Ethical issues and challenges in bioethics education from a gender perspective

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Abstract

In this paper I argue that attention for sex and gender should be included as an important element in medical ethics and bioethics education. What is the added value of a gender perspective? There is an epistemological basis (how knowledge is created) as well as an ethical basis (gender justice and equity) for this argument. Gender relations are major defining features of science and technology and their social organization in terms of who does science, how it is organized and how knowledge is constructed. A gender perspective can help to elucidate specific relations of power, opportunity, and resource distribution in the practice of science. Gender is an important dimension in research ethics and in clinical ethics. Gendered power relations pose several challenges in clinical situations where patient autonomy and informed consent are considered salient ethical principles. Gender interacts with health and illness on many dimensions that, in addition to sex differences, produce different outcomes for males and females. Attention for sex and gender are essential to all the processes of medical research, ultimately for patient benefit, and to improve the quality of health care for all. My insights are derived from secondary sources as well as own empirical research on the application of reprogeneric technologies in India.

Sex and Gender

Sex is the biological difference between women and men. Sex differences are about the fact that men produce sperm, women bear and breastfeed children; men and women have different bodies, hormones and chromosomes. Gender refers to socially constructed and widely shared ideas and expectations, norms and values about women and men based on sex differences. Gender interacts with other social differences, such as class, ethnicity, race, age, religion and sexual preference on multiple and often simultaneous levels - referred to as ‘intersectionality’ (Crenshaw 1991) - to create situations/relations of dominance and subordination, contributing to systematic social inequality.

Why gender? What is the added value of a gender approach?

In this paper I argue that attention for sex and gender should be included as an important element in medical ethics and bioethics education. I posit that there is an epistemological
basis (how knowledge is created) as well as an ethical basis (gender justice and equity) for this argument. In order to support my argument I will first look at the role of gender in science, technology and medicine in general, and thereafter, its role in research ethics as well as clinical ethics. I will start with the epistemological argument.

Gendered power relations are major defining features of science and technology and their social organization. “Science and technology are not just structured by gender but pervaded and constituted by and through gender” posit Hearn and Husu. They emphasize “It is very important to understand that science and technology are conducted for the most part in organizations such as research groups, research networks, laboratories, research institutes and universities, with their own profoundly gendered features” (Hearn and Husu 2011: 104).

Several authors, including Klinge (2008) and Wacjman (2007), have pointed out that science is not value-neutral. They have also documented the gendered nature of science, in terms of how gender inequalities which are built into society and research institutions have influenced science, medicine and technology. Gender operates in terms of who does science and technology? For instance, who are the leaders, inventors? It relates to the broader question of the gendered organizing of science and technology: how science and technology are managed, organized and practiced. There is also the question of gendered knowledge in science and technology: the relevance of gender in understanding how scientific knowledge is constructed, produced and validated - what has been called the “woman question in science and the science question in feminism” (Harding 1986; Wacjman 2010).

In her guest editorial of a special issue of the journal *Interdisciplinary Science Reviews* Elizabeth Pollitzer (2011: 101) addresses the question “why gender should be a priority for our attention in science”. She argues that “As a relationship between biological sex and behavior governed by social norms, in the context of science, gender both shapes and is shaped. Its influences are created, reinforced, and cross over at three key junctions of scientific activity: participation, which governs how women and men are organized within and across disciplines; scientific culture, which determines attitudes to gender roles and differentiates treatment of women and men; and research process, which controls how the similarities and differences between men and women are regarded in science knowledge-making.” While gender is an organizing principle of societal institutions and scientific disciplines, gender also refers to biological and social factors affecting research itself. “Weeding out errors in the knowledge base is one of the core conditions of scientific excellence. It has been said that such weed-control could be made easier and more robust by diversifying the values of participants in scientific discourse” (Allchin 1988, cited in Pollitzer 2011: 101).

How do aspects of social identity, such as sex and gender (besides other dimensions of diversity), influence the way people see the world? Donna Haraway (1988) uses the concept of “situated knowledges” to explain that the production of technoscientific knowledge is historically and culturally specific and not transcendent. It involves a set of material practices undertaken by particular groups of people in specific times and locations. Knowledge is always partial, and in some ways, “interested”. 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: 584). Only through such partial perspectives, she claims, can we
approach objectivity. What is true of science and technology in general is also true of the disciplines of medicine and bioethics.

