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A Critical Intersection

Human Rights, Public Health Nursing, and Nursing Ethics

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Public health nurses must make moral decisions regarding practice in complex situations fraught with competing moral claims. While nurses often frame practice decisions within the context of ethical theory, consideration of human rights perspectives is more recent. Basic concepts of nursing and public health ethics and of human rights, in relationship to public health, will be discussed and related to the practice of public health nursing. Intersections of human rights, ethics, and public health nursing practice will be discussed in light of the assertion of health as a human right and described using the issues of HIV/AIDS and genetics/genomics. **Key words:** *bioethics*, *ethics*, *genetics*, *genomics*, *HIV/AIDS*, *human rights*, *nursing ethics*, *public health*, *public health nursing*

ALTHOUGH concern with ethical decision making is a common component of general as well as public health nursing practice, familiarity with the discipline and principles of human rights and consideration of how they might inform nursing thought and action are much more recent and not nearly as widespread. What are human rights and how do they intersect with nursing and public health ethics? What are the areas in which these concerns are compatible and in what ways might they come into conflict as public health nurses seek to fulfill the responsibility of providing healthcare for individuals, groups, and populations?

NURSING ETHICS AND ETHICAL STATEMENTS

Ethics may have many definitions. It can be viewed as "a generic term for various ways of understanding and examining the moral life."[1(p1)] With a primary concern for the duties of human beings, the study of ethics includes both social morality and philosophical reflection.

Bioethics, a subfield of ethics, is concerned with ethical concerns that result from advances in healthcare. Bioethical concerns became salient when the Nuremberg Tribunal after World War II reviewed the human rights abuses that Nazi physicians perpetrated in the name of scientific experimentation. The resulting Nuremberg Code of 1947 provides the foundation for the protection of human subjects in research. Bioethics in its development has continued an emphasis on such individual human rights as freedom, choice, and self-determinism. The individualized focus of bioethics has represented the self-interest of the individual as more significant than the interests of family or community.[2,3]

Major social movements of the 1960s and 1970s, including the campaign for nuclear disarmament, the civil rights movement, the peace movement, and the protest against the war in Vietnam, as well as the development of new medical technologies that raised seemingly unanswerable ethical questions, led to the further development of bioethics. A frequent concern was the equitable

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distribution of scarce healthcare technologies such as renal dialysis and organ transplants. Other bioethical concerns include the ethics of informed consent by research subjects, environmental ethics, ethics of sexuality and reproduction, ethics of genetic choice and manipulation, and the ethics of research. From its inception, bioethics has been a multidisciplinary enterprise, involving not only nurses, physicians, and other biomedical scientists, but also thinkers from law, economics, and public policy.[4,5]

Nurses have practiced within a context of ethics since the beginning of professional nursing in the 19th century. The impetus for the professionalization of nursing found expression in the "Nightingale Pledge" in 1893 and the subsequently suggested ethical codes that led to the first formally adopted code in 1950. Ethical codes, in nursing as in other professions, serve not only to define such groups as "professional" as opposed to "occupational," but also to outline primary duties, responsibilities, and obligations. The most recent revision of the American Nurses Association's[6] (ANA's) ethical code as well as the International Council of Nursing's[7] (ICN's) code include provisions and standards that address human rights duties and obligations.

HUMAN RIGHTS AND HUMAN RIGHTS DOCUMENTS

Human rights are rights that all people possess by virtue of being human. These rights are universal, inhering in all human beings equally regardless of other duties they may have or statuses that they occupy. Rights are legally or morally recognized claims or entitlements to something or against someone else.[8-10] Human rights in their modern conceptualization derive from 2 interrelated streams: ideas of moral or natural laws that are not codified and provisions of international law that can be ratified by nation states. The United States Declaration of Independence reflects the former in its assertion that "all men are created equal and are endowed by their Creator with certain inalienable rights." The Bill of Rights embodied in our constitution is an example of the latter.

Contemporary concern with the enunciation and enforcement of human rights sprang from global revulsion from the gross crimes against humanity perpetrated during World War II. The aim "to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small. . . ." is found in the Preamble of the Charter of the United Nations.[11] Early in its history, the United Nations Organization developed the foundational document of international human rights, the Universal Declaration of Human Rights[12] (UDHR). Declarations embody broad general principles and are not legally enforceable. Such documents promulgated by the United Nations are generally elaborated by conventions or covenants to which nation states may choose to subscribe through the process of ratification. These statements are more specific and have the force of law. The provisions of the UDHR were specified in 2 subsequent documents: The International Covenant on Civil and Political Rights[13] (ICCPR) and the International Covenant on Economic, Social and Cultural Rights[14] (ICESCR). These 3 documents with additional optional protocols to the ICCPR form what is called the International Bill of Human Rights. Adherence by national governments to ratified principles of human rights is monitored by designated bodies within the United Nations and by independent nongovernmental organizations (NGOs) such as Amnesty International, Human Rights Watch, and Physicians for Human Rights.

