Genetic Counselors’ Impact on the Genetics Revolution: Recommendations of an Informed Outsider

By Patricia McCarthy Veach, PhD, LP

For the past 13 years I have used my training as a counseling psychologist to collaborate with Bonnie LeRoy, Director, Genetic Counseling Program, and Dianne Bartels, Associate Director, Center for Bioethics, University of Minnesota. Our research and training endeavors have given me an informed perspective on the genetic counseling profession. What I have learned is that genetic counselors possess a rare combination of genetics knowledge, insight into human behavior, and strong interpersonal skills. These qualities in conjunction with their unique training make genetic counselors eminently qualified to prepare society for rapidly expanding genetic tests and technologies.

Genetic counselors should be in the forefront of educational efforts in this genetics revolution, including training allied health professionals and informing potential consumers. Traditionally, genetic counselors have provided such services (Walker 1988), but their scope of influence has been limited. This may partly be due to how new genetic counseling is as a profession, approximately 30 years old. But I think another important reason for their limited influence is that...

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Stem-Cell Policy: A Stark Choice

By Jeffrey Kahn, PhD, MPH

Science matters – that’s a lesson taught a generation ago by Mr. Wizard and more recently by the likes of Bill Nye the Science Guy. The same lesson is playing out in this presidential election, as embryonic stem-cell research policy occupies a prominent place in the campaign.

Three years ago in August, President George W. Bush announced his administration’s policy regarding public funding for embryonic stem-cell research. In short, the policy allowed public funding for research on all the human embryonic stem-cell colonies (or lines) that existed on that date—eventually reported to be 72 lines in all.

In a compromise, Bush allowed limited research to go forward while promising that no new embryos would be used in stem-cell research involving federal funds, a decision based in part on his position regarding the moral status of human embryos—that they should be viewed as human beings and therefore deserve protections. To be consistent on such a view, however, would seem to argue for an outright ban on all research on embryos, public or private.

A total ban is much harder to accomplish, requiring legislative action by Congress before the President could sign it into law. While some have argued that stem-cell research funding is at its highest level ever, such claims are misleading.

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genetic counselors are settling for less than they deserve with respect to professional status and recognition. One way that genetic counselors can increase their professional status, and therefore their impact, is by setting clear boundaries vis a vis their profession. In order to do this, they must: 1) establish a model of practice; 2) seek licensure; and 3) increase their educational requirements.

Models of Practice

My colleagues and I studied genetic counselors, physicians, and nurses and identified 16 ethical and professional challenges that they encounter when their patients have genetic concerns. The third most prevalent ethical and professional challenge for genetic counselors was professional identity, and it involves uncertainty about the nature and extent of one’s roles and responsibilities. I believe that this uncertainty is largely due to the lack of an empirically-established model that clearly defines the scope of genetic counseling practice. Currently the profession relies on models borrowed from other fields, with little or no empirical validation in genetic counseling (Djurdjinovic 1988; Kessler 1999). For instance, historically genetic counselors have based their clinical practice on a nondirectiveness tenet which describes what they do not do (i.e., they do not make decisions for or coerce their patients).

Nondirectiveness has been criticized, however, for its failure to adequately describe what genetic counselors do (Kessler 1997). Furthermore, it is not well-understood. We have found that genetic counselors differentiate directiveness about process and outcome, but they still believe that being directive about process is undesirable. Genetic counselors should direct the genetic counseling process, for example by helping patients determine the factors they need to consider in making an informed decision. Additionally, they should provide input into outcomes by offering their professional opinions.

Despite doing an excellent job of explaining complex genetic information in understandable terms and being caring and involved in their interactions with patients, some genetic counselors resist sharing their professional wisdom (i.e., they refrain from disclosing what other patients have done). This is unfortunate, because although the individual patient’s perspective is essential, it represents an “n of 1.” In contrast, experienced genetic counselors have a data base consisting of hundreds of patients’ decisional processes and outcomes. Their clinical data base is a valid source of information that should be shared. Experienced genetic counselors also have listened to enough patients to recognize when their decisions are based on rational or irrational factors. They have a responsibility to point out when their patients’ thought processes and/or their decisions are atypical, and to confront patients whom they perceive as acting in haste, or failing to consider all relevant factors.

