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Perspective: Balancing Personalized Medicine and Personalized Care

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Abstract

The current description of personalized medicine by the National Institutes of Health is "the science of individualized prevention and therapy." Although physicians are just beginning to see the promise of genetic medicine coming to fruition, the rapid pace of sequencing technology, informatics, and computer science predict a true revolution in the ability to care for patients in the near future. The enthusiasm expressed by researchers is well founded, but the expectations voiced by the public do not center on advancing technology. Rather, patients are asking for personalized care: a holistic approach that considers an individual's physical, mental, and spiritual well-being. This perspective considers psychological, religious, and ethical challenges that may arise as the precision of preventive medicine improves. Psychological studies already highlight the barriers to single gene testing and suggest significant barriers to the predictive testing envisioned by personalized medicine. Certain religious groups will likely mount opposition if they believe personalized medicine encourages embryo selection. If the technology prompts cost-containment discussions, those concerned about the sanctity of life may raise ethical objections. Consequently, the availability of new scientific developments does not guarantee advances in treatment because patients may prove unwilling to receive and act upon personalized genetic information. This perspective highlights current efforts to incorporate personalized medicine and personalized care into the medical curriculum, genetic counseling, and other aspects of clinical practice. As these efforts are generally independent, the authors offer recommendations for physicians and educators so that personalized medicine can be implemented in a manner that meets patient expectations for personalized care.

Personalized medicine has become the buzzword in translational research with the promise to revolutionize patient care. To many physicians, this revolution will come in the form of improved disease prediction, preventive medicine, diagnostic testing, and treatments.[1] By contrast, patient expectations focus less on technology than personalized care: namely a more holistic approach to healthcare that encompasses their physical, mental, and spiritual well-being.[2] This perspective considers the challenges presented by mismatched physician-patient hopes for personalized genomic medicine, particularly in regard to the role of religion and spirituality in medical care. Rather than offer a detailed review of the literature,

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we discuss select manuscripts that highlight key issues in order to argue that the goals of personalized medicine may pose new challenges to the spiritual care of patients. We conclude by suggesting strategies for overcoming, or at least mitigating, these challenges to create a kind of personalized medicine that is also personalized care.

In general terms, personalized medicine is an attempt to synthesize an individual's clinical history, family history, genetic make-up, and environmental risk factors to individualize the prevention or treatment of disease. With enhanced electronic medical records and the cost of whole genome sequencing predicted to drop to $1,000 in the near future,[3] medical providers hope to soon use an individual's genetic information to identify risk factors, initiate preventive measures, and—if disease has already occurred—personalize treatment plans. This is already in practice in the treatment of chronic myeloid leukemia, where patients failing standard therapy undergo DNA sequencing to distinguish mutations suitable for drug therapy from those that require bone marrow transplantation.[4] More recently, genome sequencing has shown promise by uncovering novel mutations that impact surveillance recommendations and treatment options for leukemia patients.[5,6] Moreover, when drugs are prescribed, personalized medicine will use genetic testing to predict how individuals will metabolize the compound. One example of this pharmacogenomics approach is the FDA approval of genetic tests that can predict the appropriate starting dose of the blood thinner warfarin (trade name Coumadin).[7]

Challenges to Implementing Personalized Medicine

Psychological

Implementing personalized medicine will require attention to psychological issues already encountered by genetic counselors and physicians. Before genetic testing was possible, 60%–75% of individuals at risk for Huntington disease indicated that they would undergo testing, but when a test became available only 3%–21% opted to be tested.[8] In cancer where positive genetic testing could encourage women or their daughters to participate in vigorous screening or pre-emptive surgery (such as mastectomy), testing is not universally accepted. Even among insured women with recently diagnosed breast cancer, a significant number (approximately 20%–30%) refuse genetic testing.[9,10] Additional data suggest that women who perceive their risk of breast cancer as high are less compliant with surveillance recommendations, indicating that the stress of future disease may paradoxically promote avoidance behaviors.[11] Extensive research now exists on the negative psychological factors associated with genetic testing.[12,13] Research will need to move from descriptive studies to interventions that can promote informed decisions if the full potential of personalized medicine is to be realized.

