ARTICLES

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

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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 and 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,

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2001; Venter et al., 2001). These discoveries are revolutionizing health care by expanding genetically based diagnostic, prevention, and treatment options.

The list of thousands of diseases with genetic etiology and the tests to identify them grows daily, as do emerging complex issues. More than 800 genetic tests now are available commercially or are in research development (Burke, Pinsky, & Press, 2001; Gene Tests, 2001). The benefits of genetic testing are many and range from early detection of treatable disorders to prevention interventions before the onset of symptoms for those who are at risk for a genetic disorder (International Society of Nurses in Genetics [ISONG], 2000). Genomic medicine will allow providers to identify a person's genetic predisposition to a given disease; predict its onset, extent, and severity; and provide prognostic indicators based on a basic molecular profile (Lea & Williams, 2001). Because an individual's genetic information is permanent and cannot be altered at this time, any decision about health care can have major implications for patients and family members across generations (Scanlon & Fibison, 1995). The identification of disease-causing genes, opportunity for gene transfer, genetic enhancement, or the replication of a person from the genetic material of a single cell present possibilities for good and harm. Concerns that arise include whether an individual should undergo genetic testing, whether a disruption in family relationships would occur if such tests are done, and whether gene treatments are accessible and available to everyone.

Nurses have been recognized for their ability to guide patients and families through the wellness-illness continuum. They are likely to be the first providers to whom patients turn with questions about genetic risk, the meaning and interpretation of genetic tests, and whether they should be tested or treated. As providers of genetic services, oncology and genetic nurses should be especially prepared to incorporate ongoing scientific advances in genetics into everyday care. Recent advances in genetics will have an impact on oncology clinical practice in an unprecedented way because they will improve cancer detection and diagnosis. Nurses must be knowledgeable about this expansion of genetic knowledge to effectively translate this information to patients and families (Stolzfus, Rust, & Ried, 2001). For example, a major developing genetic area is the emerging proteomics field being elucidated within the Human Proteome Project.

Understanding of global and temporal protein expression patterns can lead to the early diagnosis and therapy of cancer and other diseases (Patterson & Aebersold, 2003). Oncology nurses, who are being called on to conduct genetic risk counseling, cannot effectively counsel patients without an understanding of basic molecular biology as it relates to DNA testing for cancer predisposition (Loescher, 1998). Few healthcare providers understand basic genetic principles or the science underlying the genetic testing process (Jacobs & Deatrick, 1999). With the growing availability of molecular genetic testing, major issues that nurses are experiencing include concerns about how to counsel and assist patients and families in making complex decisions, ensure confidentiality of genetic information, and give sufficient and relevant information for patients to make informed decisions about genetic interventions (Cassells et al., 2000; Gaul, Cassells, Lea, Calzone, & Jenkins, 1999).

Standards of nursing practice recommend that nurses consider using an ethical framework when addressing these potentially complex ethical issues (ISONG & American Nurses Association [ANA], 1998). Core competencies in critical thinking require knowledge and skill in using an appropriate ethical framework (American Association of Colleges of Nursing, 1998). An Ethical Assessment Framework (EAF) can provide nurses and other healthcare providers with specific actions that can assist the decision-making process in resolving ethical dilemmas as they occur in clinical practice (Brody, 1981; Cassells & Gaul, 1998; Cassells, Gaul, Lea, Calzone, & Jenkins, 1999; Christensen, 1988; Jonsen, Seigler, & Winslade, 1992; Silva, 1990; Thompson & Thompson, 1985).

Recognizing the potential clinical value of ethical frameworks to assist nurses when confronted with such issues, an ethics project committee evaluated the usefulness and importance of the EAF (Cassells et al., 1999, 2000; Cassells & Gaul, 1998; Cassells & Redman, 1989; Cassells, Redman, & Jackson, 1986; Cassells, Silva, & Chop, 1990). The EAF was chosen for the study because it had been adopted by the Maryland Nurses Association's Center for Ethics and Human Rights as a model to address ethical case studies and used as survey instrument in a number of research undertakings. The committee was comprised of members of the Oncology Nursing Society (ONS) and ISONG, as well as other nurses with expertise in nursing ethics who were concerned about emerging ethical issues in oncology and genetic health care. Permission was obtained in 1998 from ISONG and ONS's Cancer Genetics Special Interest Group to survey their members. These two cohorts of nurses were two convenience samples identified as having an interest in genetics or experience in confronting genetic issues. They were asked to assess the importance in clinical practice of 12 action skills outlined in the EAF (see Figure 1). Additionally, participants were asked to identify selected major ethical issues of concern and how frequently they encounter them.

