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Making Sense of Genetic Uncertainty: The Role of Religion and Spirituality

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Abstract

This paper argues that to the extent that religious and spiritual beliefs can help people cope with genetic uncertainty, a limited spiritual assessment may be appropriate in genetic counseling. The paper opens by establishing why genetic information is inherently uncertain and why this uncertainty can be medically, morally, and spiritually problematic. This is followed by a review of the range of factors that can contribute to risk assessments, including a few heuristics commonly used in responses to uncertainty. The next two sections summarize recent research on the diverse roles of religious and spiritual beliefs in genetic decisions and challenges to conducting spiritual assessments in genetic counseling. Based on these findings, religious and spiritual beliefs are posited as serving essentially as a heuristic that some people will utilize in responding to their genetic risks. In the interests of helping such clients, a limited spiritual assessment is recommended and described. Some of the challenges and risks associated with this limited assessment are discussed. Since some religious and spiritual beliefs can conflict with the values of medicine, some decisions will remain problematic.

Keywords

risk perception; genetic counseling; spiritual assessment

Introduction

This exploration of the intersection of religion, spirituality, and human genomics will examine why and how genetic counselors might want to include some discussion of their clients' religious and spiritual values in counseling sessions. For people for whom religious and spiritual values are important, genetic testing may raise complex moral quandaries. Patients may struggle to reconcile their religious and spiritual values with the ambiguity of genetic risks and the sometimes tragic choices they face. Genetics professionals may experience conflicts between their own religious values and the priorities of their clients and patients. Some counselors may wonder how to respond when clients' religious beliefs lead them to make decisions that are not in their best medical interests. In these and countless other ways, religion and spirituality may intersect with genetic testing and counseling. However opinions will differ as to how these concerns may best be addressed, depending on how the authority of religious and spiritual beliefs is understood, and the proper role of genetic counselors is perceived.

This discussion focuses on genetic risk assessment and decision-making, exploring in turn: 1) why genetic information is medically, morally, and spiritually problematic; 2) a range of

factors that may contribute to the interpretation of genetic risks; 3) how religious and spiritual beliefs may contribute to genetic decision-making, and 4) challenges to incorporating religious and spiritual beliefs in genetic counseling. The final section offers an argument for a succinct, reasoned, and bounded line of inquiry to be used in genetic counseling to assist clients in recognizing how their spiritual and religious values may contribute to their responses to genetic risks.

Conceptual Challenges of Genetic Information: The Problem of Uncertainty

A person usually seeks genetic testing because he or she is concerned about a risk, perhaps a suspected or potential birth defect, a late-onset disorder, or an occupational hazard. Genetic counseling is a common first step, and may be provided by a physician, a licensed genetic counselor, or other qualified professionals. The counselor begins by exploring relevant family history, medical history, behavioral, occupational, and sometimes environmental factors to establish the nature and degree of the risk. She then describes the testing options available and explains the kinds of choices that may need to be made, depending on the test results. Test results are usually given in terms of numerical probabilities or risks for the disease or disorder in question.

Importantly, in order to avoid suggestions of coercion, manipulation, or eugenic values, genetic counseling has a long-standing commitment to nondirective counseling [Andrews et al., 1994]. This commitment requires that counselors typically provide genetic information but refrain from giving advice. When testing offers medical benefits such as prevention or treatment opportunities, more directive counseling is sometimes called for, but clients are always encouraged to make decisions that are consistent with their own values and goals. The significance of clients' knowledge, experience, values, and intuition in decision-making is thus well established, but religion and spirituality may or may not be included in counseling discussions. To date, there are no guidelines governing when and how to conduct a spiritual assessment in genetic counseling, or how to make use of information obtained in the course of such an assessment.

Religious and spiritual values may arise in genetic counseling for a number of reasons:

- Genetic testing provides information about a person's heritage, health, and reproductive risks that can create new burdens and/or new responsibilities, some of which may be frightening and about which little can be done.
- Testing often calls for decisions most people have never had to make before, some of which are tragic.
- Decisions must often be based on probabilistic, not definitive, information.

Genetic testing thus raises existential questions about a person's biological identity that may have profound implications for the person's sense of security, confidence in his or her physical health and reproductive capacities, and may link the person directly with his or her mortality. As with serious illness, genetic diagnoses may sometimes lead to spiritual questioning. Genetic testing is particularly challenging due to its probabilistic and prophetic dimensions. Genetic probabilities always suggest some people will and some will not develop disease, suggesting their destinies are subject to the random luck of a lottery. Nor do genetic diagnoses generally specify the severity of symptoms the client can anticipate. Genetic testing thus offers opportunities for information, but that information is rarely determinative.

