Introduction

As obstetricians our every day job is to help the mothers bring to life their waited children and make pregnancy and childbirth a safe and happy experience. But what if it isn’t and won’t be like that? What if joy is mixed with anxiety? What if an unborn child is diagnosed with a life-limiting condition? Do we really know what to do?

Infant deaths from birth defects in most European countries have been cut in half since 1960. Poland has one of the highest rate of congenital malformations, deformations and chromosomal abnormalities in neonates in Europe and it is correlated with the low acceptance of termination of pregnancy as an option in case of positive results of prenatal testing. The rates are similar in Ireland or Malta. Eugenic abortions in most of the European countries make these numbers much lower. At the same time Poland is a country with a high family stability rate.

In 2010 there were 2160 still births in our country. Prematurity is one of the most important causes of neonate death (1,8/1000), but it often cannot be diagnosed and prevented beforehand. In 2008 there were 726 infant deaths caused by congenital abnormalities. Statistics show that 0,6/1000 are caused by heart defects, 0,3 by chromosomal abnormalities and 0,1 by nervous system abnormalities.

During the centuries there have been two pathways directing the attitude towards disabled or not fully healthy newborns. In ancient times, when physical strength was admired, it was acceptable to kill or abandon sick children. The opposite point of view is presented by the judeo-christian culture, which affirms the life from the moment of conception and demands care for every life from its very beginning.

“Before I formed you in the womb I knew you, before you were born I set you apart; I appointed you as a prophet to the nations.”

Which experience should we follow in the 21st century?

Eugenic abortion.

The word ‘eugenic’ derives from the Latin eu- (meaning good) and genes (meaning born). It divides into two parts: positive and negative.

Positive eugenics help people genetically perfect, with features like athletic skills or a high IQ, to copy their genes and pass the to the next generations. Negative eugenics stop sick, poor and less intelligent people from procreation.

In concentration camps like Auschwitz only perfectly healthy children with blue eyes and fair hair were allowed to survive and were adapted as new citizens of Third Reich. People who didn’t have the strength to work were killed straightaway.

This is how legal situation looks now around the world. The countries in black allow eugenic abortion and the countries in red do not. Eugenic abortion lets only healthy children be born. Only in case when prenatal tests to the recognized pathologies are negative a pregnancy is not terminated.

Nowadays the attitude for maternity is changing. We live in the times of beauty, comfort, intelligence and modern technologies. Is there any place for devotion, even devotion of parents for an own child? Or is eugenic abortion a thoughtful help for the unborn child which doesn’t have to suffer anymore? Or is it choosing an egoistic comfort? These days the right to choose seems to be worth more than the right to live.
Abortion is always a harmful experience. There is no doubt about this. In Poland, practiced up to the time when the child can live separately from the mother, eugenic termination is made on children who can see, feel, move and even when the mother can already feel his or her movements. I definitely is not a humanitarian act.

During my practice in Italy I took part in consultations in a perinatal cardiology centre. One of our patients was pregnant with a child affected with two chambered heart. She was straight away advised to terminate the pregnancy. A couple of days later a child aged 2 with one chamber heart (a worse pathology), a son of one of the most popular Polish sportsmen was deintubated and finally cured. I’m not saying that all of this kind of situations have a good end but if you look at the face of the child and its parents happily playing together there is only one question which comes to my mind- isn’t it worth fighting for?

Cancer and is also an untreatable condition for now but we won’t treat cancer by killing patients affected with cancer. Eugenic abortion blocks the way for further research on perinatal life-limiting diseases. Even in the third world countries patients who die of diseases which are untreatable there but we treat them easily in developed countries are not killed on purpose of the lack of sufficient therapy. In my country the number of legal eugenic abortions is growing. It can be caused by better availability of prenatal testing or by changing the attitudes of women. The detailed information however is hardly available and there are important messages that we get that there may be much more abortions made in Polish hospitals which are not reported later on. It’s also impossible to tell the percentual eugenic abortion rate as there are no legal structures responsible for this problem. From October 2013 it will be legal to perform eugenic abortion in other counties of the European Union if it is refused in Poland by conscientious objection of the physician.

Preimplantation testing.

A new method of testing a human being from its very beginning, in the stage of 4-8 cells is the pre-implantation testing, possible because of IVF. Embryo screening is supposed not even to eliminate a sick embryo, but one with a possibility of developing a disease. The ways of making a diagnosis are: polar body biopsy, blastomere biopsy and blastocyst biopsy, then genetic techniques like PCR and FISH are administered. Not only chromosomal trisomies are rejected but also sometimes BRCA gene or cystic fibrosis gene carriers. Afterwards the embryos which can be called healthy, which means that screening is negative, are put into uterus.

