mishandled a situation involving genetics. Consequently, clinical genetics profes-

sionals applied this perception to the entire class of pastoral counselors.

The inability to distinguish among the different kinds of pastoral counselors can function as another barrier. It is as significant a misconception as a failure to distinguish geneticists working with childhood illnesses from those addressing adult neurological diseases. Those who can be categorized as pastoral counselors range from those who have had seminary training in the doctrine of a religious tradition, yet little or no pastoral training, to those who have a master’s level education in religion and have spent significant training hours in clinical pastoral education. Again, for the purposes of this study, the designation “pastoral counselor” refers to all those listed above as pastoral counselors, broadly construed. However, in the recommendations below, note that certain subcategories of pastoral counselors with specific education, skills, and certification are deemed to be better prepared to address genetics issues.

Knowledge and Skills

Those interviewed consistently identified the genetics knowledge base of pastoral counselors as a major stumbling block. Clinical genetics professionals discount those without an understanding of genet-

ics. While there was no agreement about the extent of genetics knowledge that pastoral counselors need, interviewees reached broad agreement that the lack of a rudimentary understanding of inheritance patterns, prognosis, and social consequences of genetic diagnoses was an obstacle to pastoral counselors' participation. Of particular concern was misinformation that some pastoral counselors had given to patients and families. In one case, for example, misunderstanding the prognosis prompted the pastoral counselor to advise termination of life-sustaining treatment of an impaired newborn whom geneticists judged to have a good prognosis for survival.

Most pastoral counselors are not adequately prepared by their training to deal with the technical issues raised by genetics. A large portion of their training focuses on the theological doctrine of their tradition, and specialization usually concentrates on those skills needed for teaching, preaching, and other aspects of ministry. Very little theological education is devoted to science, and specifically to genetics, except in courses about healthcare ethics. Of those who specialize in pastoral ministry, most undertake extensive preparation in clinical programs such as clinical pastoral education; however,

Clinical genetics professionals discount those without an understanding of genetics

even those programs that are situated in a healthcare setting do not provide sufficient exposure to the science of genetics. Pastoral counselors' ignorance of clinical genetics can lead to feelings of inadequacy in addressing any aspect of genetics, even though they may be familiar with the religious and spiritual issues associated with other, non-genetic causes of illness and death, issues which genetic conditions might also raise. The complexity of the science can obscure the vision of pastoral counselors and prevent them from recognizing that they have valuable professional services to offer. Several informants noted that pastoral counselors are unaware they can assist, and so need to be informed about the contribution they can make.

Clinical genetics professionals interviewed believed that pastoral counselors are unaware of psychosocial issues that patients and families face in dealing with genetic diagnoses or conditions. Interviewees' perception, accurate or not, was that congregational clergy are so involved in administering organizations

Bad experiences with one pastoral counselor often established the stereotype for everyone else

that they might not have encountered the problems that genetics concerns pose for congregants. The absence of particular knowledge was thought to be one of the reasons pastoral counselors did not integrate this information into their preaching, teaching, or counseling on health- and faith-related issues. Also, some moral options that genetic knowledge presents are controversial in particular faith communities; thus some pastoral counselors fear to discuss them.

A significant number of those interviewed identified inadequate pastoral knowledge and skills on the part of pastoral counselors as the greatest obstacle to participation. “I’m afraid they [pastoral counselors] are going to do more harm than good” was a common refrain. Most focus groups surfaced several horror stories in which the genetics professional had directly experienced a pastoral counselor who, for lack of pastoral knowledge or competence, had significantly harmed the patient, family, or

both. Those interviewed also believed that pastoral counselors did not adequately understand counseling techniques, which the healthcare workers assumed should always be nondirective. Not surprisingly, bad experiences with one pastoral counselor often established the stereotype for everyone else.

Clinical genetics professionals questioned whether some pastoral counselors understood the nuances of their religious tradition sufficiently to provide patients, families, and healthcare providers with options that were consistent with the patient’s religious tradition. Pastoral counselors who had provided misinformation about a religious tradition created a need for additional resources to reeducate the patient.

Genetics professionals’ level of knowledge of religious issues was also a barrier. Subtle differences within or between religious groups complicated referrals, because clinical genetics professionals did not feel they understood the differences among religious perspectives or recognized whether the differences would help or hinder treatment. Several respondents suggested that the healthcare team does not know enough about how religious or spiritual communities look at the genetics issues. As one interviewee stated, “Medical training

does not focus enough on spirituality and ethics; doctors are used to thinking in scientific method.”

Those interviewed also noted that the limited skill base of pastoral counselors was an impediment. This lack of skill might cause them to “botch the job,” as one interviewee put it. Almost all focus groups listed a range of worst practices that should, in their view, never be employed in counseling. These include being too directive or condemning, and then ostracizing patients and families who acted contrary to the pastoral counselor’s recommendations.

Finally, one interviewed religious professional noted that even if pastoral counselors were more willing to study and understand the psychological, social, and religious ramifications of genetics, a significant barrier would remain: it is hard to get busy pastoral counselors to attend seminars for education on genetics.

Practice Patterns

The practice patterns of healthcare professionals also pose a hurdle. One problem is timing. Clinical genetics professionals acknowledge that they make most referrals when patients or families are in crisis. Absent a crisis, even though a genetic condition might raise religious

Lack of skill might cause pastoral counselors to “botch the job”

and spiritual issues for the patient, referrals to pastoral counselors for these issues are not routine. As a result, some respondents observed that pastoral counselors are brought in too late—when, for instance, the patient is already hospitalized. Some interviewed considered another problem to be the intrusiveness of inquiring into a patient’s religious background. This hesitancy created a pattern of avoiding religious issues. Another obstacle is the nature of the clinical setting where genetic diagnosis and treatment first occur. Geneticists indicated that referrals to pastoral counselors from the physician’s office (for example, after genetic diagnosis and counseling) are more the exception than the rule, and are generally made only at the request of the patient. Still another obstacle, previously mentioned, is that clinical genetics professionals are reluctant to refer to unknowns. If they are unsure of a pastoral counselor’s training, they don’t know what they are getting and are therefore more likely to be protective. Finally, some clinicians reported that

Where there was teamwork, genetics professionals made more referrals

referrals were problematic because there was a lack of teamwork. In situations where there was teamwork and pastoral counselors were available, clinical genetics professionals made more referrals.

Interprofessional Relations

Interprofessional relations, or the lack thereof, are another hindrance. One interviewee stated that professional location is an obstacle, that is, some genetic counselors have little or no contact with pastoral counselors, and the same is true for pastoral counselors' contact with clinicians working in genetics. More critical is the issue of professional turf, viz., what issues should and should not be addressed by pastoral counselors. For example, one informant contended that pastoral counselors should not be involved in providing any diagnostic or medical information to patients or families. Professional turf issues were also raised when the clinicians felt that they needed to protect a patient from a pastoral counselor who might contradict the clinician or be directive in a way

that the clinician could not accept.

Ideologies and Biases

Healthcare professionals' ideologies and biases are formidable obstacles. As observed by a few focus group members, and confirmed in the literature, many clinicians are unaware of their own value assumptions. For example, in the drive to be nondirective, geneticists and genetic counselors list options for patients without recognizing that these have religious implications. During interaction among the geneticists and genetic counselors in focus groups, a few self-conscious clinicians observed that as much as clinicians intended to be nondirective, they were very directive in making sure that patients did not go to pastoral counselors who clinicians thought were directive.

A few participants stated that they never had made and would not consider referrals to pastoral counseling. It was not their "place as scientists to promote religion." Less subtle were geneticists who were wary about the benefit of religious resources. Some geneticists' bias against religion was tempered in the focus groups, perhaps because the overall premise of the research was to find ways to better integrate pastoral counseling into the new genetics.

Genetics professionals and pas-

Many clinicians are unaware of their own value assumptions

toral counselors noted that a barrier to involvement for some pastoral counselors includes some religious professionals' distrust of science. From certain religious perspectives, genetic science seems to undermine or contradict religious doctrine. Acceptance of the genetic inheritance of all life, for example, supports evolution, and thereby contradicts some interpretations of Abrahamic religions' view of creation. Also, behavioral genetic theories that are believed by some to foster moral determinism and diminish free will, add to the suspicion. Finally, as one informant noted, some pastoral counselors from the Catholic and Evangelical traditions paint genetic counselors as professionals who will recommend only morally problematic options (such as abortion) that may be proscribed by a religious tradition.

Barriers Created by System/Institution

Some interviewees noted that there is a lack of capacity in the system because too few individuals have an under-

standing of both genetics and pastoral counseling. This dearth of professionals with dual expertise in genetics and pastoral issues is an obstacle to referrals, cooperative work, and the translation and communication of meaning between the medical and the religious/spiritual realms. Some clinical genetics professionals admitted that they were unsure what the religious issues related to genetic diagnosis look like. They added that if it was important for healthcare institutions to have these issues addressed, the institutions would have to look for ways to bridge this translation problem.

Institutional priorities that are shaped by limited resources pose a barrier to adequate funding for pastoral counselors who could address the religious needs of patients and families with genetic diagnoses. With constant pressure to reduce the cost of delivering health care, healthcare institutions are reexamining pastoral care budgets, reducing funding, and in some cases "outsourcing" responsibilities to volunteers from local congregations. One interviewee noted that while a clinical genetics professional might follow a patient and family through an entire chronic illness or long-term need for hospitalization, an equivalent continuity of pastoral care is unlikely.

Too few professionals have an understanding of both genetics and pastoral counseling

A few interviewees with backgrounds in religion noted a dual barrier created when inadequate training in pastoral counseling receives de facto support from institutional hiring practices. For budgetary reasons, persons may be allowed to function as pastoral counselors in health care even though they have insufficient theological and pastoral education. In many areas, shortages of clergy have resulted in the delegation of their role to lay chaplains who have minimal training in theology, pastoral care, or healthcare ethics. Over the past decade graduate theological education has been compressed into two-year programs, and many shorter certificate programs have emerged. The result has been an increased number of lay ministers who have minimal knowledge and skills in pastoral counseling. While there has been a significant movement in healthcare institutions to require adequate preparation in pastoral counseling, there remain a signif-

icant number of institutions that, for various reasons, will allow less well-prepared pastoral counselors to serve despite inadequate preparation.

SOLUTIONS

The potential volume of pastoral counselors, the paucity of genetic counselors, and the positive features that pastoral counselors bring to persons with genetic conditions all argue for better integrating pastoral counselors into the provision of genetic services. Yet any attempt to do so will require addressing knowledge, skills, and best practices for all the parties involved: pastoral counselors, geneticists, genetic counselors, social workers, and institutions that train and sustain them. The solutions offered below emerge both from the interviews and from scholarly literature. While many of the proposed solutions respond to the obstacles described above, they also address issues that did not arise in the focus groups but were acknowledged in other venues as problems.

Knowledge of Genetics

The amount and kind of genetics knowledge needed by pastoral counselors was a significant thread in conversations with interviewees. Informants did not

agree on how much genetics pastoral counselors should know. Opinions ranged from a recommendation to skip genetics entirely, to a proposal that all theological education have required courses in genetics and certification of pastoral counseling competency in genetics. Despite the range, most agreed that genetic misinformation is dangerous. Clinical genetics professionals discount input from pastoral care when it demonstrates ignorance about the complexities of genetic science. Yet, as one geneticist noted, “in the healthcare world where [even] the family physician is not as versed in the advances of genetic science, it is unrealistic to expect extensive knowledge on the part of the pastoral counselor.”

Most interviewees agreed that pastoral counselors need at least rudimentary genetic knowledge, such as knowledge of basic patterns of inheritance. Misunderstanding about the probability of inheriting a genetic condition can lead to inappropriate pastoral counseling. One interviewee told of a pastor counseling a couple whose child had died of thanatophoric dysplasia, a lethal form of dwarfism. The couple had no prior history of this condition in their family; it had arisen as a copy disorder of genes between generations. The genetic

Informants did not agree on how much genetics pastoral counselors should know

condition was thus an isolated event, and quite unlikely to occur in future children. Without adequate information, the local pastoral counselor informed the couple that it was a sin to have another child and pass on a horrible disease.

Knowledge of recurrence risks could have helped the pastoral counselor function competently. The local pastor needed to know that even if the genetic disorder followed an autosomal-dominant pattern of inheritance, in which only one copy of the gene is needed to pass the disorder from parent to child, there is only a 50 percent chance that the next child will inherit the gene. Similarly, the pastor needed to understand another pattern of genetic inheritance called autosomal-recessive, which requires the child to inherit two copies of the gene, one from each parent. When both parents carry an autosomal-recessive gene, there is a 25 percent chance that any child born to them will

It is important for pastoral counselors to know something about basic disease processes and prognosis

inherit the genetic disorder. If the child receives only one copy of the gene, he or she is a carrier for the genetic disorder but will never express the disorder. Further, the pastor needed to understand that other patterns of inheritance arise because of random mutation in genes between generations, as in this case of thanatophoric dysplasia. Pastoral counselors need to know these basic patterns and the probabilities of passing genetic anomalies from one generation to another.

