ARTICLE

Religion, Spirituality, and Genetics: Mapping the Terrain for Research Purposes

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Genetic diseases often raise issues of profound importance for human self-understanding, such as one's identity, the family or community to which one belongs, and one's future or destiny. These deeper questions have commonly been seen as the purview of religion and spirituality. This essay explores how religion and spirituality are understood in the current US context and defined in the scholarly literature over the past 100 years. It is argued that a pragmatic, functional approach to religion and spirituality is important to understanding how patients respond to genetic diagnoses and participate in genetic therapies. A pragmatic, functional approach requires broadening the inquiry to include anything that provides a framework of transcendent meaning for the fundamental existential questions of human life. This approach also entails suspending questions about the truth claims of any particular religious/spiritual belief or practice. Three implications of adopting this broad working definition will be presented.

KEY WORDS: religion; spirituality; genetics; research methods

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"A large acquaintance with particulars often makes us wiser than the possession of abstract formulas."—William James, *The Varieties of Religious Experience*

INTRODUCTION

The primary matter under investigation in this essay is how to define religion and spirituality for purposes of humanities and social science research in genetics. This is an important question because genetic maladies often result in existential probing for both individuals and families, probing into one's self-understanding, including one's history and destiny. These deeper questions have commonly been seen as the province of religion and spirituality. How we define these key terms is a matter of considerable importance.

In this essay I will illustrate a few of the many ways that these religious or spiritual questions arise. I will also sketch some of the most prevalent definitions of the terms "religion" and "spirituality" in scholarly work over the past 100 years. My aim is to identify a definition of these key terms that works well for research purposes and explore its implications. In the end I will offer an illustration of why even our best efforts to define this fundamental element of our humanity are likely to be incomplete, and why epistemic humility continues to be an important virtue for researchers in this area.

DEFINING RELIGION AND SPIRITUALITY: WHY IT MATTERS

Several years ago I was interviewing couples who were candidates for an experimental surgical procedure to close the backs of fetuses with spina bifida prenatally, a procedure that carries risk to both the fetus and the woman, and so with an extensive informed consent process [Rothschild et al., 2005]. After hearing an explanation of the risks one candidate said: "This may sound weird to you but after my grandfather passed away I've felt his presence, like he's watching over us from heaven, and if I have this procedure done he's not going to let anything happen to me." Worried that this young woman might be grossly underestimating the risks, and seeking to better understand her thinking, I responded: "Is your religion a big part of your decision-making about whether to have this procedure?" She said,

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"Oh no." After further conversation it became clear that religion, in the conventional sense of attendance at religious services or belief in God played little part in her life. She simply had a powerful feeling of being protected by her deceased grandfather, and this feeling was related to her recent history. She had missed her grandfather's funeral in order to keep her appointment with us at the medical center to be evaluated for the prenatal surgery study. What I encountered here is what I would have termed "religion," but for her it was not religion but "spirituality."

Why does it matter what we call it? For precisely the reason illustrated above. Imagine, for example, that I had asked this surgical candidate to fill out a questionnaire which included the standard queries about religiosity, such as church attendance, prayer life and belief in a benevolent deity, and then conducted the interview. I might well have missed entirely a dominant thread in her current self-understanding. Had I not pursued the conversation in some detail, after my initial mislabeling, I likely would not have known of the deeply personal sense of providential protection this young woman felt, a sense that profoundly shaped her perceptions about participation in the trial.

This illustration echoes the findings of researchers like Bellah et al. [1985], who in *Habits of the Heart* described American religious beliefs and practices as eclectic and pluralistic, often composed of a variety of traditional public and individualized private elements. As an academic student of religion and its role in ethics I have come to think of religious phenomena as a multi-sourced mixture, but this is not necessarily true for the general public. At least some people, like the young woman seeking admission to the prenatal surgery trial, differentiate sharply between "religion" and what has come to be called "spirituality."

Solomon [2002] captures this distinction in a recent book entitled *Spirituality for the Skeptic.* Religion, Solomon argues, is fundamentally about belonging. This is in keeping with one of the root etymologies of "religion," from the Latin "religare," meaning "to bind" or "to connect," bespeaking the importance of group bonding and communities of shared interpretation and validation. Of course belonging

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can have other connotations. In an earlier study Bellah [1964] defines religion as "a set of symbolic forms and acts which unite man to the ultimate conditions of his existence." So the binding and connecting can be social or metaphysical, or both.