The overall purpose of this descriptive, exploratory study was to gather baseline data about nurses' ethical assessment skills and their ethical issues of concern when caring for patients facing complex decisions about genetic health care. The EAF provided the conceptual framework for the study and a construct of behaviors that assist in assessing and resolving ethical issues in clinical practice. Dickoff, James, and Wiedenbach (1968), in a practice-oriented theory, advocated that nursing action should be governed by the steps of a procedure for the activity. They wrote that the procedure should emphasize the paths, steps, rubric, or, more generally, the problem for which the activity is performed. In this study, the EAF provided the steps for the activities to be used in assessing and evaluating ethical issues as they occur in practice. Nurses must take continual action to evaluate methods to enhance the effectiveness of nursing activities.

Methods

In the spring of 1998, a study packet containing an explanatory letter, a copy of the 12 action skills listed in the EAF, and two survey instruments was mailed to 225 nurses who were members of ISONG. One hundred and one ISONG nurses (45%) returned the Ethical Assessment Skills Survey (EASS) and Genetic Ethical Issues Survey (GEIS). In the fall of 1998, the same survey tools were mailed to 89 members of ONS's Cancer Genetics Special Interest Group. Thirty-four nurses (38%) completed and returned their surveys. The final combined number of study participants was 135.

Ethical Assessment Framework

Assessment

1. Identify the concern or issue that may be an ethical problem.
   - Uneasiness, uncertainties, and/or conflicts
2. Gather relevant facts about the problem(s).
   - Medical data: objective and subjective
   - Contextual data: circumstances and people involved
   - Institutional policies and state and federal laws
3. Determine if the problem is an ethical dilemma.
4. Propose actions and options to assist in resolving the ethical dilemma.
5. Apply methods of ethical justification to each action and option to assist in resolving the dilemma.
   - Consequentialism (consequences), deontology (duty), principalism (principles), care (relationships), casuistry (cases), virtue (character)
6. Identify and clarify values, rights, and duties of patient, self, and significant people associated with the dilemma.
7. Apply relevant guidelines from nursing and professional codes of ethics.
8. Identify and use relevant interdisciplinary resources (e.g., ethics committees, consultants, administrators, clergy, ethicists, lawyers, colleagues, literature).
9. Prioritize the identified actions and options to assist in resolving the dilemma.

Plan of action

10. Select an ethically justified action or option from those identified.

Implementation

11. Act on and/or support the action or option selected.

Evaluation

12. Evaluate the selected action or option (short- and long-term outcomes).

Figure 1. Ethical Assessment Framework for Clinical Practice

© 1998. Ethical Assessment Framework (EAF). Ethical Assessment Skills Survey Instrument (including EAF): Judith M. Cassells, RN, DNSc, and Mary C. Silva, RN, PhD, 1990; revised: EAF/11 Steps in Nursing Process: Cassells, J.M., Johnson, E., & Littlejohn, J., 1996; revised: EAF/12 Steps with Definitions: Cassells, J.M., & Gaul, A.L., 1998. Reprinted with permission.

Participants were assured that all survey data would be confidential and that only aggregate data would be reported. Completion and return of the survey indicated a desire to participate.

Instruments

Development of the EAF and EASS was initiated in 1983, and they have been tested in a number of national and international studies that have included more than 2,000 nursing students, administrators, and practicing nurses (Cassells et al., 1986, 1990, 1999; Cassells & Redman, 1989). An 11-step framework for ethical action was incorporated into the nursing process in 1996 and expanded to 12 ethical actions skills in 1998 (Cassells & Gaul, 1998). The EAF served as a curriculum model for implementing continuing education courses in ethics for practicing nurses by the Maryland Nurses Association. Content and expert validity tests were undertaken during the development and revision of the instruments. Reliability for the EAF and EASS was established by the test-retest method, with a coefficient alpha of 0.87.

