

Healthcare Ethics

The Midwife's Dilemma

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INTRODUCTION

In this seminar work I will focus on Act No. 373/2011 Coll. on specific health services. In the first, theoretical part, I will lightly touch on the history of the creation of this law, mention its main meaning and then briefly summarize the individual Heads of the law. In more detail, I will mainly focus on Chapter II, where I will outline the individual medical procedures regulated by the legislation.

In the second, practical part, my goal is to express my opinion on assisted reproduction and genetic examinations in combination with findings from professional articles. I chose this issue for the practical part because of the close relationship between my work as a midwife and the subsequent connection with knowledge from the rehabilitation field of occupational therapy, which I also studied.

1 THE THEORETICAL PART

1.1 Emergence of the Act on Specific Health Services

Due to the very diverse spectrum of areas covered by the Ministry of Health, in the course of the 21st century all areas that were not legally covered in more detail had to be legally treated. The key act was Act on Health Services No. 372/2011 Coll. This is based on health law, which deals with the rights and obligations of patients, health professionals and persons who participate in the provision of health care in any way. However, it was very general and non-specific for certain areas of health care provision. And therefore, in an effort to protect the patient's interests and rights as much as possible, the general legislation was gradually adjusted in more detail.

Already the legal predecessor of the Health Services Act, which was the People's Health Care Act No. 20/1966 Coll., expanded the general level of legislation to include specific interventions in the healthcare sector, such as assisted reproduction, castration or interventions for transsexuals.

The legal sector and the health sector perceived the need for a change in legislation, and therefore defined these specific areas of health care in the Act on Specific Health Services No. 373/2011 Coll. It entered into force on April 1, 2012 and thus replaced the aforementioned legislation of the Act on the Care of People's Health. In 2018, it was expanded and supplemented by Act No. 202/2017 Coll. In common practice, the Act on Specific Health Services complements the Act on Health Services (Záleská, 2012).

1.2 Assisted reproduction

The law sets the conditions for assisted reproduction, in which germ cells are harvested and manipulated, which lead to the creation of a human embryo when a sperm and egg fuse outside the woman's body. It also discusses the preservation of human embryos. Among the criteria for undergoing assisted reproduction is the condition when it is unlikely or completely impossible for a woman to become pregnant or carry a viable fetus naturally, and another criterion is that infertility treatment for one of the couple is not very promising. The law deals with the possibility of genetic examination of the embryo, in the case when the life of the embryo is threatened by the transmission of genetic pathologies from the parents.

This law also discusses the possibilities of assisted reproduction, possible donors and recipients, as well as the specific age and formal requirements of the applicant for the procedure. The law does not allow the possibility of choosing the sex of the child, except in the case of the occurrence of a sex-linked disease. The issue of embryo storage, disposal or possible donation to another infertile couple is also addressed here.

1.3 Genetic examinations

The specification of genetic testing arose from the requirements of the Convention on Human Rights and Biomedicine (Additional Protocol to the Convention on Human Rights and Biomedicine on the Prohibition of Cloning of Human Beings). They include genetic laboratory and clinical examinations used to determine the proportion of genetic variants in the human genome to the development of the disease in the examined person or their descendants. The performance of this examination must be justified in the medical documentation. The law defines the conditions of genetic examination, the provider of this health service and emphasizes the prohibition of providing financial rewards for undergoing genetic examination and defines the conditions under which this examination can be performed (Záleská, 2012).

2 THE PRACTICAL PART

In the practical part of the seminar work, I would like to think about the specific facts contained in the law on specific health services. In particular, I would like to dwell on the areas of assisted reproduction and genetic testing, which affect me the most as a midwife.

