



# KEY POINTS FOR DEVELOPING AN INTERNATIONAL DECLARATION ON NURSING, HUMAN RIGHTS, HUMAN GENETICS AND PUBLIC HEALTH POLICY

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Human rights legislation pertaining to applications of human genetic science is still lacking at an international level. Three international human rights documents now serve as guidelines for countries wishing to develop such legislation. These were drafted and adopted by the United Nations Educational, Scientific and Cultural Organization, the Human Genome Organization, and the Council of Europe. It is critically important that the international nursing community makes known its philosophy and practice-based knowledge relating to ethics and human rights, and contributes to the globalization of genetics. Nurses have particular expertise because they serve in a unique role at grass roots level to mediate between genetic science and its application to public health policies and medical interventions. As a result, nurses worldwide need to focus a constant eye on human rights ideals and interpret these within social, cultural, economic and political contexts at national and local levels.

The purpose of this article is to clarify and legitimate the need for an international declaration on nursing, human rights, human genetics and public health policy. Because nurses around the world are the professional workforce by which genetic health care services and genetic research protocols will be delivered in the twenty-first century, members of the discipline of nursing need to think globally while acting locally. Above all other disciplines involved in genetics, nursing is in a good position to articulate an expanded theory of ethics beyond the principled approach of biomedical ethics. Nursing is sensitive to cultural diversity and community values; it is sympathetic to and can introduce an ethic of caring and relational ethics that listen to and accommodate the needs of local people and their requirements for public health.

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## Introduction

As the twenty-first century begins, health care professionals worldwide are preparing for the impact on their practice of human genetics, medical genetics, genetic nursing, genomic medicine and human diversity research.<sup>1</sup> These advances at the cutting edge of genetic science and technology will have implications for the interfaces of human health, human rights and public health policy.

Although many commentators are aware of the possible threats to human rights as genetic research and practice globalize, legislation and regulation is scarce and patchy. As yet there is no international legislation pertaining to human rights and genetics. The precursors of international legislation emerged in 1996 and 1997 from leadership organizations such as the United Nations Educational, Scientific and Cultural Organization (UNESCO), the Human Genome Organization (HUGO), and the Council of Europe; work on them accelerated as a result of the cloning of a sheep in Scotland in February of 1997.<sup>2</sup>

Nursing has begun to recognize the desirability of professional guidelines concerning genetics. The International Council of Nurses (ICN) set forth a position statement on human cloning in 1998. We suggest that the next step is to facilitate international debate and consensus in collaboration with the World Health Organization (WHO), the International Confederation of Midwives (ICM), and the International Society of Nurses in Genetics (ISONG) to create a declaration on nursing, human rights, human genetics and public health policy.

## Human rights

The globalization of biomedicine has not been accompanied by a comparable globalization of legislation and regulation governing biomedical research and practice. The Universal Declaration of Human Rights, promulgated by the United Nations in 1946,<sup>3</sup> is the most widely accepted framework for the formulation of human rights, although it has no legislative status. According to article 25:

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 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.

There have been a number of documents expanding on the health-related implications of this foundational document, and several conventions binding upon the signatory states invoke similar language.<sup>4</sup> The human rights perspective typically assumes that the proclaimed rights are rights of individuals, because they are human. These apply to individuals around the world and principally involve the relationship between individuals and the State, although there is increasing recognition in the human rights literature that other societal institutions and systems, such as transnational businesses, may also influence the capacity for the realization of rights, although they elude state control (p. 10).<sup>4</sup>

To agree that every human being has a 'right' to food, clothing or social

services is not so much an assurance that those things will be available to every individual, rather it is an ideal towards which governments commit themselves to work. Human rights standards serve more typically as demarcations of 'negative' rights: states or institutions that are internationally seen as systematically failing those expectations are subject to criticism by other governments and may risk international intervention. Discrimination against groups, unjustified exclusion from benefits available to other citizens of the same country, and offences against human dignity, such as torture, illegal executions or false imprisonment, are particularly scrutinized.