The EASS describes the 12 skills for ethical action in the EAF. Participants were asked to rate the importance of each ethical action skill in column A and their skill level for each action in column B. After completing the EASS survey, par-

ticipants were asked whether the EAF was useful for clinical practice and if they would add or delete any steps.

The second part of the study was the completion of the GEIS, which was constructed for this study. The GEIS was divided into two sections. Section A consists of ethical issues in general nursing practice. Section B consists of ethical issues considered to be specific to genetic nursing practice. Participants were asked to rate their level of moral concern with each issue and how often they encountered each issue in their clinical practice. Content validity was established by selecting items from current ethics literature, constructing the questionnaire, and submitting it to a panel of experts (i.e., nurse practitioners, educators, and researchers) who had expertise in genetics, research, or ethics. After completion of the pilot test, the survey was revised. Reliability was established by the test-retest method, with a coefficient alpha of 0.92. Respondents identified their level of moral concern for both general and genetic issues (column A) and the frequency with which they encountered the issues in practice (column B).

Data Analysis

Outcome variables on the EASS are rated on a four-point Likert scale (1 = not important to 4 = very important); the level of skill for each ethical action is rated similarly (1 = not skilled to 4 = very skilled).

The GEIS outcome variables also are rated on four-point Likert scales. The level of concern for each general and genetic issue is rated from 1 (not concerned) to 4 (very concerned); the level of frequency that the issue of concern is encountered is rated from 1 (not frequently) to 4 (very frequently).

The ISONG and ONS data were combined to provide a comprehensive database from the two nursing groups evaluating the same framework and issues. SPSS® PC Version 4.0 (SPSS Inc., Chicago, IL) was used to conduct analyses of the data. Statistical tests included frequencies, percentages, ranges, means, and standard deviations.

Results

Sample

The mean age of the 135 nurse participants was 46 years (range = 26–65 years). The mean number of years employed in nursing was 20.8 years, with a range of 3–47 years. More than 55% (n = 74) of the respondents reported working either in a hospital or an outpatient clinic and 13% (n = 18) in schools of nursing. The majority of the participants were employed in clinical practice, with 46% reporting to be in advanced practice (n = 62) and 5% in staff positions. Twenty respondents were employed in educational positions, and 15 held administrative or managerial positions. Only 4% of the respondents (n = 5) indicated that they were certified genetic counselors. The remaining 24 participants (18%) indicated that they were working in other positions, including clinical research nurse, clinical nurse specialist, and case manager.

Eighty-one of the participants (60%) reported that they had either a master's degree or a doctoral degree in nursing. Forty nurses (30%) also reported having degrees in other fields, including public health, science, education, genetics, psychology, and liberal arts. Thirty-eight nurses (29%) reported that genetic nursing was their primary clinical nursing specialty

area, whereas 33 nurses (25%) indicated that oncology was their specialty area.

Importance of and Skill Level for Each Ethical Action

Table 1 lists each ethical action skill from the EAF from the highest to the lowest skill level reported followed by the perceived importance of each action by the respondents. More than 90% of the 135 participants reported that each ethical action skill in the EAF was highly important (mean importance ranged from 3.4–3.9), although they reported being minimally skilled in 60% of the steps ($\overline{X}$ skill range = 2.5–3.5). Most nurses indicated that they were very skilled in gathering relevant medical and contextual (i.e., circumstances and people involved) data and able to identify the concern or issue that may be an ethical problem. Moderate skill was reported in (a) using interdisciplinary resources, (b) determining if the problem is an ethical dilemma, and (c) gathering facts about institutional policies. Although reported as very important, the three skills for which nurses perceived they were least prepared were applying methods of ethical justification to actions proposed, gathering relevant facts about state and federal laws, and evaluating actions or options taken. Ninety percent of the respondents (n = 122) said the EAF was useful for clinical practice. Only 13 nurses recommended adding, deleting, or changing any of the ethical action skills. Many recommendations were to clarify the specific ethical action skill, not to eliminate, add, or change the ethical actions skills listed in the EAF.

General Issues of Concern

Table 2 lists each general ethical issue from the highest to the lowest level of concern followed by how frequently it was encountered in clinical practice. More than 90% of the respondents reported that the four general issues of most concern in their nursing practice were related to confidentiality, managed care, informed consent, and allocation of healthcare resources. These issues also were the most fre-

quently encountered issues in clinical practice. A child or surrogate decision maker's role in the decision-making process was expressed as a concern by 83% of the respondents (n = 112), although the issue was encountered less frequently. One hundred thirteen respondents expressed concern about observing a healthcare team member in a noncaring or noncompassionate interaction with a patient; however, the issue was not encountered frequently in practice. The remaining issues identified in Table 2 caused a level of moderate concern even though they were encountered less frequently in clinical practice.