Another prominent model is the genetic counselor as educator. At its inception genetic counseling was primarily an educational activity (Kessler 1980). Given the options available to patients at that time, this model made sense. The counselor’s role primarily was data gatherer and lecturer, and her or his goals included obtaining a patient history, providing a genetics lecture, presenting options, and asking patients what they thought they would do. This educator model has lost its utility for current practice. Although education is a necessary component of genetic counseling, it is insufficient to describe the totality of the experience. One problem with the counselor as educator model is that it pretty much ignores another prevalent ethical/professional challenge that we identified in our research, that is, patient and counselor emotional reactions. The reasons that patients seek genetic counseling and the counseling experience itself often precipitate intense affect. When genetic counselors restrict themselves to an educator model, emotions are at best contained, and at worst overlooked.

Over the years, I’ve heard a number of genetic counselors question whether counseling appropriately describes their clinical practice. Although I used to think there might be a better term, I now believe that counseling is the best word and that a contemporary model of practice should emphasize counseling. In order to provide effective services, genetic counselors must be able to describe, understand, and predict patient behavior, and they must engage their patients in a decisional process that takes into account thoughts, feelings, actions, and the systems within which patients live. They have to listen to patients with a third ear, that is, intuiting the latent content in their situations. They also have to connect empathically with patients, which means feeling distress, uncertainty, and grief, and continually walking a fine line between connection and countertransference.
Patricia McCarthy Veach is a Professor in the Counseling and Student Personnel Psychology Program, Department of Educational Psychology, and Center Associate, Center for Bioethics, University of Minnesota. She received her masters and doctoral degrees in Counseling Psychology from Ohio State University. She is a licensed psychologist engaged in the professional preparation of mental health counselors and genetic counselors. Professor McCarthy Veach is a recipient of the University of Minnesota's College of Education and Human Development Distinguished Teaching Award and the award for Outstanding Contributions to Post-Baccalaureate, Graduate, and Professional Education.

Her primary research interests involve investigations of the genetic counseling process, and training and supervision of students in both genetic counseling and mental health counseling. Professor McCarthy Veach co-authored the first helping skills manual for genetic counseling students and the first book chapter on clinical supervision in genetic counseling. She was a co-investigator on a grant from the Josiah Macy Jr. Foundation to develop educational materials to help primary care providers address ethical and professional challenges posed by patients who have genetic concerns.

Currently she is co-developing a counseling skills videotape and a workbook intended to serve as supplements to the helping skills manual. She also serves as supervisor on several student research projects regarding genetic counseling. These projects are being conducted by students from both the Genetic Counseling program and the Counseling and Student Personnel Psychology program.

Professor McCarthy Veach is an associate member of the National Society of Genetic Counselors (NSGC), and an Editorial Board member of the Journal of Genetic Counseling. She is a frequent contributor to the journal and has made several presentations at NSGC annual meetings. She also conducts workshops on clinical supervision for genetic counseling training programs across the United States.

One of the missions of counseling psychologists is to “give psychology away.” Professor McCarthy Veach feels very fortunate to be able to do this through cross disciplinary research and training projects. The genetic counseling profession has been very generous in opening its door to her endeavors.

Selected Publications

Books

Articles


Of course, this is my opinion, and it suffers from the same lack of empirical validation as the nondirectiveness and counselor as educator models. It is essential that the genetic counseling profession generates an empirically-derived model of practice or it will continue to struggle with threats to its identity and professional status. Lack of a model leaves genetic counseling at risk of being co-opted or worse yet, eliminated.

**Professional Licensure**

In our research, colleague error was another major ethical challenge reported by the genetic counselors, and it consists primarily of errors committed by other health care professionals who either lack knowledge of genetics or apply their knowledge incorrectly. Genetic counselors need to continue educating other medical and allied health professionals regarding basic genetics, psychosocial concerns experienced by individuals who have genetic risks, and ethical and social implications of genetic testing and technologies. They also need to have a strong voice in determining how other health care professionals will use their knowledge of genetics. In doing so, genetic counselors must guard against attempts by other professionals to co-opt their work (something that may be prompted by shrinking client bases). It has been my experience that a number of professional groups would like a piece of the genetic counseling pie. Genetic counselors must retain their unique role in service provision. One way that they can preserve their characteristic functions is by seeking licensure for their profession. Genetic counselors in a few states are pursuing licensure, but their efforts have been met with resistance by some members of their own profession.

**Professional Preparation**

Currently, the terminal educational level for anyone interested in becoming a certified genetic counselor is a master’s degree. As genetic tests and technologies and subsequent patient decisions become increasingly complex, training programs are struggling to adequately prepare practitioners and researchers within a two-year framework. I believe that in order to meet the growing challenges, a certain percentage of genetic counselors needs to be trained at the doctoral level. Similar to many doctoral programs in counseling and clinical psychology programs, a scientist-practitioner training model would provide intensive preparation in basic science and applied skills. The validity of theory and research would be tested on a patient base, and clinical issues would shape the theories and research that are generated. Students would be prepared to be critical consumers and producers of research that furthers practice.