The uncertainty of genetic risk assessments has many dimensions: biological, psychological, social, economic, and moral, regardless of the type of testing. Consider amniocentesis, a

prenatal test that examines fetal cells for chromosomal abnormalities. Most of the time, negative results provide prospective parents with reassurance. But if an abnormality is identified, the parents must decide whether to continue or terminate the pregnancy. This decision is especially difficult when the meaning of a diagnosis is ambiguous. Many genetic abnormalities have a wide range of expression and some are so uncommon that their significance may be unknown. In addition, prenatal diagnosis of an abnormality almost always raises questions about what a child with a disability might mean for prospective parents and other children, what the child's medical needs and prospects might be, whether the family will be able to provide adequate support for the child, and how others might respond to a decision to continue or terminate the pregnancy. Uncertainty, in other words, is multifactorial, and there are few resources available to provide reassurance.

Genetic testing for single gene disorders raises a similar range of questions. While some single-gene abnormalities indicate a clear prognosis for disease, most genetic diseases are caused by a combination of genetic, environmental and behavioral factors. Tests for these diseases vary in their predictive value depending on what is known about the mutations in question—their frequency in the population, the likelihood that those who carry the gene(s) will experience symptoms, and the range in variation of expression and severity of those symptoms. Moreover, with ongoing research, our knowledge of genetic risks is constantly changing. Genetic testing also carries social risks of employment or insurance discrimination, concerns for the health of family members, and possible social or psychological burdens, all of which may contribute to uncertainty for the decision-maker.

Factors Contributing to the Interpretation of Genetic Risks

No one likes uncertainty. In some less technologically-developed parts of the world, uncertainty is so ubiquitous that to some degree it may be accepted as inevitable or unavoidable. But in the West, much of social, medical, technological, and institutional innovation is designed to minimize disease risks and other hazards beyond human control. With Western confidence in personal agency, reason, and biomedical research, coupled with the tendency to focus on the future, the importance of controlling risk is for some akin to a moral imperative. Insurance for virtually all contingencies is now normative for the affluent. Where quantities of public and private funding are dedicated to overcoming illness, injury, accidents, suffering, and aging, genetic testing is marketed and perceived as an opportunity to responsibly manage risk. Indeed, when testing rules out certain risks, a limited kind of confidence is attained. But risk assessments, by virtue of their ambiguity, are highly stressful. Of interest here is how people respond to genetic risks and probabilities—how they interpret these numerical figures in the effort to reduce stress or to guide a decision.

It is well known that genetic probabilities and risks are difficult to grasp and interpret rationally [Shiloh and Saxe, 1989; Wertz and Fletcher, 1987]. This is illustrated in an early study of decision-making in which, regardless of risk magnitude or personal circumstances, genetic counseling clients were commonly found to construe their numeric risks simply as either “high” or “low,” or as something that would or would not happen, ignoring the nuanced implication that a probability implies [Lippman-Hand and Fraser, 1979]. Why probabilistic thinking is so difficult is not entirely clear—it has been suggested that perhaps as human beings evolved, given the need for immediate action, survival depended on coping with problems chiefly by trial and error. This led to reliance on habit and simple rules rather than learning to manage uncertainty [Slovic et al., 1976]. Alternatively, since several different parts of the human brain are known to be associated with numerical cognition, it is possible that these different parts of the brain do not work together in an integrated fashion. And because human memory is associative, a certain amount of energy must go into keeping

various kinds of knowledge from interfering with each other, which also could make mental processing of probabilities difficult [Dehaene, 1997].

In general, people experience risk as the possibility of a loss. The significance of a risk depends on how the person at risk perceives the magnitude of the potential loss and the likelihood that the loss will occur. But individuals differ over what they consider a loss, the significance of that loss, and its likelihood. A risk therefore has little or no objective value; it becomes meaningful only when it is interpreted [Kaplan and Garrick, 1981]. Genetic risks are particularly abstract. In much of medicine, when a risk is conveyed, there is medical data of some kind to support it: symptoms, lab results, imaging—something tangible. But genetic risks may not be accompanied by any concrete evidence of a problem. They are generally presented simply as a single number, understood narrowly as “the probability of occurrence of a negative genetic outcome” [Shiloh, 1996].