Consideration is made for limitation or derogation of certain rights in the face of emergencies that threaten public welfare, provided that these actions are not in violation of international law and do not involve discrimination. Rights to life and against torture, involuntary participation in medical or scientific experimentation, and slavery, however, are not subject to derogation.[12] "Thus, some restrictions on certain human rights in the interest of public health may be allowed when the situation leaves no alternative, but this action should always be preceded by a careful and deliberate process of decision making, should be monitored, and should be lifted as soon as possible.[10]

Fundamental concepts introduced in the UDHR and embodied in the ICCPR and the ICESCR include the recognition of the inherent dignity, freedom, and rights with which all humans are born; the equality of all people; self-determination; the repudiation of discrimination on the basis of race, gender, religion, political or other opinion, nationality, socioeconomic class, or any other status; life, liberty, and personal security. The family is recognized as the natural and fundamental unit of society with entitlement to protection by society and states.

The right to health is recognized in the International Bill of Human Rights and in other United Nations and World Health Organization (WHO) documents including the Constitution of the WHO,[15] the Declaration of Alma-Ata (Alma-Ata),[16] the Ottawa Charter for Heath Promotion (Ottawa),[17] the Convention on the Rights of the Child (CRC),[18] the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),[19] and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD).[20] Additional UN statements speak to concerns for the rights and welfare of various vulnerable groups such as prisoners, migrants, indigenous persons, and refugees.

In 2005, the United Nations Educational, Social and Cultural Organization (UNESCO) adopted the declaration on bioethics and human rights. It established normative principles in 15 areas, including human dignity and human rights; equality, justice, and equity; and protection of future generations.[21] While some of the fundamental documents that address the right to health, such as the CRC and CEDAW, have not been ratified by the United States, the practice and advocacy action of public health and other nurses can be and are informed by the imperatives they assert.

CONSIDERATIONS OF PUBLIC HEALTH AND PUBLIC HEALTH NURSING

Public health has been defined as "what we, as a society, do collectively to assure the conditions for people to be healthy."[22(p1)] This definition, which stresses the societal responsibility for the health promotion of the population as a whole, raises an important question about the scope of public health. Is public health responsibility confined to the prevention of the immediate causes of injury and disease, or should public health be more concerned with the alleviation of the larger social and economic problems that have an impact on health and disease, such as poverty, violence, and inadequate housing?[2(pxix)] In a consideration of the intersection of human rights, public health, and ethical concerns, these questions may serve to point up the areas of discontinuity between the several perspectives, particularly as each perspective finds expression in public health nursing praxis.

Immediately we can see some lack of congruence in the concerns of bioethics and public health. The bioethics emphasis on the rights and interests of the individual is not always decisive in public health, and may, in fact, hinder critical thinking about healthy communities. "The field of public health is concerned primarily with prevention rather than treatment, populations rather than individuals, and collective goods rather than personal rights or interests."[2(pxxiii)] Public health is more concerned with public goods that can be achieved only by collective action, such as clean water, adequate housing, and public safety, and with societal regulation of shared risks. The public health perspective shows no hesitation to call on individuals to sacrifice some of their self-interest in order to gain the benefits of a safe and healthy society. Bioethics poses the question: "What desires and needs do you have as an autonomous, rights-bearing individual? By contrast, public health asks another kind of question: What kind of community do you want and deserve to live in and what personal interests are you willing to forego to achieve a good society?"[2(pxxiv)]

The nature of public health nursing practice makes it ideal for an examination of the application of human rights concepts to nursing. Public health nursing practice is focused directly on the extension of nursing care from the individual to the family, the group, and the community. Public health nursing has a particular concern for the vulnerable population groups that are frequently the target of human rights abuses, for example, those who are poor, marginalized, members of ethnic minorities who experience discrimination in the society. The ethical position of public health nurses, unlike other nursing specialties, is founded not only on nursing ethics but also on public health ethics. This adds additional complexity to the attempt to integrate a human rights perspective into public health nursing practice.

The 1999 *Scope and Standards for Public Health Nursing Practice* was published by the ANA as a collaborative revision of previous documents that described public health nursing. In it public health nursing is defined as

> the practice of promoting and protecting the health of populations using knowledge from nursing, social, and public health sciences.... Public health nursing is population-focused, community-oriented nursing practice. The goal of public health nursing is the prevention of disease and disability for all people through the creation of conditions in which people can be healthy.[23(p2)]

With its primary concern for maximizing the greatest good of the greatest number, 19th-century utilitarianism provides the philosophical basis for modern public health practice, including public health nursing practice. The public health gives primacy to population rather than the individual, and may use the coercive powers of the state to enforce public health interventions, such as immunization, reporting, and quarantine.

