

Competent genetic and genomic nursing practice requires the incorporation of various ethical approaches, or tools, into patient decision making. Using different decision-making approaches, which converge to answer an ethical issue, nurses can be confident that their judgment is justified. A lack of convergence can signal a need to reexamine the nurse's ethical decision-making skills. This article describes four approaches that nurses can use to facilitate ethical decision making, which is a skill that must be learned and practiced; these will then be applied to a genomic case study.

#### AT A GLANCE

- No one universal approach or tool can be applied to every ethical issue.
- Nurses must assemble a toolkit of ethical approaches to assist patients and their families in making the right decisions for the ethical issues they face.
- When nurses use several tools to arrive at the same decision, they can be confident in their decision-making skills.

#### KEYWORDS

decision making; ethical issues; genetics; genomics; ethical approach; toolkit

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# Decision Making

## Approaches and tools to respond to ethical issues in genetic and genomic nursing

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**E**thical decision making often involves ethical dilemmas, which are defined as occurring when an individual must select among two or more choices, and none of these choices are ideal (Finkelman & Kenner, 2016). In such situations, action and inaction have the potential to significantly affect the individual (Wueste, 2005). Issues specific to genomic nursing that require shared ethical decision making among the patient, his or her family, and the genomics nurse may encompass equitable access to genetic technologies, privacy and confidentiality of a patient's genetic information (e.g., family medical history, genetic testing results), and the potential for an individual to be discriminated against based on his or her genetic information.

According to the second edition of the American Nurses Association's (2008) *Essentials of Genetics and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators*, "competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills in order to . . . advocate for the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action" (p. 11). Traditional nursing curricula include a brief overview and discussion of nursing ethics, morals, and values. The purpose of this article is to describe various tools that nurses can use to guide ethical decision making in genomic nursing. These tools include the utilitarianism, rights-based, and virtue approaches, as well as the identify, analyze,

justify, and decide (IAJD) model. Each of these tools will be applied to a genomics case study.

### Ethical Tools

#### Utilitarianism Approach

The utilitarianism approach is also known as the consequentialist approach. Although decisions based on this approach could lead to harm for one individual or a few individuals, the decision is considered to be right when it foreseeably provides the most good for the largest number of individuals (Lea, Williams, & Donahue, 2005; Mandal, Ponnambath, & Parija, 2016). One variant of utilitarianism is termed *act utilitarianism*, which addresses decisions made for an individual. With the act utilitarianism approach, the decision maker asks the following question: "The overall happiness of a group is at what cost to an individual?" (Mandal et al., 2016; Masters, 2017). However, the act utilitarianism approach does not consider the rights of the individual; therefore, the rights-based ethical approach should be considered.

#### Rights-Based Approach

The rights-based approach may be better known as the Golden Rule: "Do to others what you want them to do to you" (Matthew 7:12, New Century Version). The tenets of this approach are that all people deserve respectful treatment and that the rights of others should be respectfully considered. Decision making using the rights-based approach is considered to be right if it can be used for everyone involved in every ethical situation. Consequences