

## CASE STUDIES IN HEALTH AND HUMAN RIGHTS

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### CASE STUDY #1

#### WOMEN LIVING WITH HIV/AIDS AND FORCED STERILIZATION

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## NARRATIVE<sup>1</sup>

Maria started to use drugs at the age of 18. She injected with a group of friends, who would share needles. "I wouldn't call myself a sex worker, but sometimes I traded sex for drugs." After several years of drug use, when a friend tested positive for HIV, Maria visited an AIDS Centre to be tested herself. When she returned to the Centre, Maria learned she was HIV positive. "I didn't know what to say, what to ask. I was in shock. The counsellor was concerned about everyone but me. Who had I shared needles with? had sex with?" The counsellor instructed Maria that she must change her behaviour. "If you spread the virus, you can be criminally charged and sent to jail." Maria was required to sign a document that she understood these conditions. She left the AIDS Centre feeling judged and angry. "It wasn't my fault. Someone gave me the virus." Maria thought the system was unfair. She convinced herself the test was wrong. She did not experience any symptoms and did not seek any treatment.

Through a community outreach program, Maria received treatment for her drug use. At 28 years-old, Maria was drug-free for two-years and lived with her husband, Nikolay. Maria recently became pregnant. Maria and Nikolay were ecstatic about being parents.

When Maria experienced pain in her lower abdomen, she visited a public hospital. Dr. Minkov diagnosed a tubal ectopic pregnancy, the fertilized egg had implanted outside the uterus in the fallopian tube. Dr. Minkov informed Maria that he must perform surgery, and that she would lose the pregnancy. Devastated, Maria disclosed that she tested HIV positive several years ago. She worried that her status had affected the pregnancy. Maria admitted she had lied on her paperwork. She was fearful of disclosing her status given the AIDS centre counsellor's warnings.

Dr. Minkov replied that there was little time to discuss the matter before surgery. He stated: "I will treat the ectopic pregnancy by surgical intervention. Given the circumstances, I assume you do not plan to have any future children, so we will not worry about preserving fertility." Maria asked again about the effect of her HIV status on her pregnancy: "Can I have a healthy child?" Dr. Minkov curtly answered, "Sure prevention exists to protect against mother-to-child transmission, but it's not as effective. Sterilization is 100%." He then informed Maria that sterilization is a general condition of maternal care for HIV-positive women. "It's hospital policy. If you don't agree, I will need to call senior administration." Maria asked for more time and an opportunity to talk with Nikolay before making a decision. Rather than informing Nikolay of Maria's request, Dr. Minkov had Nikolay sign the consent form on her behalf and performed the sterilization.

Nurse Bondar gave Nikolay updates on Maria's care, but was hostile toward him. She asked: "Are you that selfish? You would pass this terrible disease to your child. It is a blessing you did not have the chance." Nikolay did not know Maria was HIV positive. He knew of her past use of

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<sup>1</sup> This narrative is based on the following sources: UNDP. *Ukraine and HIV/AIDS: Time to Act: Ukraine Human Development Report Special Edition* (2003); K. Burns. *Russia's Epidemic Generalizes: HIV/AIDS Among Women and Problems of Access to HIV Services in the Russian Regions*. (2006); Center for Reproductive Rights & Federation of Women Lawyers. *At Risk: Rights Violations of HIV-Positive Women in Kenyan Health Facilities* (2008); G. Babakian et al., *Positively Abandoned: Stigma and Discrimination against HIV-Positive Mothers and their Children in Russia* (Human Rights Watch: 2005).

drugs, but Maria had not disclosed her HIV status. From early in their relationship, Maria and Nikolay rarely used condoms. He did not like them. He accused Maria of being unfaithful when she insisted on them.

In recovery, Maria learned about the disclosure of her HIV status to Nikolay. He called the hospital and told her not to return home. He threatens to report her to the police. Maria asked Nurse Bondar when she could try for another child. "You're sterilized from the surgery. There will be no more pregnancies." Maria was inconsolable. "No longer a wife, never a mother, I am not a woman. I have nothing to look forward to."

## BACKGROUND

In 2008, an estimated 1.5 million persons lived with HIV/AIDS ("PLWHA") in Eastern Europe and the Commonwealth of Independent States ("CIS").<sup>2</sup> HIV/AIDS has been a predominantly male epidemic in the region.<sup>3</sup> Women constituted roughly a quarter of PLWHA.<sup>4</sup> Rates of HIV-positive women, however, have rapidly expanded in recent years. Of the approximately 110,000 persons in the region who became infected with HIV in 2008, 41% were women.<sup>5</sup> Moreover, 15% of diagnoses occurred in persons between 15 and 24 years of age. In some countries, persons in this age group constitute almost half of new HIV cases.<sup>6</sup> These statistics suggest that women of reproductive age are a growing PLWHA population in the region.

The vulnerability of women of reproductive age to HIV exposure is multi-fold. First, many young persons, faced with poverty and high unemployment, have turned to the drug trade to make a living and to substance use as a means of escape.<sup>7</sup> Injection drug use is the primary means of HIV transmission in the region<sup>8</sup> and disproportionately affects a younger cohort.<sup>9</sup> Among injecting drug users ("IDUs"), women face greater risk of HIV infection because they are more likely to inject with shared syringes.<sup>10</sup> Second, women are at risk of HIV infection through

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<sup>2</sup> U.N. Joint Programme on HIV/AIDS. *AIDS Epidemic Update 2009 - Fact Sheet: Eastern Europe and Central Asia* (2009) at p. 1. Online: [http://data.unaids.org/pub/FactSheet/2009/20091124\\_FS\\_eeca\\_en.pdf](http://data.unaids.org/pub/FactSheet/2009/20091124_FS_eeca_en.pdf).

<sup>3</sup> U.N. Development Programme, *Meeting the Challenge: Addressing HIV/AIDS in Eastern Europe and the CIS Region: The Answer Lies Within: Regional Report on HIV/AIDS 2005* (New York: United Nations Development Programme, 2005) at 8 ("Meeting the Challenge").

<sup>4</sup> See U.N. Joint Programme on HIV/AIDS, "Country Responses," online: UNAIDS <<http://www.unaids.org/en/CountryResponses/Countries/default.asp>>. In Ukraine, however, women represent 43.2% of all PLWHA as of 2008.

<sup>5</sup> AVERT. *European HIV and AIDS Statistics*. Online: <http://www.avert.org/hiv-aids-europe.htm>.

<sup>6</sup> In 2003, almost half of new HIV cases in Ukraine were from the 20-29 age group. UNDP. *Ukraine and HIV/AIDS: Time to Act: Ukraine Human Development Report Special Edition* (2003) at p. 6. "Ukraine and HIV/AIDS". In 2005, 43% of new HIV cases reported in Russia were women of reproductive age. K. Burns. *Russia's Epidemic Generalizes: HIV/AIDS Among Women and Problems of Access to HIV Services in the Russian Regions* (2006), at p. 1.

<sup>7</sup> *Ukraine and HIV/AIDS*, at p. 12, 14; M. Struthers et al. *Fanning The Flames: How Human Rights Abuses are Fueling the AIDS Epidemic in Kazakhstan* (Human Rights Watch, 2003) at p. 15.

<sup>8</sup> D. Operario et al., *Living with HIV in Eastern Europe and the CIS: The Human Cost of Social Exclusion: Regional Human Development Report on AIDS* (U.N. Development Programme, 2008) at 6.

<sup>9</sup> *Meeting the Challenge*, at p. 6.

<sup>10</sup> *Ukraine and HIV/AIDS*, at p. 13; S. Pinkham & K. Malinowska-Sempruch, "Women, Harm Reduction and HIV" (2008) 16(31) *Reproductive Health Matters* 168 at 169.

sexual contact with partners.<sup>11</sup> Heterosexual transmission is the second most common means of HIV transmission in the region.<sup>12</sup> Women represent more than two-thirds of persons who acquire HIV through heterosexual contact.<sup>13</sup> Women's increased risk is attributed, among other factors, to lack of knowledge of their sexual partners' HIV status and lessened capacity to negotiate safer sex.<sup>14</sup> Women who use drugs are more likely to have sexual partners who use drugs as well, and may barter sexual services for drugs, diminishing their capacity to insist on condom use.<sup>15</sup>

With more women of reproductive age living with HIV, risk of mother-to-child transmission ("MTCT") is of increased concern.<sup>16</sup> HIV can be passed from mother to child *in utero*, through the birth canal at the time of delivery and via breastfeeding.<sup>17</sup> The risk of MTCT can be successfully minimized and transmission prevented through health care intervention. For HIV-positive women who wish to carry their pregnancies to term, successful prevention of MTCT includes: antiretroviral medication during pregnancy and delivery, elective caesarean section, and replacement infant-feeding and counselling.<sup>18</sup> Used in combination, these measures can reduce the risk of MTCT to below 2%.<sup>19</sup>

Family planning services can reduce unintended pregnancies.<sup>20</sup> Most contraceptive methods are safe and effective for women living with HIV, and family planning counselling can assist women to select a method most suitable to their needs.<sup>21</sup> Sterilization is one means of contraception.<sup>22</sup>

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<sup>11</sup> *Operario*, at p. 7; *Ukraine and HIV/AIDS*, at p. 8.

<sup>12</sup> *Operario*, at p. 7. See also: AVERT. "HIV and AIDS in Russia, Eastern Europe & Central Asia."