Balancing interests of the individual against those of the state is a historical and contemporaneous issue in public health practice. Smallpox vaccination was the concern in the early 1900s. Beginning in the 1980s the HIV/AIDS epidemic has given rise to the questions regarding reporting and confidentiality. Issues related to giving emergency protective powers to governors and state health departments in the face of the anthrax scares subsequent to September 11, 2001, and the possibility of widespread quarantine to combat severe acute respiratory syndrome (SARS) have been controversial in recent years.[24]

In 2000, the American Public Health Association adopted the following principles on Public Health and Human Rights that were developed under the leadership of the International Human Rights Committee:

1. All human beings are equal in dignity and rights.
2. All human beings are entitled to the enjoyment of all human rights without discrimination.
3. The realization of the highest standard of health requires respect for all human rights, which are indivisible, interdependent, and interrelated.
4. An essential dimension of human rights is the right to health, including conditions that promote and safeguard health and access to culturally acceptable healthcare.
5. Human rights must not be sacrificed to achieve public health goals, except in extraordinary circumstances, in accordance with the requirements of internationally recognized human rights standards.
6. The active collaboration of public health and human rights workers is a necessary and invaluable means of advancing their common purposes and values.[25]

SOCIAL JUSTICE

Social Justice is an expression used in the disciplines of ethics and theology to refer to fair, equitable, and appropriate distribution of social benefits and burdens determined by justified norms that structure the terms of social cooperation; and the distribution of primary social goods, such as economic goods and fundamental political rights; but burdens are also within its scope.[26,27] Decisions related to social justice affect human mortality. Despite a high and growing global economy, billions are condemned to severe, lifelong poverty with a related annual death toll from related causes of approximately 18 million or one third of all human deaths. Those living below the $2/day World Bank international poverty line constitute 44% of the world's population. They consume only 1.3% of the global product and would need only 1% more to escape poverty as defined above. The high-income countries have 955 million citizens who consume about 81% of the global product. Their average per capital income is nearly 180 times greater than that of the poor.[28] The issue of social justice is integral to many of the concerns of ethics, human rights, and public health as will be seen in the discussion that follows.

INTERSECTIONS OF PUBLIC HEALTH NURSING, NURSING ETHICS, AND HUMAN RIGHTS

While both human rights and ethics find a basis in moral philosophy, they employ different perspectives. Ethical discourse focuses on the rationale for and determination of right behavior, often seen in the moral codes of various professions or in models for ethical decision making. By contrast, human rights, is concerned with the legal obligations of nation states to their citizens that are codified in national and/or international law. While both disciplines stress respect for human beings and the preservation of human dignity, conflicts may occur, for example, when utilitarian ethics may indicate that individual rights should be subordinated to the good of the whole.[29]

The critical intersection of human rights, nursing ethics, and public health nursing provides an opportunity to examine the nuances of the moral stance of the nurse as he or she encounters real-life nursing situations, either in providing direct care or in advocating for more distantly related health issues. Each of these conceptualizations—human rights, nursing ethics, and public health nursing practice—represents a particular perspective, or worldview, that may or may not be compatible with the other perspectives in every respect. Understanding each perspective and the relationships among them can assist in the integration of human rights concepts in nursing's self-understanding of its roles and obligations.

Mann[30] believed that the interaction of health and human rights would contribute more to the advancement of human wellbeing than either field could alone and proposed 3 types of linkages:

The impact of health policies, programs, and practices on human rights, especially as seen in the use of state power in public health. Here the stress point that must be addressed is the potential for human rights violations against vulnerable populations through policy formation or the implementation of measures designed to fulfill the core public health functions of assessment, policy development, and assurance. While in some cases, human rights must be limited to protect the community, such actions must be carefully restricted. Certain rights, for example, the right to be free from torture or slavery, are considered inviolable under all circumstances. The restriction of other rights must be in the interest of a legitimate objective, determined by law, imposed in the least intrusive, nonarbitrary means possible, and strictly necessary to the purposes of a democratic society.

Health impacts resulting from violations of human rights. Serious or possibly life-threatening consequences will always result from severe violations of human rights such as torture or inhumane imprisonment. Furthermore, the violation of the right to information or the failure to provide for safe workplaces may also cause harm to physical or emotional health.

Health and human rights: Exploring an inextricable linkage. Examples of this connection include cases in which discrimination, stigmatization, and lack of respect for human dignity have increased the risk of vulnerable groups being exposed to HIV. In addition, health can be seen as a precondition to the capacity to realize and enjoy human rights.

Nurses are generally familiar with utilitarian and deontological ethics, with many subscribing, at least in theory, to deontological concepts. Central ethical principles of autonomy, beneficence, nonmaleficence, and justice can be identified as basic assumptions in nursing's ethical codes. Human rights perspectives, however, are less explicit in nursing's worldview. This is not to suggest that nurses are not concerned with human rights issues, but only to note that for most nurses, a human rights perspective is not an explicit foundation for conceptualization or practice. As the discipline of nursing expands its conceptual repertoire to include human rights more explicitly, it is important to consider how a human rights perspective is integrated appropriately with nursing's traditional and formalized ethical stance.

