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This is the third issue of the revised format of the ejournal, *Health Care Ethics USA*, published by the recently expanded Catholic Health Ethics Partnership (CHEP). The ejournal will continue to use the year and number identifiers in continuity with the original format. The journal is designed to assist ethics committee members and other health professionals in Catholic health care. And the electronic format is adopted to facilitate easy and widespread distribution of the ejournal across different health systems. The new format for the ejournal presents essays of just 1000 words (previously they were considerably longer) with a brief executive summary - the new format is designed to make it easier for busy health professionals to find time for the essays.

The original version of each issue of *Health Care Ethics USA* is archived online for CHEP members who have online access to the current and all of the previous issues at: [http://chce.slu.edu/chep.html](http://chce.slu.edu/chep.html). After connecting to "log in to the current issue", the User Name is, *hceusa* (lower case only), and the Password is, 2005.

This third issue of the new format for *Health Care Ethics USA* contains three essays. The first essay is by John Paul Slosar, PhD, who is the Director of Ethics at Ascension Health, Saint Louis, Missouri. His essay discusses "Ethical Issues in Genetic Testing," addressing some implications of the human genome project for Catholic health care. The second essay is by John Brehany, PhD, who is the Director of Mission Services and Ethics at Mercy Medical Center in Sioux City, Iowa. His essay addresses an increasingly neuralgic issue for Catholic health care organizations: "Health Charities, Unethical Research and Organizational Integrity." The third essay is by Rev. Greg Manship, M.Div., PhD(c), who is a senior doctoral student at Saint Louis University's Center for Health Care Ethics. His essay considers the patient-physician relationship in terminal care by considering "Hope and the Ethics of Disclosure for Terminally Ill Cancer Patients." I hope you enjoy the essays and I look forward to receiving suggestions for topics that we might address in future issues. For ejournal email, please contact: *hceusa@slu.edu*

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Ethical Issues in Genetic Testing

John Paul Slosar, PhD

Executive Summary. Genetic testing is becoming ever more prevalent in the post-genome project practice of medicine. Subsequently, genetic testing for disorders lacking any therapeutic interventions is also becoming more prevalent. This article will examine some of the ethical challenges raised by our ability to know but not to cure.

Ethical Issues in Genetic Testing

One of the most immediate consequences of the completion of the Human Genome Project (HGP) is a steady stream of new information and an exponential growth in the understanding of disease and its genetic basis. The steady flow of information arising from the HGP has resulted in a nearly ubiquitous trend in the post-genome era of medicine. The trend unfolding within many subspecialties of medicine is an increase in the ability to test for genetic disorders or, more often, screen for genetic susceptibility to certain diseases despite the absence of any therapeutic, i.e., preventative or curative, intervention for the disease in question. Indeed, many of the current ethical issues in genomic medicine arise from our ability to know but not to cure.

A resulting ethical challenge of the post-genome era of medicine is to resist the temptation toward genetic reductionism and the tendency to view genetic testing as the ubiquitous solution for all that ills us. The first step in resisting genetic reductionism is to determine whether and when genetic testing for disorders with no therapeutic intervention ought to be performed in particular cases. Even when there is no therapeutic intervention for a particular disorder, there are still some morally valuable reasons why one might want to undergo the testing. Such reasons could include psychological relief from uncertainty, improved personal planning (including reproductive decisions), avoidance of harms through life-style changes, advanced care planning, and preventative treatment of associated co-morbidities. Whether these considerations justify genetic testing for a disease without a therapeutic intervention will need to be determined on a case-by-case basis in light of the disease in question and the circumstances of the individual patient.

The Complexities of Genetic Testing

Several factors give an added dimension of complexity to the question of when genetic testing is appropriate. First, not all families and individuals will yield a positive test result for some genetic conditions, though they may in fact have some form of the condition. Thus, just because an individual receives a negative test result does not necessarily mean that the patient is free of that disease. A second difficulty is identifying appropriate candidates for testing in the first place. For example, patients with early onset dystonia are better candidates for genetic testing than those patients with late onset dystonia. Third, there are certain genetic markers for which two different patients could both test positive, and one patient may acquire the disease while the other does not. Many types of cancer and many neurological disorders, for example, are the result of a complex interaction of genes modifying other genes and environmental factors acting on those modified genes. This complexity arises in part from gaps in our current state of knowledge, which may either be due to limitations in our understanding of the role of genetic mutations in the disease mechanism or due to an incomplete genetic map of a particular disease. Regardless, physicians have a moral obligation rooted in beneficence to ensure that a patient is an appropriate candidate for a particular genetic test before recommending it.