<sup>13</sup> Women constituted 67% of Ukrainians who became infected with HIV in 2003 through heterosexual sex. *Ukraine and HIV/AIDS*, at p. 1. 70% of Russians who contracted HIV through heterosexual contact in 2005 were women. Burns, at p. 8.

<sup>14</sup> *Meeting the Challenge*, at p. 10.

<sup>15</sup> *Ukraine and HIV/AIDS*, at pp. 12-13; Pinkham & Malinowska-Sempruch, at pp. 169-170.

<sup>16</sup> According to data from the ministry of health in Russia, the number of childbirths by HIV-positive women in the country jumped from 60 to 9,371 between 1997 and 2004. G. Babakian et al., *Positively Abandoned: Stigma and Discrimination against HIV-Positive Mothers and their Children in Russia* (Human Rights Watch: 2005) at pp.7-8. In Ukraine, the HIV prevalence among pregnant women rose from 0.12% in 1998 to 0.34% in 2004. *Operario*, at pp. 10-11.

<sup>17</sup> World Health Organization. *Prevention of Mother-To-Child Transmission (PMTCT): Briefing Note* (2007) at p. 3. ("WHO PMTCT")

<sup>18</sup> *Operario*, at p.11. See also: *WHO PMTCT*, at p. 8-9; *WHO Women Living with HIV/AIDS* at pp. 31-32, 35-37.

<sup>19</sup> *Operario*, at p. 11. See also *WHO Women Living with HIV/AIDS* at p. 31.

<sup>20</sup> World Health Organization, *Sexual and Reproductive Health of Women Living with HIV/AIDS: Guidelines on Care, Treatment and Support for Women Living with HIV/AIDS and their Children in Resource-Constrained Settings* (2006) at p. 17 ("WHO SRH Women Living with HIV/AIDS"). See also: T. Delvaux & C. Nostlinger, "Reproductive Choice for Women and Men Living with HIV: Contraception, Abortion and Fertility" (2007) 15:29 (Supp) *Reproductive Health Matters* 46 at p. 57.

<sup>21</sup> *WHO SRH Women Living with HIV/AIDS*, at p. 17-18.

<sup>22</sup> Sterilization is a permanent contraceptive method. Surgical sterilization involves an operation in which the fallopian tubes are cut or blocked in order to prevent fertilization. Medical and chemical sterilization are non-surgical methods that involve either the placement of a coil in the fallopian tubes or the administration of a medication that causes the fallopian tubes to seal. See: Center for Reproductive Rights (2010). *Dignity Denied: Violations of the Rights of HIV-Positive Women in Chilean Health Facilities*.

Because of its generally irreversible nature,<sup>23</sup> many jurisdictions have restrictions and guidelines concerning its use, especially pertaining to younger women.<sup>24</sup>

Stigma against PLWHA, compounded by existing stigma against IDUs and other marginalized groups, limits effective efforts toward HIV prevention and treatment. HIV-related stigma leads many PLWHA to hide their serostatus<sup>25</sup> and to avoid seeking information and services.<sup>26</sup> A recent international trend to use the criminal law to curtail HIV exposure and/or transmission has exacerbated these effects.<sup>27</sup> Adopted in response to the perceived failure of existing prevention strategies,<sup>28</sup> criminalization has in fact undermined prevention efforts as PLWHA are further deterred from accessing services, particularly public services affiliated with government.<sup>29</sup>

HIV-related stigma also leads to mistreatment and discrimination against PLWHA in the clinical health context. Despite laws that expressly prohibit such practices, PLWHA are routinely denied care, asked to pay supplementary service charges, and mistreated by health providers.<sup>30</sup> HIV-positive women are often subject to judgment and mistreatment based on their decision to bear children. Some health providers may question their long-term ability to care for children. Others routinely encourage HIV-positive women to terminate their pregnancies and/or undergo sterilization without proper information on MTCT prevention and with no relation to the health status of the pregnancy.<sup>31</sup>

## Background on Ectopic Pregnancy

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<sup>23</sup> WHO SRH *Women Living with HIV/AIDS*, at p. 23.

<sup>24</sup> See e.g., *The Application of Medical Sterilization of Citizens*, Regulation 303 of the Ministry of Health of the Russian Federation, December 28, 1993 (except otherwise considered medically indicated, sterilization is only allowed for women over the age of 35 unless she has had at least 2 children). See also International Federation of Gynecologists and Obstetricians, *Ethical Considerations in Sterilization* (London: FIGO, 2000), s. 8(a).

<sup>25</sup> Babakian, at pp. 9-10.

<sup>26</sup> Operario, at p. 19. *Ukraine and HIV/AIDS*, at p. 14.

<sup>27</sup> In the following countries exposing another person to the risk of HIV transmission is a criminal offence: Armenia, Georgia, Moldova, Russia and Ukraine. Global Network of People Living with HIV/AIDS Europe & Terrence Higgins Trust, *Criminalisation of HIV Transmission in Europe: A Rapid Scan of the Laws and Rates of Prosecution for HIV Transmission within Signatory States of the European Convention of Human Rights* (2005). (“Criminalization in Europe”).

<sup>28</sup> R. Jurgens *et al.*, *10 Reasons to Oppose Criminalization of HIV Exposure or Transmission* (2008) at p. 1.

<sup>29</sup> See generally, U.N. Joint Programme on HIV/AIDS, *Policy Brief: Criminalization of HIV Transmission* (2008) at p. 3 (“UNAIDS Criminalization Brief”).

<sup>30</sup> Although the law in Russia and Ukraine prohibit medical practitioners from discriminating against patients because of their HIV status, PLWHA in these countries report that such practices continue to exist. See e.g., Babakian, at pp. 10-11, 17-19. See also: T. Gerbert & S. Mendelson. *Draft Report: A Survey of Russian Doctors on HIV/AIDS* (2005) at p. 12; R. Schleifer & J. Buchanan, *Rhetoric and Risk: Human Rights Abuses Impeding Ukraine's Fight against HIV/AIDS* (Human Rights Watch, 2006) at pp. 44-48, 50-51.

<sup>31</sup> Babakian, at pp. 19-21; Burns, at pp.10-11; Scheifer & Buchanan, at pp. 14, 54-56. With respect to sterilization of HIV-positive women under coercive conditions, only anecdotal reports are found in Eastern Europe and the CIS region. Systemic evidence of such practice has been documented in countries such as Namibia and Dominican Republic. See: A. Ahmed & E. Bell, *The Forced and Coerced Sterilization of HIV Positive Women in Namibia* (International Community of Women Living with HIV/AIDS, 2009); M. Mollmann & J. Walsh, *A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic* (Human Rights Watch, 2004) at pp. 1-2, 29.

Women who present with pain and bleeding in the first trimester of pregnancy may have an ectopic pregnancy. This condition is not related to HIV status. In an ectopic pregnancy, the fertilized egg implants outside the uterus. Most commonly, this occurs in the fallopian tube, resulting in a tubal ectopic pregnancy. It is not possible to bring an ectopic pregnancy to term and preserve the fetus. Ectopic pregnancy can also be a life-threatening condition for the woman, but significant improvements in the diagnosis and treatment of ectopic pregnancies have greatly reduced mortality rates. Although spontaneous resolution, where the pregnancy ends on its own, can occur in a tubal ectopic pregnancy, medical or surgical intervention is required for women at risk of tubal rupture and hemorrhage. There are several treatment options, including:<sup>32</sup>

- **Medical Treatment:** The standard of care for ectopic pregnancy has been traditionally surgical, but medical treatment with drugs, namely methotrexate, is now more common. Medical treatment has replaced surgical treatment in many cases.
- **Surgical Treatment:** Salpingostomy (removal of gestational sac through incision in the tubal wall) is now preferred to salpingectomy (removal of the tube). The former is less invasive and carries equal rates of effectiveness. The latter is rarely performed, reserved for emergency situations in which the patient is unstable or hemorrhaging from rupture.

Preservation of tubal integrity to maintain future reproductive capacity is a main objective in the treatment of ectopic pregnancy. Fertility is recognized as an important component of many women's health related to their quality of life. The patient's reproductive desires are therefore an important aspect of informed decision-making about treatment options. Preservation of severely compromised tubes, however, will not increase the patient's prospects of a successful pregnancy. Following even aggressive treatment (tube removal), pregnancy may remain possible with assisted reproduction, such as in vitro fertilization.

## **I. CRIMINALIZATION OF HIV EXPOSURE AND/OR TRANSMISSION**

**Human Rights Standards** (For each issue area, this section outlines the major, relevant human rights standards.<sup>33</sup> The "human rights analysis" sections below draw on these standards, as well interpretations by courts and treaty bodies.)

### Right to Equality and Non-Discrimination

*International Covenant on Civil and Political Rights*<sup>34</sup>  
Article 26

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<sup>32</sup> D.E. Luciano et al. "Ectopic Pregnancy—From Surgical Emergency to Medical Management" (2004) 11(1) *Journal of the American Association of Gynecologic Laparoscopists* 109-121.

<sup>33</sup> The human rights standards used in analyzing this case study are not exhaustive. For instance, for criminalization of HIV exposure or transmission, the right to liberty and security of person and freedom from arbitrary arrest (International Covenant on Civil and Political Rights, Article 9) is implicated when the criminal law is overly broad and vague, leading to arbitrary enforcement. Similarly, the right to freedom from unlawful interference with privacy, family, and the home (International Covenant on Civil and Political Rights, Article 17) can be used to argue that how individuals conduct their sexual relations is no business of the state.