Those concerned with human rights in general are necessarily concerned with health, because access to adequate nutrition and health care are among the most important determinants of human well-being worldwide. Conventions and covenants specifically concerned with health have received considerable attention; organizations already working on international conventions are directing attention to the implications of advances in genomics. Because of the impact that genetics is beginning to have on health care practices, it is important that organized nursing should also be considering these issues.

## **Genetics, nursing, ethics, public health care and human rights**

The notion of using genetics 'for explaining a wider range of human problems' (p. 506),<sup>5</sup> including common diseases such as cancer, heart disease, congenital conditions of the newborn, genetically-mediated paediatric developmental disability, and some chronic illnesses is changing the face of health care and research worldwide. Gradually, the notion of genetic epidemiological databases, genetic risk calculations, genetic diagnoses, genetic tests and genetically-mediated therapies are being introduced into all corners of the globe.

An extensive review of the genetic nursing literature shows that, out of 1114 publications, over half of the literature (53%) mentioned the ethical principle of justice in terms of access to genetic information and services as an ethical priority. The second most prominent area discussed regarding ethics was beneficence (i.e. the desirability of or benefit to the patient and family) of genetic health care services. The third most prominently discussed aspect was that of discrimination on the basis of genetic status. Approximately 45% of the literature overall had some discussion of the principles of autonomy, personal choice and informed consent with regard to genetic services, testing and therapeutics. An ethic of care and relational ethics were discussed in merely 0.06% of the entire body of genetic nursing literature. Nurse authors have come to rely heavily on a principled approach to thinking and writing about ethical issues involving genetics.<sup>6</sup> In the genetic nursing literature, ethical issues are all too often a recitation of the principles of justice, autonomy, confidentiality, privacy, benefits versus costs, and beneficence, without clear explication of what these may mean in different cultural settings.<sup>7-14</sup> We make the claim that nursing, above all other disciplines involved in genetics, is in a good position to articulate an expanded theory of ethics because it is sensitive to cultural diversity and community values. This kind of sensitivity is

needed in human genetic research and clinical practice.<sup>15</sup> Theoretically, nurses have the knowledge and ability to clarify and support an ethics of caring and relational ethics that accommodate the needs of local people and the goals of genetic health care. By expanding the human rights discourse to include these ethical approaches, a declaration on human rights, genetics, public health and nursing would make a significant contribution to how genetic science is applied across international borders.

Nurses are the professional work force by which genetic services and research will be delivered not only in developed countries but also in developing countries where physician services are less widely available. Nurses are often the gatekeepers of public health care. The route of access to public health care services may now include genetic information from many converging sources, such as professional genetic literature, medical and nursing standards of practice, clinical and research laboratories, pharmaceutical companies that market genetic tests, oral family histories, medical records, and diagrammatic genetic pedigrees. The introduction of genetics as preventive health care into public health and hospital services<sup>16</sup> and research blurs the lines of communication and alters role responsibilities in ways that are confusing to nurses, physicians and the public (personal communication with nurses in Japan, Israel, England, Brazil and Korea).

Nurses mediate and facilitate the transfer and translation of genetic science and genetic interventions into the hands of the public. We see that genetics is already making an impact on (and will do so even more in the future) the role of nursing in three significant areas: (1) medical and public health practices; (2) research; and (3) policy formulation and intervention.

### **Medical and public health practices**

In practice roles, nurses will increasingly be responsible for providing genetic assessments and genetic information to 'affected' or 'at-risk' third parties, whether those parties are individuals, relatives or whole communities. Just as it is now often the nurse who takes the patient's history, it may well continue to be the nurse who generates the family tree in the form of a standard genetic pedigree. It is reasonable to think that nurses will be the primary professionals to deliver genetic information related to reproductive planning and prenatal care, congenital newborn conditions, and paediatric conditions. Their role may be especially important in developing countries, where women will inevitably call for equal access to possible benefits from genetic science and technology. A belief that just societies must provide information about genetic science and technology is driven by the assumption that information about advances in health care is necessary for and is the right of all citizens.<sup>17</sup> However, 'reproductive freedom and the liberty to construct and conduct family life are potentially both enhanced and threatened by the genetic revolution' (p. 321).<sup>18</sup>

Nurses worldwide are the primary providers of that care. Some areas of health care, especially public health, are already feeling the impact of the new genetics. Nurses will be asked to help women and families to think about the social and ethical issues that arise in the face of genetic information related to reproduction. Policy makers will turn to individuals and professional groups who

are knowledgeable about genetics 'to determine which services to offer individuals' (p. 304)<sup>18</sup> and to develop innovative public health programmes in continuing efforts to improve maternal and infant mortality and morbidity. Nurses will become direct sources of information about genetics and a referral resource for both medical genetics and genetic research because they are the health care professionals who most often provide continuity of care in families and the community. They can help patients and the public to interpret the meaning and significance of genetic information within a broader sociocultural community context.