“The power relations within the sphere of biomedicine remain deeply gendered, not simply on the material ground of differential bodies, but also with regard to the conceptual framework of bioethics itself, which dictates what is considered ethically adequate practice” writes Margit Shildrick (2008: 29). Susan Wolf (1996) demonstrates that “mainstream bioethics had been impoverished by ignoring feminist theory and perspectives”. By 1995 several (feminist) bioethicists had begun to question the value of abstract universal norms in science and ethics. “Early on scholars coalesced around the idea that doing justice, not only to the experience of women and other marginalized groups, but also to our human experience would require a fundamental refiguring of the concepts of ethics” (Rawlinson 2008: 2). In the inaugural issue of the International Journal for Feminist Approaches to Bioethics, Mary Rawlinson brings together several authors who demonstrate “not only the necessity in bioethics, as in medicine, of taking into account the specificity of women’s experience and women’s bodies, but also the possibility of finding in them new figures of universality for bioethics itself. By departing from the difference of gender and taking into account the specificity and irreducibility of the experiences and bodies of women, feminist approaches to bioethics are producing new concepts and strategies for bioethics that better articulate and more effectively address our human situation with respect to health and health care” (p.3).

Feminist approaches in bioethics criticize in particular “the focus of bioethics on individual agency and the principled calculation of rights and duties between individual subjects” (Rawlinson 2008: 2). Susan Dodds (2000, cited in Donchin 2008: 153) emphasizes “a consequence of the tendency among bioethicists and physicians to reduce autonomy to informed consent and restrict its exercise in medical practice to a patient’s selection of choices from a restricted set of options”. Feminist bioethicists developed a concept of the ethical subject as relational (relational personhood) and defined by action in a world of others (relational autonomy). Sherwin (2008: 12) explicates the relational concept in ethics. The concept of relational autonomy makes us aware that autonomy is not achieved by simply choosing from among an array of options before us. It requires us to examine what are the options on offer, how these have arisen, and why certain options are not available or accessible. Further, it requires us to understand that “we must go beyond the standard bioethical requirements for informed consent (i.e. ensuring competency, adequate understanding of relevant information, and freedom from explicit coercion) and seek ways of ensuring that the options available to women include those that support their overall well-being” (p.13). Often rights-based approaches do not take cognizance of the fact that some women’s choices are highly constrained due to unequal familial power relations or hierarchical power relations with physicians based on their authority. This is the case, for instance, regarding the use of pre-conceptional testing of the embryo, or pre-natal testing of the foetus as demonstrated through my research (Gupta 2010).

Also, there is a tendency to treat reprodogenetics as if it were gender-neutral. Much of the public and intellectual debates around reproductive issues are framed around the question of the moral status of the embryo or the foetus (Sherwin 2008: 20). The fact that it is women who are hyperovulated to procure human eggs, and that pregnancies take place in women’s bodies is often forgotten even in ethical debates, whether it is the issue of abortion, or the use of human embryos for stem cell research and cloning.

I will now discuss the added value of a gender perspective in biomedical research.
**Sex and gender as a dimension in biomedical research**

The fields of science, technology and medicine are dominated largely by men and male perspectives. In medical research men’s bodies are often still taken to be the norm. The assumption is that results from research performed on men would apply equally to women. Feminist biologists (Haraway 1985/1991; Fausto-Sterling 1992), social scientists (Martin 1992; Clarke 1998; Balsamo 1996, Hird 2004; Roberts 2006, 2007) and humanities scholars (Jordanova, 1989; Schiebinger, 1989, 1999) are among those who critique and challenge that assumption and map the ways in which “technoscientific and biomedical knowledges and practices describe and, indeed, produce material (anatomical, physiological, genetic, hormonal, brain, behavioural, neurological) differences between women and men, girls and boys, female and male fetuses and babies” (McNeil and Roberts 2011: 30). These scholars criticize the assumptions inherent in the field (evident for example, in the metaphors used to describe biological processes, the hypotheses developed in empirical studies or the interpretation of results).

In recent years increasingly irrefutable evidence is available that good research must take into account biological (sex) and social (gender) differences between women and men. It should not be assumed that results from one sex will fit both sexes. Studies have identified huge sex differences in the gravity, symptoms, frequency, and age of onset of various diseases. This is hardly surprising as both epidemiological research and research in medicines is organized in ways that cell lines, laboratory animals and participants in clinical research are often male.