Genetic Ethical Issues of Concern

Table 3 lists each genetic ethical issue from the highest to the lowest level of concern followed by the frequency the issue was encountered in practice. The majority of the 18 genetic ethical issues listed were rated at a high level of concern by more than 85% of the respondents. As part of the GEIS, section B, participants were presented with four theoretical clinical situations regarding potential cloning and germ line therapy. About 90% of the nurses expressed major concern about cloning to replace a deceased child ($\overline{X}$ = 3.66, SD = 0.74) or cloning a genetic child for a genetic offspring ($\overline{X}$ = 3.47, SD = 0.76). Three-fourths of the respondents expressed concern about germ line therapy for serious illness or personal enhancement.

Discussion

Limitations and Recommendations

Findings from this study should be interpreted with caution. Conclusions were based on a small sample from two nursing organizations. Replication studies with larger nursing samples are recommended and should include nurses with different educational backgrounds, from various specialty areas, and representing more nursing organizations. A longitudinal design would help to establish a comprehensive database of the

Table 1. Skill Level and Importance of Each Action or Activity in the Ethical Assessment Framework

Action or Activity	Perceived Skill Level		Perceived Importance	
	$\overline{X}$ [a]	SD	$\overline{X}$ [b]	SD
Gathering relevant medical facts	3.469	0.65	3.891	0.31
Gathering contextual data	3.362	0.70	3.775	0.44
Identifying a concern or issue that may be an ethical problem	3.299	0.55	3.815	0.39
Using interdisciplinary resources	3.090	0.86	3.677	0.56
Determining if the problem is an ethical dilemma	3.083	0.64	3.609	0.58
Gathering relevant facts about institutional policies	3.038	0.73	3.651	0.55
Acting on action selected	2.977	0.81	3.699	0.46
Proposing actions and options	2.932	0.73	3.729	0.46
Clarifying values, rights, and duties	2.872	0.76	3.722	0.48
Applying guidelines from relevant codes of ethics	2.855	0.79	3.534	0.54
Prioritizing actions identified	2.789	0.80	3.451	0.58
Selecting an ethically justified action	2.774	0.77	3.654	0.54
Evaluating action or option taken	2.729	0.87	3.617	0.52
Gathering relevant facts about state and federal laws	2.611	0.77	3.677	0.52
Applying methods of ethical justification to each action proposed	2.511	0.83	3.433	0.60

N = 135

[a] 1 (not skilled) to 4 (very skilled)

[b] 1 (not important) to 4 (very important)

Table 2. General Ethical Issues of Major Concern and Frequency Encountered

General Ethical Issue	Level of Concern		Frequency Encountered	
	$\overline{X}$[a]	SD	$\overline{X}$[b]	SD
Protection of patient confidentiality	3.78	0.51	3.50	0.72
Impact of managed care delivery systems on the quality of patient care	3.72	0.54	3.25	0.90
Provision of sufficient information for informed consent for treatment or research	3.59	0.71	3.29	0.86
Equitable allocation of healthcare resources	3.56	0.67	2.74	0.95
Prolonging life in patients with poor prognosis or terminal illness	3.40	0.77	2.18	1.05
Nondisclosure of pertinent information and truth telling	3.39	0.78	2.45	0.92
Observation of members of healthcare team in noncaring or noncompassionate interactions with a patient	3.39	0.87	2.24	0.85
Respecting the patient's refusal of treatment	3.36	0.84	2.59	0.84
Accurate evaluation of the patient's competency to consent	3.29	0.81	2.57	0.97
Resuscitation (to perform or not)	3.27	0.82	1.82	0.98
Removal of life support that includes artificial nutrition or hydration	3.21	0.84	1.64	0.84
Recognition of validity of a child's assent for or against treatment	3.15	0.86	1.72	0.90
Concern about a surrogate decision maker acting in best interest of a patient	3.07	0.73	2.01	0.91

N = 135

[a] 1 (not concerned) to 4 (very concerned)

[b] 1 (never encountered) to 4 (frequently encountered)

types of ethical issues that nurses are encountering in a changing healthcare system. The status of their skill levels to address ethical dilemmas also should be monitored, in addition to specific sources that supported the development of their ethical decision-making abilities. The instruments could be adapted to expand the research to include patients and comparisons made to the nursing data.

