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Religious and Spiritual Concerns in Genetic Testing and Decision Making: An Introduction for Pastoral and Genetic Counselors

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Genetic testing, while still considered somewhat of a novelty, is nonetheless firmly established in mainstream medicine. Prenatal genetic testing, newborn screening, disease susceptibility testing, and diagnostic testing are now commonplace, such that at some point many of us can expect to be confronted with decisions involving whether and when we or our children should be tested, and how to respond to test results. Much of what we will want to know will require genetic and medical expertise, which will in most cases be a dominant factor in decision making. Religious values may also play a role in some kinds of decisions, although how and when is less predictable. Clearly, decisions regarding pregnancy termination may be based on religious values, as is evidenced by the abortion debate, and we might assume patients' religious backgrounds may influence their responses to genetic technology. However, a literature search of "religion," "spirituality," and "genetic counseling" reveals remarkably little information as to how religious values contribute to genetic decisions or the attitudes and behaviors of healthcare providers.

Religious values have been shown to be influential in certain kinds of testing decisions,[1] in how people handle the stress raised by genetic information,[2] and in the attitudes of genetics professionals,[3] but such studies are few in number and reveal no consistent patterns. Because genetic testing often raises issues that are, at root, existential, having to do with illness, suffering, loss, and death, we can anticipate that spiritual and religious values will influence how some people respond to genetic information. Spiritual and religious concerns are usually considered the domain of clinical pastoral counselors, who are specifically trained to address these needs in patients, families, and medical staff in hospitals and other healthcare settings. However, at present, pastoral counselors are rarely involved in genetic decisions.

A major study published in 2004 by the Park Ridge Center for Health, Faith, and Ethics explored the current and potential role of pastoral counselors in counseling individuals who face genetic decisions. Among its findings, the study revealed that because most pastoral counselors are unfamiliar with genetics, few genetics professionals refer their patients to them; moreover, genetics professionals rarely ask about their patients' spiritual concerns, as they feel they do not have the expertise to do so.[4]

This article is written for both genetics professionals and pastoral counselors who are interested in addressing the religious and spiritual concerns of those who pursue genetic testing. I begin with a brief discussion of the medical, moral, and existential challenges raised by genetic information, and why religious and spiritual concerns are rarely addressed in the care of genetics patients. After a review of basic genetics and types of genetic tests, the rest of the article focuses on the different ways that questions of religious faith and spirituality may arise in the genetics arena, in particular, the charge of "playing God" and responses to grief and loss. I emphasize the variety of religious and spiritual perspectives people may bring to their circumstances and suggest some resources and counseling skills that may be helpful. I write primarily from a Christian perspective; however, much of this discussion may also be useful for adherents of Judaism and Islam.

CHALLENGES OF GENETIC INFORMATION

Genetic tests can be said to include a number of methods of obtaining hereditary information or information about gene function, including taking a patient's family history and conducting laboratory tests for gene products. This discussion focuses primarily on genetic tests that examine human chromosomes or DNA sequences. These tests include prenatal testing, which examines chromosomal structure of developing fetuses *in utero,* tests for specific genotypes that confirm suspected genetic conditions in children and adults, and tests for known or unknown mutations that may identify people at high risk of developing diseases for which they have no symptoms at the time of testing.

While the medical benefits of genetic testing are well understood, testing is medically and morally controversial for a number of reasons:

- It is new, and calls for decisions most of us have never had to make before, some of which are tragic.
- It gives us information about our heritage, our health risks, and certain characteristics of our children that can create new burdens and/or new responsibilities.
- It raises questions about the sources of our identity, personality, and behavior.
- It offers hitherto inconceivable opportunities for reproductive choice by means of selective pregnancy termination based on genetic information, preimplantation genetic diagnosis for the positive selection of genetic traits, or, possibly in the future, by manipulating the genetic characteristics of our offspring.
- Decisions almost always take place in a context of uncertainty. Questions of whether to test, what to test for, when to test, how to interpret test results, and what to do if results indicate a disability or disease risk, all must be answered with inadequate information.