Issues related to health as a human right

The UDHR asserts in Article 25 that

1. everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control; and
2. motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.[12]

The right to health is further elaborated in several articles of the ICESCR. Article 7, which describes rights to favorable conditions of work, includes the right to "safe and healthy work conditions." Article 11 recognizes the right to adequate living standards for individuals and families, including adequate food, clothing, and housing. Article 12 presents the most far-reaching statement, "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." Steps to be taken to ensure this right include the reduction of stillbirths and infant mortality and for healthy child development; improvement of environmental and occupational hygiene; the prevention of disease; and the assurance of all medical services in the case of illness.[14]

The Constitution of the World Health Organization provides a comprehensive definition of *health* as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." It reasserts the right to the highest attainable standard of health without distinction due to personal status and as "fundamental to the attainment of peace and security."[15(p1)] The 1978 international conference on primary healthcare resulted in the declaration of Alma-Ata, a widely referenced treatise on the delivery of community-based primary healthcare. This document proposed the responsibility of governments for the health of their people and stated that "The promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life and to world peace."[16] Other international treaties such as the CRC and CEDAW also address health as a right of the specific populations with which they are concerned.[18,19]

To speak of health as a human right or to refer to the "right to health" is to employ a shorthand expression that denotes the specific language found in international human rights treaties and fundamental human rights principles.[31] The statements on health as a human right referenced above involve a number of value issues of concern to public health nurses, including universal access to healthcare, determinants of health status, healthcare of vulnerable populations, provision of culturally sensitive/competent healthcare, and participation in healthcare research.

While some economists and thinkers on healthcare regard the concept of the right to health as overly vague and idealistic, others maintain that it at least implies equity in the provision of healthcare services.[31] Nurses and public health nurses have made significant contributions to the extension of healthcare to all, including vulnerable populations. The practice of public health nurses and nurse practitioners, in particular, demonstrate commitment to the care of those populations who by reason of race, class, socioeconomic status, and urban or rural/frontier residence have often been marginalized in the delivery of basic healthcare. This commitment to health as a human right is enjoined in the ICN code of ethics for nurses statement, "The nurse shares with society the responsibility for initiating and supporting action to meet the health and social needs of the public, in particular those of vulnerable populations."[7] Public health workers are called upon to "advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all."[32] International human rights documents emphasize the need for special protection of mothers and children and of other vulnerable populations.[14]

Extension of the implications of the right to the highest attainable standard of health may involve shouldering the obligation to advocate for access to universal healthcare in this country and globally. The plight of more than 45 million Americans who lack health insurance and the looming issue of increased demand as the baby boom generation ages provide the imperative for concerned nurses to lead in the development of cost-effective and community-based systems that will maximize resources and ensure the provision of quality healthcare for all. Public health nurses must help their communities and community leaders realize the relationship between the health of populations and the overall well-being of the society as a whole.

The right to health as described in international human rights documents and as understood by public health nurses embraces not only the provision of healthcare services but also consideration of the environmental and contextual factors that are important determinants of health status. The ICN code speaks of nurses sharing "responsibility to sustain and protect the natural environment from depletion, pollution, degradation and destruction."[7] One of the principles of the Ethical Practice of Public Health is that "Public health programs and policies should be implemented in a manner that most enhances the physical and social environment."[32] These statements may well be expanded to include attention to other social determinants of health including issues of poverty, access to education and clear health communications, housing, and occupational safety, as well as the overall health of the community. The Ottawa Charter for Health Promotion identifies fundamental conditions and resources for health as "peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity."[17]

Concern for safeguarding the right to health for all peoples of the world will lead nurses and other leaders in the delivery of healthcare to functional ethically with regard to the recruitment of nurses and other healthcare professionals from other less financially able countries abroad. Shortages of nurses in many two-thirds world countries result from a number of complex factors, including the inability for some nations to adequately compensate healthcare providers.[33] As the nursing shortage deepens in the industrialized countries, aggressive efforts to recruit well-prepared nurses from countries in Africa and the Caribbean exacerbate problems with provision of healthcare to their populations, especially as they confront growing incidences of HIV/AIDS. The ANA code for nurses refers to the ethical obligation of nurses to collaborate "with other healthcare professionals and the public in promoting community, national, and international efforts to meet health needs."[6(p23)]