Religious

Understanding current areas of potential conflict between religion and medicine can be informative when anticipating the public's concerns regarding personalized medicine. The most extreme conflict currently is between the medical community and churches that reject modern medicine, such as the Indiana-based Faith Assembly and the Christian Science Church.[14] Personalized medicine will not be relevant to these individuals as they reject most medical assistance. Where conflict will arise will be in the care of their children. The majority of the estimated 172 children who died between 1975 and 1995 because prayer was used in lieu of medical care were from such churches.[15] Most states have since established or revised statutes that allow parents to refuse medical treatment for their children, except in situations where refusal of medical treatment will endanger the life of the child or lead to significant disability.[16] If genetic testing can be shown to be lifesaving, especially if

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diagnosis is critical before the age of eighteen, these religious exemptions may need to be revised.

Another group of Americans who may challenge personalized medicine are those who question evolution and, by association, genetics. In a June 2008 Pew Forum poll,45% of Americans rejected evolution as the best explanation of the origins of human life.[17] Results of a national survey of 1,472 physicians conducted in 2007 by the Louis Finkelstein Institute for Social and Religious Research, only 63% of physicians agreed that the theory of evolution is more correct than intelligent design;54% of Protestant physicians agreeing more with intelligent design.[18] Population genetics, which will form the basis for much of the scientific advances in personalized medicine, relies on certain tenets of heredity that stem from evolutionary biology. As such, certain religious groups may reject personalized medicine, while the majority of patients and physicians are likely to continue to accept the technologies while distancing themselves from the theoretical foundations.[19]

Religious views on the cause and meaning of illness may also challenge personalized medicine, the primary goal of which is the eradication of disease. Atheists may view illness as a statistically based combination of genetic and environmental factors, while believers of certain religions may view illness as punishment or a test of faith by a higher power, as illustrated in the story of Job. Others may see suffering as part of the natural world, but believe that a higher power will judge their response to adversity. A qualitative interview study conducted by Evans across a group of religious and secular Americans found that those with a more secular viewpoint tended to see elimination of suffering as an overarching goal of medical therapy; they were generally more accepting of genetic technologies that may affect the viability of embryos and were more accepting of genetic engineering.[20] Those with stronger religious affiliations see potential value in suffering and believe that the seriously ill have much to contribute to society; as such they are less accepting of reproductive genetic technologies. Many Pentecostal and Charismatic Christians envision Satan as the author of sickness and Christ as their healer; in this framework, they view spiritual and physical healing as complementary rather than conflicting.[21] Acceptance of predictive testing and genetically based treatments will likely be influenced by an individual's views on the value of suffering and whether an illness is influenced by factors outside the natural world.

If personalized medicine matures to the point where each individual undergoes whole genome sequencing, we learn significantly more about individuals' risk of heritable disease. If religious or other groups believe this information will be used to encourage embryo selection prior to implantation, significant opposition is likely to be encountered. This has two implications. First, individuals may reject personalized medicine to comply with religious doctrines or their own ethical values. Second, similar to the current debate over coverage for contraception, individuals may find their access to care restricted if they work for or receive care from faith-based institutions, which encompass not only churches but also faith-based hospitals and universities.[22] Although the majority of religious institutions, including Roman Catholic and conservative Protestant churches, have been supportive of DNA-based research and diagnostics, this view could change if personalized medicine appears to conflict with the sanctity of human life.

Ethical

Personalized medicine could also encounter resistance if it appears that the technology is used to limit therapeutic options based on financial considerations. For example, let us assume that the only viable therapy for a cancer is an expensive chemotherapy regimen that currently cures 40% of patients. Presently there is no means to distinguish those who will respond from those who will not, so all patients are offered treatment. If a new genetic test

