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Introduction: Religious and Spiritual Issues in Medical Genetics

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Abstract

This article provides an overview of a special issue on the religious and spiritual concerns that arise in the provision of genetic services. It introduces some of the challenges in defining religion and spirituality and provides contexts and summaries for the empirical and normative research that appears in the issue.

Keywords

genetics; genomics; religion; spirituality; ethics; eugenics; enhancement; conscientious objection

In April 2008, Vanderbilt University hosted a conference titled, “Religion and Genomics: Navigating Pathways and Perspectives of Patient Care,” where an interdisciplinary group of speakers and participants addressed three important questions: 1) What religious and spiritual concerns arise in the provision and reception of genetic services? 2) How are we to understand these concerns?; and 3) How should care providers respond when these issues arise? This issue of the *American Journal of Medical Genetics* brings together a selection of the conference proceedings that offers findings and commentaries from clinicians, social scientists, historians, philosophers, and theologians. The goal for presenting this research is to promote greater understanding of the ways religious and spiritual concerns affect the responses of patients and clinicians to genetic information.

The articles in this issue explore the hypothesis that in the U.S., religious and spiritual resources play a significant role in the process of interpreting and responding to genetic information. The most religious of all the industrialized nations, over 80% of the U.S. population self-identifies as being a member of a religion [Baylor, 2005; Kosmin et al., 2001]. In one national survey 61% of respondents reported praying about their own health in their most recent prayers [Baylor, 2005]. Research in medicine has consistently documented that patients use spiritual and religious resources to understand and cope with morbidity and mortality [Koenig et al., 2001]. Directing our inquiry to medical genetics both acknowledges a common experience in medicine and asks whether genetic conditions elicit distinctive religious and spiritual concerns.

With genetic assessments, patients and clinicians can learn about a present condition, an individual’s family history, or prospects for the future. This information can be challenging. Armstrong et al have suggested that genetic descriptions can function as “revealed identities” that uncover hidden truths and can disrupt previous accounts of persons, families and communities [Armstrong et al., 1998]. The patient is not who she thought she was; she

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will not live the life she thought she would lead; she faces decisions she never anticipated. Having or being at risk for genetic disease may prompt patients to revise or draw upon deeply held beliefs about self, family, and other sources of existence. Many of these beliefs and the rituals that accompany them stand squarely in the provinces of religion and spirituality.

If genetic assessments raise these kinds of issues for patients, then discussion with other stakeholders such as clinicians, clergy, and religious communities is needed to understand whether they have witnessed the religious and spiritual concerns of patients, whether they have their own concerns, and how they work through these issues with patients. For the most part, this terrain is unmapped.

This special issue brings together 12 articles organized into three areas. The first manuscript considers the challenges around defining religion and spirituality and recommends one strategy for research in this area. The next five manuscripts report findings from empirical studies that together explore the perspectives of patients, the lay public, clinicians, religious advisors, and religious communities. The last six papers address explicitly normative questions concerning appropriate professional practices and broader theological and societal issues such as enhancement and eugenics.

DEFINING RELIGION AND SPIRITUALITY

Religion and spirituality are difficult to characterize and measure. The existence of over 100 psychometric tools for measuring religion and spirituality suggests that these are complex phenomena that resist well-defined and easily integrated definitions [Hall et al., 2008; Hill and Hood, 1999]. Religion or religiosity has been studied by a wide range of disciplines from neuropsychology to theology, and each method brings distinctive questions. Although most researchers would agree that religion refers to a distinctive set of human behaviors and attitudes, they have not agreed on the criteria for recognizing what makes religion different from other phenomena. The dominant strategy has been to define religion as the set of attitudes and behaviors that correspond more or less to the beliefs and practices of historical religions, e.g. belief in God and worship attendance [Fetzer/NIA, 1999]. Instruments that use this approach often include items about non-organized religious behavior such as prayer and meditation, but these activities often have some precedent in historical religions. An established alternative is to define religion or religiousness as the set of attitudes and beliefs that fulfill specific functions or roles in a person’s life such as providing frameworks of meaning and resources for coping [Pargament et al., 2000].

Research on spirituality also displays a plurality of definitions. For some researchers, spirituality refers to a general phenomenon of which religion is an instance [Anandarajah and Hight, 2001]. Definitions along these lines look similar to functionalist accounts of religion where attitudes and behaviors attempt to fulfill some need for transcendence or coherence in life. Other researchers identify spirituality as a special form or derivative of historical religions [Koenig, 2008] Many studies measure both phenomena without precise articulations of their relationship and as such acknowledge the various ways these terms might be understood by subjects within the U.S. context.