Though significant, these complexities do not necessarily preclude the moral validity of genetic testing for diseases that lack therapeutic interventions. Rather, the implication from an ethical perspective is two-fold. First, when considering whether genetic testing is appropriate for a particular patient, one must distinguish between diagnostic testing to confirm a symptom-based diagnosis and pre-symptomatic screening (predictive testing). Genetic testing is often appropriate as part of the...
diagnostic workup of symptomatic patients to confirm more efficiently and with greater certitude the presence of a particular disease. However, additional issues need to be considered when the screening is pre-symptomatic. Distinguishing between causal genetic mutations and genetic susceptibility is critical when considering pre-symptomatic screening. Pre-symptomatic tests for a single predictive genotype may not be appropriate for diseases with a multifactorial etiology. For example, predictive testing for early onset AD is not considered appropriate, except in families with autosomal dominant inheritance. So too, the Ethics Committee of the American Geriatrics Society holds the position that genetic testing for late onset AD should not become the standard of care.

Genetic Testing, Informed Consent & Genetic Counseling

The second implication of these complexities from an ethical perspective is that the informed consent process for genetic testing must be absolutely thorough and pristine. Physicians have an obligation rooted in respect for human dignity, respect for autonomy and the norms governing informed consent to ensure that the patient understands the rationale for the testing in his or her particular case. This information should also include the ramifications of a positive or negative result with regard to the patient's prognosis as well as its implications for family members (who may not themselves be consenting to the test). Informed consent for genetic testing is generally - and always should be - obtained through the process of genetic counseling. The counseling process takes place over a series of pre-test meetings with specially trained counselors and allows time for comprehension and deliberation of the information. The benefits of genetic counseling extend beyond ensuring that truly informed consent is obtained and continue into the post-test context. Genetic counseling ensures that the test results are accurately interpreted and understood. Genetic counseling in the post-test context also helps ensure that appropriate follow-up medical services as well as necessary psychological, emotional and social supports are available and coordinated. Subsequently, employers and society in general have an obligation rooted in respect for human dignity, the common good and justice to ensure that any benefits coverage for genetic testing is accompanied by coverage for genetic counseling. At a time when medical practice is especially vulnerable to the creeping threat of genetic reductionism, genetic counseling is an essential and indispensable component of holistic, spiritually-centered care.

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5. Jill Goldman and Craig Hou, "Early-Onset Alzheimer Disease: When is Genetic Testing
Executive Summary. Organizations, particularly Catholic hospitals, schools and social service agencies, should re-examine their relationships to health and medical charities promoting unethical research such as human embryonic stem cell research and therapeutic cloning. Part 6 of the *Ethical and Religious Directives* provides a helpful framework for ethical analysis and action.

In America, health and medical charities (HMCs) play a key role in educating the public about debilitating diseases and in raising millions of dollars annually to fund research for cures (see www.healthra.org). In raising awareness and contributions, HMCs not only appeal to individuals, but also seek to establish partnerships with corporations, including Catholic institutions. Over time, HMCs like the March of Dimes, Juvenile Diabetes Research Foundation (JDRF), Muscular Dystrophy Association, and the American Cancer Society, have become successful, highly respected organizations.

Recently, however, some HMCs have become advocates for unethical scientific research, e.g., involving human embryonic stem cells and therapeutic cloning, and some are using fundraising efforts to support such research. For example, JDRF, one of the most successful HMCs, not only publicly endorsed research involving human embryonic stem cells, but has dedicated millions of donated dollars to fund it. Moreover, JDRF engages in political advocacy to promote such research, donating over $1 million to a California initiative to provide state funds for human embryonic stem cell research. Other HMCs that have publicly supported human embryonic stem cell research include March of Dimes, the American Diabetes Association and the American Cancer Society. Given the significance of the ethical issues at stake in research, Catholic institutions, particularly health care organizations, should re-examine their support of these HMCs as a matter of organizational integrity.

Some might question whether an ethical issue exists, preferring to focus on the valuable services HMCs perform and the many legitimate activities they fund. Some see support for HMC campaigns as a tradition and a concrete sign of community involvement. However, a more searching ethical analysis is required. The principles addressing cooperation in evil and scandal in Part 6 of the *Ethical and Religious Directives* provide a helpful guide for this ethical analysis.