Ethical Skills

Most participants indicated that each ethical action skill listed on the EAF was very important to the ethical decision-making process and useful for clinical practice. In a prior study, nursing administrators reported that each action skill was important and that applying ethical theories and principles was the skill that their nursing staffs were least prepared to undertake (Cassells et al., 1990).

Regarding perceived skill level for each action, the majority of participants reported being moderately to very skilled in gathering relevant medical and contextual data. This is congruent with one of the most important roles of nurses as primary care providers. The data indicate that nurses are prepared to collect relevant information that will assist them in planning and implementing effective patient care.

Respondents perceived that they had minimal skill level in their ability to propose actions and options to resolve ethical dilemmas. Nurses can expand their knowledge and skills in identifying alternative options to resolve ethical dilemmas as they occur in their practice through discussion with colleagues and others associated with the dilemmas (Erlen & Burns, 1992). They also reported being minimally skilled in evaluating the actions taken. The current emphasis on utilization in the United States healthcare system may be impeding healthcare providers' ability to evaluate long-term outcomes of patient care given.

Nurses reported being minimally skilled in applying methods of ethical justification for each action proposed and gathering relevant data about state and federal laws. Similarly, more than 1,000 RN and generic students in previous

EAF surveys indicated they were least prepared in applying state and federal laws and applying ethical theories and principles in resolving ethical dilemmas (Cassells & Redman, 1989). Basic and advanced education courses in ethics and law as they relate to healthcare issues must be integrated into nursing programs because laws need to be considered in directing actions, seeking consultation, and requesting necessary assistance in selected patient care situations. The ultimate goal of laws is to protect individual rights without jeopardizing the welfare of the general population (Cassells & Gaul, 1998). Nurses need ethical and legal knowledge to fulfill their responsibilities to protect patients' rights. Healthcare institutions should provide continuing education programs in these areas for their nursing staff. The Human Genome Project recognized the importance of considering the ethical, legal, and social ramifications of human genetic information. At its inception, the Human Genome Project established the Ethical, Legal, and Social Implications Program (ELSI) to identify and analyze ethical, legal, and social issues as they arise from genetic research (Lea, Jenkins, & Francomano, 1998). ELSI is an important and excellent resource for information as well as policy suggestions for nurses as they confront complex genetic ethical issues in their practice.

General Issues of Concern

Protection of patient confidentiality was identified as the major general issue of concern by participating nurses and the most frequently encountered issue in their clinical practice. The lack of adequate protective coding systems and laws and concerns about who has access to healthcare records, including insurance companies, compound this major moral concern of nurses (Giarelli & Jacobs, 2000). Although patients' privacy is protected by confidentiality measures, nurses continue to feel challenged to ensure this important responsibility. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created new requirements for healthcare providers to protect the privacy

Table 3. Genetic Ethical Issues of Major Concern and Frequency Encountered

Genetic Ethical Issue	Level of Concern		Frequency Encountered	
	$\overline{X}$ [a]	SD	$\overline{X}$ [b]	SD
Confidentiality of information gathered from genetic screening	3.76	0.52	3.05	1.04
Provision of sufficient information for consent for genetic screening	3.68	1.19	2.91	1.11
Sufficient qualified providers to give genetic counseling	3.66	0.67	2.78	1.06
Potential for disruptions in family relationships as a result of genetic screening	3.59	0.61	2.47	0.97
Adequate understanding by the patient of information provided for genetic screening	3.59	0.67	2.98	1.04
Clear designation in advance who receives the information obtained from genetic screening	3.53	0.76	2.69	1.07
Genetic screening of children for adult onset of genetic disorders	3.52	0.74	1.68	0.81
Equitable access to genetic screening	3.50	0.72	2.52	1.06
Provision of insurance benefits for genetic screening or somatic gene therapy	3.49	0.71	2.03	1.13
Preimplantation or in vitro fertilization genetic screening to select personal characteristics	3.46	0.86	1.12	0.43
Coercion of patients to be genetically screened	3.42	0.84	1.81	0.87
Ambiguity of genetic screening test results	3.40	0.68	2.70	0.92
Genetic screening of children for gene carrier status	3.37	0.86	1.83	0.93
Preimplantation and in vitro fertilization genetic screening for sex selection	3.36	0.90	1.23	0.55
Somatic gene therapy for personal enhancement (e.g., height, obesity)	3.06	0.95	1.09	0.40
Somatic gene therapy for behavior control	3.02	1.01	1.07	0.35
Somatic gene therapy for serious illness (e.g., cystic fibrosis)	2.94	1.02	1.32	0.68
Equitable access to preimplantation or in vitro fertilization genetic screening	2.91	0.99	1.28	0.63