Interviewees stressed that while detailed knowledge of all genetic disorders is not necessary, it is important to know something about basic disease processes and prognosis. As one informant noted, "Clergy who are misinformed about critical conditions can mislead families in thinking through their options." For example, pastoral counselors should understand how variable circumstances can be within one

genetic condition, such as Fragile X disorder, a common form of mental retardation that can express itself with varying degrees of severity. Knowing whether the disease process will end in death or disability will aid the counselor in knowing how to walk or talk with the patient and family. As one informant put it, "Enough medical facts so that you don't counsel someone about death and dying who is really not [dying]." "Knowing enough not to say anything stupid," another remarked. "Pastors need to see enough to know what they're talking about. In other words, not like right-to-lifers who are prognosticating about a child with birth defects and never having seen one—that is dangerous. . . . Clergy need to know that things aren't always so concrete."

Finally, one informant summed up a shared view: "Clergy need to know that lifestyle doesn't influence genetics. For example, don't blame the alcoholic dad for the kid with Down Syndrome." Although the informants admitted that some environmental factors can spontaneously cause genetic mutations, it is important for pastoral counselors to have some notion of the etiology of genetic anomalies so that they avoid compounding the guilt of parents whose child may inherit a genetic condition.

Are there any guideposts for pastoral counselors in the range between knowing a little and knowing a lot of genetics? Several informants noted that adequate understanding would include enough knowledge in genetics to dispel misinformation. Such understanding need not include knowing every medical detail, but in a given instance should permit an appreciation of the disease process and what the patient and family will face. A pastoral counselor, like a patient's family, needs some basic resources to understand the patient's disease, but perhaps more fundamentally needs to know what the patient understands about the disease. Like family members, pastoral counselors should not assume the role of providing information about a patient's disease—they are not “physician extenders”—or providing information about care options. Since normally they are not trained in the details of genetics, this role is not appropriate for pastoral counselors or family members.

One informant nicely summarized the amount of genetic knowledge that pastoral counselors need:

Genetic literacy is the key factor in how effectively pastoral counselors will play this role. This is not to say

“Clergy need to know that lifestyle doesn't influence genetics”

that pastoral counselors are expected to become geneticists. But in the absence of a solid understanding of genetics, its clinical applications, and its pastoral implications, it would be difficult for pastoral counselors to interact with professionals working in genetics, to carry out appropriate referrals, or to counsel congregants confronted with genetics-based anomalies.

The informant highlights a point often made in the interviews, namely, that the professional credibility of pastoral counselors is commensurate with their general knowledge of patterns of inheritance and their familiarity with the physical and social ramifications of any particular genetic condition.

In some limited situations when the pastoral counselor and patient come from a religious tradition that is very directive about what actions are approved or proscribed, the pastoral counselor's genetics knowledge base must be greater than that of religious

peers. One respondent who is a clinical geneticist explained, "I have been heavily involved with decision-making because of Jewish law . . . self-mutilation is forbidden. Therefore, the question of how much validity to give to prophylactic success of mastectomies becomes a part of the decision-making process. And because I am actively involved in the scientific area . . . I hold a pastoral position. I have a large number of such questions that come in regularly by phone and by email."

Knowledge of Psychological and Social Consequences

Beyond the medical facts, pastoral counselors can provide accurate information about the psychological and social considerations that a person with a genetic diagnosis and his or her family will face. Many theological issues related to genetics initially arise in conversations when the person with the genetic condition or a family member articulates the problems in terms familiar to those who grasp the psychological dimensions of genetic disorders. For example, some genetic conditions create circumstances that elicit a grief response, an issue that trained pastoral counselors have experience addressing.

Five prominent associations that

represent pastoral counselors have identified the skills that are necessary for professional healthcare chaplaincy, and have created a gold standard for anyone, including the clergy person, rabbi, imam, and lay minister, who serves the religious and spiritual needs of patients and families.

Professional chaplains reach across faith group boundaries and do not proselytize. Acting on behalf of their institutions, they also seek to protect patients from being confronted by other, unwelcome . . . forms of spiritual intrusion. . . . They provide supportive spiritual care through empathic listening, demonstrating an understanding of persons in distress. Typical activities include:

- Grief and loss care
- Risk screening—identifying individuals whose religious/spiritual conflicts may compromise recovery or satisfactory adjustment . . .
- Crisis intervention . . .
- Spiritual assessment
- Communication with caregivers
- Facilitation of staff communication
- Conflict resolution among staff members, patients, and family members

- Referral and linkage to internal and external resources . . .
- Staff support relative to personal crises and work stress . . .

These recommendations make it clear that, in addition to understanding the religious dimensions evoked by the genetic condition, pastoral counselors must possess a skill set needed by any counselor working in health care.

Pastoral counselors will be focused on dealing with religious coping; however, they need to be aware of the psychological needs of the patient and family. As one informant put it, "Pastoral counselors should have some sense of human compassion and community and hope." That said, "Pastoral counselors can't and shouldn't handle all diagnoses. When clinical depression or violent behavior is an issue, psychiatric referral is vital."

Pastoral counselors will also need to be familiar with the ethical and social issues that arise in cases of genetic diagnosis and illness. Most obvious, and perhaps what sets genetic disease apart from other forms of illness, is the fact that most genetic information is not only about the patient but also about the family. Genetic information has ramifications for the parents who transmitted

Pastoral counselors must possess a skill set needed by any counselor working in health care

the condition, present or future siblings, and extended family members who might also inherit the condition. This sensitive genetic information can be used to label people and to discriminate in insurance, employment, and other areas of social life. Thus, pastoral counselors must understand the risks associated with genetic privacy and confidentiality. From an institutional perspective, the existence of these issues does not necessarily mean that schools for professional education in genetics, genetic counseling, social work, and theology need to offer more bioethics courses, but at a minimum it does require more focus on the integration of scientific, ethical, and pastoral issues.

Knowledge of Theology and Pastoral Counseling

Several interviewees who were religious professionals pointed out that the religious issues raised by genetics are not applicable only to genetics. Pastoral

counseling issues that arise in genetics are transferable in large measure to non-genetics contexts, for example, to issues raised by death, dying, and chronic illness. Anyone who is afflicted with some kinds of chronic illness in childhood, early adulthood, or later life will potentially face eclipsed possibilities in career and family life, and may face functional impairment. Whether or not the cause of the chronic illness is genetic, the patient or family might reveal a range of religious responses and questions, including anger at God, bargaining with God, seeking healing from God, and attempting to understand God's will. Those affected might ask whether the condition is punishment from God or results from the sins of the parents, or why an all-good God allows suffering.

These religious responses and questions are commonly occasioned by illness and the prospect or reality of death, and each religious tradition responds in a manner informed by its sacred texts and traditions. Consequently, pastoral counselors who are working with patients and families from their tradition need to know enough of the tradition to theologize and apply it to the particular circumstances of the patient and family. Such education would include abilities to connect the

Pastoral counseling issues that arise in genetics are largely transferable to non-genetics contexts

medical facts with ethical concerns and principles from the religious tradition, and to apply them effectively in the concrete pastoral situation. The pastoral counselor should be aware of whether the religious tradition has already addressed the issue comprehensively or in part. One Muslim respondent noted, for example, that imams need to be aware of positions taken by the Islamic Medical Association of North America so they can avoid giving inappropriate guidance to families.

Those interviewed also wondered whether there are theological and pastoral counseling issues that are unique to genetics. Interviewees most frequently identified ethical mandates that arise out of a particular tradition, for example, Roman Catholic perspectives prohibiting abortion and artificial means of procreation such as in vitro fertilization. While those interviewed were less certain about the ethical mandates of other religious traditions, there were ques-

tions about whether specific elements of Judaism, such as Orthodox Judaism, had ethical mandates prohibiting marriage between persons who carry lethal genetic conditions. In these cases some interviewees said they thought it necessary for pastoral counselors either to know these particular ethical prohibitions or to know from whom to obtain relevant information. The few comments made did not suggest that pastoral counselors need to know world religions, but rather that they should know the limits of their knowledge and be honest with patients and families about those limits.

Genetics professionals in health care who were interviewed speculated about the amount of theological education that they as professionals need to have. A few believed that clinical genetics professionals should not be involved with anything religious, either because it extended beyond their professional competence or, as one respondent noted, because “religion was destructive and undercut their ability to appropriately treat patients.” A more frequently expressed view was open to the usefulness of religion, and maintained that genetics professionals need enough familiarity with what counts as a religious issue to allow them to refer patients

appropriately. A few expressed personal interest in understanding how religious coping differed from other forms of psychological coping. They believed that if they understood this difference they could explain it to patients and families and, in turn, be better able to make referrals suited to the patient’s need. In sum, the original research question framed the issue as that of what pastoral counselors need to know about theology and pastoral counseling; however, a few interviewees restated the question by asking what theological and pastoral counseling information genetics professionals in health care need to know.

Skills and Competencies

All the focus groups in one way or another described the skills and competencies that delineate the best practices of pastoral counselors. Many of the criteria they identified are similar to those agreed upon by the consensus group of pastoral care associations listed above. It is important to note that some of the best practices suggested below might run counter to practices of particular religious traditions or to pastoral counselors’ professional self-perception and sense of their obligations. While those interviewed painted a broad consensus, some criteria they proposed would neverthe-

Genetics professionals need familiarity with what counts as a religious issue

less be controversial in religious denominations whose theologies are less sympathetic to religious pluralism.

First and foremost, most interviewed thought that pastoral counselors need to be empathetic listeners, which they frequently described as being a “good listener,” “compassionate,” and “sympathetic.” As one interviewee put it: “hearing the loss of [the family and] trying to bring some peace [to the situation] or to manage it . . . being able to hear the complexity and to be patient with [the] patient’s process.” Often this approach requires “knowledge of [the] family and individual’s background.” Some other features of empathetic listening include gestures (“holding patient’s hand, being supportive”) and perhaps participating with the patient and family in the informed consent process (“listening to the same information [the] patient gets so that discussion is possible later”). One interviewee noted that building bonds with families requires “being present every step of the way”: “Availability at all hours builds

trust” with patients, families, and clinical genetics professionals. One religious professional with credentials in pastoral counseling stated that empathic listening requires “pastoral openness, [an] ability to be teachable.” The interviewee added that pastoral counselors need “to meet people where they are” and to be “open-minded” by not prejudging the situation because of prior experience or preconceptions of the problem and its resolution.

Several of those interviewed thought that listening also entails a translating function. One person called it “helping families understand doctors’ language.” Under certain circumstances, such translation might mean “helping families to accept medical recommendations to stop life support.”

Many interviewees believed that pastoral counselors could help patients and families cope with suffering and loss, and expected that at times this role would include crisis counseling: “Help [the] family to come to grips with loss and with the sequence of events that lead to loss.” Generally, as one respondent noted, this process entails “asking patients/couples what kind of meaning-making they want to come out of that experience, be it a termination (e.g., abortion) or something else.” Another

“Availability at all hours builds trust” with patients, families, and genetics professionals

gave this example: “Efforts to make meaning out of shortened lives—stillbirths.” Such coping support was aimed at bringing some resolution to the patient or family: “helping families to accept,” as one interviewee noted. The task is not simply to bring meaning or resolution, but also “helping [the] family and individual feel supported and comfortable with whatever decision they may have made.” As some pastoral counselors emphasized, achieving this aim may require long-term spiritual support after the crisis, for example, helping a couple cope with the death of a child due to a genetic disorder. A limited number of those interviewed voiced a need for the pastoral counselor to conduct an assessment of the patient and family as the pastoral counselor provides help in coping.

Informants were at an impasse over one crucial element of pastoral counseling skills, namely, whether to be directive or nondirective. The vast major-

ity of clinical genetics professionals and some pastoral counselors agreed with the professional chaplaincy associations’ consensus statement on healthcare chaplaincy, and insisted that pastoral counselors’ approach be nonjudgmental. They agreed that pastoral counselors could assist patients and families through ethical discernment but that it should be “nonjudgmental and nondirective.” At a minimum, this approach requires that a “counselor shouldn’t impose personal opinions about decision-making on the at-risk or diagnosed person.” Another respondent stated that pastoral counselors need to be “confident and comfortable enough to be supportive of family and individual decision-making . . . able to validate feelings even if unable to condone decisions.” A few thought that a nonjudgmental approach requires “supportive and compassionate [response] even if [a] family’s decision conflicts with its church’s position.”

