Ethical Considerations for Genetic Testing, Infertility, and Balancing Maternal–Fetal Needs

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Abstract

Among the ethical issues confronting maternal–child nurses are questions surrounding genetic testing, contraception and sterilization, infertility/assisted reproductive technology, and equality in balancing maternal–fetal needs. This article explores these issues, reviews the literature currently available, and discusses nursing clinical implications for each as well as representative case studies. The types of support needed by childbearing families who are facing ethical issues requires emotional and physical support, informational support, and advocacy support. The role of the nurse in educating women about the ethical implications of their choices cannot be overestimated. When women have been educated about the implications of their decisions and are therefore empowered to make informed decisions about their lives and their pregnancies, clinical nurses who practice ethically respect those decisions and support the women in their choices.

Key Words: Assisted reproductive technology; Genetic testing; Nursing ethics.

Nurses support childbearing families in the face of multiple ethical issues, and are called upon to provide emotional and physical support, informational support, and advocacy support, as can be seen in Figure 1.

Ethics and Premarital/Preconception Genetic Testing

Genetic testing and screening was first performed on people of Ashkenazi Jewish descent with the potential to be carriers of Tay-Sachs disease. Amniocentesis and maternal alpha fetoprotein testing are performed for Down syndrome, neural tube defects, including spina bifida or anencephaly, and other untreatable fetal anomalies. Although examination of fetal DNA is now routine, ethical issues have been raised related to the provision of information and reproductive choices that did not previously exist (Press, 2008). Both the March of Dimes (MOD, 2008) and the American College of Obstetricians and Gynecologists (ACOG) Committee on Genetics and

Ethics (2008) advise that family histories focus on the risk of genetic concerns and birth defects. Screening and diagnostic testing should be available to all women of childbearing age so they can make informed decisions about what premarital, preconception, and/or prenatal testing they want to access. Women should give informed consent, and understand they have the right to accept or refuse such testing (Lewis, 2010), rather than believe rumors that screening tests may become mandatory in the future. It is predicted that screening may become mandatory in the future.

Ultrasound systems provide high-definition quality visualization of the embryo and fetus as development progresses (Philips Electronics, 2009). However, boutique commercial fetal imaging such as "Womb with a View," "Fetal Fotos," and "Peek-a-Boo Ultrasounds" is a growing ethical concern. Ethical issues of boutique imaging include maternal psychosocial risks, concerns if there is a fetal anomaly that may be clinically diagnosed later, lack of informed consent (although seeking out this technology as well as paying for the procedure may be considered consent), and the costs of such procedures. A lapse in seeking clinical services may mean that it may be too late to terminate the pregnancy if lethal anomalies incompatible with life are discovered.

Figure 1. Supporting Childbearing Families

Attention to cultural considerations in genetic counseling is essential. For example, for Sikhs and Hindus there is a stigma associated with genetic diseases, with decisions often made based on family input (Barry, 2012; Gettig & Bhatia, 2009). In the Jewish tradition, genetic screening is usually allowed. Because of the high incidence of Tay-Sachs disease in people of Eastern European Jewish descent, premarital testing may be performed and counseling provided (Feshbach, 2009). According to Catholic doctrine, genetic testing is appropriate if it leads to the provision of anticipatory guidance or treatment (Donohue, 2009). Middle Easterners espousing the Muslim faith are at higher risk for hemoglobinopathies. Some may believe that having a child with a genetic disorder is a test from Allah and may represent the will of God *(qadr)* (Berka et al., 2009). Hispanic values including allocentrism (collectivism), positive social exchange *(simpatia)*, and family cohesiveness *(familismo)* should be respected when genetic counseling is done (Paniagua & Taylor, 2009). African Americans may experience challenges related to genetic testing, including inaccurate pedigrees and health disparities associated with lack of access to healthcare (Spruill & Coleman, 2009).

Genetic counseling and support may be lacking for multiple reasons, including insufficient resources, lack of knowledge, and understanding of the importance of support. The Federal Prenatally and Postnatally Diagnosed Awareness Act mandates quality information be provided for women and families about children with disabilities (Dresser, 2009). Nurses may have direct responsibility for case-finding, referral, and counseling when genetic testing is performed, and their recommendations are followed when they are perceived as being expert (Barnoy, Levy, & Bar-Tal, 2010).