For all of these reasons, genetic testing is ideally accompanied by genetic counseling, a process in which a family's medical history is thoroughly examined, genetic risks are identified, and patients are given an opportunity to explore their questions and alternatives with an informed and supportive professional. Genetic counselors are trained in both genetics and counseling and serve as part of the healthcare team in which they provide the most current information on genetic risks and testing options. Counseling therefore focuses on genetic and medical information, as well as on psychosocial issues that pertain to pre- and post-test genetic decisions. At present, there are approximately 1,200 clinical geneticists in the United States[5] and less than 2,000 genetic counselors.[6] Given the increasing presence of genetic testing in medicine and a shortage of trained genetics professionals in many parts of the country,[7] it is likely that, in the near future, other professionals such as physicians, nurses, social workers, and pastoral counselors will find themselves counseling individuals and couples faced with genetic decisions.

In contrast to genetic counselors, pastoral counselors are typically trained in theology, psychology, and counseling, with little or no formal exposure to medicine or genetics. Their role is to address the existential, religious, and spiritual concerns that often accompany serious illness, dying, and caregiving. Given their experience in helping patients, families, and medical personnel cope with trauma and adversity, it is reasonable to expect that pastoral counselors could be an important resource for people facing genetic decisions.

The Park Ridge Center study is the first major research effort to examine the current and potential role of pastoral counselors in genetic counseling and testing decisions. Questions explored by the study include the following: (1) whether and how pastoral counselors might help people cope with the spiritual, religious, and ethical questions raised by genetic technologies; (2) what knowledge and skills they would need to acquire, and (3) what professional or institutional boundaries might promote or impede this involvement. The study involved 140 clinical geneticists, genetic counselors, pastoral counselors, and social workers representing 37 states, two Canadian provinces, and a broad range of denominations and minority religions. Participants were divided into 17 focus groups that met via computer-assisted telephone (CAT) interviews, which were audiotaped, transcribed, and analyzed.[8] Findings included the following:

- Genetic counselors were uncertain of the identity and qualifications of pastoral counselors.
- Genetic counselors were reluctant to refer patients to pastoral counselors, because they assumed that pastoral counselors did not understand genetics, and, if misinformed, might encourage inappropriate decisions.
- Genetic counselors feared that pastoral counselors might be too directive, dogmatic, or simplistic regarding the range of possible ethical norms and religious responses.
- Few genetics counselors said they routinely inquired about patients' religious or spiritual values; most said that they felt such questions were intrusive or inappropriate for them, as scientists, to raise.[9]
- Genetic counselors acknowledged that pastoral support for patients coping with grief and loss could be of significant value and that they had much to learn from pastoral counselors about the kinds of language and approaches they could use to explore the religious concerns of those counselled.

Overall, the findings suggest that genetics professionals and pastoral counselors recognize the need for discussion of religious and spiritual issues but are uncertain about each others' knowledge and expertise. This, combined with turf issues and other institutional barriers, interferes with the optimal involvement of pastoral counselors in the care of genetics patients. The study included a number of recommendations that emphasized pastoral counselors' need for education in genetics, genetics professionals' need for training in pastoral counseling, and ultimately greater dialogue and teamwork between them. The present discussion aims to fill in some of the knowledge gaps for both genetics and pastoral counselors, beginning with a review of basic genetics and types of testing.

GENETIC TESTING: OPPORTUNITIES FOR CHOICE AND CONTROL

Most of what we call genetic testing today has to do with the structure and composition of DNA, or deoxyribonucleic acid, which comprises our human genome. DNA consists of long sequences of nucleotide bases that, when coiled tightly during cell division, are visible as chromosomes. Each of our cells contains 23 pairs of chromosomes, one member of each pair inherited from each parent. Specific segments of DNA are responsible for the synthesis of proteins and other regulatory functions within each cell. Errors in both chromosomal structure and nucleotide sequences, by interfering with cell function, can lead to disability and disease. We can look for these kinds of errors using a variety of genetic testing techniques.

The most common form of genetic testing is amniocentesis, which is a prenatal test that examines fetal cells for chromosomal abnormalities. Amniocentesis is usually recommended for couples who are considered to be at high risk of having a child with a genetic disorder, a determination that is based on the mother's age and medical history, and the couple's family history. The test is performed 12 to 16 weeks into a pregnancy and involves sampling fetal cells from the amniotic fluid surrounding the fetus *in utero.* The cells are then cultured for a few weeks and examined for extra, missing, or translocated chromosomes or pieces of chromosomes. The most common defect involves an extra twenty-first chromosome, a condition known as Down Syndrome. As with all chromosomal defects, the risk increases with maternal age, from roughly one in 1,250 at age 25, to one in 400 at age 35, and one in 30 at age 45.[10] If any chromosomal abnormality is found, the parents may either choose to continue the pregnancy and prepare for a child with special needs, or

to terminate the pregnancy. The ethical and psychological issues involved in pregnancy termination at this stage are profound, as the pregnancy will be nearing the end of the first trimester by the time the test results are known. A similar procedure, chorionic villus sampling (CVS), can be performed at about nine weeks, permitting an earlier first-trimester termination if a problem is found. This test takes cells from the chorionic villi — tiny projections on the fetal membrane that eventually becomes the placenta — that are examined for chromosomal defects. Because CVS is thought to carry an increased risk of malformations and spontaneous abortion, amniocentesis is the more common of the two tests.

