

## **Seminar on Ethical Issues in Reproductive Health** **Wassenaar, the Netherlands, 21-23 September 2006**

Organized by the IUSSP Scientific Committee on Reproductive Health and the Netherlands Interdisciplinary Demographic Institute (NIDI), The Hague, and held at the Netherlands Institute for Advanced Study (NIAS), Wassenaar

The seminar brought together thirty population specialists, medical and public-health researchers, bio-ethicists, and policy makers in order to contribute to the science-policy dialogue by clarifying ethical issues in reproductive health. Central to the seminar were the balancing of rights and responsibilities, and the rights of men and women as individuals, as members of couples, and as members of society. Nineteen papers were presented and discussed, as described below.

### SESSION 1      OVERVIEW

CHAIR: YAW OFOSU

**Saumya RamaRao** presented *A Question of Ethics: Research to Practice*, co-authored with **Barbara Friedland** and **J. Townsend**, which thematically organized some of the themes linking the seminar papers, including research issues, services, and the history of developing ethics codes.

Following RamaRao's presentation, debate covered the following issues:

- ethical problems in service provision, from political pressure and stakeholders to the influence of commercial interests on clinical trials;
- the divide between science and policy, high-minded principles and facts on the ground (especially in the case of abstinence-focused sexual education);
- the ethical issues posed by the symbiosis between researchers and pharmaceutical companies;
- ethical issues posed by the incentives offered to participants in risky medical trials; and
- the issue of informed consent and the extent to which signing informed consent papers is often just a rubber-stamp and may not reflect informed understanding.

### SESSION 2      THE INDIVIDUAL VERSUS OTHERS

CHAIR: INGE HUTTER

**Karin Ringheim** summarized her paper, *Ethical and Human Rights Perspectives on the Adolescent's Right to Privacy and Confidentiality*. She pointed out that in the countries worst hit by the AIDS epidemic, one quarter of all girls 15-24 are infected with HIV, and half of all 15 year olds will eventually die of AIDS. She argued that the face of AIDS in Africa is that of a young girl, and showed how leaving school early to marry young exposes girls to risk, while lack of confidentiality was a key barrier to accessing reproductive health services. Yet despite CEDAW and CRC provisions asserting the rights of adolescents to confidentiality, providers are generally unaware of their duties of confidentiality or disagree with them, impeding implementation of confidential services. Ringheim argued that principles of justice and individual rights are violated when reproductive health (RH) services are biased on the basis of age or gender; but societal rights and social good are also at stake when the HIV/AIDS epidemic threatens societies.

In the discussion that followed, debate touched on the following issues:

- Teens are people, but are they adults? They may make bad decisions, but when they are sexually active, there is a clear need for confidential RH services.
- Service providers also face a dilemma: To whom do they owe allegiance? Who is their client, teens or their parents? When family is excluded from this aspect of teen lives, what key aspects of family support do they lose.
- The topic pits private interest against public interest in several ways. There is a need for clear guidelines to be set for physicians to follow.
- The notion of “capacity for self-determination,” often used in talking about minors’ rights and abilities, contains a complicated mix of culturally-specific assumptions and biological, perhaps objectively determinable, capacities, that need to be disentangled.
- In talking about parental rights to be informed about their children’s seeking of RH services, we also need to think about parental duties.
- Children are involved in many relationships, not only with parents but with peers and authority figures at school and church, and these must be taken into account in designing policy and intervention.

**Arlette Gautier** presented *Marital Authorization and Women’s Access to Reproductive Health Care*. Reproductive health is a matter of health and survival, and yet men often initiate decisions to access RH services or are consulted by healthcare practitioners. In examining the ethical issues surrounding this, Gautier presented historical arguments for and against men having the right to interfere in women’s RH decisions, from ancient Greek philosophy to literature from the era of the French Revolution to contemporary Canadian legal scholar Rebecca Cook.

