

SLOVAKIA FORCED STERILIZATION ON RROMA WOMEN PRACTICES. AN ETHICAL CASE ANALYZE

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REZUMAT. Practici de sterilizare forțată a femeilor de etnie romă în Slovacia. O analiză etică. Acest articol prezintă câteva considerații etice referitoare la practica de sterilizare forțată a femeilor de etnie romă în unele țări din Europa de Est (cazul Slovaciei). Aceste practici sunt efectuate de zeci de ani în anumite țări, Slovacia fiind primul caz judecat la Curtea Europeană a Drepturilor Omului de la Strasbourg, Franța. Gândindu-ne la aceste fapte ne dăm seama că ne confruntăm cu riscuri imense pentru pacienți și nu numai pentru cei de etnie romă, ci pentru noi toți. Pacienții merg la medici în considerentul profesiei lor, pentru că sunt bolnavi și au nevoie de ajutor. Ei nu merg la medici, din cauza opiniei personale a acestora cu privire la ceva, iar dacă medicii nu acționează pentru binele pacienților, aceștia își vor pierde încrederea și le va fi frică să meargă la spital. Astăzi vorbim despre persoane de etnie romă, dar cine știe ce fel de criterii de discriminare vor fi mâine, sau în câțiva ani? Avem nevoie de medici care să-și exercite profesia, în mod corespunzător, și care să cunoască foarte bine natura profesiei lor și a limitelor acesteia. Acesta este mesajul de reținut din acest caz.

Cuvinte cheie: *practici de sterilizare forțată, femei de etnie romă, principii bioetice, aspecte legale, consimțământ informat.*

ABSTRACT. The paper presents some ethical considerations regarding forced sterilization practice on Roma women in some countries in Eastern Europe, a case from Slovakia. These practices are done by decades in same countries and Slovakia was the first case judged by the European Court of Human Rights in Strasbourg, France. Thinking to the facts we realize that we are facing with huge risks for patients and not only for Roma people, but for all us. Patients go to the doctors because of his or her profession, and because they are sick and they need help. They do not go to doctors because of his or her personal opinion on something, and if doctors do not act for patients good, patients will lose trust and confidence and they will be afraid to go to the hospital. Today we talk about Roma

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people, but who knows what kind of discrimination criteria will be tomorrow, or in few years? We need doctors who do their job in a properly way and who knows very well the nature of their profession and its limits. This is the take-away message from this case.

Keywords: *forced sterilization practices, Roma women, bioethics principles, legal aspects, informed consent*

Introduction

Few years ago, media presented a huge scandal from Slovakia. It was about the cases of forced sterilization on Roma women, without inform them and without any consent. It was actually about the intention of someone to regulate births on Roma people. News about this situation shocked the public opinion and in the same time raised some questions: what do medical doctors in their day-by-day practice, why they did such a procedure, and who decided it? Are medical doctors free to do correctly their job, or they must to execute some practices decided by others? This paper will present facts, ethical consequences, and legal regulations on human rights related to the elimination of all forms of discrimination against women and to their rights to informed consent.

Facts

On August 2000 a woman from Slovakia, VC, 20 years old, was sterilized at the Hospital and Health Care Centre in Prešov (Eastern Slovakia), center set under the management of the Ministry of Health, during the delivery of her second child via Caesarean section. The procedure entailed tubal ligation, which consists of severing and sealing the Fallopian tubes in order to prevent fertilization. While they were in the height of labor, hospital staff insisted that she sign a consent form for sterilization, without informing her about what the procedure entailed. She was only told that a future pregnancy could kill her and was pressured to immediately undergo the procedure. VC did not understand what she was agreeing to but, she signed the form. After learning that the sterilization was not medically necessary, VC filed a civil lawsuit in Slovakia. The pursuit of justice at home failed, and in 2007 she filed a complaint against Slovakia at the European Court of Human Rights. On November 2011, judges ordered Slovakia to pay € 43,000 in damages, costs and expenses. They ruled that forced sterilization is a violation of the European Convention on Human Rights (specifically art. 3, which prohibits torture or inhuman and degrading treatment, and art. 8, which

protects the right to private and family life). In its decision, the Court noted that sterilization is never a lifesaving procedure and cannot be performed without the full and informed consent of the patient even if doctors believe that future pregnancy may pose a risk to the woman².