Several interviewees objected to a nonjudgmental stance by pastoral counselors. Orthodox and Conservative rabbis and an imam noted that religious believers in their traditions sought directive counseling as a means of coping. Several geneticists also mentioned that families they treated were comforted when their decisions were confirmed by

religious leaders from their traditions.

Several of those interviewed highlighted important caveats in the tension between directive and nondirective pastoral counseling. The fact that the patient or family come from a religious tradition that is directive does not mean they desire direction. Professionals will need to determine sensitively whether particular patients and families want such directive religious counseling. Most interviewees believed that if patients or families desire pastoral counseling that is directive, they usually have religious connections and know to whom to turn. If the patient or family desire directive counseling but they do not know a pastoral counselor from their tradition, the referring professionals need to make certain that, for example, the rabbi or imam has a reputation for knowing the religious tradition and rulings.

Another caveat related to directive counseling is best summed up in a story recounted by an interviewed geneticist. A clergyman who had counseled a couple through their child's long-term sickness and eventual death now counseled them as they considered whether to have another child and whether to request prenatal diagnosis. During the long-term relationship he

Several interviewees objected to a nonjudgmental stance by pastoral counselors

changed his view to one that was at odds with his religious tradition. He counseled the couple that "abortion would be a sin [but] that he would absolve it for them." Such stories suggest that presuppositions about whether a counselor from a given tradition will be directive, or a patient from that tradition will seek directive counseling, need prudential examination by clinical genetics professionals.

An ability to support the professional genetics staff was frequently identified as an essential skill for pastoral counselors. Geneticists, genetic counselors, and social workers voiced the need for spiritual support and guidance when they were required to present options to patients and families but there seemed to be no good and, in fact, only tragic options. Some of those interviewed welcomed a proactive approach by pastoral counselors. They felt that pastoral counselors should ask the care team: "What could we bring?" "What would be supportive?" "What

are ways we could be part of the team?" Some genetics professionals looked to pastoral counselors to network, not only among the team and with the family, but also within the wider community. A few wanted pastoral counselors to provide appropriate community referrals and to be a bridge with community pastors.

Interviewees named some skills and competencies of pastoral counselors that were distinctly religious and set them apart from other counselors. When in doubt about which skills were necessary, one respondent stated that "spiritual qualities [are] more important than genetic competence—though it would be nice to have both." The identified religious skills included conducting religious assessments and counseling, and conducting religious rituals. The religious aspects of coping mirror psychological coping. Some informants pointed out that pastoral counselors "help people to draw upon the religious connections that they do have." Another stated that "the biggest help is providing religious insight and guidance to patients—interpreting a patient's religious background in light of [the] decision that's facing him or her." For example, by addressing the issue of theodicy, pastoral counselors "help people to under-

Pastoral counselors should ask the care team, "What would be supportive?"

stand why bad things happen to good people." Overall, pastoral counselors' "discussion of religious beliefs, faith, and direct use of religion helps make sense of [the] situation." In addition to religious meaning making, pastoral counselors, as one religious professional noted, "give permission to patients to do this or that religiously." She went on to say that such permission giving "affirms a patient's decision making in the context of God's plan."

Another decidedly religious aspect of pastoral counseling is helping clinical genetics professionals respond more sensitively and appropriately to patients' religious and spiritual needs. Several pointed out that pastoral counselors provide genetics professionals with language and tools to help patients with these issues. Pastoral counselors "educate and sensitize physicians about the religious and spiritual issues that trouble patients." Also, "some genetic counselors have found clergy helpful in educating them about the cultural and

religious values of specific traditions, which form the basis of their patients' worldviews." Beyond educating and translating for colleagues, trusted pastoral counselors can sensitively inquire about advice given by other clergy—for example, "where [a] pastoral counselor investigates whether it's 'safe' for a patient to seek pastoral services in the local community."

Many interviewed believed that pastoral counselors should be involved in religious rituals for the patient and family. Most of the best practices mentioned were characterized by rituals that were flexibly adapted to the circumstances. For example, blessing babies before death and ritual praying with fetal remains were important for families. One clinician highlighted the need for religious rites to accommodate various conditions. The clinician recounted the story of two teenage Jewish boys with renal dystrophy, a progressive genetic neurological disorder that left them spastic and wheelchair bound. A rabbi would not allow one of the boys to go through a Bar Mitzvah, and thus compounded his sense of loss, while another rabbi came to the home of the second boy and conducted the ritual with a prayer shawl, prayers, and singing.

CONCLUSIONS AND RECOMMENDATIONS

Until this study, academic professionals who consider the social, ethical, and religious implications of the human genome project lacked evidence about the nature of pastoral counselors' involvement in genetics; healthcare professionals' expectations about pastoral counselors' roles; the types of barriers that impede effective use of pastoral counselors; and approaches needed to better integrate pastoral counselors into genetic services. This study adds qualitative information to fill in the gaps for the field, and provides baseline data for reconceptualizing policies and practices that address pastoral counseling in relation to genetics. None of the barriers identified by those interviewed is easily overcome. Realizing the opportunities for improvement will require the participation of all those who have a stake in better integration, including professional societies of geneticists, genetics counselors, social workers, pastoral counselors, and pastoral educators, as well as healthcare institutions. A review of the barriers and possible remedies suggests, however, that some stakeholders have greater responsibility for furthering the needed integration.

Identity

As the interviews demonstrate, there is no clear public perception about who is a pastoral counselor with the skills and competencies to address the religious needs of those facing genetic diagnoses and conditions. This confusion should lead all stakeholders to make distinctions within the large class of professionals who can serve as pastoral counselors. The simple designation of a person as a cleric, rabbi, imam, chaplain, pastor, deacon, lay minister, or spiritual advisor does not necessarily qualify the person to provide pastoral counseling for persons and families with genetic conditions. Clinical genetics professionals who are referring patients and families should assess carefully whether the pastoral counselor has experience, or a reputation for providing competent care. They should refer only to pastoral counselors who are known to have the requisite qualifications. Healthcare institutions ought to utilize or employ only those pastoral counselors who have the professional education, skills, and competencies commended by the five prominent professional associations involved with pastoral counseling. Pastoral counselors in healthcare institutions who make external referrals to pastoral counselors should select reli-

Realizing opportunities for improvement will require participation by all stakeholders

gious professionals who have equivalent skills and competencies.

Knowledge and Skills

Clinical genetics professionals interviewed consistently said that they would not use pastoral counselors who were perceived to have an inadequate understanding of clinical genetics or insufficient pastoral skills, because they could do more harm than good. The perception, and perhaps the reality, is that a majority of those designated as pastoral counselors are underprepared in knowledge of rudimentary genetics and genetics-related prognosis. Also, many in the large group of pastoral counselors may have insufficient training or experience in pastoral counseling and in theologizing about the pastoral situations that arise in relation to genetic diagnoses and conditions. The only class of pastoral counselors who could be viewed with reasonable confidence to have the requisite knowledge and skills

Genetics professionals should refer only to pastoral counselors who have the requisite qualifications

are those who have spent hours in clinical pastoral education and who have worked in healthcare settings addressing the religious issues that arise in sickness, suffering, and grief.

The knowledge and skill problems identified were not limited to a lack of knowledge of clinical genetics and insufficient training in pastoral counseling. Rather, even with better educated and more experienced pastoral counselors, there would remain a significant translation problem in the relationship between clinical genetics professionals and pastoral care professionals. As noted by several of those interviewed, there are multiple stakeholders (e.g., patients, families, healthcare professionals, and pastoral counselors) looking at the same event but deriving multiple meanings from it—and holding differing expectations for pastoral care. Interviewees who discussed the issue agreed that genetics

and pastoral care have incommensurable foci: genetics addresses the medical issues, and pastoral care the spiritual. While the two are inextricably bound, each professional group uses a different language, and knowledge of the genetics issues alone does not resolve the religious and spiritual issues.

A few of those interviewed voiced the opinion that the translation problem will not be resolved simply by having pastoral counselors develop a greater knowledge base in clinical genetics and gain more pastoral experience. In order to provide competent care to the whole person, clinical genetics professionals will have to understand fundamental issues in religious coping, and learn both to assess patients' needs for religious counseling and determine how and to whom these patients should be referred. Instituting an assessment process will mean abandoning the practice of never intruding into the "private" area of a patient's religious needs. One genetics professional noted that she has made spiritual assessment a structural part of the overall assessment, and regularly probes patients' spiritual needs and supports related to genetic testing and diagnosis.

The responsibility to improve the knowledge and skills of all involved is wide ranging. Those providing theologi-

One genetics professional has made spiritual assessment part of the overall assessment

cal and pastoral education should examine the recommendations regarding skills in facilitating religious coping made by the leading pastoral care professional groups and evaluate whether their training programs are adequate. Schools of theological and pastoral education, and national and regional denominational organizations (e.g., dioceses), should consider the need for continuing education programs on pastoral counseling skills, and should collaborate with clinical genetics professional organizations, medical schools, or healthcare institutions to provide education in clinical genetics. Clinical genetics professional organizations should consider offering their members educational programs on identifying and assessing religious needs of patients and on the nature and content of pastoral counseling.

Practice Patterns

Those interviewed clearly indicat-

ed that practice patterns of clinical genetics professionals very much affect whether a pastoral counselor will ever reach a patient in the inpatient setting. The previously suggested practice of making spiritual assessment part of the overall assessment would go a long way toward overcoming such barriers as the practice of referring to a pastoral counselor only if there is a crisis, or never giving patients an opportunity to bring up religious matters. Referral patterns will be a more difficult issue to address, since clinical genetics professionals typically make referrals only to known entities. One respondent suggested that healthcare institutions or regional groups of clinical genetics professionals develop resource directories of skilled and competent pastoral counselors for potential referrals. Another respondent suggested that institutions need to build their own capacity to meet emergent needs. Institutions, for their part, need to examine existing practice patterns for evidence of teamwork. If capacity already exists but is underutilized, the institutions might examine whether there are any local barriers that impede better integration of pastoral counseling.

Interprofessional Relations

The barriers to better interprofes-

Interprofessional barriers are a complex mix of turf wars, stereotypes, and mistrust

sional relations are a complex mix of turf wars, unhelpful stereotypes, and, ultimately, mistrust. The turf issue that clinical genetics professionals observed was the overstepping of role boundaries by pastoral counselors in ways that might undercut the treatment of the patient (e.g., pastoral counselors' being inappropriately directive). This issue can be partially resolved if all professionals involved understand the nature and purpose of pastoral counseling, as well as the skills and competencies of pastoral counselors. Each group of professionals needs to know more about the language, training, and roles of the other. This study began with the assumption that pastoral counselors needed to know more about genetics. Some interviewees made clear that interprofessional relations would not improve until clinical genetics professionals learned more about religious and spiritual issues, in order to understand more about the worldviews of

their patients, and also learned more about the actual and possible roles of pastoral counselors, in order better to recognize when referral to a pastoral counselor would be appropriate.

Developing an antidote to mistrust is a complex process and requires frank introspection regarding unhelpful stereotypes. Foremost among these is the view that pastoral counselors are directive in counseling, whereas geneticists, genetic counselors, and social workers are nondirective. As the professional associations of pastoral counselors recommend, pastoral counselors should help patients pursue patients' agendas and not pastoral counselors' agendas. There should be a frank recognition by all parties that in some limited instances there are denominations or portions of denominations that encourage directive counseling by pastoral counselors.

On the other hand, a few of those interviewed also pointed out that clinical genetics professionals are more directive than their self-perception admits. Respondents highlighted the fact that geneticists and genetic counselors who steer patients away from some or all pastoral counselors are in fact directive. Their professional understanding of themselves as nondirective

is unlikely to evaporate anytime soon; however, an honest public dialogue about what forms of directive and nondirective counseling are appropriate in dealing with patients will go some distance toward eliminating the unhelpful stereotypes of pastoral counselors as directive and clinical genetics professionals as nondirective.

Another instance of labeling that obstructs more cooperative relations between clinical genetics professionals and pastoral counseling professionals is the view that science is complex and religion is simplistic. Of healthcare professionals interviewed, most invoked long-standing suspicions between science and religion. Clinical genetics professionals who participated in the focus group frequently remarked that focus group conversations about the role of the pastoral counselor, and the depth of the topics related to religious coping, dispelled preconceptions about the simplicity of religious ideation. Only a small minority of participants left the conversations with a still-tightly-held view that religion was not only unhelpful but harmful to patients.

