Learning Through Conflict: Ethical Debates in Sexual and Reproductive Health

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Impassioned international calls to action to protect reproductive rights—for example, the Glion Call to Action (UNFPA 2004) and the Maputo Declaration (2004)—are remarkable in their ability to mobilize activism. Indeed, there is something profound, even sacred, about the concept of health as a human right. Yet, as new cultural, technological, and institutional developments emerge, new challenges to ensuring that the sacred right to reproductive health is ensured for all social groups have arisen. These challenges pose a number of ethical issues and dilemmas, many of which have yet to be as methodically examined or as widely debated as they should be.

Since the time that consensus was reached at the 1994 International Conference on Population and Development (ICPD) in Cairo and the confirmation of the fundamental rights of women and men was declared at the 1995 International Conference on Women in Beijing, the interest in the ethics of service initiatives and research priorities in sexual and reproductive health has sharpened considerably (Cook et al. 2003). This refined concept of rights goes beyond commonly recognized civil and political rights and focuses more clearly on the right to life and health. Rights are by nature indivisible, so they are inextricably linked with each other without a clear hierarchy, and they are immutable in that they cannot be taken away from individuals. Yet they can be breached within families, communities, and institutions, and in the exercise of official power.

The fundamental principles associated with ethics in reproductive health-care service delivery and in research—namely, respect for autonomy, beneficence and nonmaleficence, and justice—are articulated in a series of international agreements and are generally accepted by national bodies responsible for the review of service guidelines, research proposals, and the oversight of professional conduct (Cook et al. 2003). This general acceptance, however, does not guarantee that the principles implicit in international law and guidance are reflected faithfully in the policies and guidelines of member states. The interpretation of ethical principles is embedded in the complex and sometimes contradictory web of international agreements, national and provincial laws, and local customs and culture. Conflicts arise during implementation of the core principles. Most of these conflicts emerge from the challenges and ambiguities associated with trying to implement ethical standards rather than from fundamental disagreements about the basic principles.

Resolving ethical conflicts requires careful analysis, consideration of competing interests and perspectives, and ideally, a forum in which ideas about rights and responsibilities can be formulated and refined. The articles that follow have been collected with the aims of raising awareness of important ethical issues and providing a starting point for further discussion and debate.

The focus of this special issue of *Studies in Family Planning* is on critical ethical issues in the areas of sexual and reproductive health services and research. The ethical debate on issues is broadened and enriched when approached from varied perspectives and when examined through distinct analytical and disciplinary lenses. The articles collected here, contributed by scholars from a variety of fields including philosophy, law, social science, and public health, and discussing developments across diverse national contexts, expand our understanding of some of the most important health-related ethical issues that have produced conflict for individuals, health-care systems, and societies.

RamaRao and her colleagues describe the turning points in the history of ethics in health research and services, such as the revelations of the Nuremberg trials following World War II and the Tuskegee Study of Untreated Syphilis in the Negro Male (1932–72), and how the lessons and guidance from this history apply to modern problems in health-care services and research. Ringheim addresses the complex issues associated with satisfying the unmet reproductive health needs of young girls and boys. She maintains that adolescents' right to protection of their health and their development should not be constrained by negative attitudes toward their ability to make appropriate decisions about their health and long-term interests. Wynn and her colleagues focus on the regulatory processes of the governments of the United

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States and Canada, where persistence and vigilance are required to ensure women's access to new reproductive health technologies. Their account shows that neither scientific research nor the interests of health and women's human rights necessarily guide drug regulation and other formal public health policies.

Testing for HIV serostatus produces a situation in which maintaining clients' confidentiality may conflict with the rights of their sexual partners for protection. Yeatman discusses the ethical consequences of transferring control of the decision to be tested for HIV serostatus from the individual to the provider and analyzes the implications of routine testing for public health policy and planning. Dixon-Mueller presents the ethical grounds for her contention that all persons should be entitled to the right to know their partner's HIV serostatus. Brockway summarizes arguments for and against instituting a routine testing regimen for HIV / AIDS in sub-Saharan Africa and proposes a solution to the disagreement that would respect the rights of individuals to autonomy. Odunsi considers whether, in the interest of stemming the HIV / AIDS pandemic, providers should be compelled to disclose patients' positive status to the patients' sex partners without consent or rather safeguard patients' right to privacy.

