

EDITORIAL

The Human Genome Impact on Health-Care Services: Are Nurses Prepared?

The future is upon us. How many times have we heard about inventions or practices that sound more like science fiction than reality, figments of a creative individual's imagination, only to become commonplace practices and integral aspects of our life and lifestyle? As I look around my own house I see many things that did not exist in my childhood — dishwasher, microwave oven, computer, CD player. Similarly, when I began my nursing career the notion of keyhole surgery, laser surgery, MRIs, and PET and CAT scans, and even electronic thermometers and blood pressure monitors, did not exist.

This situation applies not only to objects and techniques but also to biological concepts. The terms *genetics* and *genes* were not part of nursing's lexicon. In high school biology I learned about Mendel's experiments with pea plants and the principles of chromosomal inheritance. At university I read about Watson and Crick's discovery that DNA was a double helix. However, we never even considered that this knowledge might eventually be used to transform the practice of medicine and have a far-reaching impact on the practice of nursing.

It takes about 40 years for cutting-edge ideas to find their way into mainstream thinking. The first application of our knowledge of genes took place in the early 1970s, in the screening for carriers of the defective genes involved in sickle-cell anemia and Tay-Sachs disease. In both of these cases, the disease was a simple, single-locus gene alteration with readily identified and unique genetic changes. For most inherited disorders, however, the underlying genetic alterations would have to wait until the start of the sequencing of large portions of the human genome, which culminated in the mapping of the entire human genome. And it took the discovery of polymerase chain reaction (PCR), a technique that allows for the amplification of DNA, for scientists to be able to carry out the actual sequencing. This knowledge has opened up an entirely new level of understanding about how gene alterations can contribute to disease, and the application of this knowledge has revolutionized and will continue to revolutionize the practice of medicine, and subsequently the practice of nursing.

The idea of identifying gene alterations that can increase the risk for such complex diseases as cancer and heart and blood disorders is gaining wide acceptance. Increasingly, people are being genetically screened in order to determine whether they are carrying specific gene mutations that will increase their risk for a specific disease or disorder. The knowledge that a person carries the gene shifts medical practice from diagnosis and treatment of the disease, to prevention, early detection, and *then*, if necessary, treatment. For example, up until now cancer care has consisted of early diagnosis and treatment, with most of nursing's attention being focused on caring for individuals and their families after diagnosis. With the ability of medical science to identify individuals at risk, the future of health-care services lies in preventing cancer. To what extent are nurses being provided with the knowledge and skills to play an active role in this future mode of health-care delivery? How well do nurses understand the genetic basis of disease?

In looking back, one can see that changes in health-care services have often originated with discoveries in the basic and applied sciences. These discoveries have changed medical practices, which, in turn, have required nursing to change. Because nursing has often been at the end of this chain of events, its role has been reactive rather than proactive. It has been unaware of the new developments in science and therefore has been hampered in predicting and preparing for the future.

However, nursing is no longer in this position, because information on scientific developments is no longer the purview of just a few. Thus, nursing has an opportunity to alter the sequence of events and become one of the architects of future health-care services. But nursing will be invited to the table only if it has something unique to offer. Our research programs must anticipate the new directions and ask the type of questions that will contribute to new insights into how practices such as genetic screening affect people's health. Our research programs need to address such issues as how readily available genetic information can be used to promote and maintain the person's health, and how the experience of living with the knowledge that one carries a specific mutation affects the person and his or her family.

Central to nursing has been our ability to influence the person-environment interface. The genome project is making us rethink the nature of this interface. We must be prepared to rise to the new challenges.

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GUEST EDITORIAL

Decisions That Matter: Recognizing the Contextuality of Decision-Making

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The rise of individualism in modern Western societies has given rise to a conception of the self as an autonomous self-determining decision-maker (Carnevale, 1999; Taylor, 1989). It is commonly assumed that human agency involves conscious, deliberate action: given sufficient information, each person ought to be capable of rationally and freely choosing among decisional options. This view assumes a computer-like cognitivism whereby decision-making essentially consists of data management and decision-tree management (Dreyfus & Dreyfus, 1986). Yet people make choices that seem rationally incomprehensible: some teens choose to start smoking, many adults engage in unprotected sex with unknown partners, some adults ignore frightening lumps on their body, many men dismiss recurrent chest pains, and so on.

Decision-making is a much more enigmatic phenomenon than cognitivist individualism would have us believe. Decisions about matters that are highly meaningful are significantly shaped by the contextual phenomena within which such decision-making is practised (Carnevale, 1998). Human action is not as independent as the ideals of the West suggest.

Rather, an individual person is acting within what Charles Taylor calls "a horizon of significance" (1985, 1989). The substantive significance of things, formal and informal decisional hierarchies, and obligations regarding traditions, among other contextual phenomena, are shaped by socio-cultural communities within a particular time and place. Thus the meanings attributed to particular decisions, and how the substance of such decisions matters, cannot be determined by individual persons. Such decisions are enacted within a contextual horizon of significance.

The inescapable contextuality of decision-making is highlighted by the papers in this Decision-Making theme issue. In their examination of self-care decisions in chronic illness, Paterson et al. report that the perceived meaning and significance of such decisions are dependent upon disease-specific timeliness, biomarkers, social context, healthy practices, and available information. Rodney et al. have found that ethical decision-making among nurses is oriented towards a particular moral horizon, in concert with currents that favour or impede such movement. Degner's Discourse piece challenges the "illusion of control" with regard to cancer-treatment decision-making, suggesting that numerous phenomena (such as limitations on available resources) covertly constrain the accessibility of some options. Wells et al. describe their successful implementation of an integrated discharge-planning decision-making model, structured with discursive rules in order to balance pragmatic and moral imperatives. Chambers-Evans highlights the complexity of surrogate decision-making by family members striving to foster the autonomy of patients who can no longer decide for themselves. McCleary argues that the ethical principle of equipoise (a state of genuine uncertainty about the relative merits of two or more treatment options in a clinical trial) is difficult to sustain because nurses providing care need to believe that they are giving their patients the best possible care. Hurlock-Chorostecki reports that nurses' decisions regarding pain management, in patients undergoing weaning from mechanical ventilation, are influenced by their a priori beliefs about pain and their role as caregivers.

These papers highlight the constellation of contextual phenomena that underlie decision-making — that is, decisions are at least as expressive of the circumstances under which they are made as the preferences of the individual making them. This also suggests that very few "truths" regarding decision-making are universalizable. Prudence should be exercised in attempting to determine whether the findings from one context are generalizable across contexts — such universalizability will need to be demonstrated. The contextuality of decision-making calls for studies that seek to "thickly" describe the social, cultural, and historical conditions under which particular decisions are made.

I have argued elsewhere that decision-making must necessarily be examined using methodologies, such as ethnography, that seek to understand the context of human agency (Carnevale, 1997). Ethnography does not rely exclusively on self-report data, which provide little insight into extra-individual phenomena related to these data. Rather, the data are examined in light of participant observations

that seek to uncover the horizons of significance against which decisions are made. These could include community beliefs, customs, practices, rituals, tacit knowledge, social structures, and power relations.

A recognition of the contextuality of decision-making can also help bridge the longstanding divide between nursing knowledge derived from clinical practice and nursing knowledge acquired through research. In everyday practice, nurses are commonly faced with the particularity of human actions (such as decisions). Understanding such actions requires an understanding of the corresponding circumstances. Accordingly, research studies of decision-making should attend to such particulars by ensuring that the decisional context is incorporated within the scope of such studies. This will enable a more sound recognition of how decisions matter.

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