A distinct but related stereotype is the view that religious traditions share a single, extensive ethical and religious view about how to address the religious

Genetics professionals who steer patients away from pastoral counselors are in fact directive

and spiritual issues raised by genetic diagnoses. Again the interviews surfaced a broad vision of the diversity of religious views within and among faith perspectives on issues raised by genetics. With both stereotypes of religion (as simplistic or monolithic), joint meetings of the professions, and public conversations about their respective roles, could enhance mutual respect and trust, and could be an important step toward better collaboration.

Institutional Barriers

Those interviewed drew attention to the fact that institutions that do not have the capacity to integrate pastoral counseling into genetics-related cases might be unaware of the lack. In those institutions that have recognized the need and have built capacity, several respondents stressed the critical role that professionals who are both clinical genetics professionals and pastoral counselors have played. Respondents

singled out professionals who bridged the two areas of concern by translating religious issues into terms clinical genetics professionals could understand and value as important, and vice versa. Credible bridge figures, such as priests and rabbis who are also geneticists or genetic counselors, are critical to raising awareness and articulating expectations for all involved.

A significant institutional barrier to integrating pastoral counseling in genetics issues is the structure of the provision of services. Those interviewed repeatedly commented that pastoral services were provided largely through inpatient services; however, a large portion of genetic services are provided in outpatient clinics and physician offices to patients who have chronic conditions. While healthcare institutions can control the quality of pastoral counseling services within the institution, there is little control over quality in outpatient services. Pastoral counselors in the community who already have extensive obligations as community and congregational leaders will need incentives and educational programs if they are to develop the skills necessary to address genetics cases. Clinical genetics professionals—or those working at the federal level on the Human Genome Project—

who conclude that skilled pastoral counselors need to be developed in the community will face the complex task of creating incentives and identifying resources and networks.

The lack of funding as a barrier is as much a function of the rapidly fluctuating healthcare economy as of the extent to which pastoral care is recognized as essential in treating and healing the whole person. The boom and bust cycles of healthcare financing will always provide a reason to reduce pastoral counseling services, and the cycle is well outside the control of any institution or profession. However, what is in the control of professional societies is whether they will utilize the ongoing opportunity to examine the role of pastoral counseling and the value that it brings to the wholistic treatment of persons with genetic conditions. Professional associations of pastoral counselors should reexamine whether existing credentialing processes will adequately address the spiritual and religious issues occasioned by the rise of genetic diagnoses.

A final institutional barrier to better integration of pastoral counselors in genetics cases stems from the suboptimal qualifications of some professionals who are hired. Healthcare institutions

ought to utilize or employ only pastoral counselors who have the religious education and professional skills and competencies recommended by the major pastoral counseling associations.

The original aim of this study was to address a few simply stated issues: whether and how pastoral counselors might help individuals cope with the ethical and religious issues that arise in genetic diagnosis and treatment; the knowledge and skills necessary for pastoral counselors to serve effectively in genetics cases; and the professional and institutional barriers and opportunities that prevent or facilitate pastoral counselors' involvement in genetics issues. The answers identified were not as predictable as the research group first imagined.

The barriers are substantial. While there is a large reservoir of religious professionals working in many ministries, nonetheless there does not currently exist a large number of pastoral counselors with adequate education in clinical genetics and the training in pastoral counseling skills needed to address clinical genetics issues. Those who are adequately educated and trained are difficult to identify unless they are part of healthcare institutions or are known by the referring clinical genetics professional. Even if a work force of pastoral

Boom and bust cycles of healthcare financing always provide a reason to reduce pastoral counseling services

counselors educated and trained to deal with clinical genetics issues emerges, significant obstacles will remain because of prevailing practice patterns of clinical genetics professionals, their perceptions and ambivalences about the nature of religion, and their misgivings about the sometimes directive style of some pastoral counselors.

The study interviews revealed that change will not be a one-way street. Enhancing the participation of pastoral counselors in clinical genetics cases will require cooperation among and action by clinical genetics professions' educational institutions and societies. To echo one interviewee, the first step will be "for geneticists to understand the positive dimensions that religious coping can bring to the suffering and healing of patients and families."

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—Philip J. Boyle

NOTES

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experience, clinicians (medical geneticists, obstetricians, pediatricians, oncologists, genetic counselors) and chaplains working in genetics are well positioned to clarify the role of pastoral counselors in caring for patients undergoing genetic testing, diagnosis, and/or treatment. They have direct experience because they have observed their patients grappling with the ethical and religious implications of their genetic conditions or problems and asking the kinds of questions alluded to earlier, so they are able to describe the needs of patients confronted by these situations. Second, we knew from some limited research that pastoral counselors are already involved on a small scale in pastoral counseling in genetics-related areas. Presumably, then, healthcare professionals have some experience of how pastoral counselors engage their patients, how positive or negative the results of pastoral counselors' involvement have been—whether patients were helped or pastoral counselors' involvement unnecessarily complicated the clinical situation—and what steps might be taken to integrate the involvement of pastoral counselors with that of healthcare professionals. Third, healthcare professionals are not, presumably, immune to their own spiritual and religious questions, concerns, and doubts, which, left unaddressed, may well interfere with their professional interaction with patients. Thus we sought to explore, from the perspective of the ethical and religious needs of the healthcare professional, how pastoral counselors might mediate these issues in a way that would contribute to the overall improvement of the religious well-being of both patients and the healthcare professionals who care for them.

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SPEAK PEACE

BY CHARLES VILLA-VICENCIO

Reflecting on Reconciliation and Forgiveness

Book Reviewed

*Forgiveness and Reconciliation:
Religion, Public Policy, and
Conflict Transformation.*

Raymond G. Helmick and Rodney L.
Petersen.

Radnor, Pa.: Templeton Foundation
Press, 2001. 440 pp. \$34.95 (Hardcover)

F*orgiveness and Reconciliation* is about what can be done to facilitate a reconciling process between estranged individuals, hostile factions within a nation, or between warring countries. John Paul Lederach suggests in the text that, "it is a paradox of sorts that human concern for and interest in reconciliation is as old as the hills and at the same time in a preinfancy stage." This important book makes a significant contribution to our understanding of the complexities surrounding reconciliation. It edges us toward a level of maturity that affects personal, national, and international

quests for conflict transformation and reconciliation.

A dominant paradigm in thinking about reconciliation, not least in theological circles, suggests that forgiveness precedes reconciliation. The sequence is well-known: confession, repentance, forgiveness, and reconciliation. This conventional wisdom needs to be questioned in the light of entrenched social or national conflicts. In the hard world of political conflict, initiating the peace process is more important than an ideal outcome. And, ultimately, personal reconciliation may not be vastly different. There is no reason to suggest that forgiveness should necessarily precede personal reconciliation. An emerging sense of interdependence, which requires tolerance and empathy, perhaps the beginning of a relationship—even the initial phases of friendship—is frequently the first step in any reconciling process. Indeed, most nations and individual relationships survive quite well on less than ideal or complete reconciliation, which includes forgiveness and everyone living happily ever after. Put differently, to focus on an ideal theological notion of reconciliation, rather than a more modest understanding of reconciliation as a process with limited beginnings, is both conceptually confusing and practically counterproductive.

Most nations and individual relationships survive quite well on less than complete reconciliation.

The pursuit of a greater goal is at the same time necessary to ensure that the initial step in the process does not become the final one. A lack of movement beyond the first hesitant step in rapprochement can only serve to fuel the suspicion of the critics of political gradualism, who reject the process as little more than the rearranging of furniture on a vessel that drifts ever closer to disaster.

It is helpful to declare and be conscious of one's context and perspective. This review is written in the wake of the South African Truth and Reconciliation Commission. I do so mindful of the fact that few of us predicted much more than disaster for South Africa in the late 1980s. The breakthrough came not as a result of any Damascus Road experience; it came as a result of a series of encounters within which protagonists on opposing sides began to make contact with one another. Tentative, fragile steps were taken that led to "talks about

talks.” In the process, cautious relationships were forged. This opened the way to a search for peace and the beginning of a reconciling process.

Not every contributor to the book under review will necessarily agree with the underlying perception of reconciliation as a process preceding and ideally incorporating forgiveness. And yet all the contributions enrich the discussion on the complexity of the relationship between reconciliation and forgiveness. Anthony da Silva addresses the sequence question quite explicitly, drawing on Robert Schreiter’s suggestion that a more appropriate sequence may be: “reconciliation, forgiveness, repentance.” In an important contribution to the book, Miroslav Volf reminds us that there are no “autonomous and self-constituting entities” in human relations. It is through human encounter that the healing process begins. This does not suggest that repentance, justice, and other important dimensions of human relations are to be suspended indefinitely or played down in any other way. To Volf “the struggle against injustice is part of the more fundamental pursuit of reconciliation.” The pursuit of forgiveness is, in a similar sense, a goal that needs to sustain the reconciliation process. It is not, however, necessarily something that must precede

the process. I am arguing that it rarely does. Lederach speaks of the need for “a relationship-centric approach to reconciliation.” He suggests it involves a “multifaceted journey” in pursuit of a goal not yet reached. “Reconciliation is both place, as in destination, and a journey.” In the words of Ofelia Ortega, “conversion is not a momentary act of moral decision, but a process of learning and a new way of living.”

The African concept of *ubuntu*, introduced by Audrey Chapman, suggests that a person is only a person through other persons. In the words of Archbishop Desmond Tutu, it means “my humanity is caught up, is inextricably bound up in yours.” As such, “social harmony is for us the *summum bonum*—the greatest good.” It places dialogue and reciprocity at the center of the struggle to be fully human. It suggests that people are incomplete to the extent that they are alienated from one another. Often neglected at the height of war, rebellion, and conflict, it is this hope that inspires conflict resolution, peacemaking, and the need for coexistence. Is it an anthropological reality? A philosophy of *ubuntu* suggests it is. It recognizes that the process of seeking to be fully human refuses to submit to fate. It involves the creation of the kind of future that enables

people to engage one another in the creation of a society that includes all others. Da Silva speaks of “a common psychological need all humans share, which is to want to live in harmony with fellow humans while minimizing the stresses and strains of conflict.”

Of course this is not easy. There are numerous obstacles that undermine the process—bad memories, deep and abiding levels of hurt, the need for acknowledgment of past suffering, reparation, and justice. No one has the right to force victims and perpetrators to forgive or be reconciled. The question is whether victims and survivors can be assisted to move on—to get on with the rest of their lives, not allowing anger or self-pity to be the all-consuming dimension of their existence. It involves taking responsibility not only for their own lives and healing but also for the future direction of the nation. It is important for their own sake that those who suffered most are enabled to get on with life. This does not mean forgetting the ghastly deed. This is usually not possible and probably not helpful. It does not mean necessarily becoming friends with the person responsible for one’s suffering, nor does it mean forgiving that person. Very few accomplish this. Most people can only deal with their past suffering intermit-

tently, at times rising above it, at other times falling under its sway. Donald Shriver quotes William Faulkner: “The past is not dead and gone, it isn’t even past.” In da Silva’s words, “no general pattern will obtain; no uniform model need or should be imposed for peoples hoping to live together.” Put differently, any suggestion that confession and forgiveness is a precondition of reconciliation could be counterproductive in deeply divided societies. An approach that identifies reconciliation as process rather than goal could be more helpful. I am suggesting this pastoral approach not as an alternative to, but as an inherent part of, a viable prophetic ethic of reconciliation and forgiveness.

Editors Raymond Helmick and Rodney Petersen tell us their book is about “political penitence . . . Its horizon is not confessional, but public policy and conflict resolution.” This focus makes the question of “sequence” important. In the world of politics, where “the art of the possible” prevails, the question of how to attain a given end is as important as the end itself. The means is indeed inherent to the end.

This book contains a lot of theology, offered in the service of the public square rather than the pew. Such a theology is required to explore the hindrances and

potential contributions of religion to the realization of “political penitence.” Volf suggests this process may be better served by more religion of the correct kind—involving “costly discipleship”—rather than less religion. This is, however, a process that may require theologians to take seriously the challenge presented to the church more than a half a century ago by Dietrich Bonhoeffer from his prison cell, which is to proclaim the gospel in secular language. Effectively this involves using language that is understood by secular society and refraining from the kind of dogmatism that seeks to prescribe how, when, and where repentance, forgiveness, reconciliation should occur. These are, after all, gracious and mysterious gifts of a gracious God.

The book is divided into four parts. The first, entitled a theology of reconciliation, addresses the theological content of key words, the dialectic of forgiveness, and theological models of reconciliation and forgiveness, in a deepening discussion on the relationship between justice, reconciliation, and forgiveness. It ends with an orthodox perspective on reconciliation and forgiveness. The contributions come from Petersen, Volf, and Stanley Harakas.