Ethical Case Study: Genetic Counseling

A couple presented for genetic counseling after learning their 2-year-old twin daughters had been diagnosed with a rare neurodegenerative condition. The twins began to have symptoms at 15 months of age and a poor prognosis. The parents wanted to know the risks of having additional children with the disorder. The mother reported, "*I had such a healthy pregnancy and our families are so healthy. I just can't believe that this is happening to us*" (Lea, 2009, p. 352). The risk of recurrence was estimated to be 25% and prenatal testing options were discussed. The couple asked themselves, "*what we would do if the test shows that we are having another baby with MLD* [metachromatic leukodystrophy]. *We love our girls so, and it would be heartbreaking to consider ending a pregnancy when a baby has the same disease*" (p. 355). Decision-making support was ongoing. When the nurse followed up 6 months later, the mother was 14 weeks pregnant. Amniocentesis showed that her unborn child did not have MLD. When the nurse offers decision-making support at 6 months, how should she approach this mother who is expecting another child?

An exemplary multidisciplinary initiative, the Fetal Concerns Program addresses the multiple needs of families expecting a child with an anomaly (Leuthner & Jones, 2007). Some women prefer to know about potential fetal abnormalities and others do not. Some women may seek to terminate the pregnancy, whereas others may choose to carry the pregnancy to term, knowing that their newborn may have a genetic disorder. For example, a routine ultrasound at 21 weeks gestation revealed potentially life-threatening fetal osteogenesis imperfecta. The prognosis in this case was uncertain, and the woman chose to continue her pregnancy. She gave birth at 38 weeks gestation to a son who lived a few short days with palliative care. The mother was grateful for the opportunity to cherish her son's short life and appreciated the sensitive nursing care she received (Coors & Townsend, 2006).

Fetal cell sorting techniques (microsort) can identify over 1,000 disease-causing genes, referred to as preimplantation genetic diagnosis. Preembryos may be biopsied and genetically screened, increasing the chance of having an unaffected child. These techniques may be utilized to prevent minor birth defects. They can also be utilized for gender selection for family balancing (Devine, 2008), which is very controversial and considered "enhancement" rather than being therapeutic. Preembryos can also be tissue matched to potentially serve as cord blood or bone marrow donors for an affected existing sibling, raising ethical questions regarding autonomy versus the mutual dependence of family members (Hashiloni-Dolev & Shkedi, 2007).

Reprogenetics is the use of genetic technologies in reproduction. Inheritable genetic modification may modify and enhance genes, which considered a "slippery slope" moving toward the creation of the "perfect child." Evans (2008) refers to this as "recreational genomics" or having a "DNA R Us" focus (p. 709). Genetic modification is an emerging ethical issue. With the increasing use of the Internet for genetic services, the ACOG Committee on Genetics and Ethics (2008) discourages such testing without consultation with a healthcare provider. Chervenak, McCullough, and Brent (2010) provide a stimulating discussion of "the perils of the imperfect expectations of the perfect baby" (p. e1).

Implications for Premarital/preconception Genetic Testing for Nursing Clinical Practice:

1. In order to provide ethical nursing care to patients undergoing genetic testing, nurses need to learn as much as possible about the tests, and also to help the patients learn enough to make informed decisions. When decisions need to be made by the patients, it is the nurse's responsibility to provide nonjudgmental care, counseling, and referral.

2. Educating parents, respectfully supporting their decisions through a "value neutral" approach, and ensuring confidentiality are essential (Lewis, 2010).

Contraception and Sterilization

Roman Catholic tradition prohibits the use of contraception and sterilization because the natural process of conception is curtailed or prevented (Steinbock, 2008). Other religious traditions may view contraception as "playing God," believing that infertility or the number of children a couple have represents "the will of God." Religious conservatives and others may be opposed to providing contraception to adolescent women because they believe this may serve to encourage illicit sexual activities.