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terminology seems to follow at least some contemporary usage, in which "religion" is the term for beliefs and practices that have conventional names and organizational structures, such as Methodism, or Orthodox Judaism. "Spirituality" by contrast, is less sharply defined. It may include some identifiable, traditional components, but also incorporates a miscellany of beliefs and practices for which there may be no well-recognized institutional component.

Another way to map the terrain is described by Hyman and Handal, who used questionnaires with Protestant ministers, Catholic priests and Jewish rabbis to define religion and spirituality. While there was overlap between these definitions, "religion" was defined by their participants as "objective, external and ritual or organizational practices that one performs in a group setting and that guides one's behaviors." "Spirituality" was defined as "internal, subjective and divine experience or direct relationship with God [Hyman and Handal, 2006]." Solomon's delineation is preferable on at least two grounds. First, the clergy definitions presuppose monotheism. Second, their notion of spirituality carries the taint of being "subjective." Perhaps this is not surprising considering the professional commitments of these informants. Still, it important to note that assumptions of the centrality of a supreme being and the epistemic inferiority of spirituality are important ones for research methodologies to avoid. A more research oriented and less prejudicial definition of spirituality is offered by Buck, who synthesized a variety of models from nursing practice and offered the following definition: "spirituality is that most human of experiences that seeks to transcend self and find meaning and purpose through

connection with others, nature, and/or a Supreme Being, which may or may not involve religious structures or traditions [Buck, 2006]."

Those who study religion in the academy have been moving toward a more broad, functional and eclectic notion of religion for some time, but generally have not embraced the term "spirituality." They have continued to use the term "religion" to cover this collection of phenomena. Seeking to differentiate themselves from those who approach religion in a confessional way, some scholars have expanded the notion to include what is of deep existential significance to people, which often includes individualized awareness of the transcendent, or discernment of sacred dimensions of life. What distinguishes the beginnings of the academic study of religion is the effort to de-Christianize and de-theologize religion and study it as a natural and pervasive human phenomenon with many forms.

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Often these efforts still worked implicitly with Judeo-Christian categories, such as the work of Rudolf Otto early in the 20th Century. Otto relied heavily on his reading of the Christian Bible and concluded that the key "non-rational" elements were a combination of fascination, fear and awe before a mysterious, magisterial power [Otto, 1958]. Other scholars, more familiar with religious traditions of Asia such as Hinduism and Buddhism, took a comparative approach. Eliade [1959], for example, sought to isolate the essentials of religious experience and interpretation that he believed were generic features of religion East and West, such as, following Durkheim [1915], the classification of everything in life as either sacred or profane. Christian theologians also have been attentive to the broad pluralism of religious beliefs and practices worldwide and have been drawn to approaches that emphasize the existential component of religious experience. Tillich [1959] is famous for categorizing as religious whatever turned out to be a person's "ultimate concern." Yet these imaginative and expansive reconstructions of religion by scholars and innovative theologians have not forestalled wide usage in the early 21st Century of the term "spirituality." Humanities and social science research in this area needs to reflect current cultural usage in order to avoid misunderstanding, and to capture those experiences of deep significance to doctors and patients who would not consider themselves religious.

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Here a caveat is in order to avoid misunderstanding. I am not saying that researchers should always couple religion and spirituality. For example, recent studies have sought to correlate church attendance with health status. While some of these have been appropriately criticized on methodological grounds, it is possible to study conventional religious activities like attendance at worship services, or praying, as a set of practices that may have some relation to health outcomes. It is not hard to imagine how religious observances could increase a person's sense of trust and hope, and how this in turn could have positive effects on one's health. For example, it seems clear that social support affects the immune system [Kiecolt-Glaser et al., 2002] So drawing a distinction between religion and spirituality in such a way that there is overlap does not preclude worthwhile research projects that may have a more precise focus, such as a study of how ecclesiastical rituals influence stress. As in all research, defining one's terms, methods and endpoints clearly is essential in studying religion and/or spirituality.