<sup>34</sup> *International Covenant on Civil and Political Rights*, 19 December 1966, 999 U.N.T.S. 171 ("ICCPR").

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

*International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*<sup>35</sup>

Article 5

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

Article 6

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

*Convention on the Elimination of All Forms of Discrimination against Women*<sup>36</sup>

Article 2

State Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women ...

*European Convention on Human Rights*<sup>37</sup>

Article 14

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

*Right to Health*

*International Covenant on Economic, Social and Cultural Rights*<sup>38</sup>

Article 12

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<sup>35</sup> *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 30 March 2007, 993 U.N.T.S. 3 (“CRPD”).

<sup>36</sup> *Convention on the Elimination of All Forms of Discrimination against Women*, 18 December 1979, 1249 U.N.T.S. 13 (“CEDAW”).

<sup>37</sup> *European Convention on Human Rights*, 4 November 1950, Eur. T.S. 5 (“ECHR”).

<sup>38</sup> *International Covenant on Economic, Social, and Cultural Rights*, 16 December 1966, 993 U.N.T.S. 3.

1. The State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the State Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
  - (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; ...
  - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
  - (d) The creation of conditions which would assure to all medical services and medical attention in the event of sickness.

### *Convention on the Rights of Persons with Disabilities*

#### Article 25

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. ... In particular, States Parties shall: ...

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health ...

## **Human Rights Analysis**

Upon learning of her HIV status, Maria was informed by a counselor at the AIDS Centre that if she engaged in behaviour with a risk of transmitting HIV (e.g. needle sharing or sex), Maria could be criminally charged. Maria was required to sign a document that she understood these conditions. The criminal law is increasingly used to punish or deter PLWHA from exposing and/or transmitting HIV to others, which raises concerns under rights to non-discrimination on grounds of health status and gender, and the right to health.

### **A. Criminalization and the Right to Non-Discrimination: Health Status**

*Discussion Questions: Why does Maria perceive criminalization of HIV exposure/transmission as unfair? On what basis is the criminalization supported? What concerns does it raise under the right to non-discrimination based on health status?*

The application of criminal law to HIV exposure and/or transmission may be warranted in rare cases where a person acts with the purpose to transmit HIV, an intention to harm others.<sup>39</sup> In these cases, general criminal laws already cover this conduct. Criminal laws related to HIV transmission, however, are drafted and applied more broadly. They may capture all behaviour that carries a risk of HIV transmission. This may include risk behaviours in which Maria engaged: needle-sharing and sex (e.g. sex work or bartering, sex without a condom). Rather than targeting these behaviours *per se*, the criminal law targets PLWHA engagement in these behaviours. All persons who engage in such behaviours, however, increase the risk of HIV exposure and transmission in the population. Maria calls attention to this fact: “It wasn’t my

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<sup>39</sup> UNAIDS *Criminalization Brief*, at p. 2 (“ICESCR”).

fault. Someone gave me the virus.” If use of the criminal law is justified on public health grounds, intended to substitute for other prevention strategies, an arbitrary distinction is drawn between PLWHA and others who engage in risk behaviours.<sup>40</sup> It is for this reason that Maria thought the system was unfair. PLWHA, in other words, are effectively punished less for their behaviour than the virus they carry, their health status. Such targeting of PLWHA violates rights to non-discrimination based on health status.<sup>41</sup> Given the moral condemnation associated with criminal sanction, this broad application of the criminal law can lead to further stigmatization of PLWHA.<sup>42</sup> Maria remarked that “[t]he counsellor was concerned about everyone but me.” PLWHA are treated in law as vectors of disease rather than persons whose health and well-being is of equal concern.

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<sup>40</sup> Please also see the discussion below on criminalization and the right to health, which explains that targeting risk behaviors with criminal law is objectionable on health and other grounds.

<sup>41</sup> "Discrimination on the basis of AIDS or HIV status, actual or presumed, is prohibited by existing international human rights standards, and that the term "or other status" in non-discrimination provisions in international human rights texts can be interpreted to cover health status, including HIV/AIDS." Commission on Human Rights, *The Protection of Human Rights in the Context of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS)*, U.N. Doc. E/CN.4/1995/44 (1995).

<sup>42</sup> Jurgens, at p. 10.

## B. Criminalization and the Right to Non-Discrimination: Gender

*Discussion Questions: Some advocates support criminalization of HIV exposure/transmission as a measure to protect women against the risk of HIV transmission through heterosexual contact. Based on the case study and experiences of Maria, why might women in practice be more likely than men to face prosecution? What concerns does criminalization raise under the right to non-discrimination based on gender?*

Some advocates support the broad use of criminal law as a measure to protect women at risk of heterosexual transmission of HIV. For the following three reasons, however, women are more likely than men to face prosecution under the broad application of the criminal law.<sup>43</sup> Because of this disproportionate impact, criminalization of HIV exposure and/or transmission violates the right to non-discrimination based on gender. This right requires governments to repeal all penal provisions that discriminate against women.<sup>44</sup>

First, under most criminal laws, PLWHA must disclose their status to sexual partners, or insist on condom use or refuse sex to avoid prosecution. These requirements, however, subject many women to risk of harm. Nikolay and Maria rarely used condoms. When Maria insisted on their use, Nikolay accused her of being unfaithful. Women may be unable to negotiate safer sex practices with male partners without fear of accusation of infidelity or violence. When Nikolay learned of Maria's HIV status, he abandoned her, telling her not to return home. Maria may have been reluctant to voluntarily disclose her HIV status to Nikolay on expectation of this reaction. Abandonment of women upon disclosure of their HIV status to partners is not an uncommon experience.<sup>45</sup> Women are forced into a double bind: risk prosecution under criminal law, or mistreatment by partners in an effort to obey the law.<sup>46</sup>

Second, women in comparison to men engage more frequently with the health care system, in large measure because of their reproductive function, and are therefore more likely to be tested for HIV. For many women, the first point of contact with the health care system is during pregnancy and childbirth. HIV testing is also increasingly integrated into antenatal care. Women are therefore more likely to learn about their HIV status before their sexual partners. First knowledge is often wrongly understood to imply causation, that the woman was also the first to acquire HIV and was thus responsible for transmission to her partner.<sup>47</sup> It is unknown whether Nikolay is HIV positive, and if so, whether he contracted HIV prior to meeting Maria, or from other behaviour he engaged during his relationship with Maria. By first disclosure of her HIV status, however, Maria is blamed for "bringing HIV into the home" and threatened with police reporting.

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<sup>43</sup> Jurgens, at p. 12.

<sup>44</sup> CEDAW, at art. 2

<sup>45</sup> Babakian, at p. 10; J. Kehler, M Clayton & T. Crone. *10 Reasons Why Criminalization of HIV Exposure or Transmission Harms Women* (ATHENA Network, 2009) at p. 3.

<sup>46</sup> Jurgens, at p. 13.

<sup>47</sup> Jurgens, at pp. 12-13, 17-18. See also A. Ahmed, C. Hanssens & B. Kelly, "Protecting HIV-Positive Women's Human Rights: Recommendations for the United States National HIV/AIDS Strategy" (2009) 17(34) *Reproductive Health Matters* 127 at p. 129.

Third, criminal laws may be drafted and applied so broadly as to capture MTCT.<sup>48</sup> For women, such as Maria, who are uninformed or denied access to prevention measures, pregnancy and childbirth is effectively rendered a criminal offence.<sup>49</sup> In this case, Maria worried that her status affected her pregnancy, lied on her paperwork, and was fearful of disclosing her status given the AIDS centre counsellor's warnings.

### **C. Criminalization and the Right to Health**

*Discussion Question: How does criminalization of HIV exposure/transmission undermine rather than serve its public health goals? What concerns does criminalization raise under the right to health?*

Successful prevention measures encourage persons to be tested, and ensure that PLWHA have accurate information about transmission and prevention, and access to good-quality health care within a supportive environment. Criminalization of HIV exposure and/or transmission is not only ineffective but counterproductive to achieving these goals.

When Maria learned of her HIV status, she was in a state of shock, not knowing what to say or what to ask. Her reaction suggested a lack of pre-test counselling.<sup>50</sup> Rather than receiving post-test counselling, the AIDS Centre counsellor informed Maria that she may be subject to criminal prosecution for knowingly transmitting HIV. Maria only mattered as a "risk of infection." To distance herself from this identity, Maria convinced herself the test was wrong. Like many PLWHA, Maria left the centre feeling judged and angry, uninformed about how to care for own health and protect the health of others. Maria did not receive education or information about HIV/AIDS, harm reduction or treatment, nor offered any psychosocial or emotional support. Moreover, the experience at the AIDS Centre made her distrustful of health providers. Such distrust deters PLWHA from returning to the health system for monitoring and treatment.<sup>51</sup> Maria did not seek any HIV-related health care.