Implications of Contraception and Sterilization for Nursing Clinical Practice:

1. A nurse has the ethical right to refuse to participate in an abortion, sterilization, or other procedures, provided that nonjudgmental care is provided,

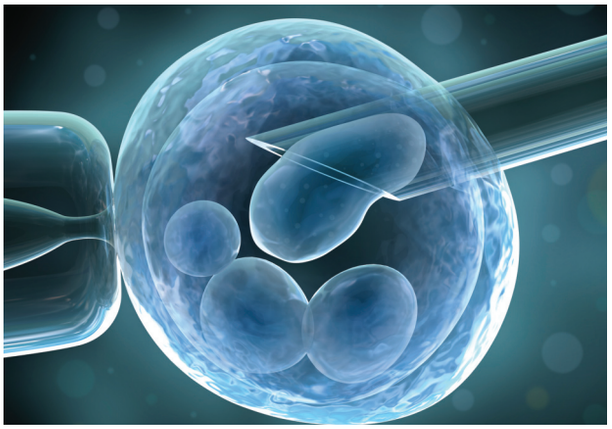
high-quality care is delivered in emergency situations regardless of the personal beliefs of the nurse, and the employer has been informed about the nurse's beliefs that may preclude caring for patients having an abortion or being sterilized (Association of Women's Health, Obstetric, and Neonatal Nurses [AWHONN], 2009).

Infertility and Assisted Reproductive Technology

Approximately 12% of couples of childbearing age in the United States are infertile (McQuillan, Stone, & Greil, 2007). There are varying cultural/religious beliefs about infertility and the use of assisted reproductive technology (ART) (Athar, 2008; Banu az-Zubair, 2007; Roudsari, Allan, & Smith, 2007). Nearly 5% of births result from non-ART ovulation treatment, and over 1% of births in the United States result from ART or 50,000 births (Munson, 2008; Schieve, Devine, Boyole, Petrini, & Warner, 2009). Fertility treatment is now a multimillion dollar business in the United States, called "a key symbol of our times, representing the growing prominence of bio-technologies in the configuration of individual, familial, and collective identities" (Inhorn & Birenbaum-Carmeli, 2008, p. 177) with a success rate of nearly 25% (Barry, 2012). Fertility treatment was initially developed for infertile couples, but has been extended to individuals and nontraditional couples who desire biologically related children. Postmenopausal women having in-vitro fertilization (IVF) may use eggs donated by young women, and posthumous reproduction means a child is born after the death of either parents using cryopreserved sperm, occytes, ovarian tissues, or embryos (Parks, 2009).

There are multiple ART methods, including IVF and intracytoplasmic sperm insertion. In addition, ART includes donors who provide sperm, eggs, or gestation services. There are multiple ethical issues related to the controversy of surrogate or contract motherhood, including "geriatric surrogacy" by maternal grandmothers (Roberts & Throsby, 2008). An increasing trend is for couples to travel to India and other countries for surrogacy, which typically only costs 20% of what it does in the United States (Gentleman, 2008). Ethical issues surrounding ART and infertility include autonomy to choose to have or not have children; informed consent; ethical recruitment of oocyte donors; the creation, selection, and disposition of embryos; and cost, insurance coverage, access, and allocation of resources (Asch & Marmor, 2008; Levine, 2010; Parks, 2009).

Procreative liberty includes the decision to bear or not bear children (Robertson, 2008). Disadvantaged women and those without health insurance may not have access to infertility treatment. Ethicists argue that procreation and parenting are pivotal to personal identity and social development and should be available to all (Parks, 2009). The United States Supreme Court determined that reproductive limitations constitute a disability covered by the Americans with Disabilities Act (www.ada.gov/pubs/ada.htm). Ethical dilemmas associated with ART were highlighted by the birth of eight babies to a single socially disadvantaged mother who had already given birth to six children by IVF, referred to in the media as "Octomom" (Johnston, 2009; Kurtz, 2009; Minkoff & Ecker, 2009; Robertson, 2009).



Addressing psychosocial issues is an important nursing intervention when providing ethical care for infertile women and those receiving ART.

In the literature there is a continuing debate about whether ART is changing the concept of motherhood, and confusing the issue as to who the mother is (i.e., the "social mother" or the "biological mother") (Hammons, 2008).

The right for offspring to know their heritage is another ethical issue. The Donor Sibling Registry provides the opportunity for those conceived with donor sperms to contact half siblings by entering the donor number and the name of the sperm bank. Because over 300,000 children are born each year from donated sperm, this may provide the opportunity for these people to make a potential family connection if desired (Munson, 2008).

Those for whom infertility treatment is unsuccessful may experience a sense of grief, loss, and depression. Healthcare providers should provide emotional support, especially during critical times such as oocyte and sperm collection, immediately following embryo transfer, after the first pregnancy test, and if there is a subsequent perinatal loss.