Most basic research with animal models focuses on males to the exclusion of females; female mammals have long been neglected in biomedical research. The National Institutes of Health mandated enrolment of women in human clinical trials in 1993, but no similar initiatives exist to foster research on female animals (Zucker et al. 2010). This creates three problems:

1. Less knowledge about disease processes in females due to underutilization of female animals. Results of studies in males are often generalized to females without justification, and even some conditions that occur more often in women are studied in mostly male animals.
2. Inability to utilize sex as a variable in studies of basic biology (Holdcroft 2007). In many cases, sex has proven an important variable — for example, in regulation of immune function.
3. Missed opportunities to examine female-specific phenomena (such as pregnancy and, in some species, menopause) that often interact with disease progression (www.genderedinnovations.stanford.edu).

Eckenwiler et al. (2008: 162) demonstrate how “Norms about ‘ideal’ research subjects historically have contributed to the exclusion of women, given cyclical variations in hormones, body size and composition, or the use of contraceptives, all thought to compromise ideals of scientific rigour. In addition, it is often assumed that women’s frequent responsibility for child care renders them non-compliant in adhering to research regimens. Similarly, scientific norms that value homogeneity among research subjects have contributed to a failure to perform sex-specific analyses in studies where women have been included, for instance, in research on cardiovascular disease and HIV/AIDS.” This results in the development of health policy and standards of care that are not in all cases clearly applicable to women.

The genSET science leaders panel (www. Genderinscience.org) analyzed gender and sex bias in basic research and found that medical treatments for women are less evidence-based than
for men. Pain research also demonstrates this point well: 79% of animal studies published in the journal *Pain* over the past 10 years included males only, with a mere 8% of studies on females only, and another 4% explicitly designed for sex differences (the rest did not specify), creating a potentially inappropriate basis for the treatment of women (Greenspan et al. 2007, cited in Buitendijk et al. 2011: 811).

“Where women have been included in research as participants, it has tended to be research on women’s reproductive capacities, reinforcing biological essentialism and reducing women to potential childbearers” (Inhorn and Whittle 2001). Also, there is an inordinate focus on women as reproducers when it comes to access to and delivery of reproductive medicine, while men are ignored in research on contraceptives and their delivery, or in procedures to treat infertility (Gupta 2000). It also results in the ignoring of women’s other health problems, such as the insufficiently recognized incidence of certain diseases such as coronary heart disease in the female as opposed to the male body (Shildrick 2008: 29).

Heart disease was for very long considered an almost exclusively men’s issue, despite plentiful evidence that women, too, are at significant risk. It is the biggest killer of women globally causing 8.6 million deaths annually (Sinha 2012). In fact, every year, more women than men die of cardio-vascular diseases. The symptoms of heart disease in women are different than those in men. Therefore, they are recognized late and often after complications have taken place. This is why outcomes are poor and the complications are higher. Mortality among women is also higher due to smaller heart vessels. However, most research into cardiovascular disease is carried out on men with the consequence that little is known about what causes these differences. On the other hand, in the case of osteoporosis, men have historically been excluded from osteoporosis research. Research done mainly on women, using diagnostic criteria based on the relationship between bone mineral density and fracture risk in postmenopausal white women results in under-diagnosis of osteoporosis in men and is used as the basis for the treatment of men.

The consequence of ignoring sex on the quality of scientific research is further demonstrated by the example of testing of new drugs. “In the US, 8 out of 10 drugs withdrawn from the market in the period 1997-2001 turned out to pose greater health risks for women than for men. These problems were not evident in the research leading up to marketing because of inadequate attention in the pre-market testing to potential differences between the reactions of men and women to the drugs” (Vogelson, 2001 cited in Rice 2011: 121). Recently, pharmaceutical clinical research has come under criticism for disregarding drug safety problems that predominate in women, perpetuating inequality by ignoring sex differences and sociocultural gender effects and allowing marketing to reinforce misleading gender stereotypes (Fisher and Ronald 2010, cited in Holdcroft et al. 2011).