In public health settings it is often the nurse who is the primary professional administrating and co-ordinating genetic service programmes, and delivering genetic tests and treatments to communities identified by genetic researchers as 'at-risk' populations. Protecting the interests of individual patients and their communities, and protecting their confidentiality regarding stored genetic information and human specimens, will be ever more necessary in medical and public health care settings worldwide.

## **Research**

Although it is unclear what the future may hold, at the current stage of genetic medicine, research is far in advance of therapy. Because of the promise of the future therapies that genetic medicine proffers, the line between therapy and research is blurring in contemporary practice. One physician philosopher has suggested that the parameters of the discipline of medicine itself are shifting under the impact of the new genetics (N Paul, personal communication).

Nurses are already involved in planning and conducting research projects. They need to be very conscious of doing so in a way that maximizes the interests of the research subjects and protects them from potential or actual misuse of stored genetic information. For example, is it appropriate for a nurse to be involved in genetic research conducted by American scientists that is aimed at collecting blood and tissue samples from indigenous people in countries where no human subject review committees (HSRC) exist, when no such review of the research is required by an American HSRC? Nurses in both developed and developing countries need to be aware of the presence or absence of national legislation and regulations that oversee ethical conduct in human subject research in genetics. Requirements associated with 'human genetics' research protocols are beginning to emerge, for instance, in Brazil (p. 27)<sup>19</sup> and currently in legislative processes in Japan and Israel.

In human genetic variation research projects that involve the collection of family histories and acquiring specimens, nurses may be the best source of information about the community in which the research is planned. They may well substantially reduce the negative impact of research by being mediators and advocates in a target community. Sensitivity is required owing to the potential for commercial exploitation, discrimination, interfamilial disruption and stigmatization. Nurses must be aware of the necessity to approach the community and not merely individuals within the community, for their consent to participate. It is important to negotiate informed consent at three levels of involvement: individual, family and community.<sup>20</sup> Nurse researchers will also be involved in documenting the

impact of various types of genetic diseases, genetic testing, treatments and interventions on the public at large, particularly in underserved or vulnerable populations. Nurse researchers in their various areas of practice will contribute valuable information about the expanding implications of genetics in health care services, research and policy. For instance, nurse epidemiologists could document and measure the effects of particular genetic risk factors in association with health or illness phenomena. Understanding the possible causal relationships between genetics and health and disease can lead to a better basis for making effective public health policies and intervention programmes.

### **Policy formulation and interventions**

By representing the largest group of health professionals, nursing has a reserved seat at any table where policies are being formulated that have an impact on individuals and populations. From the most local to the most general level, the perspective of nursing is a valuable contribution to deliberations about interventions. Nurses need to be sensitive to genetic research that may lead to public health policies that promote unjustifiable positive or negative eugenic interventions<sup>18</sup> or unintended discrimination. Individual nurses who are called upon to take positions of responsibility in national and international groups will profit from an international consensus and a declarative statement that expresses the professional perspective of the international nursing community on matters encompassing genetics, human rights and public policy. With an international declaration, nurses would be seen by other stakeholders as having the ability to make a unique contribution because they are able to see and understand the holistic impact of genetics on the public health policies and programmes in which they may be involved worldwide. With the strength of an international voice behind them, individual nurses in their local and national communities can advocate for access to advantageous innovations for underserved populations and for the protection of vulnerable populations from possible uses and abuses occasioned by well-intended health policies. Nurses can advocate for policies that are tailored to the needs and customs of indigent populations. Human rights, public health and genetics emerge as international concerns for nursing because there is a common effort to elicit the voice of the public, to make it heard and heeded by professionals and policy makers.<sup>17</sup> Nurses in local practice settings need an explicit statement on the implications of genetics and ethical issues because individual nurses are finding themselves in a position to contribute to decisions regarding genetics, ethics, human rights and public policies.