In order to deepen students’ understanding of how genetics may affect people intellectually, emotionally, and systemically, doctoral curricula should include courses in learning and cognition, individual differences (e.g., personality theory), and interpersonal and social bases of behavior. Coursework in research methods and statistics is necessary to stimulate more investigations of genetic counseling that are conducted by genetic counselors. Additional coursework should be offered in: marriage and family therapy, crisis intervention, clinical supervision, multiculturalism, group dynamics, bioethics, and public health. Doctoral preparation will deepen and broaden practitioner and researcher skills and further the status of the genetic counseling profession.

**Closing Comments**

In closing, I would like to say that I greatly appreciate my involvement with the genetic counseling profession. As an informed outsider I recognize how much this profession has to offer individuals and society. I also am aware of some of the potential pitfalls that it faces. My hope is that the genetic counseling profession will establish a clear professional identity that allows it to be a dominant force in this age of genetics.

**References**


Nearly two years after the discovery of human embryonic stem cells in 1998, President Bill Clinton directed the National Institutes of Health (NIH) to move forward with what would have been much more permissive rules for federal funding of embryonic stem-cell research. The election of 2000 put a stop to any funding until Bush could issue his own rules, culminating in the announcement of research restrictions in August 2001.

Three years later, the Bush policy has limited research in very real and important ways. Far fewer than the original 72 cell lines are available for research. The NIH puts the number at about 20, and those lines are quickly becoming the equivalent of using aging technology in an area of science that measures its rapidly advancing milestones of understanding in months rather than years.

Three years later, we are falling behind in the stem-cell race. Much cutting-edge science is taking place in parts of the world with fewer restrictions than in our own country: England, Sweden, Korea, Singapore and others. And the administration’s promise that private sector investment would pick up where public funding stopped has proven to be a hard sell.

Three years later, while President Bush continues to defend a policy that protects embryos as if they had the same rights as the rest of us, many Americans (even Nancy Reagan) believe that the gains from embryonic stem-cell research can be achieved in ethically acceptable ways, such as by using some of the 400,000 embryos left over from couples using in-vitro fertilization for reproductive purposes. There is broad bipartisan support in Congress for easing stem-cell research limits, and John Kerry has pledged to reverse the restrictions.

Three years later, the bigger question is whether science funding and science policy should be driven by expertise or ideology. Never before have the “culture wars” had such impact on science policymaking, with increasing evidence that appointments to federal advisory panels as well as eventual policies across a wide range of issues are being informed not by scientific evidence and by those with relevant expertise, but by political ideology.

Three years later, whose vision of science and stem-cell research is right for our country? Voters are paying attention to stem-cell research policy this election because the choice is stark and the stakes are real.

A version of this article appeared as an op-ed in the Minneapolis Star Tribune.

The Anonymous Mail Bag

By Steven Miles, MD

The Center for Bioethics gets (and welcomes) a lot of mail and e-mail. We are engaged in controversial issues. Most letters and e-mails get a personal reply. Then there are the anonymous letters. Some anonymous letter writers offer support for health care workers who face Board oversight for having sought mental health care. The venomous ones mostly come from people who are against abortion. (Incidentally, Center faculty do not represent a Center position. We speak our own minds and learn and debate our positions from and with each other.) During my support for MinnesotaCare and the Clinton health reform effort, a number of harsh anonymous letters came from people claiming to be physicians.

Recently, I received an unsigned letter from a budding ethicist who questioned the ethics of using the Bioethics Examiner “Calendar of Events” section to get large honorariums for public speaking. He/she had “heard” that Center faculty have agents to get these pricey talks and figured that a physician must be really cleaning up. None of the Center faculty whom I have polled use a booking agent. In my view, I am paid by Minnesota taxpayers through a land grant university to teach Minnesotans. Teaching can happen in a classroom, an art center, a Lion’s Club, a church, or a high school. Personally, I do as many talks as I can. All presentations sponsored by any Minnesota educational institution or student group are provided as a service. Here are the honorariums for the presentations that the anonymous writer was concerned about:

- Plymouth Church—Preparing for dying. This was at no charge because it is a typical non-profit community service talk and I never charge for talks at religious centers.
- Havana, Cuba—Comparing bioethics in the US and in Cuba. I financed the trip out of my pocket and do not charge honorariums for talks in developing countries.
- Cairo, Egypt—Human genomic research ethics. I waived the modest honorarium to free up more money to bring in scholars from developing countries. A small travel grant paid half of the airfare (because I was presenting a paper) and the conference covered room and board.
- Annual Meeting of Minnesota Academy of Family Physicians—Ethics and drug companies. I do not recall an honorarium; this is a non-profit Minnesota group so my practice is to waive all except travel expense.