Criminalization may also adversely affect access to other health care services. Pregnant women living with HIV, reluctant to disclose their status, may forego antenatal care and MTCT prevention.<sup>52</sup> Maria lied on her paperwork upon being admitted to the hospital, and only disclosed her status when worried that it had affected the pregnancy. (HIV/AIDS is not a risk factor for ectopic pregnancy). Criminalization, given its adverse effects on access to health care, violates the right to health. This right obligates government to provide individuals with accurate information on HIV/AIDS,<sup>53</sup> and to ensure that vulnerable groups including PLWHA can access

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<sup>48</sup> J. Csete, R. Pearshouse & A. Symington, "Vertical HIV Transmission Should be Excluded from Criminal Prosecution" (2009) 17(34) *Reproductive Health Matters* 154 at pp. 157-159.

<sup>49</sup> Kehler et al., at p. 4.

<sup>50</sup> Burns, at p. 11.

<sup>51</sup> Jurgens, at p. 9. See also: Burns, at p. 9.

<sup>52</sup> Kehler et al., at p. 2.

<sup>53</sup> Committee on Economic, Social and Cultural Rights, *General Comment 14: The Right to the Highest Attainable Standard of Health (Article 12)*, UN ESCOR, 2000, UN Doc. E/C.12/2000/4, at paras. 36, 44 ("CESCR General Comment No. 14"). See also Committee on the Elimination of Discrimination against Women, *General Recommendation 15: Avoidance of Discrimination against Women in National Strategies for the Prevention and Control of Acquired Immunodeficiency Syndrome (AIDS)*, UN GAOR, 1990, UN Doc. A/45/38 (governments shall

health facilities, goods and services on a non-discriminatory basis.<sup>54</sup> In deterring HIV-positive women from accessing quality maternal care and MTCT prevention, for example, by causing women to conceal their status, criminalization further violates specific right to health guarantees respecting access to reproductive health services.<sup>55</sup>

## II. UNAUTHORIZED DISCLOSURE OF HIV STATUS

### Human Rights Standards

#### *Right to Privacy and Confidentiality*

##### *International Covenant on Civil and Political Rights*

###### Article 17

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.
2. Everyone has the right to the protection of the law against such interference or attacks.

##### *Convention on the Rights of Persons with Disabilities*<sup>56</sup>

###### Article 22

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such inference or attacks.
2. State Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

##### *European Convention on Human Rights*

###### Article 8

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

##### *European Convention on Human Rights and Biomedicine*

###### Article 10

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intensify efforts in disseminating information to increase public awareness of the risk of HIV infection and AIDS, especially in women and children, and of its effects on them) (“CEDAW General Recommendation No. 24”).

<sup>54</sup> CESCR General Comment No. 14, at para. 43.

<sup>55</sup> CESCR General Comment No. 14, at para. 14.

<sup>56</sup> Please note that using disability frame to encompass HIV status is controversial. Some argue that it further stigmatizes and exceptionalizes HIV.

1. Everyone has the right to respect for private life in relation to information about his or her health.

*Right to be Free from Mistreatment in Marriage and Family Relationships*

*International Covenant on Civil and Political Rights*

Article 23

4. States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children.

*Convention on the Elimination of All Forms of Discrimination against Women*

Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women: ... (c) The same rights and responsibilities during marriage and at its dissolution.

*Convention on the Rights of People with Disabilities*

Article 16

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

**Human Rights Analysis**

HIV-related stigma leads to mistreatment of PLWHA in the clinical health context. Mistreatment includes unauthorized disclosure of HIV status by health providers to third-parties.<sup>57</sup> In providing updates on Maria's care, Nurse Bondar disclosed to Nikolay that Maria was HIV positive. PLWHA enjoy the right to control the disclosure and use of their personal information. This right places a corresponding obligation of health providers, and others, who receive information in confidence, not to disclose it without authorization.<sup>58</sup> Unauthorized disclosure of serostatus violates the right to privacy, and health providers' related duties of confidentiality.

Privacy is a particularly important principle in the HIV/AIDS context given the risks of violence, discrimination and abandonment that many persons face upon disclosure of their status.<sup>59</sup> These consequences arise within the family and broader community.<sup>60</sup> In recovery, Maria learned that her HIV status was disclosed to Nikolay. He called the hospital, told her not to return home and further threatened to report her to the police. Inadequate protection from consequences of disclosure violates the right to be free from mistreatment in marriage and family relationships.

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<sup>57</sup> See e.g., Schleifer & Buchanan, at pp. 54-55.

<sup>58</sup> R. Cook, B Dickens & M. Fathalla. *Reproductive Health and Human Rights*. (2003), at p. 121.

<sup>59</sup> S. Maman & A. Medley. *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes*. (World Health Organization, 2004) at p.5.

<sup>60</sup> *Schleifer & Buchanan*, at p. 55; *Maman & Medley*, at p. 18.

## A. The Right to Privacy and Confidentiality

*Discussion Questions: Should Nurse Bondar have disclosed Maria's HIV status to Nikolay? What concerns does unauthorized disclosure of HIV status raise based on the right to privacy and the right to health? How can partner notification be achieved in a manner respectful of the human rights of all persons concerned?*

In *Z. v. Finland*, the European Court of Human Rights recognized that protection of medical data, including information about health status such as infection with HIV, is a fundamental aspect of the right to respect for private life.<sup>61</sup> Likewise, the U.N. Committee on Economic, Social and Cultural Rights recognized “the right to have personal data treated with confidentiality.”<sup>62</sup> In the clinical health context, this right imposes duties of confidentiality on health providers. Providers are obligated to limit the information they solicit from patients to those relevant to the patients' care, to use the information for legitimate purposes, and to protect against its unauthorized disclosure.<sup>63</sup> Release of information to third parties requires a patient's free and informed consent. Nurse Bondar breached her duty of confidentiality. She disclosed Maria's HIV status to Nikolay without Maria's consent to do so.

The right to privacy respecting medical information is not absolute. Disclosure may be justified where there is a risk of harm to a third party. Health protection and disease prevention are legitimate public interest objectives that may justify a limitation of the right to respect for private life. Disclosure may be an obligation to protect the right to health of others.

Given her knowledge of Maria's HIV status and the evidence of unprotected sexual intercourse, Nurse Bondar may have been obligated to notify Nikolay of his HIV risk.<sup>64</sup> There are, however, means by which Nurse Bondar can fulfill this obligation respectful of the human rights of all persons involved. Nurse Bondar should encourage Maria to voluntarily inform Nikolay of her serostatus and the possibility of HIV transmission. Maria could also give her informed consent to a trained provider to notify and counsel Nikolay while maintaining Maria's confidentiality wherever possible. Medical providers are permitted to disclose without patients' consent only in rare cases where PLWHA persistently refuse to inform their partners.<sup>65</sup>

Moreover, before unauthorized partner notification, health providers are required to assess and account for risk of adverse consequences for PLWHA upon disclosure. By discussing partner disclosure with Maria, Nurse Bondar may have learned of reasons or fears that Maria had for not voluntarily disclosing her status. Alternatives to immediate disclosure may then be preferred,

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<sup>61</sup> *Z. v. Finland* (1997), 25 E.H.R.R. 371.

<sup>62</sup> CESCR General Comment No. 14, at para. 12.

<sup>63</sup> *Cook, Dickens & Fathalla*, at p. 121.

<sup>64</sup> *Cook, Dickens & Fathalla*, at p. 127.

<sup>65</sup> S. Timberlake, *Opening Up the HIV/AIDS Epidemic: Guidance on Encouraging Beneficial Disclosure, Ethical Partner Counselling & Appropriate Use of HIV Case-Reporting* (UNAIDS & WHO, 2000) at pp. 18-22.

such as delaying partner notification until Maria is recovered and can access support services.<sup>66</sup> Nurse Bondar might facilitate Maria's access to psycho-social and legal resources.<sup>67</sup>

## **B. The Right to be Free from Mistreatment in Marriage and Family Relationships**

*Discussion Questions: What are the consequences of Nurse Bondar's unauthorized disclosure? Is there an obligation to protect against post-disclosure harm in the clinical health context?*

Human rights law imposes a positive obligation of protection against post-disclosure mistreatment.<sup>68</sup> Nikolay abandoned Maria after learning of her HIV status, refusing to let her return to their home. Rights to non-discrimination on grounds of disability and gender require governments to take all appropriate measures to eliminate abuse and violence against HIV-positive women in the context of marriage and family life.<sup>69</sup> At the time of marriage dissolution, measures are required to ensure that HIV-positive women can exercise their rights to receive an equitable share of marital assets and spousal maintenance, can remain in the matrimonial home, and where relevant, can retain custody of children on equal basis with their spouses.<sup>70</sup>

## **III. FORCED STERILIZATION**

### **Human Rights Standards**

#### *Right to Seek, Receive and Impart Information*

##### *International Covenant on Civil and Political Rights*

###### Article 19

2. Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.

##### *Convention on the Elimination of All Forms of Discrimination against Women*

###### Article 10

States Parties shall take all appropriate measures ... to ensure, on a basis of equality of men and women: ...

(h) Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning.

##### *Convention on the Rights of Persons with Disabilities*

<sup>66</sup> A. Medley *et al.*, "Rates, Barriers and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes" (2004) 82 *Bulletin of the World Health Organization* 299 at p. 305.

<sup>67</sup> Timberlake, at p. 20.

<sup>68</sup> *International Guidelines on HIV/AIDS and Human Rights*, HR/PUB/06/9, 2006, at ¶114.

<sup>69</sup> *CRPD*, at art. 16(1); *CEDAW*, at art. 16(1).