The principles governing cooperation are relevant because Catholic institutions are sometimes asked to collaborate (or “partner”) with HMCs in at least one of the following: (1) to make a corporate donation; (2) to facilitate fundraising activities among their employees; and (3) to endorse an HMC in public statements and advertisements. Any of these three activities involves at least material cooperation. (Formal cooperation - the explicit approval of HMCs’ support for unethical research - certainly is possible, but most people probably are unaware that some HMCs are facilitating such research). Material cooperation in evil should be mediate and preferably not routine. The cooperation involved in donation and facilitation of fundraising could be viewed as proximate to the extent it directly assists an organization in promoting unethical research. The amount of money or assistance provided is highly relevant as a measure of involvement. This can include both the amount of money an HMC devotes to unethical research as well as the amount of money that an institution provides to such an HMC. Some HMCs contribute a great deal to unethical research. For example, JDRF contributes approximately 10% of its research budget to stem cell research (over $10 million in FY 2005, with the vast majority of such grants funding human embryonic stem cell research. It is true that, in the context of the total dollars involved in an HMC’s annual budget, any single donation might be viewed as contingent, and that mediate material cooperation in evil is allowed for certain serious reasons. However, given that charitable donations, unlike paying taxes, are voluntary and that many worthy alternative charities exist, it is hard to understand what might be a serious reason for continuing to support such organizations in their current mode of operation.
The teaching of the ERDs on scandal, properly understood, is also particularly applicable to the ethical issues involved in the case at hand. "Scandal" in ERD Part 6 does not refer to public embarrassment or damage to an organization's public image, but rather to an "attitude or behavior that leads another to do evil." When Catholic institutions provide public, organizational support to HMCs promoting unethical research, they make it more likely that their employees, and others, will support such HMCs. Moreover, they can lead others to view the unethical research promoted by such HMCs as legitimate.

Ultimately, the failure to address the ethical issues at stake can make it less likely that problematic emerging trends in scientific research will be effectively checked and constructive alternatives will be developed. An example of what is at stake here can be seen in the case of March of Dimes (MOD). For over 50 years, MOD has been the premier HMC addressing birth defects and infant health. In the 1970s, however, MOD came under public scrutiny by some for its promotion of amniocentesis (and advocacy of abortion following a positive test for a birth defect). In the 1990s, MOD publicly supported legalized abortion and funded research into selective abortion in multiplex pregnancies. More recently, MOD has publicly endorsed human embryonic stem cell research. Unfortunately, the critique of MOD was too limited to be effective. And, over these same years, a climate of eugenics has become more pervasive in the United States, one indication of which is that abortion now follows prenatal diagnosis of Trisomy 21 approximately 80% of the time. Undoubtedly, many factors have contributed to this trend. However, to avoid a similar result in the field of stem cell research, it is necessary to work even harder to build a public culture of respect for human life. Complacent acceptance of high-profile HMCs facilitating unethical research is incompatible with the effort it will take to build such a culture.

There are several practical steps Catholic institutions should take at present: (1) take inventory of which HMCs they support and research the position and activities of these HMCs related to unethical scientific research; (2) where appropriate, find alternative HMCs or charitable projects worthy of receiving organizational support; (3) if they have already committed to donate or to participate in a fundraising campaign, take steps to appropriately restrict the donations contributed to an HMC under their auspices; and (4) most importantly, educate their boards, employees and communities about how faith-based mission and values contribute to authentically ethical research and health care services. If these steps are taken, there is a much greater chance of fostering a consistent, public culture of respect for human life.

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Suggested Readings


Index | Next: Hope and the Ethics of Disclosure for Terminally Ill Cancer Patients
Executive Summary. Cancer diagnosis presents a disclosure dilemma for physicians, holding in tension the physician's obligation to provide diagnosis and its impact on the patient. To address this dilemma the traditional approach of physicians, typified as the psychological-empirical approach to hope, needs to be complemented by a patient-oriented approach, described as the phenomenological hermeneutics of hope.

Cancer diagnosis presents a disclosure dilemma for patients and physicians. One horn of the dilemma is the physician's obligation to provide diagnosis so that the patient is equipped to make informed decisions regarding care. The other horn is the impact the diagnosis has on the emotional and physical well being of the patient. Historically, physicians resisted disclosing a diagnosis of cancer to protect the patient from the "harm" of a poor prognosis. This essay discusses how ethical discourse on hope can help to resolve this disclosure dilemma. Oncologists consistently report a moral obligation to foster hope both for their patients and for themselves. "Respect for hope" serves as an ethical guideline for diagnosis disclosure by oncologists, such that "[i]nformation is tailored . . . to the goal of instilling hope." Conversely, such "information tailoring" raises ethical concerns about truthful communication, paternalism, and trust within the patient-physician relationship. There are, however, two (possibly complementary) approaches to hope that are worth considering. These approaches can be described as the psychological-empirical approach to hope and the phenomenological approach to hope.