Tubal ligation, a surgical technique first proposed in early 19th century England, has been promoted as a permanent birth control method ever since³. While voluntary sterilization is an important contraceptive option, tubal ligation has also been forcibly performed upon women in marginalized populations worldwide, motivated all too often by frankly eugenic considerations⁴. Sterilizations performed against the will or without the knowledge of the patient go by many names: forced sterilization (when a patient is never consulted or informed about the sterilization); coercive sterilization (when patients are threatened or offered incentives to undergo sterilization); and involuntary sterilization, which is sometimes used to speak about both forced and coerced sterilization⁵.

Forced Sterilization on Rroma Women in Central Europe

The experience of Rroma women in Europe is a case in point. With a conservatively estimated population of 10 million people⁶, the Rroma are Europe's largest ethnic minority. Their forebears are posited to have come to Europe from India more than a millennium ago, when they were defeated in

² *Sterilized Roma woman wins human rights appeal*, available at

<http://www.humanrightseurope.org/2011/11/sterilised-roma-woman-wins-human-rights-appeal/>, last accessed on the 12.12.2015

³ See Medscape Reference, *Tubal Sterilization*, by Robert K Zurawin, MD (22 April 2011), available at <http://emedicine.medscape.com/article/266799-overview#a0101>, last accessed on the 12.12.2015

⁴ Matthew Connelly, *Fatal Misconception*, Cambridge, MA/London, England: Belknap Press of Harvard University, 2008

⁵ Men have also been targeted for vasectomy in some Asian countries, notably India, where incentive programs promoting tubal ligations and vasectomies still continue; see The Times of India, "Get sterilized in Rajasthan, drive home a Nano", Ali, Syed Intishab, Syed Intishab Ali June 30, 2011, <http://timesofindia.indiatimes.com/india/Get-sterilized-in-Rajasthan-drive-home-a-Nano/articleshow/9045645.cms>. For more on the global nature of this abuse, see www.stoptortureinhealthcare.org

⁶ According to the Council of Europe, Roma and Travelers Division, the average estimate of the Romani population in Europe (i.e., the 47 member states of the Council of Europe area, which includes most of the CIS countries, Russia and Turkey), is 11,256,900, with a maximum estimate of 16,118,700 (August 2009 update). The World Bank provides a map with Romani populations listed as a percentage of country populations based on data from 2007, but this does not include any of the CIS countries; see <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/EXTROMA/0,,contentMDK:20339787~menuPK:904252~pagePK:64168445~piPK:64168309~theSitePK:615987,00.html>

warfare against the Ghaznavid rulers of Persia around 1000 CE. After being brought to Armenia and Anatolia as soldiers and servants, they migrated further west and were enslaved between the 14th and 19th centuries in some countries in Europe.

The 20th century saw them racially targeted by Nazi Germany for annihilation, and many perished during the Holocaust. In the postwar period, most Romani people in Europe lived under communist rule throughout the Soviet bloc. Since 1989, when most countries in that region began a transition to democratic governance and market economies, members of the Romani minority have experienced a profound degradation in life expectancy, social status, and standard of living⁷. They have also been the targets of deadly pogroms committed by neo-fascist and neo-Nazi groups, and forced evictions involving police brutality throughout Europe⁸.

Thousands of Roma women were sterilized without their consent in Central and Eastern Europe during and after communism⁹. The extent of these practices in Slovakia is exposed in detail in the 2003 Report, *Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom in Slovakia*¹⁰. Countries known for these practices are: Czech Republic, Slovakia, and Hungary.

Classification of These Practices

What has been done? What were reasons for these practices? Did they a kind of research or they only put in act some decisions of others? What was the goal of physicians?

Research Ethics

Research Ethics is defined to be the ethics of the planning, conduct, and reporting of research. Research ethics should include protections of human and animal subjects who are involved in these practices. Medical research has

⁷ World Bank, *Roma in an Expanding Europe*, 2005, available at http://siteresources.worldbank.org/EXTROMA/Resources/roma_in_expanding_europe.pdf

⁸ C. Cahn and E. Guild, *Recent Migration of Roma in Europe*, Council of Europe and OSCE, 2008, available at <http://www.osce.org/hcnm/78034>, last accessed on the 12.12.2015.