<sup>70</sup> S. Chu & A. Symington, *Respect, Protect and Fulfill: Legislating for Women's Rights in the Context of HIV/AIDS - Volume Two: Family and Property Issues - Module 4: Divorce* (Toronto: Canadian HIV/AIDS Legal Network, 2009) at pp. 18-34. See also: Office of the United Nations High Commissioner For Human Rights, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* (OHCHR & UNAIDS, 2006) at p. 35.

## Article 21

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice ...

## *European Convention on Human Rights*

### Article 10

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. ...

### *Right to Bodily Integrity*

Note: This right has been interpreted to be part of the right to freedom from torture and cruel, inhuman, and degrading treatment, the right to security of the person, the right to privacy, and the right to the highest attainable standard of health.

## *International Covenant on Civil and Political Rights*

### Article 7

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.<sup>71</sup>

### Article 9

1. Everyone has the right to liberty and security of person.

### Article 17

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

## *International Covenant on Economic, Social and Cultural Rights*

### Article 12

1. The State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

## *Convention on the Rights of Persons with Disabilities*

### Preamble

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

### Article 17

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<sup>71</sup> Please also see the *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*.

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

#### Article 25

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. ... In particular, States Parties shall: ...

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

#### *European Convention on Human Rights*

##### Article 3

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

##### Article 5

1. Everyone has the right to liberty and security of person.

##### Article 8

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

#### *European Convention on Human Rights and Biomedicine*

##### Article 5

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

#### *Charter of Fundamental Rights of the European Union*<sup>72</sup>

##### Article 3

1. Everyone has the right to respect for his or her physical and mental integrity.

2. In the field of medicine and biology, the following must be respected in particular:

(a) the free and informed consent of the person concerned, according to the procedures laid down by law.

#### *Right to Decision-making about Children*

#### *International Covenant on Civil and Political Rights*

##### Article 23

2. The right of men and women of marriageable age to marry and to found a family shall be recognized.

#### *Convention on the Elimination of All Forms of Discrimination against Women*

##### Article 12

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<sup>72</sup> EC, *Charter of Fundamental Rights of the European Union*, [2000] O.J. C 364/01. (This is now Article II-63 of the *European Union Constitution*.)

1. State Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

#### Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women: ...

(e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

#### *Convention on the Rights of Persons with Disabilities*

#### Article 23

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: ...

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

### **Human Rights Analysis**

In the clinical health context, PLWHA are subject to coercive medical treatment, defined by the absence of free and informed decision-making. Such mistreatment is prevalent against PLWHA – in particular women living with HIV/AIDS – with respect to reproductive health care.<sup>73</sup> Women are denied rights to decide whether to become pregnant, and to continue pregnancies to term. With more women of reproductive age living with HIV, reproductive health care is complicated by concerns of MTCT and the future care of children.<sup>74</sup> Women living with HIV who become pregnant and wish to have children are judged harshly and stigmatized as inflicting harm, the harm of both infection and abandonment of their children. Research studies and anecdotal reports indicate that such attitudes are widespread among health providers.<sup>75</sup> Nurse Bondar exhibits this attitude in her comments to Nikolay, that he and Maria are selfish to risk transmitting HIV to their child. Coercive sterilization practices, efforts to avoid future pregnancies among HIV-positive women, follow from these attitudes.<sup>76</sup>

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<sup>73</sup> N. Anand et al. *Bridging the Gap: Developing a Human Rights Framework to Address Coerced Sterilization and Abortion* (HEAL Clinic, Faculty of Law University of Toronto, 2009), online: [http://www.athenanetwork.org/docs/HEAL\\_Policy\\_Brief.pdf](http://www.athenanetwork.org/docs/HEAL_Policy_Brief.pdf).

<sup>74</sup> See: M. de Bruyn. *Reproductive choice and women living with HIV/AIDS*. (IPAS, 2002); Babakian.

<sup>75</sup> Center for Reproductive Rights & Federation of Women Lawyers. *At Risk: Rights Violations of HIV-Positive Women in Kenyan Health Facilities* (2008) at 44.

<sup>76</sup> Public health “programmes targeting pregnant women ...often emphasize coercive measures directed towards the risk of transmitting HIV to the foetus, such as mandatory testing followed by coerced abortion or sterilization.”Office of the High Commissioner of Human Rights & Joint United Nations Programme on HIV/AIDS.

## A. The Right to Informed Consent

*Discussion Question: Did Maria have an opportunity to make an informed decision about sterilization?*

Maria disclosed her HIV status to Dr. Minkov because she was worried about how the status affected her pregnancy, and presumably future pregnancies. She also asked about options to protect against MTCT. In response, Dr. Minkov stated that prevention measures exist, but are not as effective as sterilization.

The right to receive information<sup>77</sup> is fundamental to informed decision-making. Individuals require information that is material to their health care choice in a form they can understand and recall.<sup>78</sup> Material information includes the nature of proposed treatment, and its relative benefits and risks compared to alternatives.<sup>79</sup> Health providers, moreover, have a professional duty to exercise care and not misrepresent treatment options based on bias or personal judgment. Dr. Minkov provided incomplete and partial information respecting treatment options that would allow Maria to maintain her fertility and successfully prevent MTCT. His statement that MTCT prevention measures were “less effective” did not adequately communicate that these measures can reduce the risk of MTCT to below 2%.<sup>80</sup> Dr. Minkov also failed to provide information on alternative contraceptive methods, which were not permanent and could more easily accommodate changes in life circumstances.<sup>81</sup>

Decision-making must also be based on the timely provision of material information.<sup>82</sup> In other words, requests to consent to treatment should be made in circumstances free of stress or duress that decision-making to be exercised in a meaningful manner. Maria was in a state of distress, having recently learned that she would lose her pregnancy, making Dr. Minkov’s timing request for consent to the sterilization inappropriate.

*Discussion Question: Did Maria have an opportunity to voluntarily consent to the sterilization?*

Decision-making must be voluntary, which includes freedom from any “force of authority” which convinces the patient that no other legal or medical alternative is available.”<sup>83</sup> Dr. Minkov inappropriately invoked such authority when he informed Maria that sterilization was hospital policy and that senior administration would be called if she refused consent.

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HIV/AIDS and Human Rights: International Guidelines: Second International Consultation on HIV/AIDS and Human Rights (1998) at 92.

<sup>77</sup> ICCPR, at art. 19; CEDAW, at art. 10; ECHR, at art. 10.

<sup>78</sup> Cook, Dickens & Fathalla, at pp. 109-110.

<sup>79</sup> International Federation of Gynecologists and Obstetricians, *Ethical Issues in Obstetrics and Gynecology*, 13 (London: FIGO, 2009).

<sup>80</sup> Operario, at p. 11. See also *WHO Women Living with HIV/AIDS* at p. 31.

<sup>81</sup> International Federation of Gynecologists and Obstetricians, *Ethical Considerations in Sterilization* (London: FIGO, 2000), s. 8.

<sup>82</sup> *A.S. v. Hungary* (UN CEDAW; Hungary, Aug. 2006).

<sup>83</sup> P. Breggin. “Coercion of Voluntary Patients in an Open Hospital” (1964) *Archives Gen. Psychiatry* at p. p173 cited in B. Meier. “International Protection of Persons Undergoing Medical Experimentation: Protecting the Right of Informed Consent” (2002) *Berkeley J. Int’l L.* at 513, at FN 178.

The use of incentives is also an unacceptable form of coercion. Dr. Minkov suggested that Maria's treatment for ectopic pregnancy was conditional on consent to sterilization. To deny women access to healthcare, unless they undergo a medical intervention which they do not desire or need, violates two principles of free decision-making: autonomy and bodily integrity. Even if Maria were given the consent form to sign, she would face severely limited options: to undergo sterilization or forego necessary medical care. Considering the implications of the latter, she would be compelled to consent to sterilization.

*Discussion Question: Did Dr. Minkov violate Maria's decision-making rights respecting the sterilization? Which rights and why?*

Dr. Minkov refused to discuss with Maria the implications of her HIV-status for healthy pregnancy and delivery, and treatment options for the ectopic pregnancy. Sterilization was based not on Maria's free and informed decision or medical need (e.g. severely compromised fallopian tube), but Dr. Minkov's belief that future pregnancies should be avoided. Sterilization, if performed with a contraceptive intention, cannot be characterized as a medically necessary intervention.<sup>84</sup> Dr. Minkov claimed there was no opportunity to discuss these matters prior to surgery, but proceeded to obtain Nikolay's signature. Sterilization for prevention of future pregnancy is never to be considered an emergency procedure, and therefore cannot be performed without informed consent.<sup>85</sup>

Informed consent of the patient is a pre-requisite for any medical intervention.<sup>86</sup> This rests on the right to bodily integrity<sup>87</sup> derived from and supported by the guarantees of the right to health,<sup>88</sup> the right to security of person,<sup>89</sup> the right to be free from torture and cruel, inhuman and degrading treatment,<sup>90</sup> and the right to privacy.<sup>91</sup> The right to non-discrimination in health care

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<sup>84</sup> Letter from Luisa Cabal *et al.* from Center for Reproductive Rights, European Roma Rights Center, and Open Society Institute to Bernard Dickens at International Federation of Gynecologists and Obstetricians Re: Updating the FIGO Ethical Considerations in Sterilization Guidelines (3 February 2010), at p. 3.