Recent efforts to assess the influence of religion on health outcomes provide a strong cautionary note. The study of Benson et al. [2006] on the health consequences of intercessory prayer is a good example. Benson et al. seem to have forgotten that while prayer might well be studied on a purely human level as a potentially beneficial health practice, it is quite another thing to study the health effects of intercessory prayer on third parties, as if one were discerning a metaphysical connection through scientific methods [Churchill, 2007]. Human behaviors can be measured scientifically but divine causal efficacy cannot be, and the effort to do so caricatures science and "dumbs down" religion [Sloan, 2006]. Studying religion or spirituality requires a human focus, a dose of metaphysical humility, and a disinterest in religious truth-claims.

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For purposes of humanities and social science research I argue that an inclusive definition will serve us well. I use the acronym R/S to designate an inclusive concept for everything that might qualify as either religious or spiritual. It seems clear that people can be religious without being spiritual, and spiritual without being religious, and

that often there are elements of both at play. Even people whose religious orientation is quite conventional are likely to affirm some unorthodox and idiosyncratic aspects in their beliefs and practices. In a similar way, many who prefer to call themselves spiritual often have residues of conventional religious beliefs or practices lodged within their views. For some, this religious residue will be more or less standard; for others, the religious residue may be peculiar to them, just as their personal transcendent experiences may be unique to them. For example, imagine a former Presbyterian who still carries within her current spiritual beliefs some notion of predestination, or providential election, but now modulates that within a notion of karma, and God as the dispenser of karma. Given the creativity of our species, and especially the way that beliefs and practices meld with life experiences to form a lived coherence for each person, the combination of possibilities are endless. Borrowing from Levi-Strauss, we could say that human beings are religious and spiritual "bricoleurs," that is, creatures that are ingenious at taking whatever experiential materials are at hand and fitting them to the task [Levi-Strauss, 1973; Churchill and Schenck, 2005]. The acronym R/S I am offering here honors the vast range of novelty and creativity that I and many other researchers have encountered. It also provides a way to ensure inclusion and focus on functionality, without worrying too much how proximate or distal a particular person may be from orthodox views.

To be sure, an inclusive definition brings with it issues of imprecision and charges of fuzziness. If previous definitions, and some current research instruments, are too narrow and threaten to leave out much of importance in the meaning-making apparatus of humankind, R/S could be criticized as too inclusive and thereby tending toward imprecision. I will seek to answer the problem of a too general definition by focusing on the functional aspects of religion and spirituality. Adopting a functional approach means a focus on how these beliefs and practices work for people. If these beliefs and practices provide an avenue of transcendent understanding and give deep and unifying meaning to those who hold them, then they are worthy of our attention. I will specify this in more detail later in the article. Importantly, a functional approach means that concerns about the truth-claims of religion and spirituality are set aside to simply focus on how R/S helps people get around their world.

TAILORING A FUNCTIONAL DEFINITION FOR R/S RESEARCH

I am arguing that R/S as a subject of scholarly investigation requires not only a broad definition but also a functional one. This may not be the sort of definition that is needed for training theology students, although it might be useful for pastoral counseling, given the complex and idiosyncratic nature of people's beliefs and practices. But whatever the wisdom on this question, this broad and functional approach is usually the appropriate one for gathering information from patients and health care professionals. Here the question is: How does R/S come into play, and what jobs does it perform? When we understand the roles it plays then we can then ask about how these functions affect clinical perceptions and decisions, where normative questions are clearly in focus. In the end we may want to know more precisely whether religion and spirituality tend to facilitate or drive patients away from genetic testing and counseling. Do they help or hinder the diagnostic and therapeutic ambitions of professionals and the well-being of patients and families? Is R/S a benevolent or toxic influence, or both, depending on content and context? We may also be interested in knowing whether and how health professionals play a role in whether R/S is benevolent or toxic. Another way to say this is to acknowledge that a functional definition, like all definitions, has a particular end in mind, and the definition is, in that sense, goal-directed. As in all worthwhile research, we will need to know why we want the information gathered about R/S, in terms of what uses we intend for the data. If we need a map, is it for hiking and camping, or interstate highway driving? If we need accurate R/S topographies, is it because we want to advise our patients, or convert them, or use their beliefs as leverage for better therapy, or just to better communicate with them? Everything I am saying assumes the last alternative as the fundamental operative purpose. And if this is our agenda, we must leave behind our hankering to assess and judge the validity of any specific spiritual or religious scheme. The initial work is primarily descriptive rather than normative. The focus is on understanding just what features of R/S patients and professionals bring with them into the clinic and hospital, and how it works for them.