For prospective parents, the first question is whether or not to accept testing. Because a slight risk of spontaneous abortion accompanies either test, the risk of a birth defect must be weighed against the risks imposed by the test. This can be a hard decision, especially since those for whom the test is recommended often have had difficulty conceiving. Since the risks of a chromosomal abnormality are higher than average for these parents, they may strongly desire reassurance that their child is developing normally. For most prospective parents, prenatal testing offers this reassurance. But those parents for whom the test indicates an abnormality are faced with the decision of whether to continue or terminate the pregnancy. Much of the difficulty of these decisions is that they are usually based on limited or ambiguous information. First, depending on the abnormality, the test may indicate little about the severity of the condition. Some chromosomal abnormalities are relatively benign, others are incompatible with life, and many have a wide range of expression. For the latter disorders, the severity of the disorder cannot be anticipated from the genetic diagnosis alone. If the particular configuration is rare or its effects unknown, the meaning of the finding may be impossible to determine. Diagnosis of a genetic disorder also raises questions about the child's medical needs and prospects: the social, emotional, and financial resources required to raise the child, and the implications for existing children of having a sibling with a disability. Prospective parents may also wonder how others might respond to a decision to continue or terminate the pregnancy. Lastly, it is important to realize that a normal amniocentesis only means that the chromosomes are structurally intact; it does not rule out the possibility of genetic disorders caused by single gene mutations. For all of these reasons, while this test can offer limited reassurance, it by no means eliminates uncertainty.

Other kinds of genetic tests look for mutations — abnormal patterns — in the nucleotide sequences that make up the functional "code" of the human genome. Some of these tests look for specific genes or gene sequences in specific regions of a chromosome; others require analysis of the sequence of the nucleotide bases that make up particular chromosomes to search for particular mutations. To date, while the entire human genome has been roughly sequenced, we do not know the purpose of most of the genes, how genes work together, and how genetic, environmental, and behavioral factors can conspire to cause disease. Consequently, single-gene testing is still relatively limited in scope. Nonetheless, these tests may be used to confirm a suspected diagnosis in children or adults, to diagnose late-onset disease susceptibility, or, rarely, to diagnose disease-bearing mutations in embryos created through *in vitro* fertilization prior to implantation. But although single-gene diseases are relatively simple to diagnose, many of them have a wide range of expression, and the severity of symptoms over time cannot be known in advance. Consequently, decisions based on these diagnoses are also accompanied by a great deal of uncertainty.

The majority of diseases are multifactorial, caused by a combination of genetic, environmental, and behavioral factors. Genetic tests for susceptibility to these diseases are also limited; those that exist vary in predictive value, depending on what is known about the mutation in question — its frequency in the population and variation in expression — as well as the quality of the test. Moreover, because the diseases are also influenced by behavioral and environmental factors, it is sometimes difficult to know what the presence of a mutation signifies. While it is a source of concern, a positive diagnosis may only indicate an increased risk for disease over a lifetime. While risk assessments can be quite high, it is important to remember that they always reflect some number of people with the mutation who will never develop disease. From a psychosocial standpoint, however, testing also carries unknown risks of employment or insurance discrimination as well as potential social or psychological burdens that can compound uncertainty for the decision maker.

For most of us faced with genetic decisions, the sheer novelty of the choices reveal the limitations of our habitual patterns of moral reasoning, especially when there is no clear medically indicated choice. The fact that our genes are tied up with our identity as well as our past and future families challenges our cultural emphasis on individualism and independence, perhaps creating unwanted responsibilities. None of us is comfortable with uncertainty — we know that decisions made without adequate information can be disproportionately influenced by subjective factors, such as optimism, hope, and fear. For all these reasons, many turn to their faith for guidance and comfort when faced with these decisions.