<sup>85</sup> Committee on the Elimination of Discrimination against Women ("CEDAW"), Forty-Seventh Session (4-22 October 2010). *Concluding Observations of the Committee on the Czech Republic*. Recommendation 35.

<sup>86</sup> Regional Office for Europe, World Health Organization. *A Declaration on the Promotion of Patients' Rights in Europe*. European Consultation on the Rights of Patients. (1994) at para 3.1.

<sup>87</sup> See e.g., *Storck v. Germany*, no. 61603/00 [2005] V E.C.H.R. 406 at para. 143 (imposition of medical treatment against one's will interferes with the physical integrity of an individual).

<sup>88</sup> CESCR General Comment No. 14, at para. 8 (the right to health includes "the right to be free from ... non-consensual medical treatment and experimentation."); CEDAW General Recommendation No. 24, at para. 22 (the right to health entails provision of acceptable services, namely those delivered free of coercion and upon patients' fully informed consent).

<sup>89</sup> Treaty bodies have recognized that practices such as genital mutilation infringe on girls' right to personal security and physical integrity. CEDAW, *Concluding Observations of the Committee on the Elimination of Discrimination Against Women: Burkina Faso*, 2000. (A/55/38(SUPP)). ; see also CEDAW, *Concluding Observations of the Committee on the Elimination of Discrimination Against Women: Cameroon*, 2000. (A/55/38(SUPP)).

<sup>90</sup> See e.g., Human Rights Committee, *General Comment No. 20: Replaces General Comment 7 Concerning Prohibition of Torture and Cruel Treatment or Punishment (Article 7)*, 1992, 10/03/92, at para. 7 (prohibition against torture and cruel, inhuman or degrading treatment extends to medical procedures imposed without the free consent of the individual).

<sup>91</sup> See e.g., *Storck v. Germany*, at para. 144 (non-consensual medical treatment constitutes an interference with a person's right to respect for private life); *YF v Turkey*, no. 24209/94, 22/07/03, at para 33 (forced gynaecological

requires that health service delivery ensures a “woman gives her fully informed consent, respects her dignity ... and is sensitive to her needs and perspectives. States parties should not permit forms of coercion, such as non-consensual sterilization...”<sup>92</sup>

That Dr. Minkov received consent for sterilization from Nikolay rather than Maria did not justify the intervention. The decision to undergo sterilization belongs to the individual alone, not to a partner, spouse or health provider.<sup>93</sup> Substituting spousal authorization for the consent of a competent individual violates rights to self-determination, which is a right against interference by all third-parties, health providers, spouses and hospital administrators.<sup>94</sup> The right to self-determination recognizes that all mentally competent adults enjoy autonomy of choice with respect to their medical care. All women living with HIV/AIDS have a right to freedom and information to make decisions about their reproductive healthcare.

A lack of consent in the context of sterilization is particularly severe. The U.N. Special Rapporteur on the Right to the Highest Attainable Standard of Health explained, “Women are often provided inadequate time and information to consent to sterilization procedures, or are never told or discover later that they have been sterilized. Policies and legislation sanctioning non-consensual treatments... including sterilizations...violate the right to physical and mental integrity and may constitute torture and ill-treatment.”<sup>95</sup> The U.N. Human Rights Committee thus requires states to provide information on measures to prevent forced sterilization to comply with the prohibition against torture and cruel, inhuman and degrading treatment.<sup>96</sup> The U.N. Special Rapporteur on Violence against Women likewise clarified: “Forced sterilization is a method of medical control of a women’s fertility without the consent of a woman. Essentially involving the battery of a woman—violating her physical integrity and security, forced sterilization constitutes violence against women.”<sup>97</sup>

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exam while in police custody breached the right to privacy and bodily integrity); *Glass v. United Kingdom*, no. 61827/00, 2004 (holding that a breach of bodily integrity occurred when a son was administered dimorphine against his mother’s wishes).

<sup>92</sup> CEDAW General Recommendation No. 24, at para. 22..

<sup>93</sup> “Decisions to have children or not, while preferably made in consultation with a spouse or partner, must not nevertheless be limited by spouse, parent, partner or Government.” *Committee on the Elimination of Discrimination against Women, General Recommendation 21: Equality in Marriage and Family Relations*, UN GAOR, 1994, UN Doc. A/49/38, at para. 22. See also Human Rights Committee, *General Comment 28: Equality of Rights between Men and Women (article 3)*, U.N. Doc. CCPR/C/21/Rev.1/Add.10 (2000), at para. 20 (considering a failure to respect women’s privacy as related to reproductive functions when there is a requirement of a husband’s authorization to make a decision in regard to sterilization).

<sup>94</sup> Cook, Dickens & Fathalla, at pp. 113-115.

<sup>95</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (August 10, 2009). Report to the 64<sup>th</sup> Session of the UN General Assembly. A/64/272. See Article 55; p 16. (<http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement>; accessed November 16, 2010).

<sup>96</sup> Human Rights Committee, *General Comment 28: Equality of Rights between Men and Women (article 3)*, U.N. Doc. CCPR/C/21/Rev.1/Add.10(2000), at para. 11.

<sup>97</sup> Rahhika Coomaraswamy (1999). *Integration of the Human Rights of Women and the Gender Perspective: Violence Against Women*. Report of the Special Rapporteur on violence against women, its causes and consequences, Ms. Radhika Coomaraswamy, in accordance with Commission on Human Rights resolution 1997/44. Geneva: UN Economic and Social Council. (<http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/4cad275a8b5509ed8025673800503f9d?OpenDocument>, accessed June 30, 2010).

## **B. The Right to Decision-making about Children**

Coercive sterilization in particular implicates the right “to decide freely and responsibly on the number and spacing of their children”<sup>98</sup> and the right “to found a family.”<sup>99</sup> All women have a right to reproductive autonomy, including the right to bear children, regardless of their HIV status.<sup>100</sup> For many women, pregnancy and child-bearing is central to their sense of worth and personal satisfaction, and to their status within community and family. In recovery, upon learning that she had been sterilized, Maria was inconsolable. Being a wife and a mother was important to her identity as a woman. Women seeking reproductive healthcare are to be treated as ends in themselves, as individuals with needs and desires, rather than as means to achieve other goals.<sup>101</sup> Dr. Minkov treated Maria as a ‘*vector*’ of disease. He focused on prevention of MTCT rather than meeting Maria’s health needs including her desire for future, healthy children.

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<sup>98</sup> CEDAW, *General Recommendation 19: Violence against Women*, UN GAOR, 1992, UN Doc. A/47/38, at para. 22.

<sup>99</sup> ICCPR, at art. 23.

<sup>100</sup> CRPD, at art. 23(1)(c).

<sup>101</sup> Ahmed & Bell, at 16-17.

## Forced Sterilization of HIV Positive Women: Case Study of Ethics Issues

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### **First part of case:**

*Maria started to use drugs at the age of 18. She injected with a group of friends, who would share needles. "I wouldn't call myself a sex worker, but sometimes I traded sex for drugs." After several years of drug use, when a friend tested positive for HIV, Maria visited an AIDS Centre to be tested herself. When she returned to the Centre, Maria learned she was HIV positive. "I didn't know what to say, what to ask. I was in shock. The counsellor was concerned about everyone but me. Who had I shared needles with? had sex with?" The counsellor instructed Maria that she must change her behaviour. "If you spread the virus, you can be criminally charged and sent to jail." Maria was required to sign a document that she understood these conditions. She left the AIDS Centre feeling judged and angry. "It wasn't my fault. Someone gave me the virus." Maria thought the system was unfair. She convinced herself the test was wrong. She did not experience any symptoms and did not seek any treatment.*

*Through a community outreach program, Maria received treatment for her drug use. At 28 years old, Maria was drug-free for two-years and lived with her husband, Nikolay. Maria recently became pregnant. Maria and Nikolay were ecstatic about being parents.*

### **Discussion questions on first part of case:**

1. What does Maria expect to receive from a worker at an AIDS Centre? How should an AIDS Centre worker treat a person who tests positive for HIV? How should an AIDS Centre worker treat a person who tests negative for HIV?
2. What are the short-term and long-term consequences of the AIDS Centre worker's actions for Maria's health, the health of her needle-sharing contacts, the health of her current and future sexual contacts (including her husband), and her future as a woman of childbearing age?
3. Why is Maria treated differently by the workers at the community outreach program? What lessons could the workers in this program teach the workers at the AIDS Centre?

### **Ethics commentary on first part of case:**

Maria is a member of three groups who are subjected to social stigma. At the beginning of the case, she is an injection drug user (IDU). While she does not describe herself as a sex worker, she has traded sex for drugs. And she is HIV-positive as the result of these high-risk activities. Maria is also an adult who is capable of acting in her own self-interest, including in the interest of her own health. How health care workers respond to her when she seeks their help has consequences for her health and for the health of others. Will they act by responding to Maria as a person in need of care, or will they act in ways that perpetuate stigma and make it difficult for Maria to trust them to care for her?