⁹ According to the ombudsman's estimate, from the 1980s until today, as many as 90,000 women may have been sterilized throughout the territory of the former Czechoslovakia." (Author's translation.) Lidovky.cz, "Ministr Kocáb: Politování sterilizovaných žen je první fáze" (24 November 2009), http://www.lidovky.cz/ministr-kocab-politovani-sterilizovanych-zen-je-prvni-faze-pld-/ln_domov.asp?c=A091124_184921_ln_domov_tai

¹⁰ *Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom*, Center for Reproductive Rights, available at <http://www.reproductiverights.org/document/body-and-soul-forced-sterilization-and-other-assaults-on-roma-reproductive-freedom>, last accessed on the 12.12.2015

two main arms: *preclinical* research and *clinical* research¹¹. The first one tries to generate a better understanding of disease and new strategies for treatment. The second one evaluates new treatments for safety and efficacy. Clinical research often takes the form of a clinical trial, which is a carefully designed experiment to test the safety and effectiveness of a drug, device, or preventive measure in a group of human patients.

The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality. Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights¹².

Clinical Ethics

Ethics in the context of care is called *clinical ethics*. It deals with ethical issues arising especially in the practice of health care providers. These issues can affect patients or their families, caregivers and managers of an establishment. In addition, tensions may be in the relations between the actors, because of their different approaches or differences in their perception of the situations involved, and future complicate problem resolution¹³.

Clinical ethics may be defined as a discipline or methodology for considering the ethical implications of medical technologies, policies, and treatments, with special attention to determining what ought to be done (or not done) in the delivery of health care¹⁴.

Other issues have to do with technology and the quality of life. Indeed, we can ask ourselves if a technological means should be used every time when it is physically possible to use it and who should decide to use it. Another cause of tension is the pressure on the health system by increasing demands and resources are the same, limited.

¹¹ J. Pierce, G. Randels, *Contemporary Bioethics. A Reader with Cases*, Oxford University Press, New York, 2010, p. 487.

¹² World Medical Association, *Declaration of Helsinki*, 2013, available at <http://www.wma.net/en/30publications/10policies/b3/>, last accessed on the 12.12.2015.

¹³ Cf. Définition de l'éthique clinique, available at <https://www.chusj.org/fr/Professionnels-de-la-sante/Unite-d-ethique-clinique/Definition-de-l-ethique-clinique>, last accessed on the 12.12.2015.

¹⁴ University of Washington School of Medicine, *Law and Medical Ethics: Ethical Topic in Medicine*, available at <https://depts.washington.edu/bioethx/topics/law.html>, last accessed on the 12.12.2015.

The diversity of values encountered within society can be another source of misunderstandings and conflicts. The interdisciplinary approach of clinical ethics can address diversity issues through several angles.

Clinical ethics affects all decisions, uncertainties, values conflict and dilemmas that doctors, health professionals and social services are facing to. The purpose of clinical ethics is to improve the quality of care provided to the patient and the quality of the work of clinical staff through an interdisciplinary approach by identifying, analyzing and proposing possible solutions for ethical problems in practice clinical.

Medical Ethics

Medical ethics represents actually a code of practice by which doctors govern their professional behavior¹⁵. As well as the avoidance of *malpractice*, *medical ethics* is concerned with the many moral questions and dilemmas that have arisen in consequence of medical advances – questions such as the rightness of prolonging life by extraordinary means, choices in allocating limited resources, decisions about organ transplantation, the propriety of psychosurgery, how far research on fetuses is justified, how trials of new drugs should be conducted, whether the diagnosis of genetic defects in embryos is always justified and how far genetic engineering may ethically proceed.

Medical ethics is closely related, but not identical to, *bioethics* (biomedical ethics). Whereas *medical ethics* focuses primarily on issues arising out of the practice of medicine, *bioethics* is a very broad subject that is concerned with the moral issues raised by developments in the biological sciences more generally¹⁶. Medical ethics focused primarily on issues arising out of the physician – patient relationship. The ancient Hippocratic literature (which includes but is not limited to the Hippocratic Oath) enjoins doctors to use their knowledge and powers to benefit the sick, to heal and not to harm, to preserve life, and to keep in the strictest confidence information that ought not to be spread about (though precisely what must be kept confidential is not detailed)¹⁷. These basic values and principles remain an essential part of contemporary bioethics. However, after the Second World War it became clear that the old medical ethics was not sufficient to meet contemporary challenges.