“When deciding to perform sex-specific research, proper justification must be given for the exclusion of one sex, whether male or female” posit Ballantyne et al. (2008: 1-2). Rogers and Ballantyne (2008) demonstrate why this is important. “Inclusion in research is a question of both scientific validity of research results and just distribution of the benefits of medical research within a community” (p.36). Inappropriate sex-specific research can be avoided by attending to both scientific and ethical dimensions. “To achieve fair and appropriate sex-specific research, the issue must be framed as one of ethics and debated in terms of potential benefits and harm related to inclusions or exclusions from research” (p.54).
In 2009, the WHO also emphasized that “research must systematically incorporate attention to sex and gender in design, analysis and interpretation of findings” (WHO 2009, cited in Holdcroft et al. 2011). Attention to sex and gender are essential to all the processes of medical research conducted by researchers on their subjects, ultimately for patient benefit. For research to be fair and just it is essential that research reflects the affected population with no discrimination or stereotyping. Studies (Klinge and Wiesemann 2010; Holdcroft et al. 2011; de Visser and Kroese 2012) have demonstrated that a more even distribution of males and females in the studies would broaden the perspective and expertise, and would thereby strengthen innovation in scientific knowledge leading to a reduction in unnecessary morbidity and mortality, improvement in the quality of life of patients and better use of health budgets.

Health differentials between men and women are not a matter of sex difference alone – the biological component, but also of gender differences - associated with the interpretation given to being male or female regarding identity and expected behaviour in various socio-cultural settings. For instance, in the developed world men often tend to ignore, deny, or play down health problems, while women tend to focus on the problem, talk about it and see a doctor. In many developing societies on the other hand, the health-seeking behaviour is highly gendered in that the health problems of men and boys are taken more seriously than those of women and girls. Men seek medical help early for themselves, and sons are taken to the doctor sooner and more often when needed rather than women and girls whose health problems may be largely ignored or at best treated with home remedies. The health of females has low priority in the household. A study conducted by doctors at the All India Institute of Medical Sciences found that among children who require heart surgery, boys have a much higher chance of undergoing the procedure. For every 70 boys who undergo an operation for congenital heart defect, only 22 girls undergo the surgery (Sinha 2012). This has to do with the importance given to males and male children and the lower value attributed to women and girl children in highly patriarchal cultures, especially in income-poor settings, poor accessibility of health services and high cost of medical care (Gupta 2011).

**Gender as a dimension in research ethics**

Gender plays an important role in research ethics. This is in terms of: What issues, problems, questions are studied, and prioritized? How are theories, concepts, logics, methodologies and language used in science and technology gendered? What (if any) “background assumptions” about sex and gender are shaping or embedded in the concepts and theories of the field? “Background assumptions” refers to shared preconceptions and practices within a research community that go unquestioned (Longino 2002). What are the implications of concepts and theories about sex and gender for the way research is conceptualized and conducted – i.e. the choice of research topics (setting research priorities - what constitutes an interesting research topic, what issues are being addressed or not?), establishing project objectives, what kind of projects are being pursued and funded (how to allocate limited resources, to whose benefit and at whose cost? It plays a role in the selection of research subjects (who is included/excluded?). It affects the methodologies adopted (what methodologies are considered appropriate), data gathering, selection of analytical tools, and interpretation of data (what counts as evidence), and in evaluating results. Exclusion from research can have a cascade effect with regard to reduced access to medical resources and a lack of appropriate knowledge about women’s health (Rogers 2004, cited in Rogers and Ballantyne 2008).

Gender is also an important component of the relations between researchers and research subject(s). Ethical principles for clinical research are designed to protect vulnerable
populations from exploitation by medical researchers. For instance, it came to light in 2005 that stem-cell research led by Hwang Woo-Suk in South Korea involved the unethical procurement of over 2,200 eggs, including from some junior female members of his research team (Kim 2008).

Gender deserves attention not only in research ethics, but even more so in ethical clinical practice. By taking examples from the field reproductive genetics I will discuss below the usefulness of concepts such as gender justice and gender equity.

**Gender as a dimension in clinical practice and clinical ethics**

Justice or equality is often construed as an ethical demand to treat all individuals in the same way. In the clinic it is often assumed that women and men have or should have the same capacity for autonomous decision making and informed consent regarding medical procedures, although feminist scholars have demonstrated often through empirical and ethnographic research that patients’ engagements with biomedicine and medical service providers are as sexed and gendered bodies. Medical and scientific discourses shape bodies, both materially (through surgery and pharmaceuticals) and discursively through observing, counting, and measuring and producing descriptions of norms and deviations (Fausto-Sterling 1992; Balsamo 1996).

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 2002). However, ‘human’ is often equated with male. There are certain pitfalls of a gender-neutral language and approach with regard to reproduction which need to be avoided to achieve gender justice. A gender equity approach suggests the necessity of a feminist standpoint in decisions and policies that particularly affect women (more than men). The ethical argument is that women’s bodies and lives are generally more affected than men’s by reproductive decisions (e.g. abortion legislation). Although, in several countries around the world women have a right to legal abortion, they may not be able to exercise this right. Besides accessibility and affordability of services it may also be due to power relations within the family, where decisions regarding reproduction are considered a family matter rather than an individual’s choice. As Buitendijk (2011: 201) emphasizes “Women experience their pregnancy and birth not as mechanical events and they require care givers that are not only technically skilled but also understand the power of empathy, listening and truly caring.”