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can predict with 100% assurance who will be cured and who will not benefit, insurers will push for testing before covering treatment. In this case, most individuals would not have ethical concerns about restricting therapy to those who will benefit, since administration of ineffective therapy is counter to medical and ethical tenets. Unfortunately, it is unlikely that any test will be so black and white. Therefore, where does the line get drawn so that medicine can be provided to the public in a cost-effective manner? Should insurers cover a procedure if it is effective in 10% of patients, in 5%, in 1%? If personalized medicine advances evoke cost-containment discussions in life-threatening conditions, those concerned about the sanctity of life will likely raise objections. Lack of consensus by U.S. medical, legal, religious, and political forces in end-of-life issues is clear, as dramatically illustrated by the case of Terri Shiavo, a 41-year-old brain-damaged woman who was in a vegetative state.[23] Although that case focused on an individual's right to die, it illustrates how medical issues can mobilize opposing forces from the worlds of religion, politics, and the national media.

The Genetic Information Nondiscrimination Act of 2007–2008 protects U. S. citizens from discrimination and forbids insurers from limiting coverage or altering premiums based on genetic information.[24] The law prevents insurers from requiring policyholders to undergo genetic testing but could make testing a requirement for treatment. For example, if a woman was at high risk of breast cancer based on family history but refused on religious grounds to undergo testing, would insurers cover the cost of a preventive rug or require "definitive" genetic proof of medical necessity? In working through these ethical issues, patient advocacy groups are likely to be important players in addressing the regulatory hurdles and assuring that appropriate medical coverage is available.[25,26]

Patients' Expectations for Personalized Care

The increased precision promised by personalized medicine will move the profession from an "art" to a "science," yet patients demand a more holistic approach to care, one that also addresses spirituality. A Gallup poll in 1990 found that three-quarters of Americans believe that spirituality plays a role in wellness, and two-thirds believe that physicians should inquire about their patients' spiritual beliefs.[27] According to a 1996 poll, 82% of Americans believe in "the healing power of personal prayer," and 64% think doctors "should pray with those patients who request it."[28]In response to public pressure, the percentage of U.S. allopathic medical schools teaching religious and spiritual aspects of medicine increased from 13% in 1994 to 67% by 2004.[29,30]The United Kingdom has also moved to incorporate these issues into the medical curriculum.[31,32] The Joint Commission for the Accreditation of Healthcare Organizations' 2008 *Comprehensive Accreditation Manual for Hospitals* mandates attention to patients' spiritual needs as part of end-of-life care and treatment of emotional and behavioral disorders. In addition, undergraduate and graduate medical curricula now include complementary and alternative medicine programs, many of which present spiritual care, including prayer, as methods of healing.[33–36]

Will personalized medicine meet the demands of patients for holistic care, or will it further the divide? If personalized medicine can deliver highly accurate diagnostic and prognostic information, what room remains for faith and prayer? Predicting with 100% accuracy every disease a patient will encounter remains science fiction, but accurately predicting response to chemotherapy will likely become reality, at least for a handful of malignancies. If we can tell someone with certainty that their disease is incurable, should we encourage them to pray for a cure?

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Implications for Academic Medicine

Effectively communicating the goals and basis of personalized genetic medicine will require an understanding of the psychological, religious, and ethical challenges that arise from this new technology.. A societal dialogue that engages patients, clergy, policymakers, and practicing physicians will not only educate the public about the power of personalized medicine, but also identify ethical and moral concerns and barriers to its implementation.

Research into the psychological barriers to genetic testing will be important as predictive testing is applied to a greater number of diseases. As important, studies that focus on removing barriers to genetic testing in underserved populations will be critical to the more expansive goals of personalized medicine.[37–39] Personalized medicine research programs should follow the lead of organizations like the National Cancer Institute, which requires a robust behavioral and social sciences program within an institution's research portfolio if it wishes to attain the prestigious designation of a Comprehensive Cancer Center.