¹⁵ *Collins Dictionary of Medicine* © Robert M. Youngson 2004, 2005, available at <http://medical-dictionary.thefreedictionary.com/medical+ethics>, last accessed on the 13.12.2015.

¹⁶ World Medical Association, *Medical Ethics Manual*, 3rd Edition, 2015, p. 9-10, available at http://www.wma.net/en/30publications/30ethicsmanual/pdf/ethics_manual_en.pdf, last accessed on the 13.12.2015.

¹⁷ B. Steinbock, *The Oxford Handbook of Bioethics*, Oxford University Press, 2007, p. 2.

Ethical Questions

Trying to understand and analyze this particular case, many questions raised up.

1. The first set of questions is related to the forced sterilization practice: **What is wrong** and **why**? The practice? Physician's decision to proceed with forced sterilization? Their intention or purpose to regulate some social issues? Or the consequences of these practices? All they did is wrong. The forced sterilization is bad and wrong, because it produces bad medical consequences for this woman life. Their decision to put in act these practices is wrong, because this is not something normal and specific to the doctor-patient relationship. The patient needs to trust physicians and they go to the doctor because they are professional and they work for the good of their patients, and not for other reasons. If they thought that they could regulate some social issues doing the forced sterilization of their patients, this is also wrong. Why? Because regulating social issues is not a physician job. Always in the history we had social problems, but never had we thought that a doctor profession is to find solutions and regulate social problems. The consequences are huge: patients lose confidence in doctors and we are afraid that doctors can put in act their personal opinions on social and cultural problems in the society.

2. What are the **ethical principles** violated by these physicians?

In their current medical practice, all physicians need to respect the following ethics principles: autonomy, beneficence, non-maleficence, and justice. Definitions of these principles and the rules that are set up in the following table:

Principles	Definitions	Rules
<u>Respect of the autonomy</u>	Each individual: <ul style="list-style-type: none"> • Is unique and free; • Has the right and capacity to decide; • Has value and dignity; • Has the right to informed consent. • Respect the choices and personal positions and decisions of patients. Giving weight to the opinions	<ul style="list-style-type: none"> • Truth Telling • Respect for private life • Protect the confidentiality • Get the Informed Consent

Principles	Definitions	Rules
<u>Beneficence</u>	and choices of autonomous persons; refraining to obstruct their actions unless, obviously, these actions cause harm to others. The obligation to act for the well-being of others.	<ul style="list-style-type: none"> • Prevent harm • Remove harm • Make and promote good.
<u>Non-maleficence</u>	The obligation not to harm others.	<ul style="list-style-type: none"> • Avoid harm.
<u>Justice</u> (proportionality or equity, non-exploitation/non-discrimination)	The obligation to treat equally cases, in the same way (formal justice principle).	<ul style="list-style-type: none"> • For every person : <ul style="list-style-type: none"> ○ Its legal part ○ According to its needs ○ According to its efforts ○ According to its contribution ○ According to its merit.

In our case, **all principles of medical ethics are violated by doctors:** the autonomy, because they did not respect patient’s wishes; beneficence, because they did not act for the good of the patient; non-maleficence, because they did harm for patient life; and justice, because they discriminate the patient, they did not treat her equally, in the same way like other patients. Also, we wonder about the Informed Consent form.

Why Informed Consent?

Because it is the key to respecting autonomy and provides a reasonable assurance that the subject or the patient has not been deceived or coerced¹⁸. Council for International Organizations of Medical Sciences (CIOMS) defines the Informed Consent as a decision to participate in research, taken by a competent individual who has received: the necessary information, who has adequately understood the information and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation¹⁹.

¹⁸ O. O’Neil, *Some limits of Inform Consent*, in “Journal of Medical Ethics”, 2003:29:4-7.

¹⁹ Council for International Organizations of Medical Sciences (CIOMS), *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, 2002, p. 4.

In fact, Informed Consent Guidelines from the International Federation of Gynecology and Obstetrics assert that “informed consent is not a signature but a process of communication and interaction,” and that the “difficult and time-consuming” nature of obtaining informed consent does not “absolve physicians caring for women from pursuing ... informed consent”²⁰.