Leo Morris thanked Gautier for introducing many to the French-language literature. In the discussion that followed, topics addressed included:

- DHS data that showed that about 25% of women say they made healthcare decisions alone, while 50% said the couple made decisions. These fell along curious class lines: illiterate Mayans were more likely to say that women should decide, while educated doctors most often said that men should decide;
- whether husband and wife constitute one indivisible person; and
- the way societal arguments about the right of men to dominate health-seeking decisions because of their role in the economy played out in different ways in rural and urban areas, confounding any simplistic predictions based on class.

**Inge Hutter**, session chair, briefly summarized the paper by **Gebremariam Woldemicael** (not in attendance), *Is Female Genital Cutting a Violation of Human Rights and Unethical Procedure? Evidence from Eritrea*. Woldemicael presented data on different variations of female genital cutting (FGC) and their prevalence in Eritrea by ethnic group, Eritreans’ attitudes to FGC, and the social and cultural grounds used to justify the procedure. Seminar participants discussed:

- Woldemicael’s interesting point that parents often choose FGC for their daughters to benefit the daughters socially by preventing rape or facilitating marriage; what can that teach about creating incentives to stop FGC?
- Calls to eliminate FGC often lead to accusations of Western cultural imperialism; little can be accomplished without local desire to end the practice.
- A recent WHO study provided the most concrete evidence to date of the threats FGC poses to women’s health and communities.

- Health is very socially defined and applied; one strategy for reducing the practice is to retain symbols and rituals but replace the rituals that threaten health with more benign ones. Evidence was presented that legislatively banning FGC has in some cases diminished its popularity.
- Other conference participants questioned the efficacy of legislative bans and medical stigmatization of the practice. Medical evidence of the harm posed by FGC is no silver bullet; cultural, rights, and religious dimensions need to be addressed by policy interventions.

SESSION 3 THE INDIVIDUAL VERSUS THE STATE CHAIR: YAW OFOSU

**Amir Hooshang Mehryar** presented his paper co-authored with **Shirin Ahmad-Nia** and **Shahla Kazemipour**, *Reproductive Health in a Theocratic System, Iran: Pragmatic Achievements, Unmet Needs, and Ethical Challenges*. Mehryar reviewed the history of the reproductive health policies of Iran since 1979, the views of Shiite jurists on reproductive health and family planning before and after the Revolution, and noted the success of the Islamic Republic of Iran at establishing a family planning program, the fact that family planning clinics were instructed to not ask for proof of marriage when providing services, and availability of locally made, inexpensive condoms.

Subsequent discussion addressed:

- the striking finding that there was a higher prevalence of withdrawal as a contraceptive method in urban than rural areas;
- the interesting combination of top-down implementation of reproductive health policies by the central government and the way policy seemed to change in response to societal demands;
- the status of abortion in Islamic law, the timing of “ensoulment,” and actual availability of abortion services in urban, but not rural, areas; and
- the extent to which low fertility levels reflect changes in society such as the role of women and women’s participation in the labor force.

**John Santelli** presented *Abstinence and U.S. Abstinence-Only Education Policies: Ethical and Human Rights Concerns*, coauthored with **Rebecca Schleifer** and **Lila J. Lande**. Santelli listed multiple critiques of US abstinence-only education: it is not medically accurate; it leads to censorship in schools; it advances a moral, not scientific, agenda; it contributes to poor sexual health; and does harm to international public health. Santelli reviewed the epidemiology of abstinence, including the changing median age of first intercourse and first marriage, demonstrating that abstinence-only education (AOE) programs are not grounded in contemporary sexual practices. He argued that public health professionals have the ethical obligation to provide objective, nonjudgmental information and to respect persons and informed consent, and that such ethical guidelines extend to children and adolescents. That the promotion of abstinence can be ethical, but only if it is presented with medically accurate information as one possible sexual choice.

Subsequent discussion included issues such as:

- efforts to contest AOE in court on the grounds that it restricts freedom of speech;
- the religious ideology of sexuality (heterosexual and occurring only within marriage) behind AOE;

- factors that led to the paradigm shift in sexual education in the US, and the influence of a strong and vocal minority social movement in giving identity and status to virginity-pledging teens;
- the contradiction between the ideology of sexual education and children's bombardment of sexuality by the media; and
- support by racial or ethnic minorities for AOE, and whether its goals are restricting teen sexuality or controlling fertility of minority groups.

