An Ethical Assessment Framework for Addressing Global Genetic Issues in Clinical Practice

Judith M. Cassells, RN, DNSc, Jean Jenkins, RN, PhD, FAAN, Dale Halsey Lea, RN, MPH, APNG, FAAN, Kathleen Calzone, RN, MSN, APNG, and Eunice Johnson, RN, MSN

**Purpose/Objectives:** To describe the perceptions of nurses regarding the importance of each action skill listed in the Ethical Assessment Framework (EAF) to their ethical decision-making process and how prepared they were to undertake each action when confronted by moral dilemmas in clinical practice, and to identify general genetic ethical issues of concern and frequency encountered.

**Design:** Descriptive, exploratory.

**Sample and Settings:** Members of the Oncology Nursing Society’s Cancer Genetics Special Interest Group (n = 34) and the International Society of Nurses in Genetics (n = 101).

**Methods:** Participants completed the Ethical Assessment Skills Survey and Genetic Ethical Issues Survey.

**Main Research Variables:** Perceptions of level of importance and preparation for each action skill in the EAF and level of concern and frequency encountered regarding ethical issues in clinical practice.

**Findings:** Each ethical action skill listed in the EAF was rated as important to the ethical decision-making process, although minimal skill level was reported in 60% of the steps. Nurses reported major concerns about the frequently encountered issues of confidentiality, managed care, and informed consent.

**Conclusions:** The EAF proposes action skills that can assist nurses in developing expertise in ethical decision making and offers a model for addressing genetic ethical issues in clinical practice. Protection of patient confidentiality was the number one ethical concern of nurses surveyed.

**Implications for Nursing:** Nurses are challenged to have comprehensive and current genetic knowledge, which is necessary to advocate for, educate, counsel, and support patients and families confronting difficult genetic healthcare decisions. Nurses will be able to effectively translate genetic information to patients by developing and using ethical decision-making and counseling skills. Effective measures to protect confidentiality of patient data are important to ensure that genetic information is safeguarded.

**Key Points . . .**

- The Ethical Assessment Framework outlines action skills that assist nurses in making ethical decisions in genetic oncology practice.
- Continuing education programs in ethics are needed to support nurses in developing their ethical decision-making skills as genetic issues become more prevalent in patient care.
- With the rapid scientific advances in genetics, additional qualified providers to give genetic counseling, especially nurses with oncology and genetic expertise, are needed to prepare patients and families to make informed decisions about their health care.
- Safeguards and procedural guidelines must be continually developed, implemented, and revised to protect confidentiality of patient information.

**Biologic and technologic advances generated from genetic research are having a dramatic impact on the expanding role of nurses in current healthcare practice. Important international research is under way with the Human Genome Project. The National Institutes of Health, in collaboration with researchers in the United States, England, France, Italy, Japan, and China, have successfully identified the basic DNA code of the human being. The goal of this research is to provide a map of the entire human genome. The genome is estimated to contain 30,000–35,000 genes that control every aspect of human life, from what a person looks like to the health problems that he or she might develop, including cancer (Baltimore, MD, Bethesda, MD).**

Judith M. Cassells, RN, DNSc, project investigator, is a research consultant at the National Cancer Institute, National Institutes of Health, in Bethesda; Dale Halsey Lea, RN, MPH, APNG, FAAN, is the assistant director for Southern Maine Genetic Services at the Foundation for Blood Research in Scarborough; Kathleen Calzone, RN, MSN, APNG, is a nurse specialist (research) at the National Cancer Institute, Center for Cancer Research, Genetics Branch, in Bethesda; and Eunice Johnson, RN, MSN, is a board member for the Center for Ethics and Human Rights for the Maryland Nurses Association. This project was supported by the Oncology Nursing Society’s Cancer Genetics Special Interest Group and the International Society of Nurses in Genetics. (Submitted April 2002. Accepted for publication December 1, 2002.) (Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society.)

Digital Object Identifier: 10.1188/03.ONF.383-390