VARIETIES OF RELIGIOUS AND SPIRITUAL EXPERIENCE

In any discussion of spirituality and religion, it is important to avoid assumptions about what constitutes religious belief, spirituality, or what it means to be a person of faith. Generally speaking, "religious beliefs" refer to beliefs that are formally articulated by a recognized religious tradition or faith community. By contrast, "spirituality" represents a personal view of one's relationship with other people, the natural world, and a larger framework of meaning or purpose that may or may not be understood theistically. But while many people identify themselves as denominationally religious — perhaps as a Presbyterian, Seventh Day Adventist, or Roman Catholic — their individual beliefs may have little to do with the doctrines espoused by the traditions with which they identify themselves. For some, religious identity may indeed be a considered reflection of denominational beliefs; for others, it may reflect the faith in which they were raised, the tradition of the community they primarily inhabit, their interest in a particular religious community or religious leader, or the most accessible house of worship in their neighborhood. Moreover, despite statistics that suggest the U.S. population is deeply religious,[11] American culture is still largely secular.[12] While many of our social values have religious origins, few, if any, are articulated in overtly religious terms, and, for most of us, religious language rarely appears outside of church-related activities. As a result, when faced with situations that provoke religious reflection — often those that involve suffering, loss, and death — many may have difficulty articulating their religious concerns. They may be confused if they find their faith at odds with what they know to be fact, or feel that religious language or categories are not meaningful in their present circumstances. Some may find religious language limiting or oppressive. For these reasons, careproviders must be acutely sensitive to patients' religious and spiritual perspectives, aware that religious identification does not indicate a person's beliefs or preferences, and that questions involving religion and spirituality may not always be framed in clear or obvious language.

That said, across the field of healthcare, the religious beliefs and spiritual orientations of patients and their healthcare providers can powerfully impact both how people respond to their illnesses and what kinds of care are provided. Patients may find their religious beliefs offer hope and strength, or compound their suffering. Physicians may find their motivation for service in their religious beliefs or spiritual values, or may feel their beliefs constrain or inhibit their ability to provide some forms of care. Because individual beliefs take many forms, are generally grounded in faith rather than reason, and may shift with time and circumstances, negotiating their influence in healthcare can be challenging.

PLAYING GOD

Questions of faith and spirituality generally arise in two ways in the genetics arena. The first has to do with the ethical concern that in our use of genetic technologies we are somehow "playing God"; the second encompasses the pastoral issues that accompany genetic testing and decision making, which include grief, suffering, and loss. The charge of playing God is often used to suggest that humans, through our genetic technologies, are exceeding the bounds of what we ought to be doing. Because adverse reactions to new technologies are common and often diminish over time, some may dismiss this charge as stemming from anxiety and fear of change. However, in the context of reproduction, the new choices open to us do suggest powers of design and control that we formerly ascribed to God. As in the abortion debate, some people feel

human life is a gift from God; that at every conception God has endowed a new soul with a divine mission, and human interference in who survives to birth is a violation of God's intentions. Similarly, some critics of prenatal testing view selective pregnancy termination as suggesting a kind of "quality control" of the characteristics of children — or a medically sanctioned form of discrimination against people with disabilities or undesired traits.[13] From perhaps a more secular standpoint in Western cultures, some parents may feel that part of the wonder of parenting is the continuing discovery of who their child is becoming, and that unconditional acceptance of one's child is essential if the child is to successfully develop as a unique individual.

Part of the concern underlying charges of playing God is that, as medical technology advances, much of what was once attributed to God, such as control over life and death, has been challenged by medical technology. We can now manipulate and sustain life to a considerable degree; as a result, we sometimes find ourselves confused about where our human capabilities and responsibilities end. At its root, the issue of how much one should control human life, disease, death, and the genome is a moral question about how we perceive ourselves in the world and in relation to God. Here the Christian tradition offers a variety of perspectives. In one view, humans are perceived as God's creation, part of the natural world, and thus subject to the same natural laws as other living things. In another, we stand apart from nature, perhaps as "co-creators" with God or made "in the image of God," and by virtue of our reflective capacities and intelligence, empowered to manipulate nature. These two images often come into play in decisions at the beginning and end of life and are likely to surface in genetic decisions, depending on the decision maker's personal attitudes, values, goals, and beliefs.