In this case, the right of foreign nurses to emigrate to seek employment and enhanced opportunities may conflict with the healthcare needs of the sending country that in many cases paid for the education of these nurses.[34] The monetary loss to the sending country might well be seen to include not only the cost of education but also the loss of tax revenue over nurses' careers, poorer population health due to the lack of adequate care, and the high cost of hiring expatriate nurses to fill vacancies. In addition to international agreements to compensate the sending countries for costs related to nurse migration, some innovative ideas for "recirculation of skills" have been proposed. Some of these involve partnerships among funding agencies, healthcare facilities, and educational institutions to support technology and knowledge transfer; and facilitate the temporary return of immigrant nurses to their native countries to enhance nursing education and practice.[35]

The UDHR asserts that "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits."[12] These ideas are echoed in the ICESCR.[14] Concern for cultural rights is reflected in the UN Draft Declaration on the Rights of Indigenous Peoples[36] that asserts their rights to distinct cultural characteristics and to be different. Ethical public health programs and policies will "incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community."[37] Nurses are enjoined to provide "an environment in which the human rights, values, customs, and spiritual beliefs of the individual, family, and community are respected."[7] From a tradition of over 100 years of practice in a variety of cultural communities, public health nurses are familiar with the challenges of intercultural delivery of care. A logical extension of this mandate could be the need for nursing research to be developed and implemented in collaboration with diverse communities and populations such that advancements in nursing knowledge are appropriately applicable to the enhancement of their health status. The development or rebuilding of trusting relationships between health researchers and populations such as African Americans and American Indians/Alaska Natives who have suffered exploitation by health researchers is a critical need.

HIV/AIDS AS A SEMINAL EXAMPLE OF THE HEALTH AND HUMAN RIGHTS INTERSECTION

The human rights issues raised by the HIV/AIDS pandemic have focused attention on the intersection of health, public health, and human rights. The late Jonathan Mann, Director of the Francois Xavier Bagnoud Center for Health and Human Rights at the Harvard University School of Public Health until his tragic death in 1998, and noted for his work as founder of the United Nations AIDS program, was a theorist on the global impact of the disease. The HIV/AIDS pandemic for Mann[37] marked the first time in history that human rights issues became central to public health strategies for an infectious disease. Bioethical and human rights issues are central to public health strategies for the prevention and control of HIV/AIDS. The violation of human rights, particularly the rights of women and children, plays a direct role in the spread of the virus. The 2-phased movement of the linkage between the disease and human rights reflects the complexity of the interaction between health, ethics, and human rights.

The first phase involved problems of "discrimination, stigmatization, and the marginalization of people infected with HIV, people with AIDS, and members of population groups considered at high risk for HIV infection."[37(p1)] Because of these problems, people resisted being identified as having acquired HIV, leading to decreased effectiveness of public efforts to prevent and control the infection. The global approach to this situation was motivated, not by concern with fundamental human rights, but rather with more pragmatic concerns with coercive approaches to HIV prevention. Violations of human rights were seen as tragic and preventable effects of the pandemic. So the prevention of human rights abuses—discrimination against people infected and affected by a disease—became an integral part of the global public health approach to epidemic control.

The second phase of the relationship between health and human rights in the context of the HIV/AIDS pandemic revolved around the concept of vulnerability: the extent to which persons are able to make and act upon informed decisions about their health. Mann contended that people who were able to make and effectuate free and informed health-related decisions were least vulnerable to HIV. Three categories of societal preconditions for reducing vulnerability to HIV were identified: political/governmental, for example, lack of political interest in the disease or governmental inference with free access to information about the disease; sociocultural, for example, societal norms about gender roles or sexual taboos; and economic, for example, poverty, income disparity, and lack of resources for prevention. Addressing these societal preconditions to vulnerability became part of the strategy for public health work in relationship to HIV control.

The progression of the pandemic, regardless of the population group that was affected initially, has always moved eventually to those in the society who are most stigmatized and marginalized and who face discrimination. For example, in the United States, where gay men were first affected, HIV/AIDS is now increasingly found among inner-city minority populations, injecting drug users, and women. Currently, 67% of new cases of HIV are found among black women. While blacks made up 12% of the US population, they accounted for 51% of the incidence of HIV infections between 2001 and 2004, and for 50% of new AIDS diagnoses in 2005.[37–39]

The complexity of the intersection of health and human rights issues in relationship to HIV/AIDS is illustrated by the seemingly paradoxical fact that in many societies, being married and monogamous is a risk factor for HIV infection. The explanation for this situation is that for many women, risk is determined by the sexual behavior of their primary partner. Thus, married monogamous women who have little or no control over their own sexual decision making cannot insist upon the use of condoms by husbands who may have multiple sexual partners. In this case, the lack of human rights for women has a direct effect on their health status.[37]

In its *2006 Report on the Global AIDS Epidemic* UNAIDS,[40] the Joint United Nations Programme on HIV/AIDS, holds that the AIDS response in many countries is insufficiently grounded in human rights. Although 6 of every 10 countries surveyed reported laws and regulations to protect people living with HIV from discrimination, many countries indicated that such laws were not fully implemented or enforced, largely due to lack of funding. In addition, half of countries surveyed indicated the existence of policies that interfered with accessibility and effectiveness of HIV prevention and care measures, such as prohibiting condom and needle access for prisoners and using residency status to prevent access to prevention and treatment services. Many countries have opted for less effective generalized prevention efforts rather than targeting funding to populations at highest risk.

