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21A.216: Dilemmas in Biomedical Ethics

Bioethics and the Debate over Universal Standards for Medical Care

Bioethicists, doctors, and anthropologists constantly argue over the role bioethicists should have in the health care system, emphasizing the unique aspects inherent in the world of medicine. These arguments are complicated by the fact that the medical realm is affected by cultural values and stereotypes. Recently much of the debate over the universality of bioethical principles, especially in the mass media, has focused on the plight of women in Muslim countries. Thus topics like female circumcision and the access Muslim women have to health care (including contraceptives and abortion) lead to the question of whether women, regardless of their nationality and religion, should have the same basic rights. No answer has yet been found, but the need for an answer has become increasingly urgent with the development of international committees for reviewing human subject research. For these committees to succeed, questions over the universality of bioethical principles, and who should apply these principles, must be answered. Though bioethicists ought to define the basic philosophies governing health care, the involvement of bioethicists in the application of these principles should be limited. Bioethicists should be involved in the application of these ideas only so far as to ensure that this process results in equal treatment for all members of a society.

As writing from both within the medical community, as represented by Gawande's *Complications*, and from outside of it, by anthropologists such as Byron and Mary-Jo Good, has shown, the world of medicine is very distinct from other enterprises. As Gawande describes, "doctors belong to an insular world – one of hemorrhages and lab tests and people sliced open

[...] And it is easy to become alien to the experiences and sometimes the values of the rest of civilization" (2002: 86). Recent research by the Goods has focused on how doctors become part of this world – how medical students are constructed as doctors. Mary-Jo Good argues that students' feelings about the anatomy lab reflect their journey through this construction process. The uniqueness of the anatomy lab derives from its role as "a ritual space in which the human body is opened to exploration and learning" (1998: 72). As a result of this ritualistic or sacred quality students feel uncomfortable when outsiders visit the lab. One medical student explained that when a visiting student spent time in the lab, the medical student "felt very violated in some funny way" (M.-J. Good 1998: 72). The medical student worried that the visitor, without the context of a medical education, would find the medical student's behavior coarse and unfeeling.

This construction of doctors concerns anthropologists and bioethicists because cultural values and stereotypes influence this process. Though most people outside of medical professions do not realize it, the view of the body in the Western world – and in any culture – is constructed, just as truth is constructed. As Haraway argues, "social constructionists make clear that official ideologies about objectivity and scientific method are particularly bad guides to how scientific knowledge is actually *made*" since science, like everything else, is constructed (1991: 184). The current Western construction of the body, for example, is very biologically based, and the experiences during medical school in the Western world have been designed to promote this view. Thus Byron Good argues "medicine formulates the human body and disease in a culturally distinctive fashion" (1994: 65). As a result students are told to focus on the protein causes for disease, to disregard psychological causes, and to question the efficacy of treatments with no obviously biological link, such as prayer. Though critics like Byron Good recognize that in Western society "disease is [seen as] fundamentally, even exclusively, biological," most do not

realize that culture can affect ideas this fundamentally (1994: 70). This presents a problem because this realization is one of the keys to appreciating that though bioethicists can espouse ethical principles, there is no easy way to describe how these principles should be applied.

In Western medicine doctors and ethicists have defined four guiding principles: autonomy, beneficence, non-maleficence, and justice (Rosenberg 1999: 39). Many medical practitioners in the developing world have been pressured to incorporate these principles as well. These principles, though sometimes expected to apply worldwide, intertwine with local culture and as a result, their meanings vary from place to place. An excellent example is the principle of autonomy, since in most cultures the Western notion of autonomy does not apply. Thus when leaders apply principles like autonomy blindly problems often arise. As Diniz and Vélez discuss "Brazilian medicine, typical of the medicine of the periphery, imports medical theories and practices from countries at the center of medicine [...] [As a result] all too many Brazilian bioethicists assume not only that all medical practices are transcultural but also that all bioethical theories are transcultural" (2001: 67).

Thus bioethicists have to be careful when discussing how ethical principles should be applied across the world. For example state A should not tell state B that because procedure one is more "beneficial" than procedure two, the former must be performed. Though it may not appear so initially, even basic terms like "beneficial" can assume complicated roles since their definitions may vary with the view of end of life care, the role of the medical domain in major life events, and the conception of disease. As a result Western doctors need to refrain from judging other doctors based on Western principles and must instead support developing nations in seeking their own guiding principles. Otherwise developing countries, in the desire to be supported by the United States, will succumb to the pressure to follow the lead of the West and apply ideas that are not compatible with their own cultures.

The discussion by Oguz of research ethics committees (REC's) in Turkey shows the problems that can arise if ideas from more developed countries are blindly applied to developing ones (2003: 292-6). Many developing countries, like Turkey, have recently formed committees to evaluate the ethics surrounding research studies. These countries have experienced problems because the West has gone beyond espousing the necessity of reviewing research to stipulating how these reviews should function and the main principles – autonomy and informed consent - upon which they should focus (Oguz 2003: 293-4). However Oguz argues that differences in the view of autonomy "stem from the conceptualization of the universe: life, community, and human" (2003: 294). These fundamental differences, Oguz argues, will lead to variation in decision-making processes, differences that must be respected. When these differences are not respected, the review process, as seen in Turkey, breaks down (2003: 294-5).