Some people may try to discern what counts as playing God in terms of a "natural" versus "unnatural" distinction. But this is also a difficult dichotomy to draw in the medical arena. Many medical treatments are described as unnatural, but most function by harnessing existing biological systems. Vaccines work by stimulating the body's immune system to develop resistance to infectious disease. Assisted reproduction technologies may seem extremely unnatural, but largely consist of manipulating intact biological systems. In fact, there are no medical interventions that are not in some way grounded in natural mechanisms and biological processes. Like the charge of "playing God," the primary purpose of the natural-unnatural distinction seems to be to categorize those technologies of which we approve and disapprove; as a moral guideline, it is otherwise not very illuminating.

Most frequently, charges of playing God refer to events some believe *should* be left to God, to chance, or to nature, even if the means for intervention exist. These are usually life events that are to some extent mysterious and beyond our control — typically those involving life and death. In these contexts, claims that God's powers are infinite serve to remind us of our fallibility and limitations. For example, we hesitate to make beginning or end-of-life decisions for others, knowing our decisions are irreversible and profound and that to be done properly require wisdom beyond our grasp. Similarly, we may recoil at the thought of "designing" children, knowing our attempts at creation are poor imitations of the evolutionary process or the wisdom of God's design. In these contexts, charges of playing God may be useful, reminding us that we are prone to error, bias, arrogance, and ignorance, and that those who would overreach our human limitations are playing with high stakes, with consequences for other lives.

Equally compelling is the belief that God is beneficent, our protector and loyal companion. It is this view that assures us that God is always with us, supporting us, guiding us, and providing us with adequate strength for whatever life delivers. And if God is beneficent, we might assume God also hopes we will do our utmost to help ourselves, to reduce suffering, and to act humanely. Thus it is possible to argue that the effort to control disease by manipulating the human genome is a highly moral activity, and to the extent that our technological capabilities are construed as God-given, we can and should use them to serve God's purposes. Along these lines, advocates of genetic testing may argue testing is morally legitimate if it is done out of a loving impulse, such as trying to maximize a child's opportunities in a highly competitive world. Some may feel testing is socially responsible if it enables parents to avoid burdening the world with the suffering and expense of a disabled child. Noticeably, framing our capabilities as God-given fails to set any moral guidelines on how much manipulation of human life is acceptable, suggesting that if something can be done that will benefit others, there is no reason why it shouldn't be done.

PASTORAL CONCERNS

Once the decision is made to go forward with genetic testing, there is always a risk that testing will bring unfavorable results. In the prenatal arena, when faced with a choice between continuing or terminating a pregnancy, most parents want to find out all they can about what the disorder would mean for their future child and their family. They may want to meet children with the same diagnosis and speak with their parents. They may need financial advice and psychological support. Possible resources include advocacy organizations for the the genetic disorder, support groups, and genetics specialists. Pastoral counselors who wish to address genetic concerns need to know what and where these resources are in their communities. Prospective parents may wish to evaluate their emotional, social, and spiritual resources, and whether they feel they have the strength, support, and faith to raise the child. They may reconsider their feelings about abortion and worry about how their family, friends, and religious communities may react. They will undoubtedly worry about what the future might bring for the child, knowing that life is, at some level, always a struggle, but that it may be harder for those who are different or disabled.

Genetic and pastoral counselors can be a tremendous help to parents grappling with these questions. Specifically, they can help parents identify their psychological, social, and spiritual resources, seek to dispel any misperceptions about the cause or effects of a genetic abnormality, and minimize destructive thought patterns such as guilt or blame. But counselors also need to know their limitations. If pastoral counselors do not understand the mechanics of genetics or the significance of a diagnosis, they need to enlist the help of people who do. If a genetic counselor feels ill-equipped to assess or address spiritual concerns, she or he should be prepared to refer to a trusted pastoral counselor.

How a counselor offers his or her counsel is a central question. Since its inception, the genetic counseling profession has been committed to being nondirective, meaning that counselors provide information and support but not advice, unless there are clear medical reasons to recommend a certain choice. In this way, counselors hope to avoid coercion and maximize the chances that decisions made will be ones their clients can live with.[14] A significant point of disagreement noted in the Park Ridge study was whether counseling should be directive or nondirective. Genetic counselors repeatedly voiced concern that pastoral counselors might be rigidly dogmatic and impose their religious values on their clients. Conversely, some pastoral counselors felt that the people in their faith communities want and expect directive guidance.[15] While some counselors agreed that some patients are comforted when their decisions are approved by their religious authorities, respect for autonomy is likely to remain the foundational ethical principle in genetic counseling. That said, some flexibility for patients that clearly wish directive guidance may be advisable.