Although incidence rates for HIV are declining in the United States, public health nurses must be aware of the human rights context in which HIV/AIDS prevention and care resides. As noted earlier, HIV/AIDS eventually affects those who are marginalized in any country. In the United States, the HIV/AIDS is increasing at the greatest rate among black women. The demographic profile of women at highest risk for HIV infection is young women, women of color, and low-income women. While both black and Hispanic women are at greatest risk, the rate of new AIDS diagnoses among black women is 4 times that of Hispanic women (and 24 times the rate for white women). What is often overlooked is that this same demographic profile characterizes women who have incarcerated sexual or drug partners. Because HIV prevalence is over 5 times greater among incarcerated males than among men in the general population, the partners of incarcerated males are at greater risk. The human rights implications of the disproportionate percentage of black males in the US society that are incarcerated completes the contextual circle that places black women at higher risk of HIV infection.[38-45] Knowledge of the human rights context for the HIV experience of a high-risk subpopulation, black women, provides the public health nurse with a critical understanding that should inform assessment, contextually sensitive care, and prevention efforts.

The prevention and control of HIV/AIDS represents a clear obligation for public health and human rights efforts to be combined. Human rights violations that increase vulnerability to HIV infection, such as the right to information, equal status of women and men in marriage, and nondiscrimination, must be targeted by all categories of healthcare professionals who are involved in the care of patients and communities affected by HIV/AIDS. Public health nursing practice implications for those infected with and affected by HIV, both in the United States and abroad, include consideration of ethical and human rights concerns. Patients and families must be protected from discrimination and provided with privacy and confidentiality; equal access to healthcare and insurance; and basic human resources, such as job security, housing, and educational opportunities.

GENETICS/GENOMICS: AN EMERGING ISSUE IN ETHICS AND HUMAN RIGHTS FOR PUBLIC HEALTH NURSES

Genetics, the study of the functions and effects of single genes, is often associated with diseases such as Down syndrome or Huntington disease. Genomics is the study, not only of single genes, but also of the entire human genome and the interactions of multiple genes with each other and with the environment.[46] Genomics has become very important since the mapping of the human genome has pointed to a relationship among genetic factors, environmental exposures, and a variety of chronic diseases. The public health nursing emphasis on health promotion and prevention renders competence in the delivery of healthcare informed by new genomic discoveries very important. The significance of this area of public health practice will only intensify as the population ages and the adverse effects of childhood obesity and lack of exercise lead to an overall increase of chronic disease across the lifespan. Public health nurses must be ready to interpret both avoidable and unavoidable risk factors for disease to individuals, families, and communities.

Genetic risk factors, while unavoidable, may be ameliorated by healthy lifestyle choices, but this fact raises significant ethical and human rights issues. Should persons be held accountable for making unhealthy choices? To whom should information about genetic predispositions be available? Should societal resources be expended to provide healthcare for those who knowingly place themselves at risk for ill health? Should society pay the cost when parents choose to have children that they know will be impaired? These troubling ethical questions with the potential for human rights abuse are among many concerns that arise from the failure of our ethical and human rights understandings to keep pace with rapid development of healthcare technology. The public health nurse, indeed each nurse, must develop a personal professional philosophy that guides his or her practice. Placing genetic issues within the context of ethics and human rights will provide a rational and principled approach to complex public health practice dilemmas.

The project to map the human genome has been funded by the US Department of Energy

(DOE) and the National Institutes of Health (NIH). Since the inception of the project in 1990 these 2 agencies have devoted a small portion of the budget toward the study of the ethical, legal, and social issues (ELSI) surrounding the availability of genetic information. This effort is now the world's largest bioethics program, serving as a model for other ELSI programs worldwide. Ethical and human rights issues addressed by the ELSI program include fairness in the use of genetic information, privacy and confidentiality, stigmatization, and genetically modified foods, among others.[47]

Public health genetic screening programs have been used for many years to identify persons at risk for genetic diseases. The public health nurse may sometimes encounter African American patients who are suspicious of screening programs and the healthcare delivery system in general because of past problems created by the sickle cell screening program of the 1970s. A brief history of genetic screening highlights the intersection of public health, ethics, and human rights, particularly in the case of ethnic minorities.