In order to bring meaning to this abstraction, people draw on a host of factors. A recent systematic review summarizes findings from 59 studies that explore different ways genetic risks are constructed and interpreted. These studies confirmed that probabilities and risks are difficult to grasp, retain, and interpret, that clients have poor understanding and recall of objective risk estimates regardless of the format in which they were presented, and that most people tend to over-estimate their risks. Factors contributing to risk perception included environmental factors, diet, stress and worry, physical resemblance to an affected relative, genetic and family history factors, social concerns, and individuals' personal and emotional experiences with illness in themselves and others [Sivell et al., 2008].

Risk assessments may also be strongly influenced by how a risk is “framed,” or presented relative to other risks. For this reason, counselors usually make an effort to present risks and probabilities in a number of ways: numerically, visually, as a percent, part of a pattern, or in comparison with other risks [Shiloh and Sagi, 1989]. Certain kinds of discussions may also contribute to how risks are understood. For example, discussions involving the impact of an affected child on other children, or whether the client would have a child, have been found to be associated with pessimistic interpretations of risk [Wertz et al., 1986]. And risks are always understood relative to other goals and uncertainties; for this reason, some people may dismiss a long-term genetic risk when other stresses are more pressing [Cox and McKellin, 1999].

Personality may also make a difference--a person's general sense of optimism, confidence in “luck,” belief that “it won't happen to me,” or distaste for preventive measures may diminish his or her perception of risks. Conversely, anxious individuals may overestimate their risks or underestimate their ability to cope with what they consider a “bad” outcome [Slovic et al., 1980]. Some people may use their emotions as a source of information, creating best and worst case scenarios to explore how they would feel in either event--joyful, despondent, regretful, guilty--and use these emotional responses to guide their decisions [Lippman-Hand and Fraser, 1979]. Of all of our emotions, fear may be the most powerful contributor to judgment. The rational component of fear may be characterized as prudence--as reasonable precaution in the face of the unknown. The irrational dimensions of fear may be experienced variously: as an “anticipatory emotion”--a visceral response that may overwhelm reason altogether; as “risk of the unknown”--the extent to which a hazard is considered novel, invisible, or delayed in producing harmful effects, or as “dread,” which refers to perceived lack of control and catastrophic potential [Loewenstein, et al., 2001]. Because genetic decisions are unfamiliar to most people, sometimes have invisible or delayed effects, and may have catastrophic consequences over which individuals have little or no control, these kinds of fear responses may be common. And fear may also be overblown or underestimated, depending on a person's experience and personality.

How people think about an illness—its identity, cause, duration, consequences, and controllability - also invokes subjective factors. These “illness representations” evolve over time and are known to be highly influenced by personal experience with disease, sociocultural messages, education, the media, and social modeling. Rightly or wrongly, one's sense of vulnerability is known to be influenced by the number of one's relatives that are affected, perceived patterns of disease relative to gender and age, and perceived similarity to affected relatives. “Objective” information is thus modified according to each individual's subjective interpretation, which is tied to patterns in wider belief systems [Shiloh, 2006].

That people routinely violate principles of reason when interpreting probabilities is well known. In the genetics arena, this is particularly evident in certain non-rational cognitive strategies people commonly use to make sense of genetic risks. These strategies, referred to as biases and heuristics, are mental short cuts that we use to impose meaning on uncertain or unintelligible information. Heuristics have been strongly associated with risk perception and probabilistic thinking in a variety of disciplines, and function by drawing on an individual's prior experience, knowledge, and personality in predictable ways [Tversky and Kahneman, 1974; Slovic et al., 1980]. Four heuristics that have been found operative in genetic decisions have been described as “representativeness,” “availability,” “anchoring,” and “illusion of control” [Wertz et al., 1986; Kenen et al., 2003]. Representativeness refers to the tendency to rely heavily on limited or anecdotal experience, neglecting the full range of possibility across a population. For example, upon receiving a diagnosis of some kind of cancer, a person may recall one acquaintance with the disease, assume he will have a similar experience, and base his decision accordingly. Availability has to do with the tendency to judge the likelihood of an event by the vividness with which an impression of the event comes to mind. This is why a person exposed to disease in a family member is likely to have a heightened perception of her own risks [Rees et al., 2001]. Anchoring refers to a person's baseline knowledge about a risk. Prior knowledge or assumptions may be difficult to shake, especially if they are long-standing, and even when they are mistaken [Wertz et al., 1986; Kenen et al., 2003]. Anchoring may be the reason that people who have grown up knowing they are at risk for a serious disease, such as Huntington disease, may have difficulty adjusting if they eventually test negative for the disease. Finally, some for whom fear is high may adopt a heuristic known as “illusion of control” by which they believe that through behaviors such a diet or prayer they can moderate the risk. They may adhere to these beliefs even when data indicate no such correlation [Kenen et al., 2003].