Sherman and Fetters question the validity of existing systems of oversight in research by warning that the use of data in conjunction with geographical markers can reveal the identity of service-delivery sites, providers, and their clients, thereby increasing their vulnerability. The training of data analysts and dissemination staff in matters of ethics and in their role in implementing ethical procedures are rarely considered in the review of proposals or in plans for data sharing. In a new look at methodology and the risks and benefits of public health evaluations, van den Borne examines a practice long deemed problematic: the use of "mystery clients."

Kulczycki documents the consequences for critical reproductive health issues such as abortion and emergency contraception when political leaders allow ideology to supersede scientific evidence. He points to the necessary role of evidence from research in forming public policy and the ethical implications of disregarding such research. Mehryar and his colleagues demonstrate that religious leaders may have the courage and fundamental commitment to support the welfare of women and their families, even in the context of profound ideological changes.

The topics of these articles are not the esoteric themes of bioethics commonly addressed in the media, such as the appropriate character of stem-cell research or the challenges of biotechnology in prolonging life. The discussion here is squarely about the right to reproductive health and to life for individuals and communities. Particular attention is paid to the disparities in access to health information and services that are the consequences of gender, ethnicity, wealth, and race. These differences are not insignificant; as Gwatkin (2000) reports, they constitute major differences in access to key interventions for achieving the fifth millennium development goal (reducing maternal mortality). For example, life-saving interventions such as childbirth aided by a skilled birth attendant and the practice of family planning are at least five times more common within the wealthiest than within the poorest quintile in a number of countries reporting in the Demographic and Health Surveys. Typically, the ratios for these health indicators between the richest and poorest segments of the population within these countries are even higher.

In the articles, a focus on learning from conflict emerges from the process of how reproductive rights are exercised in their implementation within social systems, such as in health-care services, or when the rights of individuals conflict with the rights and interests of others. As one example, the right of individuals and couples to decide on the number and timing of their children cannot be properly exercised without access to the information and services necessary to make these decisions effective. As a second example, the behavior of one member of a couple may affect his or her partner's ability to exercise the right to make health-related decisions.

Although a wide range of conflicts is raised here, with each article addressing an important existing or emerging issue, a consideration of additional overlooked perspectives might be helpful as well.

Assessment of Ethical Concerns Versus the Quality of Ethical Assurance

The requirements for ensuring ethical practice include not only the development of consensus on the guidance for good clinical practice and research—for example, the World Health Organization's Medical Eligibility Criteria for Contraceptives, or guidance on the ethical management of clinical trials—but also the oversight of the implementation of this guidance over time as it affects health-care-service clients or participants in research. The availability of budgetary resources for this oversight is crucial for ensuring the continued competence of providers and for monitoring and reporting the results of these efforts to hold policymakers, program managers, and leaders of research organizations accountable for the protection of human rights.

The oversight of ethical practice is a complex process and is not limited to those in direct contact with clients as service providers or to those who interact directly with research participants. One best practice in this area is the use of whole-site training, the training of all staff at a site who might come into contact with a client, including receptionists, cleaners, and others to ensure that maintaining clients' confidentiality is not solely the job of health-care providers. Those who handle data and those responsible for the analysis and dissemination of the results must be made aware of the project's commitment to the protection of research participants' identities and information.

When potential violations are identified, those responsible for oversight should be clear about how to investigate breaches in ethical conduct, where to document and report the context in which they occurred, and the how these breaches will be redressed. Each such case should be archived systematically in accessible databases in order to facilitate review and foster better understanding of the necessity for remedial measures and quality assurance.

The Role of Legal Frameworks in Addressing Ethical Issues

Although the principles of ethics are articulated by international agreements, national law and practice often define how a particular issue will be addressed. In the United States, for example, the Office of Health and Human Services defines how institutional review boards (IRBs) should be formed and should operate and specifies the documentation they require to remain compliant (see, for example, USOHHS 2005). Diverse national IRBs and legislative bodies develop the legal frameworks for penalties and sanctions for noncompliance, with the support of international treaty bodies and the precedents of civil law and custom in the local context. Other policy and legal precedents include professional associations' reviews and sanctions for violation of their ethical standards, such as failure to provide the mandated standard of care. Violations of ethical practice may result in the loss of professional licenses, in fines, or in other context-appropriate forms of sanctions.