In the 1970s, a major program was implemented to screen African American children and young adults for the mutation associated with sickle cell disease. As a result of inadequate information, lack of sensitivity to ethnocultural issues, and misuse of personal test data, the ethical and human rights interests of many of the subjects were violated. Persons who carried sickle cell trait were inaccurately labeled as having the disease, and subsequently ostracized, deprived of employment and educational opportunities, and denied health and life insurance.[48] Sensitive to the public health problems that advances in genetics and genomics might pose for some segments of the public, the DOE has sponsored conferences and professional education materials to explore the ethical impact of genetic and genomic information on minority communities.[47]

Some public health professionals note a similarity between genetic screening and historical public health screening measures used to detect communicable diseases such as tuberculosis. Genetically based diseases are comparable to communicable diseases in the possibility of spread from an affected person to others. However, rather than spreading horizontally through the population, as in tuberculosis for example, genetic disease is spread vertically through generations. Persons that carry the genes that cause disease can be warned about their risks of having genetically impaired children. The use of genetic screening could provide the public health system an opportunity to reach and treat the approximately 3000 babies born each year with diseases where early intervention could be lifesaving.[27]

Laws mandating screening programs could be justified by the power of the government to secure the welfare of its citizens. Again, public health measures that are used to control communicable diseases can provide a model to control genetics diseases For example, in the same way that parents are not allowed to decide whether or not their children are vaccinated against smallpox, it could be argued that the government also has a duty to identify newborns with phenylketonuria (PKU) so that they can receive the appropriate treatment.[27]

There is an argument, however, against the application of the contagious disease model to genetic screening programs. A smallpox epidemic could threaten millions, while only a few persons, by comparison, are at risk for a particular genetic disease. In addition, the lack of follow-up or counseling services for some genetic screening programs leads to questions about the benefits to participants. Being told they are the carriers of a genetic disease may cause more harm than good to some people.[27]

Thus, public health genetic screening programs raise several ethical and human rights questions. Do the benefits of such programs outweigh their liabilities? Are screening programs so valuable that they justify the denial of individual choice that is involved in required participation? What about the rights of parents who do not want to know whether their child has the genes responsible for a particular disease? Is the state justified, in the interest of protecting the child, to require parents to know this information whether they want to or not?[27] These are questions the public health nurse must ponder when rendering care to families affected by genetic conditions.

UNESCO adopted the International Declaration on Human Genetic Data in 2003 to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, human proteomic data of the biological samples from which they are derived ... while giving due consideration to freedom of thought and expression, including freedom of research.[49(p3)]

The document references the special status of genetic data in view of their predictive power, the potential for significant impact on the family that can extend over generations, the unknown potential significance of biological specimens at the time of their collection, and the cultural significance that genetic data may hold for persons or groups.

The Genetic Information Nondiscrimination Act (GINA) is a bill currently before Congress that would prohibit discrimination on the basis of genetic information for the purposes of employment or insurance. Specifically, this act would prevent health insurers and employers from using genetic information to determine eligibility for insurance, to set premiums, or to hire and fire employees. Genetic nondiscrimination legislation is highly controversial. It has been introduced during every Congressional session since 1995, each time without becoming law.[50]

IMPLICATIONS FOR THE PROFESSIONAL PUBLIC HEALTH NURSING ROLE

Principles of human rights along with professional ethics serve to inform and enrich the quality of care that public health nurses provide in situations that are increasingly complex, both technologically and morally. This process begins with recognition of the imperative of human rights as foundational to responsible decision making regarding healthcare and a willingness to confront the dilemmas that will necessarily arise with deep reflection and humility. Action to ensure that all people are able to enjoy the right to health and related human rights will involve not only informed care delivery but also advocacy and community education on the part of committed public health nurses.

Continued collaboration of human rights activists and public health professionals, including public health nurses, can be expected over time to result in advances in areas such as the health and human rights of vulnerable groups, the achievement of environmental and occupational safety and health, the protection of human rights in the face of public health emergencies, and the realization of the economic and social conditions that are necessary to the highest attainable standard of health.

RESOURCES

The following list of organizations and journals is provided for those who may wish to access additional references on human rights and ethics or to contact related organizations.

American Nurses Association. The ANA has developed a number of position statements on ethics and human rights, including such topics as stem cell research, cultural diversity in nursing practice, discrimination and racism in healthcare, and patient self-determinism acts. http://www.needlestick.org/readroom/position/ethics/.

Amnesty International. An organization that promotes the rights of incarcerated persons around the world. www.amnesty.org.

BMC Medical Ethics. Published by BioMed Central. Open access, peer reviewed journal that contains articles on the ethics of medical research and practice. www.biomedcentral.com/bmcmedethics.

Case Western Reserve University, Center for Genetic Research Ethics and Law. Funded by the National Human Genome Research Institute (NIH) to address issues raised by advances in genetic and genomic research. http://www.case.edu/med/bioethics/cgreal/index.htm.

Center for Medical Ethics and Health Policy. A joint project of Baylor College of Medicine and Rice University. www.bmc.edu/ethics/?PMID=3823.