The overriding message from participants in the Park Ridge study is that counselors — whether genetic or pastoral by training — must be sensitive to the needs of those counselled, and remain flexible in their responses, which precludes easy retreat to dogmatic answers. For people of faith, one of the most intractable questions is why an omnipotent and loving God would permit suffering and death, especially of children and premature or newborn infants. Traditional responses are often unsatisfying or oppressive, including notions of sin, blame, and destiny, or the mystery of God's wisdom or design. Rather than, or in addition to, appeals to traditional theological explanations, counselors may wish to explore how patients interpret their loss, taking special care to dispel destructive interpretations such as those that would impose burdens of guilt. It may be helpful to ask patients how (or if) faith in God can provide hope in times of crisis and loss, or to ask what they feel their faith requires of them in terms of a response. It may also be worthwhile to discuss notions of natural error. Approximately one in every 28 children born has some kind of birth defect due to a variety of genetic defects, developmental errors, and environmental factors.[16] Moreover, there is a long path between conception and a living, healthy baby, such that more than half of conceptions, perhaps up to 80 percent, do not result in the birth of a child.[17] This is nature's way of correcting mistakes. That mistakes are a natural occurrence is something many people, when stricken with grief and remorse, may fail to appreciate.

Similar questions arise in genetic testing of children and adults, which is usually done to confirm a suspected diagnosis or to identify people at high risk of hereditary disease. Testing in these circumstances is

usually a considered decision, made with the understanding that an underlying risk exists. While reassurance that one does not carry a suspected mutation is often sought, most patients are aware that test results may carry bad news. As in much of medicine, after receiving unexpected and disappointing news, patients' first reactions may include shock, grief, guilt, and confusion. Many will attempt to answer the universal questions: "Why me?" "Why now?" "What did I do wrong?" They may turn to their faith to ask, "Why is God doing this to me?" "What should I do now?" "What does God want me to do?" It is not uncommon for people to blame themselves when facing bad news, to assume the diagnosis is a consequence or punishment for some act of stupidity or moral flaw. Or they may blame God, angry that a supposedly powerful God has let this misfortune occur. Or they may simply be morally and theologically confused, wondering if and how their faith can help them. Each person will find a different answer for these questions, drawing on her or his understanding of science and medicine, notions of fate, destiny, or chance, and the person's perception of her or his relationship with God.

Again, God may be construed in a variety of ways. Some may see God as the Ultimate Judge, one who hands out blessings or punishments depending on a person's life choices. Those who perceive God as such may blame themselves for their misfortune, feeling that their diagnosis is a response to some prior fault or action. Or God may be seen as omnipotent and omniscient. Those who feel this way may accept their misfortune, but have trouble understanding why an all-powerful God permits suffering to happen. Or God may represent something like an ideal parent, whose boundless love, support, and wisdom can be counted on through all adversity. Seen this way, some people may accept their suffering with confidence that there is a purpose for it, and that, with God's help, they will get through it. There are many variations on these perspectives, but it is likely that, if pressed, most people will have a difficult time articulating their beliefs about God and why a God that is claimed to be omnipotent, merciful, and beneficent would permit humans to suffer. The counselor's task is to help patients explore their questions and beliefs as constructively as possible. This may entail finding images of God that provide strength, hope, and forgiveness as necessary, clarifying medical or biological mechanisms, and providing rational explanations when appropriate. Doing this well requires counselors to take time with patients to search for their primary concerns and a religious or spiritual perspective that best meets their needs.

The Park Ridge study participants made a number of recommendations for pastoral counselors. In addition to substantial training in genetics, these included counseling skills such as being a "good listener," being compassionate and patient with the patient's decision-making process, knowing individuals and families well, and supporting them as they make difficult decisions and deal with loss. They also encouraged counselors to "meet people where they are," to ask them what meaning they find in their situation, and to be "open and teachable." Valued skills of pastoral counselors include the ability to conduct religious assessments and rituals, helping people draw on their religious beliefs to make sense of their circumstances, interpreting and affirming patients' decisions in view of their religious background, and helping them cope with tragedy and loss. Correspondingly, genetic counselors were encouraged to learn about different religious belief systems, how to conduct a spiritual assessment, and how to use language and religious frameworks effectively to explore patients' spiritual needs.[18] Beyond that, integration of pastoral care into genetics services requires that genetic counselors become acquainted with qualified pastoral counselors and be willing to make appropriate referrals. In short, both groups recognized that each could benefit from better understanding of the skills and expertise of the other. But, while the study recommendations clearly called for flexibility and responsiveness to individual needs, there was lingering disagreement over if and when counseling may be appropriately directive. Both genetic and pastoral counselors may wish to be cautious about directive counseling, but remain open to the possibility that some people expect and appreciate guidance and affirmation.