Although the ethical review process for proposals for research are well articulated, those for services are less commonly understood, particularly where they involve clear violations of rights. Such violations include failure to allocate resources for critical health services; failure to provide necessary information to preserve health; coercion; and systematic denial of services to individuals. When violations are discovered, local laws, civil sanctions, and social opinion must be mobilized to end the violations and to prevent them from affecting others. Sanctions must be explicit for those who violate the principle of nonmaleficence (doing no harm). Where such violations occur under international jurisdiction, oversight bodies may be called upon to intervene at political and judicial levels.

Whereas all individuals are due respect and protection, vulnerable groups often require special vigilance to ensure that they are provided with the services and support they need. Such groups include those who are poor, in ill health, pregnant, underage, or institutionalized. Men who have sex with men and members of the lesbian, gay, bisexual, transgender, and questioning community often suffer discrimination when they seek care in traditional health-care settings, and require special attention and protection. The disempowered require government and civil support, especially where health-care providers do not approve of their priorities or lifestyles.

The Uncertain Role of Ideology and Religion in Assessing Ethical Practice

The role and importance of culture in the definition of what is good ethical practice remains controversial. Most religious institutions do not oppose the idea of providing health care for all and may serve as potentially strong allies in the defense of human rights within service provision and research. Autocratic ideology, alone or in combination with religion and patriarchy, by contrast, remains a formidable obstacle to the exercise of rights in many settings. Where the autonomy of individuals is not respected or health care is denied to those who suffer the greatest risks, the protection of rights is trumped by political ideology. The exercise of ethical leadership is one of the principal responsibilities of service organizations, including nongovernmental and faith-based organizations that operate health-care facilities or provide guidance to service providers in their public roles. Such organizations should be held accountable for making these principles function in practice.

Protections for Decisionmakers within the Ethical Review Process

The risks and benefits associated with receiving existing health-care services differ from those associated with participation in research on services for which the benefits

are unknown. Likewise, the risks and responsibilities of decisionmakers in health-care-service settings differ from those of decisionmakers in the ethical review of research efforts involving data collection. Yet, both incur risks that warrant protection. Gatekeepers are easily identified in conflicts concerning approval of a research project or the provision of services. Within the ethical review process, members of IRBs and decisionmakers reviewing service guidelines should not only be free of conflicts of interest but also be safe from external threats from those who might not view the protection of human rights and the exercise of fundamental rights as primary desired outcomes. Within the ethical review process, responsible assessments of ethical practice should be conducted and public scrutiny of the review process fostered, but members of committees must be protected from retribution for positions they have taken. Similarly, in service-delivery audits, performance improvement must be achieved without compromising the identity of providers who fall behind in their work for reasons beyond their control—for example, because the context of that work lacks even minimal resources and does not enable them to ensure the rights of clients or research participants.

Dissemination and Use of Findings as Key Elements of Justice

Ethical review is often treated as a front-end process focused on the early identification of those who will participate in research, how they are selected, whether they are subject to undue risk of harm, and whether they have given their informed consent. Much less attention is given to the distribution of the benefits of research, however, such as an increase in knowledge, access to findings, or monitoring of indicators of health. Rosling (2007) laments that much of what the public knows about the status of maternal mortality is filtered through communications from program managers or policymakers or though the media. Dissemination of research findings rarely reaches the affected population because the publication of results usually is directed at scientific audiences.

Sexual and reproductive health issues requiring clarification through ethical analysis are real-life problems that dramatically affect the health and well-being of millions of women and men who seek health-care services. The interests of those who volunteer to sample new technology, new medicine, or new strategies for delivering health services must be protected. When the rights of women, children, and other vulnerable populations are denied, the public response is often timid. Challenging the powerful is perceived as inherently risky. But the imbalance of power in reproductive health care and family planning must be challenged so that their unfinished agendas (Cleland et al. 2006) may be advanced. In her plenary address to the Women Deliver Conference in 2007, Francis Kissling praised the benefits of "being an irritant." Change does not occur when only patience and accommodation are employed; progress is made when brave souls are willing to enter into conflict wherever women's autonomy and social justice are not respected. Differences in perspective such as those articulated in these pages are, therefore, to be celebrated for the vision they bring to the issues of ethics in reproductive health care and research.

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