Ethical, Legal, and Social Issues (ELSI). The US Department of Energy (DOE) and the National Institutes of Health (NIH) devoted 3% to 5% of their annual Human Genome Project (HGP) budgets toward studying the ELSI surrounding availability of genetic information. This represents the world's largest bioethics program, which has become a model for ELSI programs around the world. ELSI focuses on the various social concerns arising from advances in genetics and genomics. http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml.

Ethics and Public Health: Model Curriculum. From the Association of Schools of Public Health (ASPH) Curriculum Resources. A joint project of the ASPH, the Health Resources and Services Administration, and the Hastings Center. www.asph.org/document.cfm?page=723.

Francois Xavier Bagnoud Center for Health and Human Rights. A center for human rights education, research, and policy at the Harvard School of Public Health. Publishes Health and Human Rights: An International Journal. www.hsph.harvard.edu/fxbcenter.

Georgetown University Medical Center, Center for Clinical Bioethics. The center, which complements the Kennedy Institute of Ethics, serves as an ethics resource for those who shape and provide healthcare. http://clinicalbioethics.georgetown.edu/.

Global Human Rights Education Network. BioMed Central International Health and Human Rights. www.biomedcentral.com/bmcinterhealthhumrights.

Hastings Center. An independent center dedicated to advanced research and studies in biomedical ethics. The Center publishes The Hastings Center Report, a quarterly journal focused on issues in healthcare ethics. www.ascensionhealth.org/ethics/public/issues/hastings.asp.

Human Rights Directory. Listing of thousands of human rights organizations around the world. www.idealist.org.

Human Rights Quarterly. http://muse.jhu.edu/journals/humanrights_quarterly.

Human Rights Watch. A major international human rights organization dedicated to protecting the human rights of people around the world. www.hrw.org.

InterAction. Works to overcome poverty, exclusion, and suffering by advancing social justice and basic dignity for all. www.interaction.org.

International Society for Health and Human Rights. www.ishhr.org.

JME Online. An international peer reviewed journal for healthcare professionals and researchers in medical ethics. Editor's choice section free of charge. Subscription needed for general access. http://jme.bmj.com/.

Joseph P. and Rose F. Kennedy Institute of Ethics. The world's oldest and most comprehensive academic bioethics center serves as a resource for research, study, and policy development. The institute publishes the annual *Bibliography of Bioethics*. http://kennedyinstitute.georgetown.edu/index.htm. Accessed October 17, 2007.

MacLean Center for Clinical Medical Ethics. This center at the University of Chicago fosters diverse activities and multidisciplinary partnerships. http://medicine.uchicago.edu/centers/ccme/index.htm.

Nursing Ethics. Fifty-seven issues of this journal are available online, some free of charge. www.ingentaconnect.com/content/arn/ne.

Nursing Ethics. The Student's Gopher. www.freedomtocare.org/iane.htm.

Nursing Ethics at Boston College. At William F. Connell School of Nursing, this project provides book abstracts, lectures, ethics tools, databases, dissertations, library collections, and links. www.bc.edu/nursingethics.

Nursing Ethics Network (NEN). A nonprofit organization of professional nurses committed to the advancement of nursing ethics in clinical practice through research, education, and consultation. http://jmrileyrn.tripod.com/nen/nen.html.

People's Movement for Human Rights Education. See Health Page. www.pdhre.org/rights/health.html.

Physicians for Human Rights. An organization that works to expose and prevent human rights violations around the world and provide education in human rights for healthcare professionals. www.phrusa.org.

Public Health Ethics. A short course developed by the North Carolina Institute for Public Health. www.sph.unc.edu/oce/phethics.

Public Health Ethics Mini-Course. From the Health Policy Student Association at the University of Michigan. http://sitemaker.umich.edu/hpsa/public_health_ethics_mini-course.

Resource Center of the Americas. Educates and organizes to promote human rights, democratic participation, economic justice, and cross-cultural understanding in the context of globalization in the Americas. www.americas.org.

The Center for Genetics and Society. Developed the Genetics Bill of Rights. http://geneticsandsociety.org/article.php?id=1991.

United Nations Office of the High Commissioner for Human Rights (UNHCHR). The United Nations vision is of a world in which the human rights of all are fully respected and enjoyed in conditions of global peace. The High Commissioner works to keep that vision to the forefront through constant encouragement of the international community and its member States to uphold universally agreed human rights standards. www.ohchr.org.

University of Minnesota, Human Rights Library. Provides Bioethics and Human Rights Links for online research. http://www1.umn.edu/humanrts/links/bioethics.html.

University of Washington, Ethics in Medicine. An electronic resource developed as part of the Bioethics Education Project, a collaborative effort to expand and integrate bioethics education throughout the medical school curriculum. http://depts.washington.edu/bioethx/toc.html.

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