The second part, dealing with forgiveness and public policy, includes

chapters by Helmick, Joseph Montville, Donna Hicks, and Shriver. The question is posed whether religion is a source of fuel or healing in situations of conflict. There is a chapter on religion and peacemaking; another on religion and foreign policy. Religion is considered in the reconstruction of identity, and the important question is asked concerning the form and nature of forgiveness in secular politics.

Part three considers the relationship between forgiveness and reconciliation. It provides diverse voices from the fields of clinical psychology, regional conflict mediation, the social sciences, and global youth ministry. The contributions are by Everett Worthington, Lederach, Ervin Staub and Laurie Anne Pearlman, and John Dawson. This is an important and action-driven section of the book that provides a number of practical ways of “reducing unforgiveness” (Worthington), discussion on “qualities of practice that lend themselves to reconciliation” (Lederach), and a focus on “healing, reconciliation and forgiving after genocide and other collective violence,” with special attention to Rwanda (Staub and Pearlman). Dawson points to several areas of concern in Western civilization that require attention in pursuit of less violence and conflict.

Part four, seeking forgiveness after tragedy, addresses specific situations of conflict. These include South Africa, Northern Ireland, and Mozambique. Specific mechanisms and ways of promoting forgiveness and reconciliation are considered within these situations and more generally. These include truth and reconciliation commissions, a two-track diplomacy methodology, a Gandhian approach to reconciliation, and a Christian notion of conversion (*metanoia*) as means of peacemaking. In an afterword, George Ellis explores the concerns raised in the book that apply to personal, regional, national, and international life. In the foreword, Archbishop Tutu provides the inspiration that keeps the debate going.

An important message of this book is that there are no neat and tidy formulas that make for forgiveness and reconciliation. Lederach's word is an important one: "unlike other areas of conflict management more narrowly defined, reconciliation processes do not lend themselves to reductionist techniques . . . Qualities of practice point us less in the direction of technique and more towards attitude and character." The consideration of reconciliation techniques is imperative, talk about reconciliation is important, and the identi-

There are no neat and tidy formulas for forgiveness and reconciliation.

fication of lessons learned from reconciling initiatives is essential. This is what makes this particular book such an important one. And yet who, one must ask, is ultimately in a position to define the meaning of reconciliation for another or to prescribe the techniques of the process?

Ultimately the Spirit blows where it wills, and reconciliation happens in different ways in different places. Vigilance is required in order to discern the possibilities of reconciliation where and when they occur. Wortherington's careful analysis of mechanisms that lead to the "reducing of unforgiveness" and that promote reconciliation and forgiveness can only facilitate such discernment. Equally important is the insight provided by Joseph Montville into the "psychological man" and the "religious man." He speaks of the separation of consciences in Nazi doctors, "the half that accepted systematic murder and the other half that enjoyed a quiet evening at home with wife, children and dog"—posing the important question

concerning the societal and personal causes of perpetration.

Indeed, this is frequently a key ingredient to the reconciliation process. The South African Truth and Reconciliation Commission was mandated to do more than account for who did what to whom. It was required to discern the “causes, motives and perspectives” of perpetrators. The aim of this requirement was not to lessen the culpability of perpetrators. It was rather to identify these factors with a view to ensuring that their reemergence in the future is at least minimized, if not eliminated. The most effective way to counter gross human rights violations is, of course, through prevention. It is here that the present anticipates the future. And it is here that reconciliation work needs to begin.

The discernment of causes, motives, and perspectives can also affect the attitudes and behavior of victims and survivors. Without condoning or justifying the behavior of perpetrators in any way, in some instances it enables victims and survivors to begin to see perpetrators as victims of a different kind—of propaganda, religious indoctrination, fear, disillusionment, and a culture of submission. Madame de Staël, the late eighteenth century French intellectual, suggested that “to understand all is to

forgive all.” Understanding does not, of course, necessarily lead to reconciliation. It may even aggravate the sense of anger and alienation. And yet, when the story of a perpetrator is thoughtfully told, empathetically heard, and deeply understood, it can soften the perception the victim, survivor, or observer has of the perpetrator concerned. It can open a space for the possibility of a new kind of interaction between adversaries. Jozef Garlinski, a Polish underground fighter who survived Auschwitz, tells of the horrendous evil he both witnessed and suffered. He ends his account by saying, “please remember those young SS officers could have been your sons or mine.” In understanding the perpetrator, we may begin to understand the forces that make for evil. We discover the power of these forces, and we begin to realize that the enemy—the German, the Serb, or the white Afrikaner—does not have a monopoly on moral insanity. We discover that maybe there is a little perpetrator in each of us. This makes unconditional negative judgment of another a little more difficult. As such, it can create a basis for interaction in the present that could lead to a new kind of future. ■

FUTURE DIRECTION IN ORGANIZATIONAL ETHICS

BY ANA SMITH ILTIS

Ties to Healthcare Ethics

Books Reviewed

*Business Ethics in Healthcare:
Beyond Compliance.*

Leonard J. Weber.

Bloomington: Indiana University Press,
2001. 264 pp. \$35.00 (Hardcover).

*Managing Ethically: An
Executive's Guide.*

Paul B. Hofmann and William A. Nelson,
eds.

Chicago: Health Administration Press,
2001. 276 pp. \$49.00 (Softcover).

*Developing Organization Ethics in
Healthcare: A Case-Based
Approach to Policy, Practice, and
Compliance.*

Ann E. Mills, Edward M. Spencer, and
Patricia H. Werhane, eds.

Hagerstown, Md.: University Publishing
Group, 2001. 224 pp. \$24.95 (Softcover).

Organizational ethics in health care is rooted in defense industry changes during the early 1980s and in changes in business ethics. During the former, concerns over weapons procurement motivated the development of compliance programs, in which contractors were required to develop codes of ethics, mechanisms to report misconduct, and the like. By 1991 the U.S. Sentencing Commission was urging all companies to implement ethics/compliance programs.¹ The focus on compliance with government regulations has become increasingly important in health care, especially because of the growth of government-funded health programs and in light of financing scandals and other mishandling of government dollars.

Business ethics has also influenced the development of organizational ethics in health care, with its focus on corporate moral agency and responsibility² and on particular aspects of business operations, such as advertising and conflict of interest. The Diagnostic Related Groups (DRGs) of the early 1980s and the dominance of managed care today make it clear that money matters in health care and that business decisions are made regularly in the context of providing health care. Moreover, it has become clear that healthcare institutions, such as hospitals and insurance companies, make decisions about health care and, in many cases, determine who receives care and what level of care they receive. Thus it has become necessary to examine the moral responsibilities of healthcare institutions.

Initially, organizational ethics in health care focused heavily on compliance, on ensuring that healthcare organizations abided by all relevant government rules and regulations. Today, two trends dominate organizational ethics. First is the recognition that it must look beyond compliance.³ Second is the recognition that many issues in healthcare ethics once thought to concern only patients and providers do in fact have organizational components.⁴ Despite this new focus, there is

still a quest to determine what, precisely, should be the next step for organizational ethics. Each of the three books discussed here suggests a focus for organizational ethics and contributes to the development of this growing field.

In *Business Ethics in Healthcare: Beyond Compliance*, Leonard Weber describes ethics as a discipline aimed at “assisting persons to make better practical judgments.” In the first chapter he outlines the nature, purpose, and goals of healthcare organizations and advocates a special healthcare business ethics. In particular, he suggests that healthcare organizations are or ought to be caregivers, employers, and citizens. Weber claims that these roles inherently lead to a series of responsibilities, including the basic obligation to ensure that “the needs and interests of all relevant stakeholders are balanced on the basis of a consistent and explicit understanding of priorities.” In the second chapter, Weber offers principles of business ethics, which he applies to specific cases in the remainder of the book.

The pattern of Weber’s analyses emerges clearly: balancing values. His approach is, in short, to enumerate and rank priorities—a quite common approach to healthcare ethics. For example, Baruch

Brody's conflicting appeals model of decision-making in healthcare ethics shows an appreciation for the need to balance values and value-claims. Brody recognizes that many moral appeals make a legitimate claim on us and these appeals may conflict. Thus he argues in his discussion of the patient-physician relationship that an ethical theory must focus on balancing those potentially conflicting appeals. As a casuist, Brody holds that the best way to determine how appropriately to balance those appeals is to examine a variety of cases concerning a particular matter.⁵

In chapters three through sixteen, Weber presents topics in healthcare ethics—conflict of interest, managed care coverage denials and appeals, labor issues, advertising, and mergers and acquisitions, to name a few. One important reason to read this book is that the author identifies areas that might initially be overlooked when trying to determine business ethics concerns in health care, such as socially responsible investing. For each topic, Weber discusses the need to balance values and goals of health care, provides case analyses that demonstrate that balancing, and offers principles that individuals and committees can apply in addressing concerns.

Chapters seventeen and eighteen show how to promote business ethics in health care and elucidate the relationship between ethics and the business management of healthcare organizations. Weber concludes that organizational ethics committees are essential in increasing understanding of business ethics in health care and in promoting the ethical management of healthcare organizations.

This book reveals the astounding relevance of business ethics to health care. Healthcare administrators will see in this book many issues they face and will, in particular, see routine business decisions in a new light. Patients and employees will see many of the struggles healthcare managers face. They may recognize that many issues that seem clear and one-dimensional from certain perspectives are actually multifaceted and complex. Perhaps the most important conclusions one can draw from this book are that the focus on business and organizational ethics in health care must go beyond compliance, and that a clear understanding of the nature and purpose of health care is critical to understanding and addressing ethical issues in health care.

Two very important discussions are missing from Weber's analysis. First, he

Weber concludes that religious institutions can operate as they wish as long as they ultimately balance values just as he would.

does not indicate the source of the principles he identifies as action-guiding. In fact, the background assumptions underlying his claims are not even mentioned. Weber fails to recognize the fact that with different assumptions we would have very different balancing outcomes. Thus to say that we ought to have principles and balance priorities in itself is unhelpful. We must know how to obtain the principles, why they are the right principles to hold, and what values and priorities ought to guide the balancing of such principles.

Second, Weber's discussion does not give sufficient attention to the many different natures healthcare institutions might have. The brief attention to religious healthcare institutions is insufficient. Weber concludes that religious institutions can operate as they wish as long as they ultimately balance values just as he would. For example, Weber presents a case in which a Catholic hos-

pital and a nonprofit secular community hospital are considering a merger that would result in only one hospital in the community (Case 15.2). The Catholic hospital insists that the new hospital would have to continue to abide by the *Ethical and Religious Directives*,⁶ a set of guidelines issued by the Catholic bishops of the United States that govern Catholic healthcare institutions. According to these guidelines, Catholic healthcare institutions must not provide healthcare services—such as abortions and elective sterilizations—that are contrary to Roman Catholic moral teaching. Weber claims that “within limits, it is entirely appropriate for healthcare organizations to determine on the basis of their own ethical principles which legally acceptable practices are and are not permitted within their facilities.” However, he also claims that there are limits to what healthcare institutions may refuse to provide:

The healthcare organization is a community service business. It is of the nature of a service organization that its responsibility is determined in large part by the needs of the community. Not every healthcare facility must offer every type of service, of course, and not every acute care hospital has a responsibility to permit every service to

which the community has a reasonable expectation of access. If there is only one acute care facility in the community, however, that facility has much less flexibility. This is a situation that would result from the proposed merger in this case.⁷

Essentially, Weber argues that “the basic responsibility of the organization to serve the community takes priority” over its particular moral commitments and responsibilities. It is interesting that despite the extensive discussion of the moral obligations of healthcare organizations, very little attention is given to what we might call the moral rights of an institution to adhere to its particular moral commitments and virtually no consideration is given to the idea that a healthcare institution can, as a moral agent, have moral obligations that it must satisfy at the risk of offending an individual or group of individuals. Weber’s discussion of this case reveals that he has a limited appreciation of healthcare institutions as bearers of particular moral characters and responsibilities, and of the importance of healthcare institutions living up to their moral obligations and maintaining their integrity. He sees healthcare institutions as having moral responsibilities and as having the poten-

Weber has a limited appreciation of healthcare institutions as bearers of particular moral characters and responsibilities.

tial for integrity, but only within the limits of his own conception of morality. He fails to see that, although he does not recognize certain services as morally objectionable, it may in fact be morally wrong for a particular healthcare institution to provide them. He does not understand that a Catholic institution seeking to maintain its institutional integrity never could balance values in the same way he does.

Weber offers an interesting discussion of some important areas of concern to organizational ethics, and he shows how, given certain assumptions, one might attempt to resolve organizational ethics issues. However, his approach is too simplistic and narrow to be of service to all healthcare organizations.