The World Health Organization has also indicated that “[a]ll clients should be carefully counselled about the intended permanence of sterilization and the availability of alternative, long-term, highly effective methods”²¹.

A simply signature is not enough. Doctors need to provide with information about the surgery and they need to check if patients understood this information.

3. Who decided such a practices?

If thousands of Roma women have undergone to forced sterilization, the question is who has taken such a decision? The physician him or herself? Or it was the responsible of the unit or department? It could be a public policy? If we take into account the current legal regulations in European countries, it is quite impossible to imagine another professional figure that can, in a way, to interfere between the doctor and the patient. And even if someone tries to ask to the physician to do such a thing, the physician must to respect legal norms and the professional deontology. But nevertheless, doctors are not always sufficiently protected by some influence from the society and they could be used or coerced, at least hypothetically, to carry out practices that are contrary to their professional and personal ethics.

4. Could doctors **refuse** to proceed with forced sterilization, if this kind of practices is current in some medical units?

Doctors can always refuse any practice which conflicts with their conscience, their morals or their religions. Because on the 7th October 2010, Parliamentary Assembly of the European Council, adopted a Resolution (R 1763) which regulate **the right to conscientious objection** in lawful medical care²². Conscientious clause is considered to be the possibility given to a physician through whom he or she can avoid to apply some rules of the law, of his medical profession. Norms or practices can be, sometimes, in conflict with moral or ethical values of the physician.

²⁰ International Federation of Gynecology and Obstetrics (FIGO), Ethical Issues in Obstetrics and Gynecology (2006), available at www.figo.org/docs/Ethics%20Guidelines%20-%20English%20version%202006%20-2009.pdf.

²¹ World Health Organization, Medical Eligibility Criteria for Contraceptive Use 151 (3rd Ed., 2004), available at <http://www.who.int/reproductive-health/publications/mec/mec.pdf>.

²² European Council, The right to conscientious objection in lawful medical care, Resolution 1763 (2010), available at <http://assembly.coe.int/nw/xml/News/FeaturesManager-View-EN.asp?ID=950>, last accessed on the 12.12.2015.

No person, hospital or institution shall be coerced, held liable or discriminated against in any manner because of a refusal to perform, accommodate, assist or submit to an abortion, the performance of a human miscarriage, or euthanasia or any act which could cause the death of a human fetus or embryo, for any reason.

The reasons for conscientious objection are a “deep conviction” in relation to ethical or moral values, often but not mandatory religious. It is an exercise of the doctor freedom of conscience, which is part of human rights.

Conclusion

What we learn from this case? Forced sterilization is a serious abuse that has gone unacknowledged and underreported for over a century. For patients and for us, generally speaking, is right to determine our own medical care and our destiny. Patients of the world need and deserve doctors who will respect their rights as well as their health. And we must not forget that all doctors will be, a day, also patients. And we finish with a Romanian saying: “Don’t do to others what you don’t like to be done to you”.

Relevant Human Rights Framework

1. *Convention on the Elimination of All Forms of Discrimination against Women (1982)*

Article 10 (h) – States shall ensure “[a]ccess to specific educational information to help ensure the health and well-being of families, including information and advice on family planning.”

Article 12 – States shall ensure “access to health care services, including those related to family planning.”

Article 16 (1) (e) – Women have the right “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.”

General Recommendation No. 21 - “In order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services.”

General Recommendation No. 24 - "Acceptable [health-care] services are those that are delivered in a way that ensures that a woman gives her fully informed consent. ... States parties should ... ensure timely access to the range of services that are related to family planning ... including information and counseling on all methods of family planning."

2. *European Convention on Human Rights and Biomedicine (1997)*

[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. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time."

[Article 10]: "Everyone has the right to respect for private life in relation to information about his or her health. Everyone is entitled to know any information collected about his or her health."

Other International Human Rights Law

International Covenant on Civil and Political Rights (1996)

[Article 19 (2)] - "Everyone shall have the right to freedom of expression [including the] freedom to seek, receive and impart information".

Convention on the Rights of the Child (1989)

[Article 24 (2) (f)]- States shall "develop preventative health care, guidance for parents and family planning education and services."

Committee on Economic, Social and Cultural Rights, General Comment No. 14 - "The Committee interprets the right to health [as extending] to the underlying determinants of health, such as ... access to health-related education and information, including on sexual and reproductive health." [Paragraph 11]

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