The psychological-empirical approach to hope means that hope is "grounded primarily in the biomedical dimensions" of health care, and is contingent upon the empirical "probabilities of success and failure." This approach to hope has several characteristics. First, hope is used to implement a paternalistic role for the clinician who controls the relevant biomedical information. Second, this approach to hope seeks to foster psychologically the patient-physician relationship in order to realize desired empirical outcomes. However, this approach can be problematic insofar as an oncologist can justify withholding information to achieve two conflicting goals. On the one hand, the oncologist may withhold diagnosis information in order to promote unsubstantiated hope. On the other hand, the oncologist may withhold information to protect against unsubstantiated hope. Third, this approach to hope gives primacy to the oncologist's perceptions of hope over those of the patient. Such primacy can appear in oncologists' efforts "to instill and maintain hope," "to disabuse patients of what physicians perceive as impractical forms of hope," and "to promote reasonable hope." In sum, this approach adopts a psychological approach to hope based on anticipated empirical outcomes, wherein the oncologist ascertains which empirical outcomes are attainable as a basis for the diagnosis disclosure to the patient, and the patient's hope is fostered accordingly.

Despite the goals of instilling and maintaining hope, the psychological-empirical approach to hope raises significant concerns. First, the emphasis on information disclosure by the clinician related to the anticipated therapeutic outcomes can obscure a deeper understanding of dialogic communication in the patient-physician relationship as a basis for hope. Second, the emphasis on the oncologist's diagnosis disclosure can diminish the patient's understanding of hope as a lived experience, as described below. Third, an emphasis on the empirical and psychological aspects of the diagnosis disclosure can prevent an interpretive function of hope as a means of ascribing meaning and ascertaining understanding in particular experiences of cancer. Lastly, a psychological-empirical approach can detract from the transcendental aspect of hope, which seeks to ascribe relational and religious meanings. These concerns suggest the need for another approach to hope in addressing diagnosis disclosure for terminally ill cancer patients.

A different approach to hope can be described as the phenomenological approach. This approach
ascribes meaning to and ascertains understanding of practical circumstances (such as a terminally ill patient's cancer) by interpreting the phenomena that comprise human experiences. Inasmuch as the processes of ascribing meaning and ascertaining understanding require interpretation of the phenomena that comprise human experience, this entails what I refer to as a phenomenological hermeneutics of hope. A phenomenological hermeneutics of hope offers a complimentary approach to understanding the role of hope in the ethics of cancer diagnosis disclosure.

The phenomenological hermeneutics of hope proposed by Paul Ricoeur is particularly helpful, insofar as he addresses both the theological and the philosophical aspects of hope as lived experience. Ricoeur argued that hope is essentially a theological virtue, grounded in a Christian understanding of resurrection and freedom. Resurrection is the symbol of "a new totality of being," that communicates hope as a "superabundance of meaning." Additionally, hope yields both freedom from spatio-temporal and physical constraints, as well as freedom for imagining human possibilities, instantiating divine love, and "being-in-the-resurrection." In sum, for Ricoeur, hope can enhance freedom to discover meaning both within and beyond the spatio-temporal realm of knowledge.

The phenomenological hermeneutics of hope can help oncologists deal with diagnosis disclosure to better address the disclosure dilemma when caring for terminally ill cancer patients. First, this approach to hope can help the oncologist to discover the patient's personal conceptualizations and expressions of hope. Second, this approach to hope privileges the patient's understanding of the disease diagnosis, prognosis, and prospects for palliative care. Third, this approach to hope connects the patient's disease with patient's overall well-being for which the clinician also has responsibility.

In other words, the phenomenological hermeneutics of hope can complement a more traditional psychological-empirical approach to hope. The phenomenological hermeneutics of hope is attentive to what can be called a "superabundance of meaning" that is within a terminally ill patient's grasp. The particular clinical circumstances of disease should not exhaust the totality of meaning for a dying patient. This approach to hope can foster empathic dialogue that promotes trust and mutual understanding, far in excess of a more traditional paternalistic approach, between the oncologist and patient in the extraordinarily personal pilgrimage of dying. This approach to hope frees the oncologist and the patient from interpreting "success" and "health" solely in terms of empirical outcomes. Rather, hope, as freedom to interpret the empirical present, empowers the oncologist and patient to grasp transcendent meaning beyond the spatio-temporal realm of medical knowledge.

In sum, a complementary relation between two approaches to hope can foster a better physician-patient relationship for the terminal care of cancer patients to address the diagnosis dilemma described previously. That is, the psychological-empirical approach to hope that can characterize the paternalistic role of the oncologist needs to be balanced with the phenomenological hermeneutics of hope that celebrates the interpretation of dying patients in their quest for transcendent meaning in the end stages of living.

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**Suggested Readings**


Farran, Carol J., Kaye A. Herth, and Judith M. Popovich. *Hope and Hopelessness: Critical Clinical*