Multiple gestation, which is common with infertility treatment, can be viewed either as a desirable outcome for infertile couples or a serious complication (Devine, 2008). High-order multiples involve the implantation of more than two fertilized eggs, potentially resulting in triplets and more. A reduction in the number of transferred embryos results in a dramatic decrease in pregnancies with multiples and does not reduce pregnancy rates. Some reproductive centers transfer no more than two embryos (American Society for Reproductive Medicine [ASRM], 2009). The recommended number of embryos transferred depends on maternal age and reproductive center standards. Selective reduction of embryos is fraught with moral and ethical issues associated with

complications such as total fetal loss, increased parental anxiety, violation of religious or cultural beliefs, and postprocedure feelings of guilt. Some couples may feel obligated to donate unused embryos because they were grateful for their IVF treatment.

Another ethical issue related to ART is stem cell research and related therapies. Multiple dilemmas include the destruction of life, the selection of embryos, the right to undergo the procedures versus the rights of the fetus, the rights of the donor mother and the father, and the ownership of cell lines. National Institutes of Health Guidelines on Human Stem Cell Research has been recently released (retrieved from http://stemcells.nih.gov/policy/2009guidelines.htm).

Implications of Infertility and ART for Nursing Clinical Practice:

1. Nurses may be faced with varying reproductive scenarios that require ethical knowledge. For example, one couple seeks IVF followed by prenatal genetic diagnosis to exclude the possibility of having an embryo with anomalies incompatible with life, then proceeds with embryo transfer. Another couple who is infertile seeks ovulation induction and in-utero insemination but opposes prenatal diagnosis and selective abortion and wants to bear a child regardless of the outcome. In contrast, a third couple conceives without assistance and declines to have prenatal genetic testing. They are opposed to abortion and want to have the child regardless of outcomes. These varying preferences underscore the importance of providing individualized nursing care in order to meet the needs of women and couples with varying preferences and cultural and religious beliefs.

2. Addressing psychosocial issues is an important nursing intervention in the provision of ethical care and respect for others. Understanding the perspectives of women is important to increase the sensitivity of nurses to patient needs, such as a woman experiencing perinatal loss following infertility treatment: *"I can't remember ever hurting as bad as I did that day. The pain I felt was so intense. All I could think about was, 'Why? Why me? Why us?' I couldn't stop the tears from flowing. Why was it that teenagers and drug addicts are able to get pregnant so easily, but I wasn't? Did I not deserve to be a mother?"* (Callister, 2006, p. 104).

Balancing Maternal–Fetal Needs

In the case of childbearing women, there are at least two patients: the mother and her fetus. The choices of a childbearing woman may potentially be hazardous to her fetus. For example, when a pregnant woman engages in risk-taking behaviors such as substance abuse or unprotected sex with multiple partners, there may be profound effects on the growth and development of the fetus (Kearney, 2008). An example of maternal–fetal competing needs is an obese 16-year-old Native American woman who presents for prenatal care at 22 weeks gestation. She acknowledges that she drinks alcohol "occasionally" and smokes 5 to 6 cigarettes daily. What is the nurse's duty in this case? There may be dissonance between the ethical principles of *autonomy* and *nonmaleficence* when maternal choices are being made, especially when the mother is engaged in risk-taking behaviors. In these instances, whose rights should take precedence? It is important to take an open, nonjudgmental approach so that the woman continues to access healthcare with education part of every encounter with the woman. Providing encouragement and celebrating when even "baby steps" are taken to change risk-taking behaviors can be very effective.

Another example of balancing maternal–fetal needs is a woman with a history of preterm labor who wants to go home to her family living in a remote rural area, while her healthcare provider wants her to be in close proximity to a Level III NICU. Whose rights take precedence? Negotiation may be required when there is concern about fetal well-being, which conflicts with maternal desires and preferences. Helping the woman to weigh the risks and the benefits of her decisions, understanding the sociocultural context of the mother's life and how this influences her preferences, assisting the woman to problem-solve potential resolutions to the ethical dilemma, and demonstrating respect through a positive nurse–woman relationship should prove helpful in circumstances such as these. A classic work helps us rethink the postulated maternal–fetal conflict and reframe within the framework of mutual needs (Harris, 2000).