Health care workers' actions should be aligned with the interests of those in need of the services they provide; in this case, the health care workers' first obligation is to try to help Maria with the health-related consequences of her seropositive status. This obligation applies even when workers' subjective perceptions and biases—how they feel about Maria and her actions – conflict with their ethical responsibilities. Health care workers are also persons, and they are moral agents. They have the capacity to make moral judgments about actions and their consequences. For example, patients and other members of society should be able to rely on health care workers to act to prevent harm, a situation that may involve making moral as well as clinical judgments about what constitutes harm, and weighing the consequences of different actions intended to prevent or reduce different harms. Making moral judgments often involves the identification of behaviors and practices that have harmful consequences. However, exercising moral agency should not be misunderstood as or reduced to “passing judgment” on an individual or group. A health care worker's first duty is to those in need of health care, a duty that includes respecting the patient as a person even when the worker does not approve of the patient's behavior, or knows that this patient's actions are hazardous to the patient or to others. In a health care relationship, the individual who controls access to health-related goods – including health information such as test results – holds more power, and must be careful not to misuse this power. Judgmental behavior on the part of a health care worker is also counterproductive to the goals of health care, as it is likely to drive patients away, rather than to build trust. With respect to infectious disease, a judgmental stance is hazardous both to the patient and to others at risk of infection.

After her friend tests positive for HIV, Maria decided to be tested herself: she recognized a parallel between her friend's situation and her own situation. The standard for HIV testing has for decades included pre-test and post-test counseling, to ensure that individuals are making an informed choice to be tested, are offered emotional support during a stressful time, and receive adequate education about HIV harm reduction and – in the event of a positive test result – about HIV/AIDS treatment. Maria's counselor failed to meet this standard.

A jurisdiction's health law should support the delivery of good health care, rather than make it difficult for individuals to obtain health care, or reinforce social stigma directed at marginalized groups. In this case, a law requiring health care workers to report all HIV positive individuals to the police may conflict with the duties of health care workers to persons who need health-related services. While a health care worker may have been instructed to deliver this legal warning, laws that criminalize HIV transmission are ethically problematic and of questionable value as a public

health strategy. Such laws may be the product of outdated information about HIV transmission, or extreme social fears. These laws reinforce stigma rather than addressing the social conditions that promote HIV transmission: criminalizing HIV transmission is not equivalent to drug treatment. And these laws do a poor job of distinguishing between individuals who intend to harm others (or are indifferent to the consequences of their actions), and individuals who may be temporarily unable to comprehend the harmful consequences of their actions (for example, if their judgment is impaired by drug use) or who are unable to practice safer sex for social reasons. Individuals in abusive relationships, sex workers who are pressured to have sex without condoms, and women who, across societies, do not have the power to negotiate safer sex or are fearful of the consequences of attempting to do so, are individuals whose ability to act to prevent harm is limited by social circumstances they do not control.

Health care workers frequently have legal obligations, and may struggle with ethical dilemmas resulting from laws that do not appear to serve the best interests of individual patients. Moral judgment cannot be reduced to legal compliance, and ethically sound health care practice is never a simple matter of delivering a legal warning. The leaders of an AIDS Centre should seek to change outdated or counterproductive laws, and should provide guidance to their workers on how to provide good health care despite bad laws. As ethical practice avoids shifting burdens onto those with less power, the leadership of this Centre should avoid placing workers in situations in which their dual loyalties – for example, to their patients and to the law – conflict. When workers are faced with such situations and have not received clear guidance on how to carry out their primary duty to persons in need of HIV/AIDS services, they may conclude, wrongly, that their primary duty is to their own self-interest (for example, in the form of their job security).

Organizational leaders also have a responsibility to ensure that their workers are provided with sufficient training relative to their specific responsibilities, so their practice reflects current clinical standards and accurate knowledge of ethics as well as the law.

Now that effective antiretroviral (ARV) therapy is available and it is possible to manage HIV/AIDS as a chronic disease, law and policy should support the ability of individuals who are HIV-positive to receive needed therapy, while also supporting effective public health measures to prevent new infections. If current law does not reflect current medical knowledge and treatment options, Maria's counselor should explain to her the potential legal consequences of her behavior, but should do so in the context of helping her to obtain treatment, rather than as a scare tactic.

With respect to HIV/AIDS, the longstanding position of “exceptionalism” – the idea that it is ethically appropriate to think of HIV/AIDS as different from other communicable diseases – is being reexamined by infectious-disease specialists and public health experts.<sup>1</sup> The current reassessment of HIV/AIDS exceptionalism includes a continuing debate over whether HIV should be considered a normal diagnostic test covered under general consent for medical care, or a test for which pre-test counseling and specific consent should still be required. On the one hand, making it easier for patients to get tested and learn their HIV status should lead to better health care, through earlier access to ARVs, and to more effective prevention, through earlier detection and education. On the other hand, the persistence of social stigma and the

concentration of HIV/AIDS within predominantly poor and vulnerable groups raises a caution against thinking of HIV testing in terms of the goals of public health surveillance only.<sup>ii</sup> Because HIV/AIDS is treatable, it is different from a condition that can be detected but for which no treatment exists. If there is a public health duty to promote testing, there is also a public health obligation to provide needed health care that follows from a positive test result.

The worker at the AIDS Centre was Maria's first point of contact with HIV/AIDS health care. This worker's responsibilities reasonably included providing emotional support to Maria following the initial shock of the positive test result; reassuring Maria that HIV, while not curable, is a treatable condition; making an appointment for follow-up medical care so Maria could start receiving ARV treatment; encouraging Maria to receive drug treatment; clarifying what Maria needed to do to prevent HIV transmission to others (as Maria is sexually active and is still injecting drugs, this education should cover condom use and needle exchange); and assisting her to obtain the means to protect herself and others. It is clear that effective drug treatment is available in Maria's community, but this was not mentioned by the AIDS Centre worker, with the result that Maria's drug use continued, exposing others to infection through needle-sharing. By focusing on Maria as a danger to others rather than on HIV as a danger to Maria, and by using post-test counseling solely to deliver a legal warning suggesting that Maria was a potential criminal, this worker made it difficult for Maria to pursue further health care or receive adequate education on the consequences of HIV infection. Instead, Maria felt "judged and angry," dismissed the information she had received, and did not pursue ARV treatment.

## **Second part of case:**

*When Maria experienced pain in her lower abdomen, she visited a public hospital. Dr. Minkov diagnosed a tubal ectopic pregnancy: the fertilized egg had implanted outside the uterus in the fallopian tube. Dr. Minkov informed Maria that he must perform surgery, and that she would lose the pregnancy. Devastated, Maria disclosed that she tested HIV positive several years ago. She worried that her status had affected the pregnancy. Maria admitted she had lied on her paperwork. She was fearful of disclosing her status given the AIDS centre counsellor's warnings.*

*Dr. Minkov replied that there was little time to discuss the matter before surgery. He stated: "I will treat the ectopic pregnancy by surgical intervention. Given the circumstances, I assume you do not plan to have any future children, so we will not worry about preserving fertility." Maria asked again about the effect of her HIV status on her pregnancy: "Can I have a healthy child?" Dr. Minkov curtly answered, "Sure, prevention exists to protect against mother-to-child transmission, but it's not as effective. Sterilization is 100%." He then informed Maria that sterilization is a general condition of maternal care for HIV-positive women. "It's hospital policy. If you don't agree, I will need to call senior administration." Maria asked for more time and an opportunity to talk with Nikolay before making a decision. Rather than informing Nikolay of Maria's request, Dr. Minkov had Nikolay sign the consent form on her behalf and performed the sterilization.*

*Nurse Bondar gave Nikolay updates on Maria's care, but was hostile toward him. She asked: "Are you that selfish? You would pass this terrible disease to your child. It is a blessing you did*

*not have the chance." Nikolay did not know Maria was HIV positive. He knew of her past use of drugs, but Maria had not disclosed her HIV status. From early in their relationship, Maria and Nikolay rarely used condoms. He did not like them. He accused Maria of being unfaithful when she insisted on them.*

### **Discussion questions on second part of case:**

1. Does the fact that Maria lied about her HIV status affect her medical care? Should it?
2. What are Dr. Minkov's ethical duties to a conscious, competent patient?
3. What are Dr. Minkov's ethical duties to this patient's husband?

### **Ethics commentary on second part of case:**

A diagnosis of ectopic pregnancy requires emergency surgery. An ectopic pregnancy is non-viable but can rupture a fallopian tube and trigger life-threatening bleeding. In fast-moving emergency situations, health care workers must quickly establish a relationship with the patient, and often with family members. In this case, Maria is an adult patient who is conscious and is cognitively intact: she is also drug-free, so her capacity to make decisions is not impaired due to drug use. As discussed in detail below, if a patient's capacity to make decisions is impaired or absent, such that the patient is incapable of making an informed choice – to consent or to refuse – a surrogate could give consent to or refuse medical treatment on her behalf, in accordance with the surrogate's knowledge of the patient's wishes and preferences. Situations in which a patient lacks decision-making capacity and also lacks a surrogate with knowledge of the patient's wishes and preferences present ethical dilemmas for physicians, who must act in this patient's best interests without complete knowledge of what this patient would have wanted for herself.

In such situations, it is not sufficient for the physician to substitute the physician's own values for those of the patient. Consulting with colleagues with training and experience in clinical ethics can help a physician in this situation to identify the best interests of a patient who lacks decision-making capacity and also lacks a ready surrogate. Treatment decisions made by a surrogate when a patient is unable to give consent should be carefully distinguished from treatment over a patient's objection.