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Yet the interpretation and use of these data by researchers will always be in the service of some normative goal, such as improved communication with or care for patients with genetic illnesses. Distinguishing between the descriptive process of data-gathering and the normative uses of the findings is, I believe, easier when a broad and functional definition is in play.

What work does R/S do in human life? William James, in his landmark 1902 study *The Varieties of Religious Experience*, said—among many other things—that it provides a sense of the whole, a unifying orientation, with associated beliefs and practices [James, 1999]. More recently Wilson [1982] claims that religion is whatever fulfills people's existential needs, that is, those needs specifically associated with human

existence, such as the transient nature and contingency of human life, or the recognition that our deepest values may not prevail in the world.

On a more positive note psychologist Abraham Maslow has called attention to the way that "peak-experiences" function in much the same way as traditional religious beliefs and practices. According to his research such peak-experiences are ubiquitous, and can be mediated through a wide range of human activities. Maslow's observations are corroborated by looking at the amazing variation in world religions. Think of the range of human activities endorsed as avenues to the sacred: praying, meditating, and singing, but also dancing (think here of Sufis or Shakers), sexual union (think here of Tantric practices in Hinduism and Buddhism), eating (as in the Christian Eucharist), and so on. Peak-experiences, Maslow claims, are the "raw materials" out of which religious institutions and traditions are formed, and provide a natural way that humans embrace ultimacy, beauty, ego-transcending perceptions of oneness, a sense that the cosmos is a unified and benevolent whole, and a variety of other insights. Maslow's work has great value for those who want to study R/S since his work shows that this is a natural and ubiquitous human phenomenon, occurring under many names and practices, and also because he provides one of the most detailed and sympathetic maps to what people report about R/S [Maslow, 1964].

In summary, at least one important function of R/S is to provide a framework for responding to perennial and fundamental human questions, questions that are posed in individual and communal ways. Among these are: (1) Who am I?—the question of identity; (2) How can I find meaning and hope in suffering?—the question of ultimate purpose; (3) How can I come to terms with death?—the question of finitude and the significance of my limited horizon; (4) How do I live in accord with the deepest sense of what I am called to do for myself and others?—the question of responsibility.

To study the interface of R/S and genetics is to study the interaction of two powerful interpretive schemes for self-understanding. Genetics is concerned with who we are, our identities, in the most profoundly embodied way, and so inevitably calls for an interpretive scheme. It is never just biology. It is also a system—a canonized body of facts, methods and perspectives. It is a system that not only affects our understanding of health/disease, but our self-understanding, for example, what we think about free will and moral agency, about responsibility for health and illness, about the communities to which we are included or excluded, and our fate or destiny. This shows up in choices about screening, testing, diagnosis, and treatment options. As Rothman [1998] says, "genetics isn't just a science; it is a way of thinking, an ideology."

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White [2006] suggests that spirituality and religion are "heuristic strategies." This is an apt phrase, although perhaps implying too much self-consciousness, since much of the power of R/S lies in its force as feelings and as ritual rather than as an explicit belief system. Still, these schemes or strategies do provide orientation points for people in crisis, when they are making big decisions, facing suffering, loss or death, and when they need moral guidance. People bring these interpretive schemes or heuristic strategies with them to the clinic and hospital, they show up in genetic counseling sessions, in situations of diagnostic testing, and in the ideals and aspirations people have for themselves and their progeny. To be ignorant of them is to be blind to some of the most important sources of patient actions and attitudes.