Maternal–Fetal Needs Case Studies

A woman arrived at the birthing unit in active labor. She had had no prenatal care and appeared to be about 26 weeks pregnant. She gave birth within 1 hour to a full-term 3 pound 6 ounce baby. The pediatrician was present for the birth and asked the mother if she smoked. She said she smoked a pack a day (20 cigarettes). He asked her what other drugs she used. She looked at her boyfriend. The pediatrician asked again and she said, "I did crack last night" (Murray & Huelsman, 2009, p. 197).

A woman was admitted in labor at 36 weeks gestation. During the second stage of labor, her behavior became psychotic and she hallucinated. A urine drug screen was obtained after the birth of the baby. Results were positive for cocaine. The nursery was notified and meconium drug screen performed. As a result of a positive test, protective services were notified. The woman is threatening to sue for "violating her rights" (Christensen, 2008, p. 449).

- In each of these instances, what is the role of the nurse—and whose rights are primary?
- How would you decide if you need seek consultation from the institutional ethics committee?

Currently there is a debate about mandatory HIV testing for all pregnant women. Perinatal HIV testing potentially reduces HIV transmission to less than 2% with universal screening and early perinatal antiretroviral therapy (Fogel & Black, 2008; Schuklenk & Kelinsmidt, 2007).

Criminalization of a childbearing woman is fraught with complex ethical, legal, and political issues. This may include court-ordered cesarean births against the wishes of the mother related to concerns about neonatal outcomes, or the provision of blood transfusions despite maternal refusal because of religious beliefs. The question of the personhood of the unborn child is hotly debated and highly emotional.

Implications of Equalizing Maternal–Fetal Nursing Clinical Practice:

1. Nurses may feel they are caught in the middle when competing interests of the needs of the mother versus needs of the fetus are a clinical issue. It may be helpful for nurses to consider ethical principles including respect for human dignity, the right to self-determination, commitment to the woman's interest, and respect for privacy and confidentiality in these situations. When women have been educated about the implications of their decisions and are therefore empowered to make informed decisions about their lives and their pregnancies, clinical nurses who practice ethically respect those decisions and support the woman in her choices.

2. It is essential to follow clinical guidelines in a nonjudgmental and caring way while protecting women's rights and decisions, and to maintain an open dialogue with childbearing women's and their families and the healthcare team when maternal–fetal conflict might arise.

3. If women choose not to make what the nurse considers to be the best decision to promote her own health and the health of her fetus, nurses may feel conflicted about their ethical responsibilities. Using the principles of autonomy and respect, the nurse is obligated to assess whether the woman is aware of the consequences of her decision, and then to offer her the best follow-up care available. It is possible that options might be available in the community to help a woman who is addicted to cigarettes alcohol or drugs, for instance, so that the issue can be visited again. If the woman is making a truly informed choice, her decisions are hers alone to make.

The historic phrase "women and children first" refers to the sacrifice of British soldiers in 1852 who gave their lives on a sinking ship in consideration of the lives of women and children (Chervenak & McCullouogh, 2009). Although this may refer to the allocation of resources, this statement is relevant to nursing advocacy of the fetus, the woman, and the neonate. Ethical issues associated with preconception and prenatal testing, infertility and ART, and balancing maternal and fetal needs are of importance to maternal–child nurses. ✣

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Errata

Nutrition Profiles of American Women in the Third Trimester: Erratum

In the article that appeared on page 120 of the March/April 2011 issue, the title was incorrect. The correct title for this article is: Nutrition Profiles of African American Women in the Third Trimester.

This error has been noted in the online version of the article, which is available at www.mcnjournal.com.

Reference

Gennaro, S., Biesecker, B., Fantasia, H., Nguyen, M., Garry, D. (2011). Nutrition Profiles of American Women in the Third Trimester. *MCN: American Journal of Maternal Child Nursing, 36(2)*, 120-126.

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Sailing Against the Tide: Taiwanese Women's Journey From Pregnancy Loss to Motherhood: Erratum

In the article that appeared on page 127of the March/April 2011 issue, an author's name was spelled incorrectly. Her name should be listed as Hilary Patterson, RGN, RM, Diploma Bereavement Counselling, BSc (Hons).

This error has been noted in the online version of the article, which is available at www.mcnjournal.com.

Reference

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