In these and other ways, even though we are usually unaware of them, cognitive heuristics draw on our experience, knowledge, and emotional make-up to guide our judgments, relieving us of the work of prolonged research. Due to the limited and subjective information on which they are based, heuristics can sometimes be seriously misleading. Nonetheless, most people are known to be confident of their ability to make the right decision in the absence of full information, a bias known as “overconfidence” [Slovic et al., 1980].

The interpretation of risks and probabilities is thus highly subjective, subject to a broad range of contextual, cognitive, emotional, and social factors. What is not yet clear is whether and how religious and spiritual beliefs may also have a contributing role.

Religion, Spirituality, and Genetic Risk Perception

To date, there has been relatively little research that examines the impact of religious and spiritual values on genetic risk perception and decision-making, and the few studies that have been conducted do not yield consistent findings. As a group, these studies primarily

illustrate that individuals and groups vary considerably in their religious and spiritual responses to genetic risks. But because many of them lack specific definition of which characteristics of religion or spirituality are being examined, it is difficult to draw conclusions from them.

In the studies conducted to date, high risks generally outweigh religious factors in decision-making, but when risks are low, religious and spiritual values may play a greater role. For example, one study involving 290 largely Caucasian women identified as having at least a 20% risk of a *BRCA1/2* mutation, examined the relationship between perceived risk for breast cancer, spiritual faith, and decisions to test. Spirituality was assessed with a single question: "How strong would you say your religious or spiritual faith is?" Eighty-two percent of the women were offered and received testing and results for *BRCA1/2*, the other 18% declined testing and/or results. Those with high perceived risk were twice as likely to pursue testing regardless of their reported levels of spirituality. Women who self-reported low perceived risk and as highly spiritual were 80% less likely to receive testing/results than less spiritual women [Schwartz et al., 2000].

A similar pattern was found in a study of attitudes toward prenatal testing for sickle-cell anemia and thalassaemia major among men and women from four diverse, at-risk populations: Pakistani Muslims, Indian Hindus, Indian Sikhs, and African-Caribbean Christians. Inclusion criteria required that participants identify themselves as members of one of the four populations, but beyond that, depth of religious commitment was not assessed. Focus group discussions revealed that religious and spiritual values were considered important, but the perceived severity of the condition was more significant than religious values in decisions to terminate the pregnancy [Ahmed et al., 2006].

These two studies suggest that when risks are high, many or most people may place higher value on medical knowledge, even when faith is strong. When risks are low, religion may play a greater role. A study of decisions for or against MSAFP screening involved interviews of 158 European-American and Latina women between the ages of 20-35, two-thirds of whom were Catholic and one-third Protestant. The interview included a detailed religiosity scale that explored each woman's religious background, religious practices, religious beliefs, and reproductive morality as taught by her church. Although 20% of the women declined screening, neither religious identity nor ethnicity correlated significantly with test decisions—both Catholics and Protestants, among European-Americans and Latinas, were equally likely to refuse the test. However, the European-American Catholics who scored higher on the religiosity scale, particularly on their religious background (including parochial school attendance, catechism, Lenten observance) were more likely to refuse MSAFP screening. Similarly, both Catholic and Protestant European-Americans who scored highly on observance of church teachings (when human life begins, abortion, birth control) on reproductive morality were more likely to refuse testing [Press and Browner, 1998]. But what is signified by the religiosity scale is not clear. One possibility is that high scorers simply perceive God as the locus of control. Alternatively, respondents could be strongly adherent to doctrinal prohibitions on abortion, but that could mean they were conforming to a cultural expectation, saw the test as a prohibited option, were fearful of divine retribution, were confident that God would provide for them, or something else. Absent more specific reasons for refusal, it is hard to know what to make of this study, especially since no similar correlation between religiosity and test refusal was found with the Latina women.