**Lisa Wynn** presented *Discourses on Harm Reduction, Women's Rights, and an Ethics of Accountability in Debates over Nonprescription Access to Emergency Contraceptive Pills in Canada and the US*, coauthored with **Joanna Erdman, Angel Foster, and James Trussell**. She reviewed the different trajectories towards approval of nonprescription emergency contraceptive pills (ECPs) in Canada and the US, explored the extent to which decisions about access to ECPs were made in response to social/political pressure rather than based on evidence-based medicine, and analyzed the fundamental assumptions about sexuality informing the debate.

**Andrzej Kulczycki** presented *The War on Science and Reproductive Health: Political Interference with the Research Endeavor and the Undermining of the Cairo Agenda*. He reviewed US policy reversals on the Cairo agenda and the global gag rule, and the way political and cultural context is shaping research and the interpretation of scientific facts and findings. He focused on four arenas: controversy over nonprescription access to ECPs, access to abortion, presentation of findings about condom effectiveness, and the direction of HIV/AIDS education and prevention policies. He tried to explain what was behind the antiscientific turn in the US in terms of the ascendance of conservative control over the Republican party, the radical conservative critique of morals in the US, a changing religious landscape in the US, and popular concerns over new reproductive health technologies. He drew parallels between conservative attacks on reproductive health policy and those on the environment, and linked these with the strengthening of pharmaceutical companies, tobacco and food industry lobbying groups, and widespread undercutting of evidence-based decision-making in federal agencies. He reviewed some of the strategies being used to resist this trend in the US.

Debate following Wynn's and Kulczycki's presentations revolved around:

- the recent and surprising FDA decision to approve nonprescription access to ECPs for women 18 and older in the US;
- the growing number of studies suggesting that increasing access to ECPs does not lead to population-level effects on unintended pregnancy and abortion rates, which leads some to conflate population-level effectiveness with individual effectiveness;
- the effect that US reproductive health policy has on an international level;
- bias in media reporting about differing interpretations of science;
- the creation of alternative knowledges and bases for gauging scientific research by conservative groups in the US; and
- why the issue of abortion has so captured the US imagination.

SESSION 4 THE ETHICS OF HIV TESTING CHAIR: GIGI SANTOW

**Ruth Dixon-Mueller** presented *To Know or Not to Know? The Sexual Ethics of HIV Testing and the Rights and Responsibilities of Partners*. She framed her paper as an

argument against a recent article in the WHO Bulletin arguing that routine testing, even with opt-out clauses, is unethical. She posed a series of questions about whether all men and women had the right to know about their partners' HIV status, about people's obligation to disclose HIV status to sexual partners, about the right to know or be tested, and the right to not disclose HIV status to sexual partners. She called for the ethics of provider-initiated routine HIV testing with an opt-out clause, and said that this must be seen not as a question of individuals versus the state but a matter of the rights of two people engaged in consensual relationship to know about the risk of transmitting or acquiring STIs. Routine testing, she argued, could be seen as empowering by giving people access to care and facilities that they might not seek out, rather than disempowering, as critics argue.

**George Brockway** summarized his paper, *Routine Testing for HIV/AIDS in Sub-Saharan Africa: The Pros and Cons*. He described two opposing positions in public health responses to the HIV pandemic. One calls for routine testing with an opt-out provision, while the other argues against routine testing because it may not take place in the context of sufficiently informed consent. He pointed out that the underlying assumption of both positions is that, if people know their HIV status, that knowledge will influence their behavior in ways that would reduce disease transmission; however, little is known about how knowledge of disease status influences behavior. The possible solution Brockway proposes to this debate is that, rather than focusing on individual pretest counseling, efforts should be spent on a broader public health message that could reach more people, which would expand informed consent. He posed a series of questions for discussion:

- What is the evidence that knowing HIV status motivates people to modify behavior appropriately?
- Must informed consent result from individual pretest counseling to be adequate?
- Proponents of routine testing argue that making testing rare increases stigmatization of testing. Does any individual in a high-prevalence setting have an obligation to know his or her own status, and does any individual have the right to know his or her partner's status?