2.1 Introduction to the issue of assisted reproduction

The story of assisted reproduction began on July 25, 1978, when doctors Patrick Steptoe and Robert Edwards managed to use AR technology to bring into the world the first "test tube baby", which was Louise Joy Brown. In the Czech Republic, the first child conceived with the help of assisted reproduction was born in 1982. Currently, we could find 42 centers of assisted reproduction in the Czech Republic, the vast majority of which are private workplaces with a predominantly foreign clientele - this is due to factors such as affordability, liberal legislation and high technical level of Czech centers (Vácha, 2017).

Although assisted reproduction is still a big social stigma, this forbidden topic is starting to be talked about more, thanks to the constantly evolving medicine and also to the change of mindset of modern people who care about their own health. People take more care of themselves and, in the event of pathology in their health condition, they immediately seek professional help and solutions, are interested in a possible correction of their health condition or are looking for a certain alternative that will ensure that their needs are met. One of the life needs of a large part of our population undoubtedly includes the desire to become a parent. Unfortunately, this desire is not always fulfilled for many people due to health reasons. There is a whole spectrum of diagnoses that can negatively affect a man's or a woman's reproductive capacity. This problem does not only affect women of advanced age, but also affects very young women. Nowadays, the number of infertile couples continues to increase, it is reported that 20-25% of couples in the Czech Republic are unintentionally infertile (Mardešić in Vácha, 2017).

Although people try to take more care of their health, the possible causes of reproductive failure can be precisely an unhealthy lifestyle, constant exposure to psychological pressure and stressful situations. Smoking, alcohol, diets, weight, use of certain medications, lack of sleep and exposure to synthetic chemicals are also cited as risk factors (Bisconti et al., 2021). In women, among others, long-term use of hormonal contraception can

lead to infertility, which can negatively affect the hormonal balance of a woman's body (Vácha, 2017).

2.2 Effects of late motherhood on the fetus

Assisted reproduction can be performed in a woman whose age did not exceed 49 years. Personally, I think this age limit is set very high. In general, a woman's pregnancy in the case of a first-time mother is perceived as risky already after the age of 30. In today's society, however, the average age of women giving birth has moved over 30 years. At the same time, it is stated that the best time for pregnancy is between 20-25 years of a woman's life (Mardešić in Vácha, 2017).

In today's world, there is a lot of pressure on women, where ideally they have to complete a university education, gain experience in the field, and only then comes the chance to start a family. Thus, the limit of motherhood is "naturally" pushed back to later years. Nevertheless, the set limit of 49 years seems high to me, and I think that a woman at her age will not be physically and, unfortunately, mentally prepared for motherhood. The birth itself could be very traumatic for both the woman and the child, with a greater risk of possible birth complications. If pregnancy at this age were to occur naturally, there would also be a high probability of the occurrence of congenital developmental defects or other pathologies. However, congenital developmental defects can also occur in the case of assisted reproduction, which is preceded by pre-implantation diagnostics. According to the Royal College of Obstetricians and Gynecologists in Great Britain, in addition to an increase in congenital malformations by 30-40% compared to pregnancies created naturally, in IVF there is a higher incidence of low birth weight, perinatal mortality, and caesarean section delivery is more often indicated in AR (McDonald in Hrubá and Greinffeneggová, 2017). IVF has a demonstrably negative effect on the child's cardiovascular system, which can be a risk factor for stroke and systemic and pulmonary circulation. Furthermore, AR supports the risk of developing diabetes mellitus (Kajantle et al. in Hrubá and Greinffeneggová, 2017). Some studies have pointed to a possible increased risk of malignant tumors and some rare diseases. Delayed physical development was also observed in children after AR (Basatemur and Sutcliffe, 2011).

2.3 Genetic examinations and pre-implantation diagnostics

Personally, however, I am somewhat puzzled by the specific opinions arising from the law. As part of assisted reproduction, a genetic examination takes place for pre-implantation diagnosis. Here, from an ethical point of view, a whole range of questions is offered. I would consider the selection of the "most capable" sex cells to be one of the most fundamental (Žáková in Hrubá and Greiffeneggová, 2017). From an ethical point of view, the storage of embryos is viewed rather negatively. Embryos are likened to products that are created, assessed, and those "defective pieces" in the order of millions are disposed of (Vácha, 2017).