Larry Churchill’s essay introduces examples of the diverse ways that genetic testing might elicit religious or spiritual concerns and recommends a strategy for defining religion and spirituality that is attuned to this context of research. He reviews the ways scholars have thought about these terms over the last 100 years and proposes that functionalist accounts of religion and spirituality are the most fitting for capturing the variety of attitudes and behaviors exhibited in the medical context. Churchill’s manuscript provides a backdrop for thinking about the different ways the empirical studies in this issue make religion and spirituality operational.

MAPPING PERSPECTIVES

Patients and the professionals to whom they turn for advice – clinicians and clergy –bring to the conversation their individual experiences which themselves are shaped by complex social influences. The very topic of genetics has achieved an iconic status for many in our culture, [Nelkin and Lindee, 2004] often evoking particular notions of innateness, inevitabilities, and responsibilities to self and others. The notions are interpreted and experienced through the lenses of self-concept, experience, and other obligations. For many Americans, one of their most salient interpretative frames is that of religion, a perspective that heretofore has received remarkably little attention in scholarly work on the implications of what some call the “genomics revolution.” The articles that follow explore the ways patients and those who care for them experience religious and spiritual concerns when dealing with genetics in the hope that greater awareness of the complex perspectives that individuals bring to bear will promote more effective communication.

Patients and the Public

Little is known about the relation between patients’ religious and spiritual commitments and their responses to the results or prospects of genetic assessment. For example, in 1996, Clayton et al. found that among the reasons patients declined free carrier testing was the concern that such tests interfere with God’s will [Clayton et al., 1996]. In 2000, Schwartz et al. reported that women with higher levels of spiritual faith and who perceived themselves to be at low risk for breast cancer were less likely than women with lower levels of faith to undergo genetic testing for susceptibility to breast cancer [Schwartz et al., 2000]. The studies reported in this issue shed new light on the ways patients and care providers experience the complex relationships of genetics and religion. Anita Kinney and her collaborators explored whether individuals who are more religious or spiritual (R/S) are better able to cope with the risk of having a mutation in *BRCA1*. They interviewed a cohort of African Americans in Louisiana. They found high levels of R/S and depressive symptoms among the respondents, but contrary to their hypothesis and to some other studies, there was no significant correlation between the two. They also found that Collaborative and Deferring religious coping styles were more common among this group than was a Self-Directing style, but that none emerged as superior in decreasing distress. These authors recommended that future work in this area explore the function of R/S in greater depth over time and with greater attention to the sociocultural context in which patients live.

Tina Harris and her collaborators interviewed 50 low-income African-American and European-American individuals from urban and rural Georgia about their opinions about genetics and religion. What emerged is a rich landscape of perspectives, in which respondents at times espoused views that on their face appeared contradictory. Some felt that genetic predispositions represented the will of God, which often meant a level of inevitability that exceeds scientifically understood notions of penetrance. Some believed that one could avoid ill-health, even in the face of one’s genetic makeup, through religious activities or life-style choices. Some spoke of the obligation as a person of faith to take these health-promoting steps. Thus, as was observed in the study of Kinney et al., people of faith vary dramatically in the response to genetic information, with some feeling doomed while other feel empowered and even obligated through a sense of stewardship to engage in specific health promoting behavior to avoid future risks.

Health Care Providers

Society has recognized for years that clinicians bring their own religious commitments to the clinical encounter. This is evidenced clearly in the federal statute enacted in 1973 that allows health care providers to refuse to participate in abortion.[42 USC § 300a-7] But despite the potential religious implications of genetics, almost no attention has been paid to the ways these concerns arise for clinicians.

Gail Geller and her collaborators surveyed more than 200 genetics professionals regarding their religiosity, using religious practices as a method of coping with distress, and the presence or absence of conflicts between religious beliefs and professional roles. These investigators found that many of these clinicians (nurses > genetics counselors > physicians) self-identified as religious and that religiosity correlated with turning to religious beliefs for coping. Significantly, a significant minority of the respondents stated that they experienced conflict between their religious beliefs and their professional roles, causing them at times to feel ostracized or to be unable to counsel patients. Other clinicians reported difficulty working with patients with strong religious beliefs, while some expressed concern that patients were reluctant to express their own beliefs. The distress experienced by clinicians and the barriers to conversation apparently perceived by patients are both matters requiring urgent attention.