**Emily Das** presented *Ethical Issues Involved around Antenatal HIV Testing in India*. There is an increasing rate of HIV among pregnant women, especially in southern India; several strategies to prevent vertical transmission to infants are being tested with different antiretroviral therapy (AZT and NVP). Das explored the ethical dilemmas involved in disclosure of HIV status, antiretroviral therapy (ART) during pregnancy and infant feeding practices, and discussed findings on providers' counselling strategies on pregnancy continuation/ termination, future child bearing, and use of contraception. She described a study of in-depth interviews and participant observation during counselling. The study found private practitioners not implementing guidelines while providing antenatal care: many women were informed of their status too late to abort or start ART, there was disclosure of women's HIV status to partners and relatives of the women without consent, and many women could not afford recommended ART.

**Babafemi Odunsi** presented *HIV/AIDS: Should Doctors Be Bound to Inform Sexual Partners of Infected Patients? Right to Privacy versus Public Health*. Odunsi assessed debates over public health needs to control infectious diseases and the extent

to which these can justify the curtailment of individual citizen rights, and pointed out that any human rights encroachment that had no real chance at effectively controlling the disease was not justified. He discussed “contact tracing” and the tension between patients’ right to privacy and medical confidentiality versus protection of third parties against HIV infection. He argued that laws should not mandate that doctors inform patients’ partners of HIV status, for several reasons. First, it is uncertain that the practice would have any real value in the drive to control HIV spread because of limited resources and the likelihood of patient lack of cooperation. Arguably, it would violate individual human rights. Finally, on a practical level, it might actually jeopardize efforts to control HIV/AIDS, especially in developing countries.

**Sara Yeatman** presented *(V)CT: The Growing Tension between Societal and Individual Justifications for HIV Counseling and Testing*. Yeatman examined tensions between societal and individual justifications for HIV counseling and testing, and provided a case study from Malawi where the “Voluntary” nature of Voluntary Counseling and Testing was doubtful and testing was plagued by lack of confidentiality which subsequently had serious negative effects, particularly for stigmatized HIV-infected women.

Following these five author presentations, discussion touched on the following issues:

- What level of HIV in society would compel mandatory testing? At what point does the public health impact become so critical that our decisions about individual rights change?
- How might stigma attached to HIV-positive status change if more people knew their status, or if a majority of a population was infected?
- Despite the availability of rapid-result testing and concerns about the confidentiality of testing in many communities, there does not seem to be any movement towards making testing directly available to consumers, unmediated by healthcare professionals. How might assured confidentiality change people’s willingness to be tested? What about the price of treatment – if treatment is available and affordable, does testing become more appealing and widespread?
- And even if people were willing to be tested, would that change their behavior? We cannot assume that rational decision-making to prevent disease transmission will necessarily follow testing. More research is needed on whether testing produces changes in behavior, such as correct and consistent use of condoms. Many resources are put into HIV testing, but evidence that this is effective is limited. What methodologies are the best investment of public health money?
- The right to know partner’s status depends on a person’s ability to refuse sex and enforce condom use. If a woman cannot refuse sex with her husband, then her right to know her partner’s status should be reevaluated. The dilemma is that if a woman cannot refuse sex with her husband, what good does it for her to know his HIV status?
- What are the obligations of couples towards their offspring if the couple is HIV positive? Does an HIV positive couple have the right to bear children? Early US studies found that knowing HIV status had no effect on women’s fertility behavior. When children (pregnancy) are involved, should testing be mandatory without an opt-out clause, and treatment likewise mandatory? What about the harmful consequences of ART treatment?

- What should be the role of the state? Can public education minimize the fallout and change behavior? Practically speaking, debates over mandatory ART for pregnant women is moot given that only 1 in 9 women has access to ART drugs. The HIV epidemic generally occurs in the context of weak healthcare systems.
- There is a gender dimension to testing. Women are typically “captured” for testing during antenatal care visits to healthcare providers because otherwise they may never get tested. What are the ethical consequences of focusing testing on women? Could the promotion of couple testing and mutual disclosure lessen the stigma for women getting tested?
- There is also a class and race dimension to testing practices. Human rights debate surrounding HIV cannot be divorced from a general discussion of human rights and the context of desperate poverty, famine, and lack of access to healthcare services in which the AIDS epidemic is occurring in Africa.