N = 135

[a] 1 (not concerned) to 4 (very concerned)

[b] 1 (never encountered) to 4 (frequently encountered)

and security of health information. The HIPAA privacy rules require that steps be taken to protect the privacy of patients' and research subjects' personal health information (Fleisher & Cole, 2001). Safeguards and procedural guidelines must be continually developed, implemented, and revised to protect confidentiality of patient information.

A majority of respondents (97%) expressed major concern about the impact of managed care delivery systems on the quality of patient care. The concern that the quality of patient care is being compromised under the current managed care system gives rise to the necessity for further research and evaluation to identify effective methods to improve access, quality indicators, and equitable and just distribution of healthcare resources. The managed care revolution has meant that financial imperatives, whether in the form of cost cutting or profit seeking, threaten to preempt professional judgment in the medical treatment and care that are administered (Sullivan, 1999).

The restructuring plans implemented by managed care organizations during the 1990s to cut direct care nursing staff have resulted in an increased burden of care on nurses (Fagin, 1999). In a recent ANA survey, nurses indicated that they believed the quality of care in their facilities had deteriorated in the past two years. Mandatory overtime and inadequate staffing are endangering patient care and aggravating an emerging nursing shortage (ANA, 2001).

Genetic Ethical Issues of Concern

Confidentiality of patient information is vital in data generated from genetic screening. Nurses are concerned about who will have access to genetic information and the impact it will have on patients and family members. Confidentiality is based on the value to respect people and their right to privacy. Because privacy is essential to an individual's well-being, confidentiality protects this basic right. Patient medical

records are accessible to researchers and hospital personnel, and confidentiality is not always maintained. Legislation must comprehensively prohibit the misuse of genetic information, or individuals will continue to fear genetic tests for cancer predisposition and other genetic-related disorders (Giarelli & Jacobs, 2000). Nurses' duty is to safeguard the privacy of information, particularly genetic data, as it is collected, stored, transmitted, and retrieved in a patient healthcare information system.

Issues related to informed consent clearly were important to participants in this survey, specifically as related to patients receiving sufficient information for consent for genetic screening and having sufficient qualified providers to give genetic counseling. Decision making and informed consent involve safeguarding patients' autonomy and providing impartial information about genetic testing and therapies. Genetic testing should be carried out within the context of voluntariness, informed consent, and confidentiality (ISONG, 2000). Patients have the right to voluntarily accept or reject genetic testing and therapies; they must not be coerced (Lea & Williams, 2001).

Scanlon and Fibison (1995) emphasized that valid informed consent in genetic testing requires that individuals receive complete and truthful information about testing, have the capacity to consent, and are not coerced in making the decision. Healthcare institutions and educators are responsible for providing ongoing education for employees and students so that they can keep abreast of the expansive knowledge emerging daily in cancer and genetics. This knowledge is crucial to genetic and oncology nurses in providing relevant and current information to their patients to enhance understanding, comprehension, and ability to make informed decisions. In the survey results, nurses expressed concern that patients may not be receiving sufficient information to understand the impact that genetic testing may have on their lives. In addition, a

majority of respondents (89%) were concerned that insufficient qualified providers are available to give counseling. A lack of prepared providers will directly affect how patients are able to make informed decisions about their care. With genetic knowledge, nurses can advocate for, educate, counsel, and support patients and families during the informed decision-making and consent process (ISONG, 2000). Part of informed consent is assuring individuals that the healthcare team is there to provide support and referrals to assist individuals and families in coping with results received (Rieger & Pentz, 1999).