### **Human rights and genetics**

National and international groups at various levels are already responding to the need for specific recommendations to govern human genetics. In this new area, where much research is driven by private enterprise, general agreement is problematic and politically contested. We summarize four current international drafts from: (1) HUGO; (2) UNESCO; (3) Council of Europe and (4) WHO. The dominant ethical theory used to create the current covenants, declarations and

position statements on human rights and genetics is the classic Georgetown model of biomedical ethics. Authors of the human genetics literature use this approach as the main framework for arguing ethical and legal issues relating to genetics.<sup>21</sup>

HUGO adopted a document entitled, *Statement on the Principled Conduct of Genetics Research*,<sup>22</sup> which spells out the following four considerations in planning and evaluating the ethical status of genetic research:

- 1) Recognition that the human genome is part of the common heritage of humanity;
- 2) Adherence to international norms of human rights;
- 3) Respect for the values, traditions, culture and integrity of participants; and
- 4) Acceptance and upholding of human dignity and freedom.<sup>22</sup>

Reciprocal and clear advance communication, consultation, prior and uncoerced informed consent, free choice, collaboration in free flow of, access to, and exchange of information, co-operation and co-ordination, and continual review are the cornerstones of implementing research projects nationally and internationally that respect the above principles. Privacy and protection of the confidentiality of genetic information against detrimental or discriminatory use is emphasized in the recommendations accompanying the general principles.

UNESCO published the *Universal Declaration on the Human Genome and Human Rights* in 1997 (see below, p. 276).<sup>23</sup> According to one commentator:

The declaration is based on the unity of mankind and the equal dignity of individuals, as upheld by the principle of the universality of human rights. Its objective is to reaffirm these fundamental human rights within the context of the unprecedented issues posed by genetics and its applications (p. 33).<sup>24</sup>

This declaration consists of 25 articles that address human rights issues such as: human dignity and human diversity; rigorous and prior assessment of genetic research protocols in each country in which they are conducted; prevention of discrimination based on genetic information; protection of confidentiality and privacy of genetic information in databanks; restrictions on reproductive cloning of human beings; fostering international dissemination of genetic information; promoting international collaboration with developed and developing countries; and interdisciplinary education of professionals who are involved in genetics, specifically bioethics issues. The first four articles included here provide a foundation for all the other articles because they rest upon a universal value for human dignity:

- 1) The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.
- 2) (a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.  
(b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.
- 3) The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment including the individual's state of health, living conditions, nutrition and education.
- 4) The human genome in its natural state shall not give rise to financial gains.<sup>24</sup>

The Council of Europe formally adopted The European Convention on Human Rights and Biomedicine in 1996 in an attempt to 'harmonize disparate national regulations . . . on bioethics with the principles of the convention' (pp. 13, 15).<sup>25</sup> One aim of this Convention is to 'eliminate public fear and distrust in order to allow scientific research to go ahead and to prevent abuse of science and technology and to warrant the dignity of the human being as well as his or her psychic and physical integrity' (p. 14).<sup>25</sup> Selected articles from this Convention specifically point to human rights that may arise from human genome science and have an impact on public health policies and interventions:

- 10) The respect for private life and the right to know and not to know information about one's health must be warranted.
- 11) Any form of discrimination on grounds of genetic heritage is prohibited.
- 12) Tests which are predictive of genetic diseases, of carrier status, and of a genetic predisposition may be performed only for health purposes, and their results can be passed on only for the same purposes.
- 13) Interventions in the human genome aimed at modifying the human genome of descendants are forbidden.
- 14) Medical selection of a future child's sex is not allowed, except where serious hereditary sex-related disease is to be avoided.
- 18) The creation of human embryos for research purposes is prohibited.
- 21) The human body and its parts shall not, as such, give rise to financial gain.<sup>25</sup>