SESSION 5 RESEARCH ETHICS

CHAIR: LEO MORRIS

**Brooke Ronald Johnson** discussed *Unintended Pregnancies in STI Prevention Trials: What are the Ethical Issues When They Are Unwanted, Especially in Contexts Where Safe Abortion Is Restricted or Otherwise Unavailable?* He presented information on microbicide trials in African countries and data showing that a significant minority of participants believed that the microbicide had contraceptive properties. Many of these trials occur in countries where abortion is illegal, but women who left one trial because of pregnancy on average returned to the trial after less than 3 months, suggesting that many obtained illegal abortions. Given that (1) some of these pregnancies may be trial-related, because of poorly understood pregnancy risk, and (2) there may be incentives to obtain an abortion in order to return to the trial, and (3) illegal abortions are often unsafe and health-threatening, are microbicide trials ethical in countries where abortion is illegal?

Discussion followed:

- What are the ethical implications of offering or not offering inducements/benefits to joining a medical trial? To what extent does expulsion from the study because of pregnancy constitute an incentive to abort or consider a pregnancy unwanted?
- How do US restrictions on funding abortion services shape the way people conceive of and convey risks when planning and implementing such trials?
- What are the ethical implications of a trial that is obligated to encourage condom use but whose success in being able to tell us anything about microbicide effectiveness depends on participants *not* using condoms, in countries where AIDS is prevalent?

**Jill Sherman** presented *From ‘Can we?’ to ‘Should we?’ Research Ethics, Respondent Confidentiality, and Spatialized Survey Data in Reproductive Health Research*, coauthored with **Tamara Fethers**. She explained GIS technology which assigns spatial coordinates to survey responses, thus “spatializing” survey data to produce visual maps, either as part of a survey or as a later project to link two sets of earlier data. She showed how this was done to identify non-physician abortion providers in Cambodia. Spatializing survey data can create the risk of respondent re-identification. Sherman observed that new technologies create new ethical dilemmas,

and presented techniques for reducing, but not eliminating, the risk of breach of confidentiality when using such technologies.

Subsequent discussion examined the possible gap between promises and actual expectations of confidentiality for those participating in the study in question, and the difference in risks for exposing households versus individuals.

**Francine van den Borne** presented her research on *Using Undercover Mystery Clients to Assess Condom Negotiation in Malawi: Unethical Research?* Van den Borne described a trial in Malawi where male testers were trained as closely supervised “mystery clients” who would approach suspected “bar girls” and “freelancers” (women who spend time in bars and are believed to engage in sex for money), propose sex without condoms, and evaluate the women’s abilities or determination to negotiate condom use with potential clients. At no point in time was consent ever obtained from the bar girls, nor did the mystery clients subsequently reveal to the women that they were part of a study. Van den Borne presented justifications for this technique: (1) It was being done in a country where HIV is widespread and there is an urgent need to develop effective strategies for reducing transmission. Effectiveness of strategies such as education and condom provision cannot be ascertained without seeing the actual behavior of women at risk when negotiating a sexual relationship. This cannot be known outside of simulating an actual encounter. Thus there is no way to obtain this information with informed consent. (2) This method also had the advantage of not stigmatizing women as prostitutes. But, van den Borne noted, she was experiencing difficulty in getting the results of her study published because no editor would publish a study done without informed consent.