CONCLUSION

Religious and spiritual frameworks have long provided comfort and strength for people in adversity. The questions they address — "Why do we live? Why do we suffer? Why do we die?" — are universal, existen-

tial, and cannot be satisfactorily answered by science and reason. This article introduces some of the ways that religious questions may arise in the genetics arena, but there are many variants on these themes and many other faith-related questions that have been neglected. The range of religions represented in the U.S. and the diversity of interpretations within each one makes it extremely difficult to generalize how counselors might address questions of faith and spirituality. But being acquainted with the kinds of questions that commonly arise, and prepared with the knowledge, language, and tools necessary to explore these questions, will better enable both pastoral and genetic counselors to offer comfort and support for their patients as they grapple with some of the most challenging circumstances in their lives.

NOTES

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1. M.D. Schwartz et al., "Spiritual Faith and Genetic Testing Decisions among High-Risk Breast Cancer Probands," *Cancer Epidemiology, Biomarkers and Prevention* 9, no. 4 (April 2000): 381-5.

2. L.A Keenan et al., "Family Environments of Women Seeking BRCA1/BRCA2 Genetic Mutations Testing: An Exploratory Analysis," *Journal of Genetic Counseling* 13, no. 2 (April 2004): 157-76.

3. F.A. Poppelaars et al., "Attitudes of Potential Providers toward Preconceptual Cystic Fibrosis Carrier Screening," *Journal of Genetic Counseling* 12, no. 6 (February 2004): 31-44; M.A. Albar, "Ethical Considerations in the Preventions and Management of Genetic Disorders with Special Emphasis on Religious Considerations," *Saudi Medical Journal* 23, no. 6 (June 2002): 627-32.

4. P.J. Boyle, "Genetics and Pastoral Counseling: A Special Report," *Second Opinion* 11 (April 2004): 4-58.

5. According to the American Board of Medical Genetics, as of 2002 there were 1,226 boarded (MD or PhD) clinical geneticists, *http://genetics. faseb.org/genetics/abmg/abmgmenu.htm*.

6. See note 4 above.

7. National Society of Genetic Counselors, *Education, Certification and Regional Representation Statistics: Membership Data Base* (Wallingford, Pa.: National Society of Genetic Counselors, 1998); see note 4 above.

8. See note 4 above.

9. Ibid.

10. March of Dimes, *www.marchofdimes. com,* accessed 1 June 2005.

11. Of 1,000 adults, 90 percent claimed to believe in God, 55 percent said religion is "very important" in their lives, and 29 percent said it was "fairly important" to them. Gallup Poll, May 2004, *www.pollingreport.com/religion.htm*.

12. Of 1,000 adults, only 28 percent reported attending a church or synagogue "at least once a week," and 31 percent reported that they "seldom" attended. Ibid.

13. B.K. Rothman, *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood* (New York: Viking, 1986); G. McGee, *The Perfect Baby: A Pragmatic Approach* (Lanham, Md.: Rowman and Littlefield, 1997); T. Duster, *Backdoor to Eugenics* (New York: Routledge, 2003).

14. L.J. Ciarleglio et al., "Genetic Counseling throughout the Life Cycle," *Journal of Clinical Investigation* 112, no. 9 (November 2003): 1280-6.

15. See note 4 above.

16. See note 10 above.

17. John Opitz, MD, Professor of Pediatrics, Human Genetics, and Obstetrics/Gynecology, School of Medicine, University of Utah, testifying before the President's Council on Bioethics, 16 January 2003 on the rate of natural embryo loss, stated: "Estimates range all the way from 60 percent to 80 percent of the very earliest stages, cleavage stages, for example, that are lost." *http://bioethics.gov/transcripts/jan03/session1.html;* see also E.R. Norwitz, D.J. Schust, and S.J. Fisher, "Implantation and the Survival of Early Pregnancy," *New England Journal of Medicine* 345, no. 19 (2001): 1400-9.

18. See note 4 above.