IMPLICATIONS

Given this broad, functional understanding of R/S, I believe at least three implications are evident:

1. Focus on God talk will be important, but not sufficient. Investigations that probe people's sense of identity, belonging or not belonging to a family or community, sense of normalcy or deviation, understanding of fate or destiny, or interpretations of the meanings of illness are also important registers of R/S. When people speak at this deep level their language is spiritual/religious discourse, whether or not the term "God" emerges.

   Consider the following responses from two sets of parents, both of whom had recently received a prenatal diagnosis of spina bifida:
   - "No matters what happens, it's in God's hands."
   - "We believe there's a reason for this. Everything happens for a reason. We just don't know what that reason is yet."

   Both these statements reflect efforts to find the larger meaning of this unwelcome diagnosis, and bespeak the interpretive schemes of interest to an R/S researcher.
2. Focus on explicitly stated beliefs and formal doctrine will be important, but not sufficient. As discussed earlier, individuals may either affirm or deviate from formal public views, or frequently affirm some features and deviate from others. Moreover, R/S commitments are not all conceptual, not just thought, but often felt in the gut or the heart, and are rehearsed and bodily enacted in a variety of ways. Genetic understandings resonate, or fail to resonate, with the larger spiritual and religious sensibilities of people, not just their beliefs or concepts. And this can show up in interesting ways. For example, risk assessments for genetic maladies, especially when offered as a prelude to patient choices, may be unwelcome because they threaten a sense that leaving some things unexamined

respects a providential order and design for life. This is just the reverse of the Socratic maxim that demands that we examine everything. Some religious traditions contend that examining some things, especially things considered divine gifts, is inappropriate or sinful. In these cases it is not a specific choice, such a termination of a pregnancy that is problematic. Rather, simply being presented with a choice can de-mystify life, threaten the perception that life is a gift, and de-sacralize the world by portraying it as devoid of mystery and wonder. Even to assume that one has a choice to be made is essentially as act of hubris. This response is captured in yet another etymological root for "religion" in the Latin term "religare" (to be careful, mindful), in this case, being careful to treat sacred things as sacred.

3. Recognizing conventional religious labels will be important, but not sufficient. R/S, like politics, is a local phenomenon. Nobody practices religion or spirituality in general. We are Southern Baptists, or Orthodox Jews, or atheists or agnostics (itself often an existential stance with great depth and meaning), or pantheistic Catholics with Buddhist leanings, etc. Moreover, our experiences of religion and spirituality are embodied in particular ways that may turn out to be important, like being a member of the Upper Cumberland Reformed Congregation, or regulars at the Wednesday evening dharma talk and yoga sessions. This adds a layer of complexity that we must respect and probe. My experience to date from studying religion and spirituality in the context of health care decisions indicates that we may not be able to forecast what will turn out to be important for any particular patient or family, or for that matter, for any given health care professional. If R/S resides not only in the cortex, but in the gut, in both history and the imagination, in myth and in ritual, then it follows that none of us may have transparency upon our own deep convictions, attitudes or demeanors, until they are called into play, or challenged. Hence we should not expect patients or those who care for them to be completely lucid or even logically consistent about what their deep R/S drivers are. Here it is worth remembering that one of the most persist themes in reports of R/S experiences is that they are, at least in part, ineffable, beyond language. Being a student of religion and spirituality can be humbling, as my opening example suggests. We do well to be open to novel forms of R/S, as well as well-defined and more traditional ones.

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Let me end with a cautionary tale, one about our limited ability to forecast or generalize about how R/S works. Another couple considering the study of prenatal surgery discussed above, and having traveled a great distance to learn more about the trial, was uncertain and conflicted about whether to participate. They worried over the information and pondered the risks and benefits for several days. Finally, the key element in their decision—which was to have the surgery—was their discovery that the name of the street on which their hotel was located was Mt. Moriah Church Road. This connected in their sensibility to the story in *Genesis* and the site on which Abraham was commanded to sacrifice his son Isaac, only to be reprieved at the last instant. After they noticed the street sign, this couple returned to their hotel room, read their Gideon Bible, and called the study coordinator saying they were ready to proceed. In retrospect the logic of their decision is clear, but who would have imagined that a key factor in their decision would have been a street sign?

I offer this as a cautionary tale—with a plea for humility—in thinking that we can know how and why religion and spirituality will influence health care decisions, without taking the time to ask.

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