Regarding the cloning and germ line therapy theoretical issues, nurses expressed the greatest concern for cloning to replace a deceased child. Cloning is the creation of a genetically identical individual by transferring the nucleus of one cell to an egg whose nucleus has been removed. No scientific reason why it cannot be done exists, but fundamental ethical questions arise about cloning, having to do with the status of personhood or what it means to be a human being and the careful analyses of self-determination, weighing risks and harms, and fairness. Currently, cloning is banned in the United States (Gaul & Cassells, 1998). The National Bioethics Advisory Commission (Hastings Center Report, 1997) expressed fears about harms to children who may be created in this manner, particularly psychological harm associated with a possibly diminished sense of individuality and personal autonomy.

The major concern expressed by nurses regarding germ line therapy may reflect the general concern that in correcting serious genetic disorders in today's population through germ line therapy, scientists may cause even more serious maladies in future generations. Germ line therapy to correct or eliminate deleterious genes is seen as the first step down the slippery slope into the improvement or enhancement of human traits, sometimes referred to as positive genetics. The ethics of germ line therapy are very complex and will require continued public debate and reflection (Lea et al., 1998).

Conclusions and Implications for Nursing

Oncology and genetic nurses responding to this study overwhelmingly indicated major moral concern about protecting the confidentiality of patient information. This concern supports a need for the ongoing development of measures and procedural guidelines to safeguard patient confidentiality as specified by HIPAA rules.

Nurses and other healthcare providers have an increasing responsibility to keep abreast of new knowledge, tests, and treatments to prepare their patients to make good decisions about their genetic care. As more information about cancer genetics is discovered, the need for oncology nurses with knowledge in this area increases. Nurses are uniquely prepared to provide genetic counseling. Understanding cancer in general, cancer risks, and treatments provides a strong foundation on which to build knowledge of genetic concepts (Lindstrom, 2001).

Although the data indicate that nurses working in genetic and oncology health care recognize that they are facing an increasing number of major ethical issues in daily practice, they perceive minimal preparation in a number of skills to address and resolve those issues. Educational strategies are needed to assist in the development of these skills. The EAF is one educational strategy that can provide practitioners with recommended actions that can be helpful in developing ethical decision-making skills.

The EAF can serve as a curriculum model. The outline of actions offers direction for assessing skill level and developing objectives and educational materials, and the EASS can be used as a pre- and post-test. The objectives can be synthesized into a one-day continuing education course or a longer comprehensive program. The Maryland Nurses Association's Center for Ethics and Human Rights has adopted the EAF as a model and uses it to develop ethics continuing education programs for practicing nurses in the state (Cassells & Gaul, 1998). In the spring of 2000, the EAF was successfully incorporated into a one-week advanced course for nurses in genetic cancer risk counseling sponsored by a National Cancer Institute grant at the Fox Chase Cancer Center in Philadelphia, PA (Masny, Siemers, Harrop-Stein, & Keleher, 2000). The framework provided the model for addressing ethical dilemmas arising from complex genetic healthcare issues that were discussed throughout the program.

The information generated from these surveys can serve as a foundation for future research. The data presented can guide development and evaluation of educational strategies to support the role of nurses as moral agents in clinical practice that integrates genetics. The complexity of nursing practice and challenge of current conventional skills, genetically based diagnostic testing, and evolving therapies and treatments influence all knowledge. Genetics as a component of professional practice is becoming more evident, especially in oncology health care. This study offers a foundation on which nurses can build knowledge and skills to recognize potentially difficult ethical decisions. Nurses involved in the cancer genetic counseling process frequently are faced with ethical issues. These ethical challenges can occur at every step of the education and counseling process, such as providing adequate information about genetics for patients to give informed consent and protecting confidentiality and privacy while balancing the responsibility of notification to third parties. Nurses, especially those caring for patients with cancer, must have expertise in genetics and grounded skills in counseling and ethical decision making. The nurses participating in this study indicated a particular interest in genetics based on their membership in genetic nursing organizations. Many participants indicated that they encountered genetic issues in their clinical practice. They reported that the EAF was a useful model for addressing such issues although reporting minimal preparation in the majority of the actions in the framework. The authors recommended that, as an outcome of this study, educational workshops be implemented to focus on skill development in the prescribed actions of the EAF. Skill preparation in the EAF activities will promote its use in clinical practice.

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