I charge modest honorariums to lecture to non-Minnesota educational bodies, but I do not use an agent. I hold a 75% appointment at the University of Minnesota to ensure that outside consulting does not diminish my University commitments. I do not take any funds from pharmaceutical companies. My colleagues and I at the Center for Bioethics are required annually to fill out a form addressing potential conflicts of interest in our necessarily public roles. Keep those letters coming, preferably signed.
Recent Faculty Publications

BOOK

BOOK CHAPTERS

ARTICLES


SPECIAL EDITIONS
The Journal of Law, Medicine & Ethics
Guest Editors–Jeffrey Kahn, Anna Mastroianni
Kahn J, Mastroianni A. Introduction: Looking Forward in Bioethics (pp. 196-197).
De Vries R. How Can We Help? From “Sociology in” to “Sociology of” Bioethics (pp. 279-292).
Wolf S. Law & Bioethics: From Values to Violence. (pp. 293-306).
Ethics: What Guides our Practice, A special issue of Minnesota Medicine (June 2004)
Berlinger N. Patient Trust (pp. 32-34).
Ratner E, Bartels D, Song J. A Perspective on Homelessness, Ethics, and Medical Care (pp. 50-52).
Valapour M. Ethics of Organ Distribution in Lung Transplantation (pp. 36-37).


Center News

Joan Liaschenko, RN, PhD, has been awarded funding of $15,000 from the American Association of Critical Care Nurses (AACN) for her project “An Investigation of Factors Influencing Critical Care Nurses’ Inclusion of Families in End of Life Care.”

John Song, MD, MPH, MAT, Edward Ratner, MD, and Dianne Bartels, RN, MA, PhD, have been awarded an $8,000 grant from the University of Minnesota Consortium on Law and Values in Health, Environment & the Life Sciences for their project on end of life planning for homeless persons. This grant will support an October 12 conference which will focus on end of life care for people experiencing homelessness. Homeless persons, service providers, and end-of-life providers will be invited to participate.

David Satin, MD, has been appointed as a Post-Doctoral Fellow in the Center for Bioethics beginning July 2004. Dr. Satin is practicing at Smiley’s Clinic, and is Assistant Professor, Department of Family Medicine and Community Health, University of Minnesota. The focus of his work in bioethics is how best to teach clinical ethics and professionalism to medical students and residents.
Calendar of Events

**SEPT 13**
Jeffrey Kahn, PhD, MPH, will participate as moderator for the keynote debate “Ethical Issues Surrounding Live Organ Donation” at the United Resource Networks 13th Annual National Clinical Conference, Minneapolis, MN. For information, visit www.urnweb.com.

**SEPT 14**
Jeffrey Kahn, PhD, MPH, will speak on “Embryonic Stem Cell Research — Implications for Future Medical Practice” at the Mercy/United General Medical Staff Meeting, Minneapolis, MN. For information, call 763-236-8186.

**SEPT 22**
Jeffrey Kahn, PhD, MPH, will speak on “Ethical and Policy Issues in Surrogate Consent for Living Organ Donation” at the University of Minnesota, Department of Surgery, Weekly Transplant Conference, Minneapolis, MN. For information, call 612-625-1400.

**OCT 4**
Dianne Bartels, RN, MA, PhD, will speak on “Dying Without A Home: Needs and Wishes of People Experiencing Homelessness” at the Minneapolis American Association of University Women (AAUW), Minneapolis, MN. For information, call 612-624-9440.

**OCT 6-7**
Steven Miles, MD, will speak on “US Health Care Reform” on 10/6, Dr. Miles will be the keynote speaker on the “Hippocratic Oath.” Both events will be held at the Center for Professional and Applied Ethics, University of North Carolina – Charlotte, NC. For information, email: rotong@email.uncc.edu.

**OCT 10**
“Homelessness and End of Life” conference, sponsored by the Center for Bioethics will be held on the University of Minnesota campus. For more information, contact the Center at 612-624-9440.

**OCT 14**
Jeffrey Kahn, PhD, MPH, will speak on “Little Cells, Big Issues: Ethics and the Embryonic Stem Cell Research Debate” at Medical Grand Rounds at Annenberg Center for Health Sciences, Palm Springs, CA. For information, email: gwest@annenberg.net.