The WHO, at the 51st World Health Assembly in Geneva in 1998, adopted a resolution (WHA51.10) entitled, *Ethical, Scientific and Social Implications of Cloning in Human Health*.<sup>26</sup> This resolution states that a member organization:

- 1) Reaffirms that cloning for the replication of human individuals is ethically unacceptable and contrary to human dignity and integrity;
- 2) Urges Member States to foster continued and informed debate on these issues and to take appropriate steps, including legal and juridical measures, to prohibit cloning for the purpose of replicating human individuals;
- 3) Requests the Director-General:
  - (1) to establish a group, involving also government experts, with the aim of clarifying concepts and developing guidelines relating to the use of cloning procedures for non-reproductive purposes;
  - (2) to continue to monitor, assess and clarify, in consultation with other international organizations, national governments and professional and scientific bodies, the ethical, scientific, social and legal implications for human health of the use of cloning;
  - (3) to ensure that Member States are kept informed of developments in this area in order to facilitate decisions on national regulatory frameworks;
  - (4) to report to the Executive Board at its 103rd session and to the Fifty-second World Health Assembly on action taken by the Organization in this field.<sup>26</sup>

This survey of recent international documents specifically related to genetic interventions is illuminating for nursing. It is clear that the more specific a document is, the less likely it is to receive the universal approval of all possible parties. Although, for example, the members of the European Union are likely to concur on the prohibition of genetic information for prenatal sex selection, or on some of the articles on financial transactions concerning body parts, other nations with different social expectations or legal requirements may be less likely to



become signatories of future conventions with specific restrictions. United States patent laws, as one example of controversial constraints, are productive of a great deal of international concern.

A UK critic of some of the recently published international documents claims that they were stimulated by the 'hysteria' created by the news of cloning Dolly (p. 62).<sup>2</sup> There is no doubt that there is some resistance to international movements for binding human rights documents. Some people may question the need for international legislation owing to a fear of cultural imperialism, while others may worry about unjustifiable restrictions on scientific advancement. 'The strategy has been to emphasize the risk or danger posed by certain kinds of interventions . . . and then to urge voluntary adoption or even legislation to ensure that actions of the suspect category are not undertaken' (p. 307).<sup>18</sup>

Although the existence of grounds for disagreement is clear in the documents cited, the degree of unanimity with respect to some of the provisions is equally clear. Widely accepted bioethical principles recognize the importance of the full disclosure of risk and benefit information, free and informed consent, protection of privacy and confidentiality of medical information, safeguards against discrimination, and sensitivity to cultural differences, as found in all the draft resolutions. This degree of consensus offers reason to hope that widely accepted documents with the scope and power of the original Universal Declaration of Human Rights may some day be achieved with the collaboration and support of national and international professional groups.

## **Preparing the world's nurses for genetic innovations in their local communities**

We believe that an international framework for nursing can be helpful because some countries do not have the legislative or policy potential, owing to governmental or nongovernmental restrictions. A set of standardized rules may provide a practical solution for self-evaluation and intervention at grass roots level in local communities. International nursing organizations are central to this endeavour; they have an obligation to place their views on the table so that the public can take advantage of their concerns and insights. Declarations, resolutions, position statements and conventions are one place to begin; they are antecedent but integral to the process of developing human rights legislation.

It behoves nursing to contribute a professional perspective to the development of genetic research and genetic health services worldwide in order adequately to fulfil its professional responsibility to protect and advocate for patients and families, and to improve world health through the appropriate uses of science and technology for disease prevention and health promotion. Nursing leaders need to think now about creating the tools that are needed around the world for nurses who will inevitably face genetic innovations in clinical practice, research, and public health policies and interventions. We are urging the collaboration of the ICN, the WHO, the ICM, and the ISONG to provide leadership for nurses involved in genetic services, genetic research, and public health genetics policies worldwide.