Other studies of religious and spiritual values in decision-making include a study of 95 kindred African-American men and women identified at risk for a *BRCA1* mutation in which the strongest predictors for testing were found to be: 1) perceived risk of greater than 50%;

2) having at least one first-degree relative with breast and/or ovarian cancer, and 3) not knowing one's risk. Among these variables was a six-item measure of the extent to which God was believed to be a "locus of control." This measure of religiosity was not found to be significantly associated with decisions to test [Kinney et al., 2001].

A survey of 899 women with no personal history of breast cancer found that those with a positive history of breast cancer in their families who reported frequently using spirituality to cope with stress, had lower perceptions of their risks [Quillan et al., 2006]. Faith may thus provide a mediating influence for some people.

Lastly, a series of focus groups recently held at Vanderbilt University provide anecdotal evidence of some of the ways that specific beliefs may influence responses to risk. In these focus groups, clergy and genetic counselors were invited to discuss how religious and spiritual concerns may arise in the context of genetic screening or testing. In transcripts from these discussions, clergy reported their parishioners speaking of life as "a gift from God," that "God has his purposes," of praying that "they would do God's will," that tragedy may be a blessing, that God is "in charge" and the source of meaning, that God is love, and that genetic disease may be a consequence of inadequate faith or past sin. Genetic counselors reported clients who prayed that "God will provide a miracle," or stated that "God won't give me more than I can bear." Both clergy and counselors identified difficult questions: How should they counsel clients when God doesn't provide a miracle? How should they respond when clients suggest they are being punished by God through their genetic disease? If "God is in charge," when it is permissible to intervene [Clayton, personal communication]?

Challenges to Conducting Spiritual Assessments in Genetic Counseling

Although these studies are limited, they suggest that at least for some people, religious and spiritual beliefs contribute to risk perceptions and genetic decisions. Yet exploration of these beliefs is typically not considered a standard element of genetic counseling. In the only study to date of genetic counselors' spiritual assessment practices, most respondents self-reported as mild or moderately spiritual (82%), but only 60% of counselors had conducted at least one spiritual assessment in the past year, and less than 10% did so in more than half of their sessions. Low levels of comfort with conducting a spiritual assessment were reported by 37% of respondents, and a low perceived relevance by 20%. Primary barriers to conducting spiritual assessments included lack of time and thinking such questions would make the client uncomfortable. Other obstacles included counselors' self-perceived lack of training in conducting a spiritual assessment, uncertainty over what to do with the information, ambivalence regarding the value of the information, concern that counselors' spiritual or religious values might conflict with those of their clients, and discomfort discussing spirituality. Neither years of practice, self-perceived spirituality, nor religious affiliation were significantly correlated with counselors' spiritual assessment practices [Reis et al., 2007].

Counselors' responses in this study legitimately point to the time pressures in all of modern medicine. Lacking clear reasons for doing so, some counselors may feel that opening up discussion to religious and spiritual issues may move the session in a host of directions that could take time to address, especially if discussions lead to issues counselors aren't sure how to deal with. If a client brings it up, at least the counselor has an idea of what his or her concerns are, if they are manageable, and if the client ought to be referred for pastoral care. But if counselors suspect that faith claims may lead to refusals of care or decisions that are at odds either with the client's medical interests or the counselor's own religious values, they may wish to avoid them.

An equally legitimate obstacle for genetic counselors may be lack of clarity over what aspects of their clients' religious and spiritual beliefs they should inquire about and why. This lack of clarity is evident in the hundreds of studies conducted to date that claim correlations between health and religion, religiosity, and degrees of spirituality [Koenig, 2004], most of which do not specify what they are measuring or acknowledge the diversity of forms in which religious faith may be perceived [Berry, 2005; Flannelly et al., 2004]. For example, faith may be understood as membership in social institution, loyalty to a set of doctrinal beliefs, adherence to specific religious texts or rituals, regular engagement in individual spiritual practices, belief in personal spiritual frameworks, religious/spiritual experiences approached through aesthetic sensibilities or other sensory perceptions, as spiritual states reached through meditation, fasting, silence, isolation, or other practices. Faith also provides different things for different people at different times—whether answers to the universal questions of why we live, suffer, and die; ethical orientation, coping strategies and social support; or serving as a source of hope, inner peace, and infinite love.