Virginia Bartlett and Rolanda Johnson discuss the results of 13 focus groups conducted with physicians, nurses, genetic counselors, ministers, and chaplains. In the analysis reported here, these respondents varied in two critical ways. One was the relative importance for the respondent of genetics and religion, with some placing greater emphasis on genetics and science while others put greater weight on religion and faith. They also varied in whether they thought genetics and science were complementary or in tension. This variable correlated with their comfort in providing care. Those who thought that genetics and religion could be reconciled felt that they had the resources they needed to care for patients or parishioners, citing colleagues or internet sites. By contrast, respondents who felt that genetics and religion were in conflict were quick to cite the need for more resources to help them explore this unfamiliar terrain. As was reported by Geller et al. [2009], believers among the latter group commonly felt ostracized by their peers.

Religious Communities

Rebecca Rae Anderson’s paper reports results from a survey of 31 religious groups or denominations who responded to a set of questions about reproductive genetic testing. Her analysis reveals a rich array of doctrinal views about what it means to be a person of faith confronted with genetic information. Some of the responses addressed the moral significance of the fetus. Others addressed the licitiness of the prenatal diagnosis, abortion, and the prospect of genetic intervention. Many responses were concerned about the meaning of suffering both for the child and for the family. She also reported views about the care of the critically ill newborn. Recognizing that patients’ views may not always be concordant with their denominational affiliation, Professor Anderson concludes that clinicians should be prepared to elicit patients’ *particular* religious concerns and to seek assistance from religious advisors if needed to meet patients’ needs.

PERSPECTIVES ON PROFESSIONAL, THEOLOGICAL AND SOCIAL ETHICS

In the first half of the twentieth century, governments and medical institutions used genetic knowledge to carry out programs of discrimination that instituted egregious acts such as forced sterilizations and genocide. Many of these initiatives aimed at eugenic goals of improving the genetic makeup of human populations. More recent deployments of genetic knowledge have disavowed eugenic goals and coercive tactics and instead have endorsed initiatives that aim to reduce morbidity and suffering and seek to recognize the autonomy of patients. Although these corrective measures have ameliorated many problems of the past, they have also shifted the burden of decision making to patients and clinicians whose religious and spiritual commitments are sometimes implicated. As genetic research continues to move into mainstream medicine, more patients, clinicians, and clergy will need to make sense of genetic differences and uncertainties that affect the lives of individuals, families, and communities. As the greater promise of genomics, the development of new therapies, comes to fruition, it will inevitably raise new questions about whether these interventions constitute ‘playing God.’

This section begins with two manuscripts that address ethical and professional challenges that arise for genetic service providers who must respond to their patients’ or their own religious and spiritual concerns. The next three papers provide a sample of ethical concerns articulated from diverse standpoints within the Christian tradition. The exclusive attention given to Christianity reflects an interest in understanding the complexities of one tradition among many. This editorial decision does not deny the equally important benefits that would have come from selecting perspectives from several religions. The final paper in this section challenges a social concern about modern genetic screening and the possibility that these practices promote eugenics by other means.

Some clinicians conscientiously object to medical options such as selective abortion that are often informed by genetic testing. They refuse not only to provide the specific procedure but also to inform and refer the patient to willing providers. These refusals are more often than not motivated by religious commitments [Curlin et al., 2007]. Joel Frader and Charles Bosk challenge the justifications for these conscientious objections and recommend a renewed commitment to professional responsibility. By setting out the historical and social context in which the status of physician is conferred, Frader and Bosk show the imbalance of power in the physician-patient relationship and highlight the fiduciary responsibilities involved in caring for patients. If this professional ethic is properly acknowledged, then conscientious objection, according to Frader and Bosk, should be rare and mitigated by full disclosure of the physician’s position.

Mary White’s manuscript addresses the issues surrounding the uncertainty of certain types of genetic information. She explicates the kinds of moral and spiritual problems uncertainty can elicit and identifies complexities that often accompany the interpretation of risk assessments. This analysis leads to the question of how genetic counselors should understand and respond to the religious and spiritual concerns of patients who face uncertainty. After reviewing research on the relation of spirituality and genetic decision making, White concludes that limited spiritual assessment should be undertaken with patients.

David Smith’s article signals a shift to explicitly theological ways of thinking about religion and genomics. Proposing that Christianity should support genetic research and treatment, he articulates a Christian conception of health that accepts objective measures of functioning bodies and at the same time rejects health as the final measure of a good life. Christians should take care of their own bodies but they should show greater concern for the health of others. He cautions against the theological habit of linking inheritance of disease with sin and redirects concerns about sin to unjust power structures and the inability to properly support those with genetic differences.