The starting point of *Developing Organizational Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance* is somewhat similar to

Weber's. The organization of the book reflects that the editors—Ann Mills, Edward Spencer, and Patricia Werhane—are acutely aware of the influence of organizational issues in different areas of health care and the ways in which organizational ethics permeates all in healthcare ethics. It addresses organization issues in four areas of healthcare ethics—business ethics, clinical ethics, professional ethics, and research ethics—and provides cases in each area. The appendices recommend ways to analyze organizational ethics cases, show how two healthcare organizations address such cases, and provide the codes of ethics of various professional healthcare organizations.

This book, like Weber's, demonstrates the salience of organizational ethics in health care. Moreover it has the virtue of making obvious the depth or expanse of organizational ethics and thus increases our understanding of the field. The editors, in their introduction, note that their goal is to show that organizational ethics is eclectic and broad and that it arises in all areas of healthcare ethics. They include cases pointing to numerous potential organizational issues, and they show that issues we consider strictly matters of, for example, clinical ethics may be resolved by addressing

organizational issues. This is perhaps the most important insight of the book. The relationship between organizational ethics and other areas of healthcare ethics has been grossly underexamined. Typically, organizational ethics is treated as one more area of healthcare ethics. Yet what the editors show us in their organization and selection of cases is that organizational ethics is integrated into other areas of healthcare ethics; it cannot and should not be isolated and treated as a separate entity. The compartmentalization of healthcare ethics is ill conceived.

Unlike Weber's book, this collection does not include analyses and alleged answers or solutions for cases. According to the editors, their "concern is to include cases that demonstrate the role of organization ethics activities in the formation and support of a positive ethical climate. Commentary and questions are not necessary." They prefer to let readers analyze the cases themselves. This makes the book a useful tool for generating discussion without providing a roadmap that might limit the examination of important issues. The guidelines for case analysis offered in Appendix B can be used as a starting point for such discussions. Of course, by raising issues and questions and not providing concrete answers, the book will leave readers looking for a set

of rules. Nevertheless, organizational ethics is complex, and it would be irresponsible to suggest that there are simple answers to be had.

In their introduction, Mills, Spencer, and Werhane point to the importance of institutional values to organization ethics. An organization's ethical climate, they say, is grounded in its core values, which inform its value and mission statements and code of ethics. In Appendix B, which offers guidelines for analyzing organizational ethics issues, there is again mention of an organization's mission. The importance of institutional values, although introduced, is not sufficiently developed in the text. As noted in the discussion of the Weber text above, an appreciation for an organization's values is critical. This book, like Weber's, fails to demonstrate that a rich understanding of an organization's values and goals is essential for any fruitful discussion of organizational ethics. It is from an organization's values and goals that we can develop an understanding of what it ought to do. There is likely to be a sense among many that there simply are some morally right and wrong ways for organizations to act and that organizational ethics is a fact of the matter. While there may be some basic rules of the game that are widely recognized as obligations of healthcare

organizations, the more interesting and difficult cases involve organizational values. In a secular, pluralistic society there is not sufficient agreement on the content of morality to rely solely on the so-called common morality. Ethics and ethical analysis are grounded in an understanding of the values agents hold. Thus the obligations we might associate with a Christian hospital may not be ones we associate with a Jewish, public, or private secular hospital. That does not mean that we ignore those particular obligations. On the contrary, we recognize that the particular Christian hospital at stake must in fact act in particular ways and should address organizational ethics issues in ways that are grounded in and reflect its particular values. *Developing Organization Ethics in Healthcare* would be richer if there were more recognition of moral controversy and its implications for organizational ethics.

Managing Ethically: An Executive's Guide, edited by Paul Hofmann and William Nelson, is an anthology of columns originally published in *Healthcare Executive* that introduces the reader to a wide variety of organizational ethics issues from the perspective of individuals in administrative and managerial positions. This focus on administrators and managers certainly is not meant to

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dispel any notion that
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suggest it is only the responsibility of those in management to address ethical issues or that only they are in a position to identify such issues. On the contrary, it is meant to promote dialogue among all parties. The entries, organized topically, cover issues of leadership, community relations, managed care, mergers and integrations, use of information, human resources, clinical ethics, organizational ethics, and institutional resources (i.e., programs within an institution that can help promote ethical management). Each section is short and focused and references the American College of Healthcare Executives Code of Ethics to suggest professional norms and thus how a healthcare administrator ought to approach an issue. Even for those who are not healthcare administrators and thus do not fall into the narrow scope of this text, the entries provide insight into the broad range of ethical issues that arise in health care and the issues healthcare administrators face. The volume

should dispel any notion that administrators do not struggle with ethical dilemmas when making unpopular choices, such as laying off employees, as the primary focus is on the examination of organizational ethics issues through the lens of healthcare executives.

The columns concerning leadership (Part I) attend exclusively to what we might consider personal ethical issues that healthcare executives might face, such as how appropriately to maintain their personal integrity in the workplace and how to handle potentially conflicting loyalties. Thus in Part I the focus is on the individual manager as moral agent. Part II of the collection shifts focus to community relations; the moral agent of concern is the healthcare organization itself, with its the obligations and responsibilities. In much of the remainder of the text we see greater discussion of the moral obligations of both individuals and organizations.

This collection introduces important issues in organizational ethics and business ethics in health care. Unfortunately, because of the nature of the genre, the columns lack sustained analysis. Though the text has the virtue of diversity, it should not be relied upon for a careful discussion of the variety of issues introduced.

All three volumes considered here show that organizational ethics is a growing area of interest with an increasingly demanding and widening set of concerns. The original focus of organizational ethics on compliance is outdated. What is necessary now is a vision for organizational ethics. Patricia Werhane notes that “even though business ethics contributes to our thinking about the ethics of healthcare organizations, these organizations have distinguishing characteristics that make them worth considering apart from other business or charitable enterprises.”⁸ Organizational ethics may be the special business of healthcare ethics we need. It must account for the nature and purpose of healthcare organizations, including the fact that not all healthcare organizations are created with the same set of commitments, values, and obligations. Some healthcare organizations, for example, may have religious commitments others lack. Any clear understanding of organizational ethics must attend to the particular moral characters of healthcare organizations, not merely to general claims about the obligations of such institutions. This will require an understanding of institutional integrity, of what it means for healthcare institutions to have moral commitments and to fulfill them.

Understanding healthcare institutions as moral agents, identifying institutional moral commitments, and exploring the implications of the moral obligations of healthcare organizations is or ought to be the focus of the next generation of organizational ethics literature. ■

NOTES

1. Marie J. Giblin and Mark E. Meaney, “Corporate Compliance is Not Enough,” *Health Progress* (September-October 1998): 1.
2. For a summary of this literature, see Geoff Moore, “Corporate Moral Agency: Review and Implications,” *Journal of Business Ethics*, 21 (1999): 329–34.
3. George Khushf, “Administrative and Organizational Ethics,” *HEC Forum* 9, no. 4(1997): 299–309; Weber, *Business Ethics*.
4. Dennis F. Thompson, “Hospital Ethics,” *Cambridge Quarterly of Healthcare Ethics* 3(1992): 203–210; Spencer, Mills, and Werhane, *Developing Organization Ethics*.
5. Baruch Brody, *Life and Death Decision Making* (New York: Oxford University Press, New York, 1988).
6. National Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Healthcare Services* (Washington, D.C.: United States Catholic Conference, 1995, 2001).
7. Weber, *Business Ethics*, 146–147.
8. Patricia Werhane, “Business Ethics, Stakeholder Theory, and the Ethics of Healthcare Organizations,” *Cambridge Quarterly of Healthcare Ethics* 9(2000): 169–181.

BOOKS IN BRIEF

Embracing a New Ethical Model

African American Christian Ethics.

Samuel K. Roberts.

Cleveland, Ohio: Pilgrim Press, 2001.

\$26 (Softcover).

Samuel K. Roberts presents a thought-provoking, systematic critique of African-American Christian ethics. His analysis assumes the reality of this behavior and discipline, based upon the experience of African-American Christians as it is concretized in the spirituals. This ethic emerged amidst a faith that enslaved those deemed “other,” even as they relied on this faith for lib-

eration. As Roberts notes, this ethic recognizes that neither the enslaved nor their oppressors could be free in such a status quo. Yet Roberts also observes that, for such an ethic, African-American exclusivism in response to oppression cannot be liberating. With poetic signification, Roberts resolves the paradox by claiming that God is beyond human limitations and perspectives. He articulates his framework by explicating Eurocentric cultural idolatry and Black theology, and by suggesting a model of intellectual integrity and moral consistency that posits a Tillichian God “as ground of being rather than a God of personal being.”

Methodologically, Roberts explores God, Christ as Liberator and Reconciler, and the Holy Spirit as Counselor and Inspirer, and the sources that shape this African-American Christian ethic: Bible, ecclesial tradition, human nature and freedom, and knowledge and reason interfacing with faith and God. Roberts concludes by investigating contextual praxis and addressing the foundations and resources that mold life in the African-American community—from sexuality and bioethics to justice at the polls. Roberts proposes a vision of African-American Christian ethics as interdisciplinary scholarship and critiques various thinkers and schools of thought, challenging what he calls their flawed premises and logic.

Building a theological orientation for a distinctive ethic, Roberts explores the concept of God, God's relationship to created order, the question of moral evil, and theodicy. He highlights African-American male thinkers while avoiding cultural exclusivism. From classical Christology, Roberts explores representations of Christ in Black culture and theology, and he offers a Christology of freedom through reconciliation with God in Jesus the Christ, and of freedom in God's kingdom that moves toward community participation. He deconstructs

the Holy Spirit as God's emanating grace that intersects worship and work as a creative force in the believing community, the church. Given the exegetical heritage of the spirituals, framed by their "creative genius with the historical experience of terror," an African-American concept of biblical authority must discern the glimpses of God's will in an alien world. The complex, diverse African-American church fosters spiritual alertness, works in the world, inspires without couching rhetoric in ideology, praises God, encourages faithful living, and nurtures believers. Roberts uses the spirituals to posit "the freedom inherent in human nature and human existence" with, unfortunately, an underdeveloped argument. The impetus for knowledge amid faith and reason in the African-American religious consciousness is the "interplay between victimization and vindication," where people overwhelmingly affirm the sufficiency of God's grace and the potential for human beings to make a difference. Mindful of the sexual commodification of African Americans and ongoing stereotypes, an African-American sexual ethic of commitment and integrity authenticates sex and love. A healthy bioethics involves African-American participation and inclusion within prin-

ciples of Christian faith. Roberts analyzes justice in the courts, markets, and electoral precincts, and calls for a full inclusion of African-American political interests within the American political order. He invites a new institutional and personal piety with an enlivened praxis of partnership within African-American life, moving toward an authentic interracial dialogue of diverse viewpoints and perspectives, one not steeped in guilt.

Roberts's tome speaks like a renaissance work, as his analysis juxtaposes artistic renderings with scientific investigation and interrogates early church history and classical philosophy with the present-day reality of African Americans. He allows interfaith and interreligious perspectives by not assuming that Jesus is the only mark of salvation. Yet, how do a depersonalized God and a related ethic have an impact on people who are extremely Christocentric and wedded to a personal Jesus as Lord and Savior?

Roberts's work is such a cut above that his omissions of womanist scholars, Jon Michael Spencer's work on theomusicology, and Robert Lovell Jr.'s magnum opus on the spirituals are bewildering and unfortunate. Roberts uses inclusive language for the divine, but does not offer a critique of God as

Father. Despite these exceptions, Roberts's work is a must-read for those interested in the American Christian experience, including the African-American experience. It is highly recommended for seminary or university courses that combine theology, ethics, history, liturgy, and lived experience.

—Cheryl A. Kirk-Duggan

■ ■

Ethics, Faith, Health, and Moral Freedom

Moral Freedom: The Search for Virtue in a World of Choice.

Alan Wolfe.

New York: W.W. Norton, 2001.

224 pp. \$24.95 (Hardcover).

“I don’t think you can teach a kid to follow orders,” one of sociologist Alan Wolfe’s interview respondents says. “You can try to convince the child that that’s right, but if we don’t let the child think for themselves and make their own decisions, you’re leaving them, as an adult, vulnerable to these ad campaigns where they’re told what to think.” People’s concerns about vulnerability go far beyond advertising, but that statement is moral freedom in a nutshell: Think for yourself, and make your own decisions. This idea, although “casually taken for granted” in contemporary America, is also “quite revolutionary.” “Now for the first time in human history,” Wolfe argues, “significant numbers of individuals believe that people should play a role in defining their own morality as they contemplate their proper relationship to God, to one another, and to themselves.”

Wolfe emphasizes that people have neither chosen nor lapsed into moral

freedom; instead they find it forced upon them. As he puts it with characteristically gentle wit, “Once upon a time, Americans raised families without being able to know whether their children would turn out to be good or bad. Now they raise children uncertain about what good or bad actually are.” Moral freedom is “a sometimes terrifying sense of insecurity as to what they consider it means to lead a good and virtuous life.”