Prenatal testing.

We wouldn’t be speaking about eugenic abortion before prenatal testing has been introduced. Prenatal testing is widespread in all developed countries. Most of the methods were discovered and improved to help sick children. Let’s recall Jérôme Lejeune (know well by the doctors) who invented amniocentesis-his research was devoted to help children, especially with 21 trisomy and now its used to diagnose and terminate pregnancy if accepted by the mother.

Positive results ought to be used as a help for the clinician to lead a high risk pregnancy and for the parents to seek for the best post natal care for their child and prepare for the difficult moments. Even up to 2-3 % of abnormalities are not identified until after birth and a similar number of positive results are false positive or indicate a full expression in case where it is only partial.

Parent’s and doctor’s attitude toward prenatal testing.

Some parents may not want to have their prenatal testing done and the doctor should always accept this decision. In small towns they may not be fully available. However, most of the parents want testing to be done as a confirmation of their child’s wellbeing. They are however not prepared for unfavorable results. Their expectations and the doctors’ advice that life limiting condition leads to termination causes further misunderstanding and despair.

They are so many mixed feelings in the parents’ minds that they need their doctor’s reassurance and advice. Even up to 70% of the decision depends on the way the information is given to the parents. The paternalistic medical practitioners use this knowledge to convince parents to their point of view thinking that they are actually helping the family offering eugenic abortion. They think and they are convinced that it will make the family be less hurt. The doctor’s authority level is always very high but it’s not followed by knowledge about perinatal intensive and palliative care and their results. It is correlated with no classes on this subject at the University, no courses during the specialization and little interest in conferences on
this subject. This leads to inappropriate interpretation of the diagnosis by the parents. I think that also among the practitioners gathered here we could find many who could actually share their experience.

Unfavorable diagnosis has to be given in an atmosphere of comfort and safety. Much sensitivity has to be used and the doctor has to devote his or her time to give all of the information and support that the parents may require. Catholic gynecologists and obstetricians are often known for their attitude and they work in catholic-profiled hospitals. But what if they don’t and are obliged to tell the parents about the possibility of termination?

The context of the conversation should be positive: ‘We will continue to provide the best medical care possible for your infant. This will include frequent assessments by the nurse, daily visits by the physician, and the visits of the social worker and the chaplain. We will be adjusting medications so that your infant is comfortable. What other support can I offer to you?’ (as proposed by American Medical Association's EPEC).

In opposite to the phrases that are used on daily basis in the hospitals. ‘If you keep the pregnancy going your baby will suffer and will die in pain’, ‘Seeing a deformed infant will never make you think of getting pregnant again’.

The properly directed conversation has a chance to change the attitude of previously scared and desperate parents. Research shows that even after 20 years parents remember up 80% of the first conversation with the physician about the unfavorable diagnosis. Making informed decisions should be based on real possibilities, putting perinatal palliative care in the first place.

**Attitude when if they decide not to abort.**

In practice parents aren’t given much more alternative than to terminate and if they decide not to do so, they experience unsupportive attitudes from the medical staff. Many times I have been a witness of phrases like: ‘who made you keep the Edwards syndrome baby?’ or ‘The baby will die anyway, so why did she give birth to it at all?’. During my exchange programme nobody could understand when a 35y.o. mother of a 21-trisomy child said that her neighbor had a child with Down syndrome and that the baby is so lovely and growing up well that she wouldn’t abort the pregnancy. Now you can assume what happens if it’s a bigger defect. Choosing not to abort is seen to be old fashioned and unpopular. It should be a women’s right and not an exception to give birth to her sick child. The parents nowadays have to fight to protect their children from abortion.

**Why perinatal palliative care is being blocked.**

In Poland a big part of population is covered with a children hospice net, but the understanding and need of this service among parents and doctors in case of newborns isn’t as board as it could be. Furthermore, the information given by media and not based on scientific research make parents think that if a child is born alive, modern medicine offers solutions to all of the problems.

Wrongful life causes of action certainly don’t help with maintaining a good image of perinatal palliative care. However, the time spent and love given to the child can help change so called wrongful life into wonderful life. However, there are many things that can be done to help the family.

**Perinatal palliative care- introduction.**

Palliative care is defined by the World Health Organization (WHO) as ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

It is important to tell the parents that palliative therapy doesn’t mean that nothing will be done to help the child. They must be ensured that the child will be carefully taken care of by fully trained staff. The multidisciplinary team must be trained in appropriate manner, best with nationally recognized programme with both ethical and medical issues.