**OCT 18**
Steven Miles, MD, will speak on “Concealing Lethal Medical Mistakes” at the Albert Lea Medical Center, Albert Lea, MN. For information, call 507-373-3284.

**OCT 22**
Steven Miles, MD, will speak on “Ethical Issues Inherent in End of Life Care Decisions” at “The Impact of Government on End of Life and Health Care Decisions” conference, Meriter Hospital and Clinics, Madison, WI. For information, email: jgrams@meriter.com.

**OCT 23**
Steven Miles, MD, will speak on “Culturally Sensitive and Successful Tuberculosis Treatment in a Refugee Camp” for the American Medical Students Association – University of Minnesota Chapter, Minneapolis, MN. For information, email: thom1714@umn.edu.

**OCT 24**
Steven Miles, MD, will speak on “End of Life Care Issues” at Temple Israel, Minneapolis, MN. For information, visit www.templeisrael.com.

**OCT 28**
Jeffrey Kahn, PhD, MPH, will speak on “Bioethics of Human Embryonic Stem Cell Research” for the Karolinska Institute Symposium, co-sponsored by the University of Minnesota Medical School, Minneapolis, MN. For information, visit www.maped.umn.edu/imer.

**OCT 28-31**
Joan Liaschenko, RN, PhD, Debra DeBruin, PhD, and Stashia Fischer, RN, DNSc, will speak on “Negotiating Everyday Morality in Clinical Trials” at the Canadian Bioethics Society Annual Meeting, Calgary, Alberta, Canada. For information, call 403-208-1619.

**OCT 31**
Jeffrey Kahn, PhD, MPH, will participate on a panel “Disclosing Research Results to Participants in Genetic Research: Clarifying the Debate” at the American Society for Bioethics and Humanities (ASBH) Annual Meeting, Philadelphia, PA. For information, visit www.asbh.org.

**NOV 11-13**
Carol Tauer, PhD, will speak on “Understanding the Legal and Policy Environments in Which Assisted Reproductive Technologies (ARTs) Developed” at the Serono Symposium on ART and Embryo Law: Practice, Policy, Regulation and Ethics in Cambridge, MA. For information, call 612-624-9440.

**NOV 12**
Jeffrey Kahn, PhD, MPH, will speak on “Ethics and the Making of Science Policy in the United States — Stem Cell Research as a Case Study” at the International Association of Bioethics 7th World Congress of Bioethics, Sydney, Australia. For information, visit www.bioethicsworld-congress.com.

**NOV 12-14**
Stashia Fischer, RN, DNSc, Deb DeBruin, PhD, and Joan Liaschenko, RN, PhD, will speak on “Nurses: Research Integrity in Clinical Trials” at the Office of Research Integrity’s 3rd Research Conference on Research Integrity, San Diego CA. For information, call 612-624-9440.

**NOV 14**
Dianne Bartels, RN, MA, PhD, will participate on a panel “Ethics of Stem Cell Research” at the Seoul National University/ University of Minnesota 50th Anniversary Celebration, Minneapolis, MN. For information, call 612-624-9440.

**NOV 17**
Jeffrey Kahn, PhD, MPH, will speak at the University of Tasmania Centre for Law and Genetics, topic to be announced, Hobart Tasmania, Australia. For information, email: Don.Chalmers@utas.edu.au.

**NOV 17**
Steven Miles, MD, will participate on a panel “New Areas of Liability in Research Ethics” at the Medical Alley Conference, Minneapolis, MN. For information, call 612-766-8081 or visit www.medicalalley.org.

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**Center for Bioethics Seminar Series**

Seminars will be held on the University of Minnesota campus from 12:15 to 1:30 pm. For information, contact the Center at 612-624-9440.

**Nov 19**
Timothy Murphy, PhD, University of Illinois College of Medicine will speak on “Members First: The Ethics of Donating Organs and Tissues to Groups.”

**Jan 14**
Donald Brunquell, PhD, LP, Children’s Hospitals and Clinics, and Dianne Bartels, RN, MA, PhD, will speak on “Futility Guidelines.”
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Bioethics Overviews

Overviews contain a brief summary of ethical and legal issues, key articles, and a bibliography. They are available for $5 each or may be downloaded from the Center’s website at www.bioethics.umn.edu. Topics include:

- Ethics of Organ Transplantation
- Human Stem Cells: An Ethical Overview
- Withholding or Withdrawing Artificial Nutrition and Hydration
- Termination of Treatment of Adults
- Distributing Limited Health Care Resources
- Resuscitation Decisions
- The Determination of Death
- New Frontiers in Genetic Testing and Screening

To order, make checks payable and mail to:
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