Some genetic counselors reported feeling that spiritual assessments may be uncomfortable for their clients or themselves [Reis et al., 2007]. There are many reasons counselors may feel this way, some of which may be related to the blurring of the boundaries between church and state in recent years which is now reaching into professional contexts. Some health professionals today seem to feel it is their right and responsibility to explore their patients' spiritual beliefs and to integrate their own religious values into the medical care they provide [Luckhaupt et al., 2005]. Others may feel that any mention of religion with patients is politically exploitive and professionally inappropriate. For some counselors, simply admitting their spiritual orientation in the workplace may be professionally hazardous [Geller et al., in press]. Thus depending on the local climate, the political sensitivity of religious discussions may discourage counselors from exploring religious or spiritual issues with their clients.

Faith as a Heuristic; Toward a Limited Spiritual Assessment

Despite the difficulty of discussing religion and spirituality in the genetic counseling context, when health risks are unfamiliar, uncertain, and uncontrollable, many people will look beyond medical expertise for explanations, meaning, and perhaps a way out. What is not yet clear is how genetic counselors can constructively identify and make appropriate use of their clients' religious and spiritual concerns as they help them deal with their genetic risks.

As stated at the outset, the most challenging aspect of genetic testing is the probabilistic nature of genetic information. The uncertainty of risk assessments causes stress and demands interpretation before any action can be taken. We have seen that risk interpretation defies rationality, drawing on numerous factors in addition to numerical probabilities, including family history, environmental factors, emotion, personality, and heuristics in highly subjective ways. The studies cited previously suggest that in the process of risk interpretation, some people find religious and spiritual beliefs also serve to lend meaning to abstraction, whether in the form of assurance, confidence, or optimism that “God will provide”; doctrinal prohibitions on certain choices, or judgments that certain choices suggest “playing God.” Some may find that by placing their faith in a God that is “in charge,” that they can avoid having to make a decision. Others may find it easier or possible to accept their circumstances by interpreting them in spiritual terms: God's ways are inscrutable but (his) mercy is just, disease is the consequence of a spiritual shortcoming or past misdeed, suffering has a purpose, whether to inspire hope, faith, penitence, or redemption. In these and other ways, for some people, religious and spiritual beliefs can provide explanation, coping mechanisms, and in some cases clear guidance.

Because religious and spiritual influences are so personal, so diverse, and in genetic decision-making seem to serve chiefly to bring meaning to uncertainty, they may be understood essentially as a heuristic strategy, as one more interpretive framework that may help some people move forward in the face of overwhelming or unintelligible circumstances. This “framing” of the role of religion and spirituality in the genetics arena dramatically narrows the focus of the necessary spiritual assessment. Genetic counselors need only be concerned with whether their counselees have religious and spiritual beliefs that may influence their ability to interpret and respond to their risks and circumstances, and whether these influences are authentic, reasonable, and beneficial. This limited focus may only require one or two additional questions to be added to the usual counseling discussion, questions that would invite clients to explore whether they have any religious or spiritual beliefs that help them cope with their genetic risks or that support or constrain any decisions they are considering. For those for whom these questions are not meaningful, little time is lost; for those for whom the questions are significant, the added time in discussion will be well spent.

This approach does not intend to suggest that religion can be equated with a heuristic. Nor does it make any claims about the nature or reality of God. It does, however, take for granted that religious and spiritual *ideas about* God evolved as they have to serve important purposes: among them, to provide meaning and guidance in challenging times. And if we find our answers in doctrinal beliefs, a supportive community, prayer, confidence that God will provide, acceptance of fate, or by claiming God as the locus of control—all of these and related approaches make use of particular cognitive constructs. And as do other heuristics, these cognitive constructs help to bring order to chaos, resolve uncertainty, reduce stress, and thereby enable us to move forward. This approach does assume that people will benefit by becoming more aware of how religious and spiritual beliefs may influence their responses and decisions.