Palliative care excludes intensive treatment and futile medical care. The parents who choose perinatal palliative care don’t want to feel powerless as they would in case of abortion. A traumatic experience of perinatal care may however in the future lead to disappointment and choosing or advising termination. That’s why it has to be well discussed and planned. This gives a chance for the parents to feel they have done everything they could for their child.
**Pregnancy**

The doctor who takes care of this kind of pregnancies apart from the open heart must present a deep obstetrical knowledge to be able to predict the effects of a pregnancy with a fetus with a life limiting disease. There may be complications developing in the mother’s body, like coagulation disorders and in the child’s- generalized edema, heart insufficiency or even inter-uterine death. They all have to be taken under consideration. The risk for the mother is also much higher than in physiological pregnancies. We must remember that fetus can actually feel pain from the 16th week of gestation. We can help in this situation reducing physical symptoms, decompensation, preventing preterm birth and comforting the family. Using techniques like fetal paracentesis the symptoms may be greatly reduced. Each pregnancy has to be fully taken care of. Even if prognosis is unfavorable, a pregnancy chart must be started and filled at every visit. Parents wishes should be respected as far as conducting of the pregnancy is concerned.

The outcome of perinatal palliative care is sometimes unpredictable. The parents may be living for months in scare of death of their child during pregnancy and after labour. They have to be prepared to various emotions that may accompany. As doctors we must remember about the stress coping techniques and the phases of accepting an unfavorable diagnosis. Acceptance is the last phase and before come other like denial or escape. Both parents may experience this attitudes at various times and it can be threatening for the marriage. A gynecologist and obstetrician must take this aspects under consideration to try to help the couple manage this situation together. It should be discussed how the parents recognize the fetus as their sick child or a problem to overcome. It can happen that their attitudes are opposite. The attitudes of the parents are as complex as complex is a human being. The parents who choose perinatal palliative care however respect life no matter how long it is and this thought helps them through.

**Delivery**

The delivery should be planned as for the time. The decision has to be made if vaginal delivery or c-section would be the best option. It is better to prepare the actions which will take place after birth beforehand so that there will be no need of transportation to higher reference centers and separation from the mother. Resuscitation at birth should also be discussed. It is always used in neonates without chromosomal abnormalities but may be futile therapy in severe cases. All of the staff members must be informed about the procedure so that there is harmony in care. Parents religious wishes like baptism must be accepted and performed by a priest, nun, a member of the hospital staff or by an accompanying person. After the necessary time of medical responsibilities the parents should be left with the child alone and this is time for them to know better their own child and welcome the baby in their family.

**Types of patients.**

After the birth we can distinguish four groups of neonates. Healthy, intensive care patients, palliative care patients and stillborn infants. The newborns who will take profit from the perinatal palliative care are:

- Newborns with complex or multiple congenital anomalies incompatible with prolonged life
- Genetic problems: Trisomy 13, 15 or 18, Triploidy, thanatophoric dwarfism or lethal forms of osteogenesis imperfecta, lethal errors of metabolism.
- Kidney problems: Potter's syndrome/renal agenesis and severe lung hypoplasia, some cases of polycystic kidney disease or renal failure requiring dialysis.
- CNS abnormalities: anencephaly/acrania, holoprosencephaly, some complex or severe cases of meningomyelocele or large encephalocele, hydranencephaly; congenital severe hydrocephalus with absent or minimal brain growth; neurodegenerative diseases requiring ventilation (e.g., spinal muscular atrophy).
- Heart problems: acardia, inoperable heart anomalies, some cases of hypoplastic left heart syndrome, pentalogy of Cantrell (ectopia cordis).
- Structural anomalies: some cases of giant omphalocele, severe congenital diaphragmatic hernia with hypoplastic lungs; inoperable conjoined twins.
- Some cases of extreme prematurity.
Types of treatment and support.

It ought to stay up to parents if they wish that palliative care is performed in a high reference or local centre or at home. The newborn has to stay close to the family in comfortable surrounding. There should be no visiting hour restriction. A big room with decreased light and noise, a double bed and access to music have to be provided. In the nearby area there should be chapel and a consultation room. There should be an access to obstetrical staff in case of maternal complications of recent childbirth.

After the patient is dismissed, local services have to be informed- the medical rescuers, the obstetrician as well as social services. Coordination between higher reference centres and local hospitals is extremely important. Technical issues of care should be discussed and practiced. The doctors and psychologists should be available on request. The parents who have been going the same way before may be helpful in comforting the family.

The medical approach consists of methods that secure peaceful death of an infant. Painkillers are administered as well as anxiolitics if they are needed. It is important to pharmacologically help with symptoms such as seizures or dyspnea. Appropriate skin care, mouth care and positioning aids have to be administered. If possible, breast feeding should be promoted. The most important part of the team is the nursing staff, as they spend most time with the infant and the family.

