Decision Making

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

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Ethical 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

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are not considered from the perspectives of all involved, so decisions made using this approach may yield undesirable outcomes. Consequently, the rights-based approach, used in combination with the utilitarianism approach, may not be useful enough to arrive at an ethical decision because of the inherent limitations of each approach, particularly in complex situations (Fishman & Swanson, 2011).

**Virtue Approach**

Although the utilitarianism and rights-based approaches focus on the decisions to be made, the virtue approach centers on the decision maker striving to become the person he or she wants to become: an admirable person. This approach is based on virtues, the intellectual and character traits an individual has developed throughout his or her life, along with the confidence that an individual possesses when faced with a complex situation (Fishman & Swanson, 2011). Virtuous individuals will instinctively choose the right course of action. Although no simple algorithm for answering ethical issues exists, the decision maker chooses what is right when deciding what kind of a person he or she wants to become or what an individual he or she admires would do in the same situation (Fishman & Swanson, 2011; Masters, 2017).

**Convergence of Approaches**

When the utilitarianism, rights-based, and virtue approaches are used collectively and the same outcome results, the decision maker is an admirable person who makes a decision that respects the rights of the individual or group while generating good consequences. The resultant decision, stemming from the intersection of the three approaches, then is considered to be an ethically good one, with convergence bringing about confidence in ethical decision making. However, when an ethical issue does not arrive at a convergence, but rather is divergent, there exists a need to use a systematic approach, the IAJD model (Smith, Satris, Starkey, & Fishman, 2014).}

**Case Study**

J.B., a 24-year-old Caucasian woman diagnosed with triple-negative breast cancer, was referred for genetic testing before proceeding with surgery for a double mastectomy and tested positive for a **BRCA1** mutation. In addition, J.B. has six siblings, two of whom are older than her and married but do not have children and four of whom are younger than her (including two aged younger than 18 years). J.B. reported that she has never been sexually active and does not have a partner. A three-generation pedigree did not reveal red flags on either the maternal or paternal sides of the family for any inherited cancers.

**Identify**

Although there are many ethical issues in play for J.B., including whether she should have her eggs frozen and undergo reconstructive surgery, J.B. and her genetic

**FIGURE 1.**

**IDENTIFY, ANALYZE, JUSTIFY, AND DECIDE MODEL**

**IDENTIFY**

- Who are the stakeholders?
- What is at stake for each stakeholder?

**ANALYZE**

- What is at stake?
- Analysis of options
  - Utilitarian/consequentialist approach (foresight, the greatest good)
  - Rights-based approach (intact, respectful treatment for all stakeholders)
  - Virtue approach (personal and professional character and integrity)

**JUSTIFY**

- Benefits, risks, and costs of decision
- Convergence of decision—complete or incomplete?
- Other alternatives to the decision
- What occurs if a decision is not made?

**DECIDE**

- How is this decision implemented?
- Is this a good decision (minimal or no harm)?

**Note.** Based on information from Fishman & Swanson, 2011.

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counselor identified an issue affecting others: whether to tell J.B.’s parents and siblings, who are also stakeholders, that she tested positive for the BRCA1 mutation and arrange for them to meet with the genetic counselor. Doing so would allow all stakeholders, including J.B., to possess the same information concerning genetic testing. Other stakeholders identified include the future children of J.B.’s siblings and the insurance companies of J.B.’s parents and siblings, who may or may not pay for genetic testing.

Analyze
J.B., with assistance from her genetic counselor, nurses, physicians, religious leaders, and family members, needs to analyze the issue of to whom and how results should be disclosed using ethical tools. J.B. said she is fearful about informing her family members about her genetic testing results because she is unsure how they will react to the news. She wondered whether they would be supportive, blame one of the parents for passing on the mutation, or even shun her.

After examining the foreseeable consequences, it was determined that because J.B. has six siblings, all of whom are of child-bearing age, disclosing the genetic testing results would provide the greatest good to the greatest number of people. Her siblings would then have the option to pursue genetic testing to clarify their individual risk. J.B. said she would also feel better about herself if she disclosed the genetic testing results.

Justify
Ultimately, once the issue was examined using the IAJD model, J.B. decided to disclose the test results to her parents. To do so, J.B. and her parents met with the genetic counselor. At this meeting, what to do next was discussed, with some of the following questions raised:

- Should J.B.’s parents be tested first?
- Should J.B.’s siblings be told of J.B.’s genetic testing results after her parents’ results are returned?
- Should J.B.’s siblings be tested at the same time as her parents?
- Would some family members be unable to have genetic testing because of lack of money or insurance coverage?

Decide
J.B. and her parents, with input from J.B.’s oncology team, made the decision to arrange a family genetic counseling session; voluntary genetic testing would be available immediately. The benefits of this session were that J.B.’s family members could acquire the same information concerning genetic testing and feel free to ask questions. However, risks included individual family members feeling pressured by other family members to undergo genetic testing; this was addressed when the consent forms were read, discussed, and signed. J.B.’s mother decided not to undergo genetic testing, but her father and four siblings aged older than 18 years opted for testing. Although J.B.’s two older and married siblings tested negative for the known familial BRCA1 mutation, her two younger siblings aged older than 18 years were BRCA1 positive.

Implications for Practice
Being aware of and knowledgeable about these tools is important in a nurse’s daily clinical practice, as well as in difficult situations (Grace & Milliken, 2016). Benner’s (1982) stages of clinical competence (i.e., novice, advanced beginner, competent, proficient, and expert) can also be applied to describe the development of ethical decision making. Novices in ethical decision making have a limited ability to predict what action, or inaction, may significantly affect a patient with a genetic disorder. As the nurse acquires ethical decision-making knowledge, however, the patient also benefits, becoming an advanced beginner with the use of one approach. With experience and time, the nurse will eventually become proficient in deciding which ethical approach is appropriate to use for a particular ethical issue (while also keeping the patient in mind) and will have the ability to make decisions using many tools that converge to formulate a right decision; he or she will also have the confidence to act on that decision (Benner, 1982; Benner & Wrubel, 1982).

However, some ethical issues, regardless of how carefully many tools are applied, will cause a divergence resulting in different answers and solutions. Such a divergence is not attributable to a problem with the ethical tools but rather to the presence of a complex ethical issue. Even so, a decision must still be made. In these types of situations, particularly when time is a factor, the nurse may need to apply two of three approaches (utilitarianism, rights-based, or virtue) to arrive at a decision; this means that the nurse may have to act on a less than perfect convergence. If time is not a factor, then the nurse may have to look at additional factors (e.g., time to come to a decision, access to genetic testing, money, insurance to cover genetic testing) and ethical approaches, as well as talk with ethical experts (e.g., ethics boards, ethics professors, religious leaders), to arrive at an informed decision on which to act (Smith et al., 2014).

Conclusion
Making ethical decisions is not an easy task. In addition, making decisions regarding ethical issues in genetics and genomics is even more difficult, given that genetic information can often be more easily misinterpreted and be more complex than other medical information. As noted in the case study, a diagnosis of a genetic condition in an individual may create ethical issues concerning immediate family members. Therefore, an individual who is considering genetic testing not only has to consider the implications of what a positive test result may mean for his or her health but also what the result may signify for his or her family members. As health professionals with a duty to prevent harm, nurses need a foundation of ethical approaches, or an ethical toolkit, at their disposal to assist
patients in making right decisions for themselves and their families.

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REFERENCES

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