Seminar participants were particularly fascinated by the ethical dilemmas posed by this study and the fact that so many editors refused even to consider publishing it. Discussion revolved around the extent to which informed consent is truly informed in many studies, the symbolic value of the signed informed consent form in contemporary research. Van den Borne was asked many questions about methodological details and her role in supervising the “mystery clients.” Seminar participants observed that mystery client research is frequently used for other studies (e.g. on dispensing emergency contraception in hospitals or selling cigarettes to minors in the US) where willingness to perform illegal acts is being evaluated and prior consent is not obtained; speculation surrounded whether this particular study disturbed academics not because of lack of informed consent but because of its sexual nature. Seminar participants debated the ethical implications of “proxy consent” whereby a local political leader gives consent for the research on behalf of people under his authority, and how it compared to approval from an IRB board which was much further away (geographically and culturally) from study participants than proxies.

**Leo Morris** summarized the paper of **Ademola Ajuwon** and **Olufunmilola Adegbite** (not in attendance), *Ethical and Methodological Challenges Involved in Research on Sexual Coercion in Nigeria*. He described the study’s decision to do a survey of households on sexual activity where interviewers would interview only one person per household in order to hide the contents of the questionnaire from other family members in the household. He described some of the special techniques



introduced in population-based surveys of sexual violence. Subsequent discussion focused on the ethics and barriers involved in doing research on minor populations.

SESSION 6      PROGRAMMES CHAIR: SUSHEELA SINGH

**Manas Pradhan** presented a study co-authored with **Usha Ram**, *Female Sterilization and Ethical Issues: The Indian Experience*. In India, female sterilization is by far the most common contraceptive method (64% of all methods used). Pradhan examined the extent to which consent is informed and obtained when women are sterilized, especially the extent to which they are informed about alternative, nonpermanent contraceptive methods; the quality of services available, including subsequent health risks and follow-up after sterilization; and the socio-demographic characteristics of India behind such a high rate of female sterilization.

Seminar participants observed that this was an interesting case study of the complex components of choice: historical, political, cultural, and gendered. Participants also debated the merits of using a formula (age x parity) for calculating whether sterilization was “appropriate” or not, the extent to which financial incentives to patients or providers might be contributing to the high rate of female sterilization, and the structural limitations constraining Indian healthcare workers from providing better care.

**Yulia Panayotova** presented a paper co-authored with **Irina Todorova**, *The Politics of Reproductive Rights and Reproductive Technologies in Bulgaria*. Panayotova contextualized the current state of IVF in Bulgaria in terms of a changing healthcare system in the post-Soviet era, the cultural factors driving expectations about reproduction and infertility, the economic contexts shaping how Bulgarians seek medical care, the selection of clients based on ethnicity, socioeconomic status, and age, and the lack of state regulation of assisted reproductive technology (ART) clinics, resulting in dubious ethical practices and the impossibility of comparatively analyze success rates and quality of services.

Seminar participants debated the factors contributing to the pronatalist rhetoric of providers in Bulgaria, both cultural and economic, and talked about the process by which ART facilities came to be regulated and monitored in the US and Europe.

SESSION 7      WRAPPING IT UP CHAIR: DIRK VAN DE KAA

**Dirk van de Kaa** posed a series of questions to help summarize the issues debated over the course of the seminar:

- What is new? What did we miss?
- In which tradition did we work? Western liberal tradition? Are we seeing a ‘return to demography’?
- Did we find examples to follow?
- Did we bridge theory and practice? What policy recommendations were emerging?
- What will we be laughed at for in the future in our weighty pontificating over ethical issues?

In discussion it was suggested that what looked new was also old: the return of demography in the framework of new types of population policies and new research designs. What participants felt was missed in this seminar included: more in depth

discussion of rights (e.g. the incomplete discussion over "positive" vs. "negative rights" and the way the language of rights has been appropriated by different groups); a clear definition and framework of ethics and a distinction between ethics and morality; a theory linking individual rights vs. rights of the state or society; and, more concretely, case studies of bioethics, assisted reproductive technologies, the right to die, the AIDS industry and the different layers of bureaucratic involvement in it. Finally, participants suggested several agendas to pursue: developing new theories about AIDS testing and the role/necessity of the medical provider-mediator in STI testing; more thought about the ethics of controversial research methodologies and whether IRB approval and informed consent forms were often just rubber-stamps; and ways to stand up to powerful but unethical forces in international reproductive health, particularly the US and its abstinence-only agenda.