Some steps have already been taken to make nursing's position clear on some

issues at the intersection of health and human rights. The ICN is a federation of national associations representing nurses in more than 120 countries. We recognize that the ICN as an organization endorsed the principles expressed in the 1948 Declaration of Human Rights. It has declared the importance of human rights in health care in the 1998 position statement entitled *Nurses and Human Rights*, which is published in this issue (see below, p. 272).<sup>27</sup> Human dignity as the foundational concept is expanded in the following principle in a way that elaborates its health-related implications:

Human rights in health care involve both recipients and providers. The International Council of Nurses (ICN) views health care as a right of all individuals, regardless of financial, political, geographical, racial or religious considerations. This right includes the right to choose or decline care, including the right to accept or refuse treatment or nourishment; informed consent; confidentiality, and dignity, including the right to die with dignity.<sup>27</sup>

The ICN position on human rights serves as a foundation for thinking about human genetics. The Council published a position statement on Cloning and Human Rights in 1998,<sup>28</sup> which is based on the belief that: 'Human cloning violates the right to one's unique genetic identity and dignity.' This position statement reads as follows:

'Cloning can be both useful and damaging for human health; while a range of restrictions on cloning is called for, there is also need to recognise the advantages and disadvantages; national nurses' associations and individual nurses should be involved in discussions as scientific data accumulate and the ethical, legal and social debates continue; regulatory mechanisms and global advisory panels (in contrast to legislative approaches) may provide a balanced approach for monitoring cloning and its impact on human health; the full ethical, legal, social and health questions related to human cloning have not been adequately answered. Further information, analysis, debate and monitoring are required.'<sup>28</sup>

It is noteworthy that, in the above statement, the ICN promotes 'regulatory mechanisms and global advisory panels (in contrast to legislative approaches)'. This may represent a desire to think globally while acting locally as a way of preserving respect for and sensitivity to a wide diversity of cultural, social, religious, economic and political contexts in which nurses may participate concerning health policy or research regarding human cloning.

Although the current ICN position statement on cloning is important for the international human rights movement, it is not sufficient for helping nurses who will be involved with genetics in the course of practice, policy or research in their local communities and national professional organizations. Steve Jones, author of the Milbank Memorial Fund report regarding genomics in medicine, states that:

[cloning,] in its usual sense [is not] likely to have much practical impact. Claims that human cloning is imminent are hard to take seriously. Even with legal prohibitions, its many difficulties (a low success rate, with a high incidence of birth defects in cloned animals) means that this technology will not soon affect human reproduction or medicine (p. 6).<sup>29</sup>

The goal of forging a declaration on nursing, human genetics and human rights would not only serve as a tool to evaluate violations but it would encourage the design of affirmative programmes that promote public health and well-being for

women and children. Without internationally acknowledged professional recommendations to guide careful consideration of human rights issues and professional policies, nurses worldwide are in a position of potentially responding to future genetic innovations with moral complicity. They are vulnerable to moral complicity because the science of genetics is rapidly becoming included into health services and research projects before policy makers and professional organizations have had a chance to create guidelines or regulations. Furthermore, genetics is framed as a health care benefit that is aimed entirely at health promotion and disease prevention, which creates hope and promise and is thus difficult to question or challenge, despite differences in sociocultural norms.

Nurses who are working at grass roots level in their communities need education about the genetic components of human beings and their relationship to human health and illness. They need to know the basic principles involved in protecting human rights in the context of genetics and how to assess conventional practices, research proposals and policies for potential human rights violations. A model of ethical decision making is needed that is readily applied in clinical and community practice, research, and public health policy formulation and interventions. A document that formulates nursing's perspective on the relationship between human rights and genetics should incorporate the principles that are almost universally found in the documents already under consideration. However, international nursing organizations can offer additional insight into public health policies and interventions worldwide, and adopt language that 'facilitates the feminist voice of human rights as it reflects the experiences and serves the vision of women in diverse cultural and political settings' (p. 235).<sup>16</sup>

## **Final comments**

International organizations such as the ICN, the WHO and the ICM already work collaboratively and play a significant role in advancing education to improve nursing practice, promote nursing research, and foster nursing input into the processes of policy formulation, legislation and regulations. These organizations aim to improve the standard of care for families throughout the developed and developing countries of the world. We urge international leaders in these organizations and in ISONG to collaborate in order to initiate international debate that moves nursing towards an international declaration and action plan that gives nurses around the world the tools they need to prepare for genetics in their local communities. A declaration for nursing regarding human rights and genetics could give nurses a practical tool for contending with and shaping these anticipated changes in nursing's future.

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