The paper by Andrew Lustig examines the distinction between therapy and enhancement as it relates to broader religious concerns about biotechnology. His analysis of Christian discussions of enhancement traces the variation in Protestant and Roman Catholic conceptions of nature, human nature and responsibility. These conceptions often play important if implicit roles in arguments about enhancement but as Lustig points out, these terms often lack the precision to inform specific judgments about the appropriateness of particular interventions. He proposes that more attention needs to be given to the ways enhancement might transform social practices such as medicine and cultural attitudes such as human dignity.

Timothy Jackson raises concerns about reductive forms of evolutionary theory and their potential to distort genomic research and misdirect the efforts of health care providers. Evolutionary accounts that designate the gene as the primary unit of natural selection reduce all other phenomena to means of reproductive success. If taken to its logical conclusion, this view promotes the health of genes rather than patients. Jackson endorses nonreductive forms of evolutionary theory that acknowledge a hierarchy of selective units such species, organisms, and genes. This view acknowledges the importance of attending to the health of groups, individuals, and their genes. Jackson argues that the interests of individuals as patients require safeguards for evolutionary and theological reasons.

In the final essay, Ruth Schwartz Cowan claims that contemporary critics have leveraged the history of eugenics to magnify negative possibilities of modern genetic screening, which they call the new eugenics. Such critiques, according to Cowan, ignore the history of modern genetic screening in their assessments. She recounts the history of genetic screening for beta-thalassemia on the island of Cyprus as an example to persuade them that the term ‘eugenics’ is no longer appropriate even if some of their concerns are.

CONCLUDING THOUGHTS

Religion and spirituality are important for many people – both patients and those who care for them – who confront genetics. These constructs frame the way people understand genetic information and represent commitments that shape their responses. The articles in this edition do much to define the complexity of these responses by patients, clinicians, and religious advisors and traditions as well to develop analytic approaches to understanding these reactions. Much more work, of course, remains to be done, but we contend that the importance of mapping this terrain is clear.

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References

Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. Am Fam Physician. 2001; 63:81–89. [PubMed: 11195773]

Armstrong D, Michie S, Marteau T. Revealed identity: a study of the process of genetic counselling. Soc Sci Med. 1998; 47:1653–1658. [PubMed: 9877335]

Baylor, U. The Baylor Religion Survey. Waco, TX: Baylor Institute for Studies of Religion; 2005.

Clayton EW, Hannig VL, Pfotenhauer JP, Parker RA, Campbell PW 3rd, Phillips JA 3rd. Lack of interest by nonpregnant couples in population-based cystic fibrosis carrier screening. Am J Hum Genet. 1996; 58:617–627. [PubMed: 8644721]

Curlin FA, Lawrence RE, Chin MH, Lantos JD. Religion, conscience, and controversial clinical practices. N Engl J Med. 2007; 356:593–600. [PubMed: 17287479]

Fetzer/NIA WG. Multidimensional measurement of religiousness/spirituality. Kalamazoo, MI: John E., Fetzer Institute; 1999.

Geller G, Micco E, Silver RJ, Kolodner K, Bernhardt BA. The Role and Impact of Personal Faith and Religion Among Genetic Service Providers. Amer J Med Genet Part C Semin Med Genet. 2009; 151C:31–40. [PubMed: 19170100]

Hall DE, Koenig HG, Meador KG. Measuring Religiousness in Health Research: Review and Critique. Journal of Religion and Health. 2008; 47:134–163. [PubMed: 19105008]

Hill, PC.; Hood, RW. Measures of religiosity. Vol. viii. Birmingham, Ala: Religious Education Press; 1999. p. 531

Koenig HG. Concerns about measuring “spirituality” in research. J Nerv Ment Dis. 2008; 196:349–355. [PubMed: 18477877]

Koenig, HG.; McCullough, ME.; Larson, DB. Handbook of religion and health. Vol. xii. Oxford ; New York: Oxford University Press; 2001. p. 712

Kosmin, BA.; Mayer, E.; Keysar, A. American Religious Identification Survey. The Graduate Center of the City University; New York: 2001. p. 46

Nelkin, D.; Lindee, MS. The DNA mystique : the gene as a cultural icon. Ann Arbor: University of Michigan Press; 2004.

Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: development and initial validation of the RCOPE. J Clin Psychol. 2000; 56:519–543. [PubMed: 10775045]

Schwartz MD, Hughes C, Roth J, Main D, Peshkin BN, Isaacs C, Kavanagh C, Lerman C. Spiritual faith and genetic testing decisions among high-risk breast cancer probands. Cancer Epidemiol Biomarkers Prev. 2000; 9:381–385. [PubMed: 10794482]