

Issues up close

Genetics and ethics in health care and nursing



TO HELP NURSES provide competent care in the genomic era, the American Nurses Association and the International Society of Nurses in Genetics, Inc., have co-published *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health*, a new resource for students, nurses, educators, researchers, and others in academia, government, and industry.

The following excerpts from *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health*, were written by the book's editor, Rita Black Monsen, DSN, MPH, RN, FAAN. Dr. Monsen has been involved in clinical genetics and genetics in nursing education since the late 1970s and has also served in leadership roles with the Arkansas Department of Health Genetics Advisory Board, National Coalition for Health Professional Education in Genetics, Genetic Nursing Credentialing Commission, International Society of Nurses in Genetics, and Arkansas Nurses Association. Dr. Monsen has published extensively on genetics in nursing and is also an editor of the *Journal of Pediatric Nursing*.



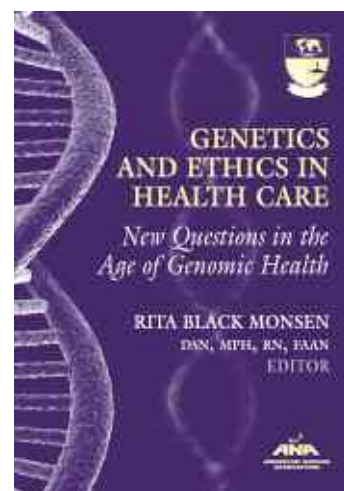
The American Nurses Association has consistently led all the nurses in our nation over the past century, as our professional organization, by its dissemination of standards of care, scopes of practice, and code of ethics. As genomic healthcare becomes more and more commonplace in the next decades, nursing will be obligated to keep its professionals ready and well prepared to serve. Certainly, this obligation supersedes any other nursing agenda for our nation and across the world.

The aim of *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health* is to bring forward the new questions associated with advances in genetics technology and genomic health care now proliferating across our nation and the world.... [As a society,] we may be offering testing for genetic mutations or treatments for gene-based health problems without totally understanding and anticipating the possible harms or undesirable effects that may accompany them.

[The book also] provides a showcase for voices that we do not often encounter in our literature, voices from communities of color: diverse religious and ethnic communities that are all around us but seldom ap-

pear in our science-based discussions of genomic health care.... While we could not include representative contributions from all of the major cultural groups, we have attempted to present a cross-section of religious and ethnic groups. This effort was made in view of the role that the International Society of Nurses in Genetics has made to invite participation by nurses in our global community. In addition, the American Nurses Association has supported, and in some instances led, efforts to educate nurses as they provide care across cultural lines and in concert with diverse providers and consumers here and abroad.

In many ways, [the] new questions about genetics and genomics in human life present dilemmas with no good answers. They are similar to the many ethical



questions we have seen over our lifetimes in healthcare arenas. In their similarity, they may engender conversations that call us to consider the basic principles of ethics and morality and the meaning of health and quality of life in the twenty-first century. Are these principles still relevant? Can we cast the questions that arise out of genetics and ge-

nomomic health care in terms of goodness or appropriate comportment as we practice our chosen profession and serve others? One valuable guide, the code of ethics of the American Nurses Association, will always continue to frame our thoughts and actions as these questions arise with new discoveries in genetics and genomics that are revolutionizing our definitions of health, illness, and cure.



This book is about what we have accomplished at this point in the history of humanity's quest to understand the causal factors in health and illness.... Part 1 presents the significant documents...that govern nursing practice in working with patients and families who have genetic concerns, [including] the American Nurses

Association Code of Ethics and the description of the scope and standards for nurses in genetics.... This section also discusses implications for human life; our understanding of identity and the legacies that we pass on to our offspring. We close with cautions about the use of genetic and genomic discoveries; the dangers of commercial exploitation of individuals, families, and communities as genetic technologies proliferate in agriculture, health care, and athletics.

We are most concerned, finally, with the possibility of inadequate preparation of healthcare professionals to utilize gene-based diagnostics and therapeutics appropriately for the improvement of health and quality of life of entire societies.

Part 2 presents perspectives from communities that represent large population segments whose religious and cultural allegiances are integral to the experience of family life and making health decisions. While not all major groups have been included, a diverse selection of voices is presented. These chapters are included to provide a glimpse into the thinking and decision-making patterns seen in several religious and cultural traditions, some not directly discussing genomic technologies. They may be helpful as we collaborate with peoples from diverse cultural and religious communities to inform them about their options with regard to genetic and genomic health.

Part 3 discusses selected applications of genetic and genomic technologies, particularly the current patterns of mutational testing that are widely available today, in areas affecting adults and children and those with known risks for cancer, Huntington's disease, and cystic fibrosis. Again, while not all highly prevalent genetic conditions are presented, a selection of some of the major health problems that affect millions of Americans as well as millions across the globe do appear here.

While these chapters present the more common tests, the reader should know that additional mutational analyses are being transferred from the laboratory to the clinical setting. One of the most rapidly advancing areas of research is expected to broaden our understanding of the appearance of such population-level causes of morbidity and mortality as heart disease, cancer, and diabetes. We are moving quickly to the place in our history when we will be able to study the interplay of several genes as well as environmental factors that result in conditions of health and illness.

Part 4 concludes the book with several case studies that illustrate what families face in specific circumstances that involve genetics, genetic testing, and the care of family members who are affected with a genetic condition. We can get a glimpse of the burdens associated with gene mutations that may spread through families and that have the potential to affect many future generations.



Nursing, as the preeminent healthcare profession, should therefore continue to lead its members to ever-evolving education coupled with recognition of the ethical obligations attendant on new knowledges and technologies. A precept such as this is timeless, no matter what social and economic pressures present themselves in healthcare delivery.



As for the greater fabric of development in health care, we can be sure that increasing successes will be sought for understanding our genetic makeup, for manipulating our genes and genomes to enhance our capacities for longer and more comfortable lives.... [T]hose of us interested in the human experience will continue to ask about the boundaries of a meaningful, fulfilling life, about the access and appropriateness of care for all peoples, about respect for cultural and religious allegiances and traditions, and about the ultimate center of control of the human experience—the individual in the context of family and community.

We will see advances in technology transfer from the laboratory bench to the healthcare setting as long as society supports excellence in scientific scholarship (and scholarship in all areas of human inquiry), human and material resource deployment for genomic testing and treatment, and proliferation of adequately prepared nursing professionals and other providers of direct care services.

...[T]here will continue to be exploitation of vulnerable populations: we haven't really learned a great deal from history (as is seen in many of the discussions in this text) and are likely to repeat some of our mistakes. To the extent that we permit inquiry into ethical practices and engage in conversations that call for truth telling (most importantly to ourselves), we can hope to realize greater benefits from our discoveries and hope to ease the suffering of all those who wish for help.

This book was intended to highlight some of the new questions facing us now, and questions that will appear on the horizon in the next decade. It is likely that our culture and our values regarding health and illness will change as these new possibilities emerge. Nurses, other healthcare professionals, and scholars in the sciences and humanities must join together to consider the immense impact of genomic developments on our civilization. This book is one early step in that direction.

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