This limited spiritual assessment also carries some challenges and risks. It is possible that many clients will not be able to respond to these questions. They may have difficulty articulating their beliefs or connecting their beliefs with their genetic risks and decisions, or they may not understand why the questions are being asked. Some may feel the questions are inappropriate, some may fear the counselor has an agenda, and some may wonder if there is a “right answer” that they are missing. Some will likely welcome the chance to talk about their faith, and some may assume their counselor knows more than she does about their particular beliefs and loyalties. Whatever the response, counselors will need to pursue this line of inquiry carefully and slowly, with an ear that is sensitive to subtle suggestions of existential concerns as well as clear expressions of faith. They may need to be deliberate in keeping the focus clearly on how their client's faith impacts the situation at hand. And as always, counselors will need to be aware that by virtue of their professional authority, they risk leading discussions and imposing their own perceptions and prejudices. But they can take confidence from knowing that their role is simply to help their patients find the decisions that are right for them by offering the opportunity to explore all relevant contributing factors. If conversations stall, it may help to explain that how people interpret risks is highly subjective, that faith may play a role in that interpretation—perhaps large, perhaps small—along with a host of other factors, and that the best decisions are usually those that are made in awareness of these factors.

The counselor's role in spiritual assessment is thus bounded—she is only to focus on whether and how religious and spiritual values play a part in her clients' risk interpretation and decision-making. She need not concern herself with her clients' religious identity, daily spiritual rituals, personal relationship with God, or the host of other factors sometimes included in spiritual assessments [Hill and Hood, 1999]. The counselor should be alert,

however, to other ways religious or spiritual values may arise in the counseling setting. Positive genetic diagnoses of disorders may raise a host of feelings involving grief, loss, the struggle to cope with chronic illness, social stigma, fear of the future onset of symptoms, health care and insurance worries, relationship consequences, and more, any of which could involve or impact faith. These kinds of concerns may suggest a need for long-term psychological counseling. Theological challenges may also surface: patients may feel abandoned by God, judged by God; they may bargain with God, or pray for miracles. For these kinds of responses, pastoral counseling may be more appropriate.

More difficult are cases in which counselors find their clients have religious beliefs or are involved in communities of faith that seem limiting, perhaps even damaging to the client's self-esteem, autonomy, or mental or physical health. When illness is seen as a test or a form of punishment, when failure to heal is considered evidence of insufficient faith, when suffering is embraced as a way of deepening religious commitment—these kinds of beliefs may seem to magnify rather than relieve the burdens of illness. Other beliefs—such as faith that God will provide a miracle, that prayer will heal, or that suffering is redemptive—may inhibit the client from considering certain medical alternatives. When such beliefs emerge, counselors need to be alert to the possibility that religious beliefs can serve as necessary defenses, and carefully consider the costs of questioning them as well as the benefits. Again, when in doubt, psychological or pastoral counseling may be helpful. Given the time constraints of most genetic counseling relationships, long-term interventions ought rarely to be the responsibility of the genetic counselor. Counselors should know enough to be able to recognize when they are necessary, but should also know when and to whom to refer.

Conclusion

This approach takes as its starting point the cognitive challenges posed by genetic uncertainty, acknowledging that people can rarely make sense of their numerical risks without resorting to some sort of interpretive framework. In the context of genetic counseling, religious and spiritual values are regarded essentially as heuristics that may assist some clients in coping with their genetic risks. Spiritual assessment should be limited to how religious and spiritual values influence interpretations of genetic risks and decisions based on those risks. But this approach is not without challenges. Even a brief spiritual assessment may raise unusual professional dilemmas, particularly if clients' beliefs lead them to make potentially harmful decisions or decisions that are seriously at odds with counselors' values. In some cases there may be legal precedents that govern counselors' responses; in others, counselors may simply need to adhere to their commitment to nondirectiveness. Such situations will cause a certain amount of moral distress and raise old questions: What are the limits of nondirectiveness? How should counselors respond if a client's decision seems either irrational or likely to cause harm? Can a decision be responsible if it is based on non-rational factors, such as religious beliefs?

The answers to these questions will be slow in coming and will require a determined effort to broaden understanding of both human biology and the diverse functions of religion and spirituality for the human psyche. Neither human health nor human behavior can be fully understood in terms of the reductionist medical models being pursued today. Nor can religious traditions expect to constructively contribute to moral dilemmas in medicine if they fail to acknowledge the findings of the biological sciences in their core teachings. The path forward requires that clergy and seminarians sincerely commit to scientific literacy, and that scientists and medical personnel equally seek to understand the kinds of meaning and value that are imparted through religious and spiritual faith. This exploration will require a certain kind of courage and openness to revising long-held assumptions. While old patterns of

thinking are hard to change, failure to make this effort will inhibit our ability to address the pressing medical and moral problems of our time.

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Biography

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