The significance of Wolfe’s argument for ethics and faith—two of the three words that subtitle this journal—is evident. I believe the book is equally significant on the issue of health, but since Wolfe does not discuss health, illness, or medicine, that significance requires some interpolation.

Wolfe reports both survey data and interviews with randomly selected people in eight diverse American communities. The book contains a few percentages but no graphs or tables. Instead Wolfe quotes respondents saying what is representative of how Americans talk about their values, morals, and ethics. He recognizes that this approach is itself a symptom of an age of moral freedom. The idea of inducing morality by asking people how they lead their lives is part of the general belief that “any form of higher authority has to

tailor its commandments to the needs of real people.” What do these real people believe, and how are they trying to live?

With respect to faith, Wolfe’s respondents confirm what other commentators have noted: People consider themselves religious but are often suspicious of organized religion. Religion, as one respondent puts it, “so often functions as keeping people in check and keeping them in this little box and makes life not messy.” People recognize that life is messy. The mess requires avoiding absolutes, even though finding a creative response to each situation is itself messy.

With respect to ethics, moral freedom is anything but the anarchy feared by conservative commentators whom Wolfe engages throughout the book. Part of what makes *Moral Freedom* such a delight to read is Wolfe’s ear for people’s sincere attempts to lead good lives, even as they are unsure what that means. Wolfe genuinely likes and admires people perhaps because of, not in spite of, their contradictions and dilemmas, which are especially apparent in ideas about honesty and forgiveness, two of his central concerns.

What does Wolfe tell us about health? A recurring theme is that when people seek explanation for others’

moral behaviors, and when they judge or refuse to judge others, therapeutic explanations trump theological and philosophical ethics, and medical explanations trump psychological. As people seek to affirm the disrepute of acts while providing leeway to actors, they look to medicine, especially genetics. If Wolfe had asked about health care, I suggest his respondents would have said that people are responsible for their own health, but individuals can rarely be blamed for their particular sicknesses. Americans, Wolfe shows repeatedly, value personal responsibility, but they also limit it in their unwillingness to blame except in extreme circumstances and, provocatively, sexual choice.

Wolfe’s counsel is to be neither for nor against moral freedom but to learn to live with its inevitability. He never underestimates the problems of moral freedom, but his attitude seems that of his respondents: for all the uncertainty they face, “they also have some reason to hope.” This generous, carefully researched, insightful book leaves me with no doubt that he is right: “The twenty-first century will be the century of moral freedom.” In this brave new world, Wolfe is an exemplary, and most hopeful, guide.

—Arthur W. Frank

The Respect Due to Persons

Who Count as Persons? Human Identity and the Ethics of Killing.

John F. Kavanaugh.

Washington, D.C.: Georgetown University Press, 2001. 248 pp. \$45 (Softcover).

W*ho Count as Persons?* is a passionate defense of the proposition that the direct killing of human life is always morally wrong. The author, John Kavanaugh, S.J., believes this proposition follows from a proper understanding of the human person. Thus his book does more than discuss the ethics of killing; it sets forth a theory of personhood.

Kavanaugh locates an essential aspect of personhood in the capacity for what he calls "reflexive consciousness." Reflexive consciousness is the ability of persons to be conscious of the fact that they are conscious. This ability, in turn, is necessary if persons are to step back from their environment to engage it, which is a necessary condition for the formation of the self.

Grounding personhood in reflexive consciousness appears to imply that human beings who lack the capacity for reflexive consciousness are not persons. Surely the fetus, the anencephal-

ic baby, and the patient in a persistent vegetative state do not possess consciousness of their consciousness. Kavanaugh insists, however, that such individuals, indeed all human beings, belong within the class of persons. The steps that lead him to this conclusion are not altogether clear to me, but the crux of the argument seems to reside in Kavanaugh's view that human nature contains potentialities, one of the most important of which is the potential for self-reflexive action. All human beings, from the fetus to the patient in a persistent vegetative state, possess this potential and are, therefore, deserving of the respect due to persons.

The argument from potential is by no means decisive, but it is stronger in my judgment than some will be willing to recognize. My one-week-old daughter may possess no more rational ability than a mouse. However, if I were to treat her like a mouse, subjecting her to laboratory experiments, I would be inflicting harm on the person she is to become. The experiments performed now would produce their harmful effects later, and those harms would be qualitatively different from the harms experienced by a mouse in full maturity. Thus, genuine regard for any species of animal requires consideration for what

that species can be, and insofar as human beings are capable of becoming more than other animals, they are deserving of a different kind of respect.

Next Kavanaugh argues that his theory of personhood leads to the ethical maxim: Affirm the intrinsic value of human beings and do nothing to negate their personhood. Intentional killing is the willed negation of personhood, says Kavanaugh, and those who justify killing must do so by disregarding human dignity for the sake of a competing value. This justification, Kavanaugh says, is unacceptable.

However, a recognition of the intrinsic value of the human person does not necessarily entail an absolute prohibition on killing. In order to draw that conclusion one must first consider a prior question about the relationship between human dignity and the right to immunity from lethal harm. If in certain circumstances persons do not enjoy moral immunity from lethal harm, then killing them in those circumstances will not violate their dignity. The just war tradition, for example, justifies the intentional killing of combatants by asserting that they do not enjoy immunity from lethal intention. They do not enjoy immunity, not because their lives lack dignity, but because life itself is a value

within an order of values that includes justice, order, and liberty, values which the just war seeks to protect.

Perhaps if one considers life an absolute value, one will think that all justifications for killing are built upon a suppression of human dignity. However, to claim life is an absolute value requires more than a theory of personhood, it requires a theory of the objective order of values in which life finds its place. This is something Kavanaugh does not provide, nor do I believe he can provide it to produce the conclusion he needs. Life has value through its relationship to higher values such as truth, justice, and the good; in other words, if there are no values greater than life, life itself has no value.

My disagreements with Kavanaugh notwithstanding, I believe he has written a thought-provoking book worthy of critical engagement. His arguments will enrich ethical discussion both in and out of the classroom.

—Helmut David Baer

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How Sexual Science Operates

Sex, Love, and Health In America: Private Choices, and Public Policies.
Edward O. Laumann and Robert T. Michael, eds.

Chicago: University of Chicago Press,
2001. 535 pp. \$48 (Hardcover).

In 1994 six prominent sociologists characterized the sexual practices of Americans.¹ Their National Health and Social Life Survey employed sophisticated scientific methods to obtain a representative sample of adults from eighteen to fifty-nine years old and to maximize truthful self-reporting. Their work represents the best that cross-sectional study has to offer about sex. It is so large in scope that their data are likely to be quoted for decades to come in professional and lay articles. The media quickly publicized some of the findings with headline-grabbing spins on the revelations about our private behaviors. Sensationalism aside, many professionals found it exciting to learn that Americans have tame sexual lives.

Two of the survey's architects, both distinguished professors at the University of Chicago, planned this volume of thirteen essays based on further analysis of the original data. With graduate students and an occasional colleague

coauthor, their essays discuss important aspects of adolescent sexuality, adult sexual behaviors, sexually transmitted disease, and public policy.

Clearly, sex is not simple. Sexuality does not lend itself to any direct definition. It is simultaneously private and public, individual and collective, biological, social, and psychological, conscious and unconscious, measurable and beyond measurement, static and evolving. Every informed professional, each relevant discipline, and all interested institutions should know that it is impossible to have the last word on the subject. This is not just because the United States contains a great diversity of opinions about everything sexual. It is also because the clinical and social sciences have learned that sex is a profoundly rich topic, and numerous perspectives are better than one.

The text's nineteen authors delve deeply into sexuality's complexity. Their data begins with the influences of age, gender, marital status, education, race, ethnicity, and religious affiliation, which is used to build models for understanding psychological topics such as abortion, sexual satisfaction, sexual dysfunction, and AIDS prevention. The essays—serious, academic, and carefully edited—invariably educate the reader. The book

is hard work, particularly for the statistically unsophisticated reader; there are so many findings, possibilities, and uncertainties. The book contains many useful contributions for those whose profession it is to grapple with issues involving teen pregnancy, sexually transmitted diseases, racial disparities, sex education, pornography, sex research, and how sexual life ought to be conducted. These professionals may include local, state, and federal government officials, legislators, academics, religious educators, teachers, clinicians, and foundation officers.

A theme of the book is the need for continued scientific study of sex. This is not because research will show us what to do with our controversies involving unwanted pregnancies, sex crimes, extramarital sex, and homosexuality, for instance, but because having an objective starting point makes the discourse more efficient. These erudite authors are not attempting to create new public policies. They are informing the public about the issues and helping to keep the rhetoric from becoming too simplified.

Funded sex research is rarely directed toward the study of health. Government agencies and foundations fund studies in the hope that they will ultimately assist in the solution of prob-

lems. Of the key words in the title, two are a bit misleading. Health is a relevant but largely implied topic in some of the essays. Love, however, cannot even be found at the edges or between the seams of these discussions. This subject is too private, subjective, and quixotic² to be grasped by the data examined here. So why is "Love" in the title? The book's focus is on selected socially relevant sexual problems; it is not about the evolution of individual sexual health. These essays induce readers to wonder how we Americans actually come to acquire our private ideas and personal rules for sexual conduct and how we actually make some of the choices that shape our fates. These questions, although thoroughly illuminated, are only partially answered.

—Stephen B. Levine

NOTES

1. R. T. Michael, J. H. Gagnon, E. O. Laumann, G. Kolata, *Sex in America* (Boston: Little Brown, 1994). E. O. Laumann, J. H. Gagnon, R. T. Michael, S. Michaels, *The Social Organization of Sexuality: Sexual Practices in the United States* (Chicago: University of Chicago Press, 1994).
2. See my essay, "The Nature of Love," in *Sexuality in Mid-Life* (New York, Kluwer Academic Publishers, 1998).

The Forest for the Trees

Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures.

Dena S. Davis.

New York: Routledge, 2001. 153 pp.
\$22.99 (Softcover).

For many women today, having a baby may require working through a decision tree, the kind of flow chart that Dena Davis lays out: Have a child? If yes, have it with/without assistance by technology? If assisted, which technology? Here, especially, the branches of the decision tree are multiple. If or if not assisted, should the embryo (or fetal) cells be tested? If tested, implant/continue pregnancy based on results? And so it goes.

Each node or choice on this decision tree raises difficult ethical questions not only about what should be done, but also about who should be deciding and for whom. It is these “should” issues that Davis examines using a fresh lens: Will our choice of reproductive technology affect the choices available to a child born using that technology?

As far back as the 1970s, when amniocentesis came into widespread use, it was clear that women’s limited reproductive choices were already over-

whelmingly painful, with no option cost-free. Even then, we knew it was one thing to have some control over the number of children we would have—and for many, even this was an unavailable option—but quite another to have some say in the kind of children we would have. The latter seemed to place a particularly heavy burden on a woman, and make being either a parent or a child possibly and troublingly conditional.

In the decades since then, the burden of decision-making has only gotten heavier, and our social and ethical analyses of these issues have failed woefully to keep pace with the multiplicity and complexity of the choices offered to us by researchers and clinicians. Our daughters and sons have a forest of options and the compass Davis offers as an aid through this thicket provides a refreshing and stimulating, if not always successful, tool.

Borrowing the concept of an “open future” from the philosopher Joel Feinberg, Davis proposes that we evaluate reproductive and genetic options with regard to how they will ensure and protect the fullest autonomy for the child-to-be. In brief, she wants us to assess our choices about the use of these technologies in terms of the choices they will permit our children to make, for exam-

ple, about their own lives, education, employment, and procreation. Will using some technology now in childbearing expand or limit the choices that will be available to the children to be born?

A philosophical analysis of this position is beyond the scope of this brief review. It is perhaps sufficient to say that I found Davis's presentation sometimes persuasive, other times inadequate—if not inappropriate. Davis herself is aware that many may reject the open future lens she prescribes for working through the ethical thickets of genetic and reproductive technology, while others may dismiss the trail she marks out while using it. She graciously invites such objections. In fact, it is almost impossible, when reading this book, not to make frequent marginal notes expressing agreement and disagreement with her positions on issues such as choosing to have a child with a disability, choosing the sex of a child, and choosing to learn what genetic disorders threaten an unborn child. Whatever a reader concludes, all will benefit from Davis's shifting our focus from the decision-maker to the potential child about whom these prenatal, even pre-conceptual, decisions are being made.