Though there is often as much variation in behavior within societies as between them, culture can still have important effects on the way one views the world. Since most modern states are heterogeneous the modern doctor must understand how people from different cultures view their bodies, their connections to others, and disease. This will allow doctors to best understand how to present prognosis information to their patients. The well-informed doctor thus understands that opinions regarding health care vary between different cultures in large part because the concept of autonomy is very culturally dependent. For example Blackhall's work has argued that the Korean and Mexican cultures have a much more communal view of people, which opposes the Western view of the autonomous individual (2001: 59-71). Even within cultures factors exist that change peoples' perceptions. For example patients may change their

views on health care when they marry, when they have children, and as they age and become more comfortable with death. Thus though doctors should be advised to be sensitive to a person's background and beliefs when giving prognoses, an attempt to standardize this process would surely fail and thus should be avoided.

Informed consent serves as an excellent example for illustrating the difficulties encountered when trying to apply a universal standard. Informed consent is a fundamentally Western idea; its application in other areas has often proved disastrous. In fact even within Western society this topic is contested. Ethicists often question whether mentally handicapped individuals are able to do fully provide informed consent, and, if they are not, who is able to give consent on their behalf. Furthermore the amount of consent (and assent) that minor patients are able to provide has recently been studied (Kuther 2003: 343-58). Such examples make it clear that, from the Western point of view, it is necessary to understand the entirety of a patient's medical, personal, and cultural history and then treat that person with this knowledge in mind. Thus doctors would be hard pressed to stipulate a universal way of determining the ability to consent since this varies so much with variables like age, intelligent, dependence, etc. Since bioethicists cannot even describe how this one idea should be applied in one culture, applying universal ethics or codes presents significant challenges.

Modern managed care programs provide a second set of examples that illustrate the potentially destructive effects of applying medical standards universally. Though many people see managed care as evil, in its conception one of its main goals was simply to benefit humanity by spreading health resources among a wider group of people (Sanchez 2003: 116-129). The concern with controlling medical resources began, in fact, with simple concerns over the distribution of what Howard Hiatt calls the "medical commons" (Hiatt 1975: 235).

However, despite any well-intentioned beginning, the modern formulation of these managed care programs severely limits the choices doctors have in determining treatment procedures for their patients. This has had both positive and negative consequences. On the positive side, more regulations have been developed; these allow doctors to be better informed as to what procedure should be applied (Sanchez 2003: 118-21). The increased dominance of managed care has also increased the system of checks and balances in medicine, as insurance companies audit doctors to assure that they are following guidelines.

Many consequences of managed care have not been positive, however. The managed care system restricts what doctors may do, often preventing them from using the most efficacious treatments. Thus doctors may have to lie or not provide the whole truth about a patient's illness in order to have a wider number of treatments to choose from. Managed care has also disrupted the important relationship between doctor and patient. The system of checks and balances inherent in managed care organizations means that more people necessarily have access to patient records, reducing the chance that confidentiality will be respected. If this leads patients, as Sanchez discusses, to not provide their doctors with all the details about their health history this could have negative consequences indeed (2003: 122-3). Thus though bioethicists should provide general principles (e.g. it is better to spread health resources among the widest group of people) applying these principles in a strict way, as done in managed care, may lead to increased distrust and uncertainty.

Certain theories support the idea that communities should have complete freedom in designing procedures and rules that conform to their moral norms. For example Diniz and Vélez argue that traditional (nonfeminist) moral relativism considers any rules deriving from community moral norms to be moral (2001: 65). However methods like these present certain

problems, if, for example, communities distribute resources unfairly because of discrimination present within the communities. Thus in these situations a system of checks and balances must be implemented. In general feminist bioethics presents a sound model that could improve the status of worldwide health, if followed. Feminist bioethics "distinguish[es] between respecting moral differences and accepting all of them as equally good" (Diniz and Vélez 2001: 65). In the viewpoint of feminist bioethics, cultures impose a moral order if they treat all members "with equal respect and consideration" (Diniz 2001: 65). Thus the role of bioethicists should be to ensure that basic ethical principles - beneficence, non-malificence and justice - are followed in such a way that "equal respect and consideration" are given to all members. Any application of these principles beyond the level needed to ensure equality should be done only by the local communities. Thus in the case of Muslim women, bioethicists should ensure that women and men have the same access to health care, the same freedom in deciding whether to participate in rituals involving their bodies, etc. However bioethicists should refrain from making value judgments about Muslim cultural traditions if these traditions do not decrease rights for a group of people.

In the future health care experts will surely examine the ethics of trials conducted internationally more carefully, since these trials have received much attention from both the general media and the medical community. In these future critiques, doctors and other officials will likely focus on determining what types of treatments (from the developed or developing world) should be given to patients. However at the same time doctors must refrain from stipulating universal moral codes. Western doctors must respect that autonomy, informed consent, and other concepts may not be transferable between cultures. Only if every culture's beliefs are recognized and accounted for will international trials on human research subjects truly become ethical.

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