In this case, Maria is facing a life-threatening emergency but is not unconscious or otherwise incapacitated, so her right to make an informed choice (under highly stressful and time-limited circumstances) should be supported. Indeed, Maria wants to talk with her physician, who says there is "little time" to talk. However, both the physician and the nurse find time before the surgery to discuss the patient's condition with the patient's husband.

The conduct of these health care workers is unethical in several ways:

First, a physician's primary ethical duty is to her patient. While this is also true for nurses and other health care providers, it is an especially stringent obligation for physicians, who are responsible for diagnosis and treatment and who supervise other health care workers. A physician demonstrates respect for her patient as a person by communicating with her patient

directly whenever possible. Avoiding a discussion with a patient who is able and wishes to communicate, while communicating with others about this patient, fails to respect this patient's right to talk with her physician about her own body, health, and life.

Second, a patient who has decision-making capacity has the right to make decisions concerning her own medical treatment. A surrogate decision-maker, such as a spouse or an adult child, becomes involved when an adult patient has been determined through a clinical evaluation to lack decision-making capacity due to temporary or permanent cognitive impairment. In some cases, such as when there is no family member capable of acting as surrogate for a child or adult without capacity, surrogate decision-making involves a court-appointed guardian or other judicial process.

Even under emergency circumstances, a conscious patient with decision-making capacity has the right to make an informed choice: to consent or to refuse.<sup>iii</sup> (Under the doctrine of implied consent, if Maria were unconscious and also experiencing life-threatening bleeding, Dr. Minkov would be ethically justified in proceeding to treat the emergent condition only without first obtaining consent from Maria's surrogate.<sup>iv</sup>) As there is no evidence that Maria lacks decision-making capacity, it is unethical for Dr. Minkov to ignore Maria's rights, to refuse to talk with Maria when she clearly wishes to do so, and to ask Nikolay to act as surrogate.

Third, medical emergencies should not be used to force other decisions. Maria needs emergency life-saving surgery due to the diagnosis of ectopic pregnancy. However, Maria does *not* need to be sterilized as part of this treatment. Maria has the right to make an informed decision about her reproductive future. This and any other decisions can be postponed until the immediate crisis is resolved. Coerced and forced sterilizations are a well-recognized threat to the rights of women globally, and human rights advocates have drawn attention to the unethical practice of characterizing sterilization as an emergency procedure in an attempt to justify treatment without obtaining informed consent.<sup>v</sup>

Fourth, physicians are responsible for honoring patient's personal privacy and the confidentiality of patient's health information. This follows from the principle of autonomy (respect for persons) and also is consistent with the principle of nonmaleficence (do no harm), as the disclosure of information to a third party without the patient's consent has the potential to do harm to the patient's other relationships, as in this case. Such a disclosure could also imperil the physical safety of the patient, if the patient becomes the target of another party's anger. If a patient discloses information that a physician has an ethical responsibility or legal obligation to report to a third party to prevent harm to the patient or others – which is possible in the case of a communicable disease – the physician must confirm that the information is accurate. The physician must also follow ethically sound processes and exercise good judgment in handling this information so as to protect the patient's right to privacy, while also acting to protect others.<sup>vi</sup> Physician-patient communications are confidential (“physician-patient privilege”) so that patients may speak freely to their doctors about intimate matters. A decision to break confidentiality without a patient's consent should never be undertaken lightly. Hospitals should support ethical practice through clear and up-to-date policies and education on situations that may require partner notification or other third-party disclosure within the context of patient care.

Fifth, physicians have a duty to tell the truth. Truth-telling is a practice closely associated with ethical conduct, a duty that moral agents owe to one another and that a democratic society owes to its citizens. These ethical norms are reflected in professional codes of conduct governing physicians and other health care workers. Practices that conceal the truth can be ethically justified in some circumstances – as when a patient’s health information is not shared with others without the patient’s informed consent – but not as a general rule.<sup>vii</sup> Physicians’ truth-telling obligations extend to their obligation to know the facts, as well as to disclose the facts. While in this case, the patient disclosed that she had not told the truth about her HIV status, this disclosure does not permit her physician to also lie, nor to present the physician’s own biases and presumptions as if they are verifiable medical facts. In this case, Dr. Minkov assumes, due to Maria’s HIV status, that Maria’s pregnancy was unintended and that she and her husband do not plan to have children, even though Maria and Nikolay were “ecstatic” about the pregnancy and Maria is “devastated” to learn that this pregnancy is non-viable. Dr. Minkov rejects these facts, and then puts undue pressure on Nikolay to give consent to sterilization – a decision that should not have been his to make – through a reference to “senior administration.” Hospital policy and practice should work in the interests of patients. In this case, a policy that permits a patient’s rights to privacy and to make informed decisions to be violated, permits a life-altering but non-emergency decision to be made under crisis conditions, and does not explain how this administrative decision is in the patient’s best interests, is not an ethically sound policy. Dr. Minkov also fails to answer Maria’s question about preventing perinatal transmission during a future pregnancy, again assuming that Maria and Nikolay should not want to have children. (Nurse Bondar is similarly judgmental – in her opinion that the desire to bear or parent a child is “selfish” if a person has HIV – without being informative.)

But the physician’s primary failure is to Maria, who was owed accurate information about her own reproductive options, the opportunity to make an informed decision among these options, and the protection of her privacy and the confidentiality of her health information as she came to terms with her own responsibilities to prevent HIV transmission to a future child and to her current and any future sexual partners.

### **Third part of case:**

*In recovery, Maria learned about the disclosure of her HIV status to Nikolay. He called the hospital and told her not to return home. He threatens to report her to the police. Maria asked Nurse Bondar when she could try for another child. "You're sterilized from the surgery. There will be no more pregnancies." Maria was inconsolable. "No longer a wife, never a mother, I am not a woman. I have nothing to look forward to."*

### **Discussion questions on third part of case:**

1. Were Nikolay’s actions inevitable, or could this case have had a different outcome?
2. What are the ethical implications of procedures that close off options for patients?
3. Should an HIV-positive woman avoid pregnancy under all circumstances, or would it be ethically permissible for her to bear a child if it is medically feasible to reduce the likelihood of

transmitting HIV to an extremely low level, and bearing in mind that society accepts a degree of risk in other pregnancies, such as those involving the potential for hereditary genetic disorders?

### **Ethics commentary on third part of case:**

By the end of this case, Maria is homeless, alone, and “inconsolable,” bereft of hope for her future, and without the structure of her relationship and home. In the absence of these social, economic, and psychological supports, she may consider returning to drug use and sex work. And as long as responsibility for protecting her sexual partners is borne solely by her, she may find it difficult or impossible to negotiate condom use. Would Nikolay have abandoned her if Maria had acknowledged her HIV status? Maria may have observed the consequences of social stigma in her friends’ relationships, and taken refuge in denial. Certainly, she received no support from the AIDS Centre nor from hospital staff in addressing the social dimensions of chronic disease, while her drug treatment, though successful, was not integrated into HIV/AIDS education and treatment.

What if Dr. Minkov had waited until after Maria’s surgery to talk with her, in private, about the implications of her HIV status, for herself, her husband, and for future pregnancies? What if Dr. Minkov had consulted with her colleagues to ensure that Maria had access to ARV therapy and to effective harm reduction education? What if Maria and a physician, or another health care worker with expert knowledge of HIV/AIDS, had discussed how to talk with Nikolay about the consequences of Maria’s HIV status for Nikolay’s health, their relationship, and the prospect of becoming parents through assisted reproduction (to prevent sexual transmission) and the use of strategies, including elective caesarean and pre-delivery antiretroviral prophylaxis plus the avoidance of breastfeeding, to prevent perinatal transmission?<sup>viii</sup> If Maria’s health care providers had made better ethical decisions and had had up-to-date information about HIV treatment and transmission prevention, how could they have helped Maria to have a healthier, safer, and more fulfilling life?

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<sup>i</sup> Oppenheimer GM and Bayer R, The rise and fall of AIDS exceptionalism, *AMA Virtual Mentor*, 2009; 11 (12): 988-992.

<sup>ii</sup> Wynia MK, Routine screening: informed consent, stigma, and the waning of HIV exceptionalism, *American Journal of Bioethics*, 2006; 6(4): 5-8.

<sup>iii</sup> Meisel A, Kuszewski M, Legal and ethical myths about informed consent, *Archives of Internal Medicine*, 1996; 156 (22):2521-26.

<sup>iv</sup> For a detailed description of exceptions to the consent requirement, see Post LF, Blustein J, Dubler N, *Handbook for Health Care Ethics Committees* (Johns Hopkins, 2007), 45-46.

<sup>v</sup> Cf. Cabal L, Kushen RA, Girard F, Albert G, Letter to Chair, Members of the FIGO Ethics Committee (8 February 2010), at 3.

<sup>vi</sup> Safken C, Frewer A, The duty to warn and clinical ethics: legal and ethical aspects of confidentiality and HIV/AIDS, *HEC Forum* 2007; 19(4): 313-26.

<sup>vii</sup> Bok S, *Secrets: On the Ethics of Concealment and Revelation* Vintage, 1989.

<sup>viii</sup> Kissin DM, Akatova N, Rakhmanova AG, et al., Rapid HIV testing and prevention of perinatal HIV transmission in high-risk maternity hospitals in St. Petersburg, Russia, *American Journal of Obstetrics & Gynecology*. 2008; 198(2):183.e1-7.