The ethics of care theory (Gilligan 1982; Tronto 1993) contrasts with more well-known ethical views, such as consequentialist theories (e.g. utilitarianism) and deontological theories (e.g. Kantian ethics). While consequentialist and deontological ethical theories emphasize universal standards and impartiality -- moral decisions must be based on abstract, impartial and universalizable principles, the care-based reasoning that women tend to practice involves concreteness, partiality and peculiarity. The ethics of care emphasize the importance of relationships. Women are more likely than men to base their ethical decisions on considerations of care rather than justice argues Gilligan, who suggests listening to women’s different voices.

Power relations characterize interactions between medical service providers and their client/patients. Gendered power relations along with class and cultural differences sometimes makes it difficult for female patients to request further explanations from medical service...
providers or challenge their competence and ask for second opinions. They play an important role in how consent is obtained for medical procedures. Several researchers including Gupta (2010) have shown that informed consent procedures may need to be rethought to ensure that consent is informed and truly voluntary, particularly in low-literacy subjects in developing countries, who are often women.

Since it is women who carry pregnancies and they are the primary care givers, both formally and informally, of persons affected by genetic conditions, the onus of pre-natal counselling and termination falls on women rather than men. Yet, there is a tendency to treat reprodgenetics as if it were gender-neutral. Parental rights and responsibilities are often considered generically – as if mothers and fathers are equally involved in childbearing and childrearing. 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 (Mahowald 2002). Non-directive counselling is based on the ethical concept of client’s/patient’s autonomy. Often there is little consideration for social pressures that may be exerted on couples, especially on women, to terminate a pregnancy thought to be affected by a genetic disorder. Gender differences are rarely noted among those who have primary care responsibility for those affected by genetic conditions. The majority of those who take care of children, the ill, and the elderly are women. Reproductive endocrinologists often speak of infertile couples, whereas it is usually one partner who is infertile and the other is not. Gamete donors are assumed equal despite the fact that the risk and discomfort of ovum donation is not present in sperm donation. It is 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.

**Conclusion**

I have tried to demonstrate above why attention to sex and gender should be included as an integral element of the curriculum of basic science, medicine, medical ethics and bioethics education. The gender dimension should be one of the main pillars of the development of new scientific knowledge. Including gender analysis in science and medicine and bioethics can offer new perspectives, pose new questions and open new areas to research. Good research must take into account biological (sex) and social (gender) differences between women and men to improve science by preventing incomplete or inaccurate research conclusions being drawn. Analysis of results by sex and gender-disaggregated data may enrich research results in many cases. Gender-blindness, defined as a failure to recognize the many less obvious ways in which gendered assumptions shape attitudes, institutions, and social practices that shape all aspects of social and personal life, must be avoided (Minow 1990 cited in Dodds 2008: 59). Feminist scientists and ethicists are questioning why gender is not on the agenda of peer reviewers of scientific journal articles and research projects (design, implementation and evaluation).

Three approaches to deal with the problem taken by policy makers, institutional administrators, and scientists in the past three decades are discussed by Schiebinger (2008) and Schiebinger and Schraudner (2011) which I endorse here. The first – referred to as “fixing the numbers of women in science, medicine and engineering” - focuses on programmes designed to increase women’s participation. “Gender equality is good for scientific quality” as Elizabeth Pollitzer (2011) says. The second approach seeks to increase women’s participation
by transforming research institutions – called “fixing the institutions: transforming structures and removing barriers”. The third approach focuses on overcoming gender bias in science and technology - called “fixing the knowledge: enhancing excellence by mainstreaming gender analysis into basic and applied research”, “Gendered innovations” – is posited as an approach which highlights the importance of gender as a resource base to create new knowledge. In this article I have concentrated on this last aspect. Besides identifying gender bias it recommends that gender analysis must become an integral part of identifying priorities and designing research in order to achieve critical rigour in science, medical research, policy and practice and to improve the quality of health care for all. The website supported by the European Commission www.genderedinnovations.eu features practical tools to analyze those differences, and also identifies research areas where this analysis has led to important and interesting new knowledge.

References


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