Pre-implantation diagnostics is a great advantage in the prediction and prevention of various diseases, but a problem could arise in the case of selection of embryos according to the parents' requirements - the child's sex, appearance, aptitudes. Then it would be possible to speculate about whether, and possibly what rights, the child has. The case of lesbian couple Sharon Duchesneau and Candy McCollough, who were deaf from birth and identified with their deaf-mute community, of which they were justifiably proud, demanded that their child be deaf-blind like them. They found a suitable sperm donor who was deaf, providing the genes the women wanted to keep in their family. Two children were born to them in succession, who were, according to their wishes, deaf and mute. The case sparked a sharp controversy about what the rights of parents and children still are (Vácha, 2017).

2.4 Premature babies vs. children with a congenital developmental defect

The issue of genetic testing in the diagnosis of genetically determined diseases, birth defects and acquired genetic changes can be speculative for some. It's great how modern medicine can reveal so much about an unborn child just through genetic testing. Unfortunately, it may not always be 100%. Personally, I think that this topic is very hot and sensitive in obstetrics. The fact that in the case of a diagnosis of a congenital developmental defect, the pregnancy can be terminated up to the 24th week of pregnancy, while the gray zone, when premature babies are saved, is already between the 22nd and 25th week of pregnancy, is somewhat scary. In other countries, for example in Japan, this limit of efforts to save the child is shifted to earlier gestational weeks. It is astonishing that one handicapped child can be euthanized in the same gestational period for a medical indication, and another, apparently healthy child, but born prematurely, is saved by doctors with an uncertain

outcome. But the great paradox is that children born prematurely can also have very serious diseases associated with their premature birth, which in the end can be more serious than a certain type of diagnosed developmental defect that was an indication to terminate the pregnancy. One disabled child, whose disability was known thanks to genetic testing during pregnancy, does not get a chance. Even the fact that premature and very immature children will have to have expensive treatment and rehabilitation throughout their lives is speculative. Therefore, an ethical question connected with genetic examination, possible selection of healthy embryos during pre-implantation diagnosis, indication of abortion because of birth defects and determination of the limit of saving premature babies is encouraged.

One of the important things which go along with prenatal diagnosis and birth defects is communication between parents and the specialist. Prognosis communication is not the strongest part of doctors. They are trying to avoid specific the diagnosis, which are connected with death and disability. Also they do not say prognosis with required empathy (Ferrand et Racine, 2022). I think woman would deserve more understanding and compassion in difficult times.

In the end, there is a great dilemma what is ethically best. What is on first place – the autonomy of the woman, mother, the good of the child and respect for human life or medical science (Barilan, 2019)?

CONCLUSION

In this seminar work, we approached the content of the law on specific health services, highlighting the topic of assisted reproduction and genetic testing. At the same time, we asked ourselves several ethical questions, not excluding the topic of saving premature babies in the context of diagnosis of congenital developmental defects, i.e. genetic examination.

Assisted reproduction is still a very hot topic in some circles, for example the position of the Roman Catholic Church has remained unchanged for years. Therefore, religious people proceeding with the method of assisted reproduction may develop a sense of guilt. In child-oriented cultures, there is a feeling of inadequacy and guilt, where childlessness leads to social isolation (Makara-Studzińska et al., 2022). From a philosophical point of view, the question of who or what is an embryo and when human life begins is being addressed.

In the area of infertility, prevention, a healthy lifestyle, open discussion and sufficient information from erudite health workers aimed at infertile couples are very important. As part of preventing the occurrence of influenceable reproductive problems, it is fully within the midwife's competence to provide education regarding a healthy lifestyle.

RESOURCES

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ABBREVIATIONS

AR	assisted reproduction
Coll.	Collection
et al.	et alii
No.	number
IVF	in vitro fertilization