Main ethical issues and challenges in bioethics from the gender perspective in education

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Gender in science and medicine

- Gender relations and gendered power relations are major defining features of science and technology and their social organization.
- Who does science and technology? (Who are the leaders, inventors)
- How are science and technology organized? (What issues, problems, questions are studied, prioritized)?
- How is scientific knowledge constructed? How are theories, concepts, logics, methodologies and language used in science and technology?
Gender in research and clinical practice

• Gender as a dimension in research process (how research is conceptualized and carried out)
  
  Overcome gender bias in research design. Good research must take into account biological (sex) and social (gender) differences between women and men.
  – setting research priorities
  – funding decisions
  – establishing project objectives and methodologies
  – selection of research subjects
  – data gathering
  – as an analytical tool
  – evaluating results

• Gender as a dimension in research ethics
  - relations between researcher and research subjects

• Gender as a dimension in clinical ethics
  - relations between medical service provider and client/patient
Reproductive genetics

• Tendency to treat reproductive genetics as if it were gender-neutral.
• Necessity of a feminist standpoint in decisions and policies that particularly affect women (more than men).
• Rationale – both ethical and epistemological.
• Ethical argument - Women’s bodies and lives are generally more affected than men’s by reproductive decisions (e.g. abortion legislation).
• Epistemological argument – “situated knowledges” and “the embodied nature of all vision” (Haraway 1988: 581). Haraway regards the impartial standpoint of traditional ethics as neither feasible nor desirable. The alternative she proposes is "a doctrine of embodied objectivity," which involves "partial, locatable, critical knowledge sustaining the possibility of webs of connections called solidarity in politics and shared conversations in epistemology" (1988, p. 584). Only through such partial perspectives, she claims, can we approach objectivity (Mahowald).
• Non-directive counselling based on client’s autonomy
• Women’s right to abortion
• Social pressures that may be exerted on couples, especially on women, to terminate a pregnancy thought to be affected by a genetic disorder.
• Listening to women’s different voices (Gilligan).
• Gender differences are rarely noted among those who have primary care responsibility for those affected by genetic conditions. Majority of those who take care of children, the ill, and the elderly are women.

• Gender differences involving genetic conditions – X-linked diseases mainly affect males (females have the preempting advantage of a second X chromosome).

• Women as carriers of X-linked diseases bear the onus of having ‘given’ their affected son the disease.

• Some genetic conditions (e.g. cystic fibrosis, Down syndrome) generally cause infertility in affected men but not in affected women.

• Men never face health risks due to pregnancy; pregnancy presents a particular health threat to women affected by certain genetic diseases (e.g. cystic fibrosis, diabetes, sickle-cell anaemia).
Pitfalls of a gender-neutral language in reproductive genetics

- Parental rights and responsibilities are considered generically – as if mothers and fathers are equally involved in childbearing and childrearing.
- Gamete donors are assumed equal despite the fact that risk and discomfort of ovum donation is not present in sperm donation.
- Often suggested that rights of sperm donors are, or should be, equal to those of women who not only provide ova but undergo artificial insemination, gestation and childbirth as well. (contd.)
Pitfalls of a gender-neutral language in genetics

• Reproductive endocrinologists often speak of infertile couples, whereas it is usually one partner who is infertile and the other is not.

• Prenatal testing is offered to couples rather than individuals despite the fact that most of the tests are performed on the female partner.

• Pregnancy terminations and fetal therapies in response to prenatal diagnoses are generally discussed in the context of couples, although neither procedure requires participation or risk by the male partner.

(Mary B. Mahowald, Reproductive Genetics and Gender Justice, Am. J. of Bioethics)
Need to reconceptualise Gender Justice

- Justice or equality often construed as an ethical demand to treat all individuals in the same way. Human often equated with male.

- Not possible with regard to reproduction – restricted women’s opportunities because of their reproductive capacity. Discriminated because of their temporary disablement.

- Gender justice requires men and women be judged on the basis of their common humanness, while respecting the differences that they embody as gendered individuals without imputing inferiority to one or the other on that basis (Mahowald).
- Women are more likely than men to base their ethical decisions on considerations of care rather than justice (Gilligan). Because women are the primary care givers, both formally and informally, of persons affected by genetic conditions, possibilities for exploitation.
- Access to reproductive health services, treatment options, and information.
- Influence of cultural values and influence of socio-economic determinants on access to pre-natal counselling and interventions.
- Onus of pre-natal counselling and termination on women rather than men.
• Genetic counsellors (males) are more committed to non-directive counselling.
• Genetic counsellors (females) are more inclined to emphasize client autonomy, because they recognize that the lives of their clients, most of whom are women, are more likely to be affected more than that of their male partners by decisions involving reproductive genetics. However, also concerned about families of their clients. This is intended to promote gender justice.
• Deontological theories - Moral decisions must be based on abstract, impartial and universalizable principles. In contrast, the care-based reasoning that women tend to practice involves concreteness, partiality and peculiarity.

• Gender is “the single most important determinant of ethical decision-making” among doctoral level medical geneticists around the world (Dorothy Wertz 1993: 81).
Gender in research ethics

Relation between researcher and research subject(s)

• Enhancing protection of research subjects
• Informed consent procedures – ensuring consent is informed and voluntary (particularly in low-literacy subjects, who are often women)
Gender in clinical ethics and clinical practice

• Relation between medical service provider and client/patient
Why gender?

• Attention to sex and gender are essential to all the processes of medical research conducted by researchers on their subjects, ultimately for patient benefit (Holdcroft et al., 2011)

• To improve the quality of health care for all.
Thank you for your attention!