Medical schools are also starting to address personalized medicine in their curricula. An international group of educators from Israel, Europe, and the United States has proposed key educational components for the medical curriculum.[40] Pharmacogenomics has been the major focus area to date;84% of medical schools in the United Kingdom and 74% of U.S. and Canadian medical schools include pharmacogenomics in their curriculum.[41,42] And, although they have few current applications, the rapidly developing fields of population genetics, epigenetics, and microRNA regulation will certainly become part of clinical practice, whether that of medical specialists developing treatment regimens for complex diseases or primary care physicians implementing preventive care plans. One could argue that these technologies are advancing so rapidly that what we teach today will be obsolete by the time personalized medicine is in common practice. What can be accomplished today is educating trainees on the tenets of genetic counseling, the challenges of interpreting complex genetic data, and more effective ways of communicating data of unknown significance. As more patients undergo genetic analysis, novel sequences and copy number variants will be found. Informing patients that test results are unexpected but the significance is unknown can be challenging for the physician and extremely anxiety-provoking for the patient. One interesting personalized medicine course has been developed at the Stanford Medical School; students can submit DNA for sequencing, then analyze their own genotype in a course that seeks to teach technical, ethical, and clinical skills by providing first-hand experience of the challenges of interpreting genetic information.[43] Others have described similar challenges to teaching this material within a medical school curriculum and proposed novel methods for educating trainees about the important issues raised when using genomic information in clinical practice.[44–47] As medical schools develop curricula for personalized medicine, the key objectives for learning are not the technology but developing the communication skills needed to discuss complex genomic test results.

Aggressive development of continuing medical education programs to assist physicians in practice is also needed. Physicians are increasingly being asked to interpret genetic data as patients utilize commercial vendors, such as 23andMe and DeCode Genetics, that provide genomic analysis and claim to identify an increased or decreased risk of certain diseases. The validity of the risk assessments, the ethical challenges of commercial DNA analysis, and the quality of genetic counseling provided by these companies has been questioned.[48–51] Understanding the limitations of the data will be critical for physicians who are asked to assist in data interpretation or request that the information be incorporated into their medical care.

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Considerations for Genetic Counseling

The expanding role of genetic testing in clinical practice presents an opportunity to reevaluate the recommendations for genetic counseling. Currently, the National Human Genome Research Institute states that, before any genetic test is performed, an individual "must be informed of the test's purpose, medical implications, alternatives, and possible risks and benefits."[52] This is in line with recommendations from other professional organizations.[53,54] In medical genetics, familial cancer, and prenatal clinics, at least one hour of counseling is routinely performed prior to testing. Many physicians outside the medical genetics community have not embraced this recommendation. For example, physicians increasingly order genetic testing for common diseases such as hemochromatosis and heritable coagulation disorders without discussing the heritable nature and broader implications of testing with their patients. They may distinguish tests that confirm diagnoses from those that assess risk, or see certain tests as not impinging on reproductive decisions, and therefore conclude that such tests do not require detailed discussion. They may simply have not received training in the current expectations for genetic counseling.

Admittedly, as genetic testing becomes more common, counseling all patients before every test may not be practical. And not all tests require it. For example, the consensus statement from the American College of Medical Genetics on pharmacogenetic testing for warfarin indicated few unique ethical, legal, or social issues outside implications for family members.[55] Gathering greater input from primary care physicians will be critical to developing a consensus on the best practices for counseling patients as well as for fostering curriculum development.

Personalized Medicine as a Component of Personalized Care

Personalized medicine must begin to consider how this technology-driven science can be balanced with a population that seeks a holistic approach to care. Failure to carefully consider implications of personalized genetic medicine could lead to a form of moral eugenics where patients refuse to participate because of conflicts with religious or moral tenets. Moreover, if medical care becomes focused on statistical probabilities, more patients may seek complementary and alternative medicine either in addition to or in place of traditional medical care. For those who do embrace personalized medicine, we would argue that they will need more attention to holistic care than ever before. Highly accurate diagnostic and prognostic information will greatly improve medical care, but will do little to does little to assist patients who must cope with the realities of life-altering disease. Accuracy could negatively influence common coping mechanisms such as hope, faith, and prayer. Medical curricula that actively combine education on holistic care and personalized medicine will help physicians deliver information with empathy. Physicians trained to consider psychological and spiritual viewpoints can better gauge their patients' responses to prognostic information and know when it's appropriate to refer them to genetic counselors, psychologists, and chaplains. This combined approach will facilitate both the implementation of personalized medicine and the delivery of personalized care.

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