In some cases tissue donation may be discussed.

Death

Parents feel hope during preparation for birth and fear of the possibility of death after birth- or death and then birth. The time of death of the fetus or an infant is hard to predict. However statistics show that most of the patients die during pregnancy or in the first day of life. It means that good pregnancy evaluation has to be performed.

The child’s appearance should be kept in good shape so that the parents can remember the child as well-looking as possible. The parents in the Holy Family Hospital in Warsaw are informed about the possibility of taking home the body of their child and organizing a funeral. If they decide not to, the bodies are guided to the funeral by the principal of our hospital- Professor Chazan and buried in the common grave.

The time of grieving should be assisted by an individual counselor who will be available to help with funeral preparation etc. Our hospital has set a memorial in the graveyard for the missed children who were born in our hospital.

Parents experience peace of mind even if the infant dies, because they know that they did all they could to spend the baby’s short life in parental love and care. It’s the kind of solution that gives them all the tranquility that eugenic abortion will never do.

Positive results, healthy children.

Not only palliative care is an alternative to eugenic abortion. Also intensive care units and pediatric departments may be good enough for children with less severe abnormalities which often lead to termination of pregnancy. A good example is Malina, a medicine student who suffers from Turner’s syndrome. This confirms the thesis that eugenic abortion causes death not only of disabled but also of phenotypically healthy children. How far eugenic abortion can go? Malina says ‘what’s the difference between me and ‘the fetus’, as pro-choice activists or women rights protectors say, that a criminal who would like to kill me would go to jail and she (Turner syndrome affects only females) can be torn into pieces and thrown away to refuse bin in the order of law? ‘

In the 20th week of gestational age a patient turned out to be pregnant with a fetus diagnosed with Dandy Walker Syndrome. She was encouraged to terminate the pregnancy but she refused to do so and she turned up in our hospital. Hydrocephalus occurred in the 36th week and spontaneous delivery in the 38th week. 2 months after delivery another incident of hydrocephalus took place, which leaded to shunt insertion and farther rehabilitation. Now Oliwia is 2,5 years old and she is a healthy child with discreet speech problems but overall developing normally. From the start her parents always loved her just the way she was.

Children born healthy.
It happens that a child which is healthy at birth can present symptoms after some days. It can occur in case of for example brain tumors or car accidents. The prognosis is unfavorable and the child cannot be aborted as it is already born. How can we help them if we don’t have a well developed palliative care system?

Also severe abnormalities may not be diagnosed or may be misdiagnosed during pregnancy. In the University hospital in Warsaw there was a case of a child born in the 40th week of pregnancy, but as the term was unsure cariotyping was not performed before even though the fetus was hypotrophic and had signs of carditis. After birth she needed artificial ventilation and her left ventricle was insufficient. It was futile therapy as later she had her cariotype test performed and was qualified to palliative care.

Further actions.

Perinatal palliative care is where foundations like MaterCare International and its participants should take action. It is essential to help to organize a good net of home hospices and perinatal palliative care centers which would share the knowledge with the local communities and hospitals. If we give the infants and the parents the best quality care and satisfaction they will go further and give the hitting testimonies. This is one of the methods that can reduce abortion rate in developed countries.

Funding is needed and it ought to be discussed locally and internationally. The managers of the hospitals should take this plans under consideration. The reality is complicated as many parents would choose abortion instead of perinatal palliative care. There is a lot we can do to bring awareness to our societies organizing meetings and conferences for doctors and students - all professional, high level with presence of specialists. They should be focused on the goals of perinatal palliative care, its methods, communication with parents and distinguishing between palliative care, futile therapy and doing nothing. It happens that perinatal palliative care is under respected and parents are taken away their rights by doctors to cure children with life-limiting diseases, especially when they are under care of peripheral hospitals. The consciousness among doctors is essential. Also parents, even future parents have the right to know about this possibilities and we should organize lectures and workshops for them, also with cooperation with catholic youth organizations.

We need to help children be born healthy promoting a good standard preconceptive care. Also further research is crucial. We have to check parent’s experience, attitude toward next pregnancies, marriage stability, and expectations and compare them to the eugenic abortion results. Nowadays research is too small to draw reliable and comparable conclusions.

Genetic and symptomatic care research must be taken onwards to allow effective treatment in the future. Positive attitude results in solutions to more and more diseases. Let’s remember that even arlequin fetuses died instantly after birth and now they grow up and this is an effect of care and support and not of abortions.

Any country that accepts abortion is teaching its people not to love but to use any violence to get what they want. Mother Theresa