Yet, welcome and important as this shift is, it remains problematic, since Davis generally ignores how an open

future resides so much more in societal (i.e., political) than in individual parental decisions. Will our society allow entry to children of all kinds? How will we ensure a full range of choices to all women now and to all children? The structures of society we create collectively, the social and political arrangements we establish, determine whether all citizens in all their diversities have a full menu from which to choose and whether they are enabled to make the fullest range of choices.

Thus, although an “open future,” rather like “unconditional love,” is a powerful construct in thinking about what parents owe their children, it cannot be idealized out of context. It must be examined in terms of what, not just who, opens or closes a future; what societal conditions allow, and not just what limits are set by the choices or behaviors of parents. Unfortunately, Davis does not fully grapple with these questions. Nor does her lens always distinguish what might be a different—non-White/middle class—array of choices.

Using protection of the right to an open future as a lens through which to assess reproductive options made available (to some) by the new technologies does lead to a fresh view of the forest, but this tool alone cannot get us through

the thicket of options. It appropriately expands our attention beyond simplistic arguments about individual autonomy and the “right” to choose, but it does not highlight sufficiently the determinants of the options available and of one’s ability to select among them. And these contextual limitations on what most of us are enabled to do and to choose—what I have elsewhere called our “response-ability”—necessarily restrict the possible futures for most.

As I was finishing *Genetic Dilemmas*, the *New York Times* ran an Associated Press article that announced: “Starting in August, expectant couples can walk into an obstetrician’s office and ask to be tested for any of 24 variations of the gene that causes cystic fibrosis.”¹ If nothing else, this news puts the matter of choice into a reality context. In the future, even more than at present, choices will be determined and futures opened and closed not by women making decisions about the use of genetic and reproductive technologies, but by insurance companies, medical healthcare providers, biotechnology and pharmaceutical companies, and government officials who determine the options put before us and set limits on our abilities to respond. Readers who keep these structural determinants in

mind will have a rich engagement with Davis’s easily read, highly accessible, and provocative (but not polemic) book. Others will at least have their conceptions of autonomy broadened if not challenged.

—Abby Lippman

NOTE

1. Leslie Gornstein, The Associated Press, “Panel: Gene Testing Not Ready for Prime Time,” June 27, 2001.

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Reformulating Professional Ethics

Ethics and Excuses: The Crisis in Professional Responsibility.

Banks McDowell.

Westport, Conn: Quorum Books, 2000.

169 pp. \$59.95 (Hardcover).

Some of us may be reluctant to read a book that asks us to take excuses seriously. This is not easy, accustomed as we are to thinking of excuses as ways to avoid responsibility. We want to promote a greater commitment to high ethical standards, and it seems counter intuitive that taking excuses seriously is a good way to do that.

Nevertheless, taking ethical excuses seriously can sometimes help us better understand the influences at work in the day-to-day lives of professionals. Taking excuses seriously is important, not because most excuses are legitimate ones, but because the study of excuses prepares both ethicists and professionals to address the most important and difficult issues in professional ethics today. McDowell leads the reader to reconsider the ways in which professional ethics are formulated.

We may suspect that someone who relies on people's excuses to reformulate professional ethics may also lower stan-

dards to the level of actual behavior. But that is not McDowell's agenda. He advocates reformulating professional ethics so that its standards and presentation can more effectively shape behavior and guide practice. The divergence between standards and practice is partly the result, he argues, of the failure by those teaching ethical duties to address the realities that professionals often face at work.

Excuses help to identify the nature of the gap between "ethical standards and the needs and the problems of contemporary professional practice." This gap is the crisis referred to in the subtitle. In chapters eight and nine, McDowell identifies some of the considerations that should influence the reformulation of professional ethics. The model or paradigm that has been used in developing professional ethics needs to be changed. The model of a lone professional who works as a generalist in a stable community, has long-term relationships with clients, and functions largely in one-on-one situations is no longer adequate. Most professionals today work in groups, often as specialists in bureaucratic organizations. The model of professionals as autonomous experts is no longer adequate; a better model recognizes that professionals often work

in an organizational setting that stresses efficiency.

Professional ethics, McDowell suggests, must be reformulated with a better understanding of the context in which professionals work today. "It may seem incongruous to talk about the ethical conduct of a law firm, a hospital, a business corporation, or a governmental department, but that may be increasingly our only alternative." Professional ethics must recognize that responsibility has shifted from individuals to institutions and organizations. This does not mean that common business perspectives should determine the standards of professional ethics. Maintaining professionalism often requires, in fact, challenging accepted business and economic models.

McDowell challenges us with questions about the compatibility of common economic ideology with professional ethics. There is a clash of values between the dominant economic theory and professional ethics, but the clash has not been addressed adequately. It must be addressed if presentations of professional ethics are going to meet the needs of professionals. Moreover, social ethics, and a social justice orientation, should play a part in formulating and instilling business ethics.

McDowell's analysis of ethical excuses and his suggestions about the need to reformulate professional ethics are worth careful consideration. His emphasis on the importance of the organizational setting for professional ethics fits well with the growing recognition of the importance of organizational ethics in health care.

—Leonard J. Weber

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Learning from Death

Compassion Sabbath: A Resource Kit. Midwest Bioethics Center and the Compassion Sabbath Task Force. Kansas City, Mo.: Midwest Bioethics Center, 1999. \$75.

The resource kit is a result of a pilot project held in the Kansas City metropolitan area in 1999, which sought to prepare faith leaders, their congregations, and the larger community to better minister to the spiritual needs of their seriously ill and dying members. Using a weekend model and a community approach, the materials prepared interested ministers to participate in the “Compassionate Sabbath” outreach held in February 2000.

Included in the three-ring, vinyl binder kit is a video “More Lessons From the Angel of Death”; a syllabus containing an introduction, an afterword, and five resource sections; the special issue of *Bioethics Forum* 16, no. 1 “Meditations by Wm. G. Bartholome”; and the “Caring Conversations” workbook and study guide.

The video presents William Bartholome giving a public lecture sponsored by the University of Kansas Medical Center’s Department of History and Philosophy of Medicine.

Bartholome, who died in 1999 of metastatic adenocarcinoma of the esophagus, spent the last five years of his life teaching an autopathographic lesson on the values of dying and living while dying. As Bartholome struggles to speak in the video, the talking-head camera angle does little to distract you from a straightforward, lengthy lecture, and it is only the compelling message that keeps one attentive.

Worship resources include materials from Christian, Jewish, Native American, Islamic, and Hindu traditions and are intended for Christian corporate worship and for private devotion. The citations are rich and varied giving ample selections for one to review.

The education/training section includes six sessions on “For Everything There is a Season—Faith Reflections on the End of Life” and five sessions on “Caring Conversations—More Lessons from the Angel of Death.” Session plans include a reflection piece, discussion questions, leadership team preparation materials, and a timeline with content and suggested teaching methods. Resource pages complete each session.

The fifth section of the syllabus lists Kansas-area and national resources on grief, children, family, and end-of-life

issues. Educating the reader about the Last Acts Coalition takes up the sixth section. The coauthors of the Compassion Sabbath Task Force write the afterword in which they restate the desire to provide “new tools and stratagems for religious leaders to inspire, educate, comfort, and console those who rely on them.”

“Caring Conversations: Making your wishes known for end-of-life care” combines the spiritual lessons of Bartholome with workbook questions designed to engage a social ritual that helps persons plan for the end of life. The workbook lists frequently asked questions about advance directives. Workbook users are introduced to questions regarding personal relationships, spiritual/religious values, healthcare decisions, career and work decisions, legal documents, and financial matters. Both “Advance Directives” and “A Durable power of Attorney for Healthcare Decisions” forms are enclosed.

As a resource kit, there are many materials here to choose from when designing a program or event of one’s own. However, there is not a clear instructional design that incorporates the video, the special edition of the *Bioethics Forum*, the “Caring Conversations” Group Study Guide and Workbook, and

the syllabus material. The parts remain separate, and the user must build a unified whole. The developers, however, have set forth a model of a community approach to handling this difficult topic, and this is the greatest contribution of the resource kit.

—Mary Ann Clemens

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Bioethics Past, Present, and Future

The Nature and Prospect of Bioethics: Interdisciplinary Perspectives.

Franklin G. Miller, John C. Fletcher, and James M. Humber, eds.

Totowa, N.J.: Humana Press, 2003.

206 pp. \$44.50 (Hardcover).

Retrospective assessments of bioethics are in vogue. The field is “old” enough (around 35, say most—not all—in this book) to offer the 21st-century surveyor some depth of perspective. This interdisciplinary collection employs retrospect in the service of prospect, and functions as a kind of introduction to the field. The editors’ intended audience includes students and “even” degreed academics and practicing professionals in bioethics’ contributing disciplines who lack an understanding of important aspects of the field.

The editors believe that many in these constituencies need a clearer picture of what bioethics is and what its practitioners do, how an aspiring bioethicist would prepare to “practice” in the field, and—presumably not least—why bioethics is a worthwhile profession. They recruited prominent scholars to trace the relationship between their respective disciplines and bioethics: John

Arras (philosophy), James Childress (religion), Howard Brody (medicine), Eric Meslin (policy), Patricia Benner (nursing), Kathryn Montgomery (literary studies), and Tina Stevens (history).

Editors Miller, Fletcher, and Humber want to achieve four broad goals: examining the roots of bioethics in the several disciplines, showing how bioethics needs these disciplines if it is to “flourish,” demonstrating “the value of bioethics as a profession,” and indicating likely future directions in bioethics scholarship. There is some discrepancy between the needs attributed to the intended audience and the goals enunciated for the book itself. Will the reader, for example, really come away with a clear sense of what bioethicists—perhaps especially clinical bioethicists—do?

John Arras’ opening chapter begins to allay such concerns. It provides a concise sketch of the field’s clinical, policy, and academic emphases and their varying relationships to philosophy. Arras also offers constructive proposals for reframing and reclaiming the usefulness of philosophy for bioethics. While Arras speaks for the discipline that has been most influential in shaping bioethics, Kathryn Montgomery advocates for “genuine interdisciplinarity” as she offers a sustained critique of “med-

ical ethics" in light of literature and literary theory. If some ethicists believe that bioethics is now largely a matter of applying known answers to clinical FAQs, Montgomery counters that the persistent reemergence in clinicians' experience of supposedly answered questions shows that, in fact, "most issues are far from settled."

Eric Meslin's illuminating presentation of the challenges of conducting policy analysis in governmental bioethics commissions provides a useful backdrop for James Childress' consideration of the role of religion and theology in public policy. Childress' chapter comes alive in this discussion, where he presses the argument that "religious perspectives and voices" have a legitimate, indeed important, role in "public reason" and the process of policy making. They can expand our moral imagination, advance moral positions that do not depend solely on underlying religious commitments, and articulate important features of the "background culture" (John Rawls) that will in any case influence public opinion on issues. (Childress adds, with equal conviction, that religious perspectives should *not* control the content of policy decisions or provide their public rationale.)

Appropriately, most of the

"prospects" the authors propose are not claims for a *likely* bioethics future, but sketches of possible or desired futures for bioethics and their discipline's relationship to it. The editors' emphasis on identifying directions for future scholarship is mirrored in the tilt of most of the essays toward the academic world and its concerns rather than, say, the world of clinical practice. On the whole, this rich and wide-ranging collection deserves to be read by its intended audience as well as others interested in what bioethics is, how it got here, and where it may be headed.

One author's assessment of bioethics as a social phenomenon speaks particularly to "the value of bioethics as a profession." Those who wonder, and perhaps worry, whether bioethics has done—or can do—the good it sets out to do may be unsettled, as I was, by this observation from Tina Stevens: "[B]ioethics plays an important role in buttressing biomedical authority by midwifing the ultimate social acceptance of exotic biotechnological development." Stevens adds that the field has played an "ambiguous role" (Charles Rosenberg) because "bioethics legitimizes authority by questioning it . . ."

The paradox of legitimizing while

ostensibly criticizing dogs the field at least in part because bioethicists have ineluctably become allied with, and dependent upon, those who invite their “critical” advice. How to address this paradox, and the social and institutional relationships that shape it, is surely a central challenge for bioethics in this generation.

—*David B. McCurdy*

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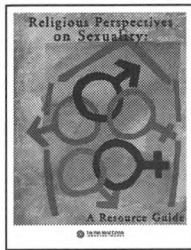
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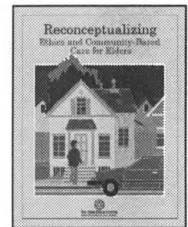
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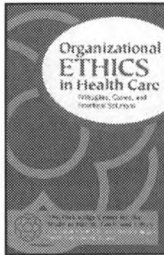
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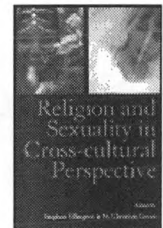
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