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Late Termination of Pregnancy

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Introduction

Up to the middle of the last century the fetus was hidden from view until birth and was inaccessible for diagnosis. The discovery and technical improvement of imaging modalities such as ultrasound, X-rays and magnetic resonance imaging meant that the fetus is no longer hidden until birth. The fetus is now potentially a patient who can be examined, subjected to diagnostic investigations and treated. As a consequence, congenital abnormalities are diagnosed earlier today with a more accurate assessment of prognosis and better-informed counselling.

Late termination of pregnancy (LTOP) in this context refers to termination of pregnancy after 20 weeks of gestation. The incidence of LTOP in South Africa is unknown. In a single centre study by Govender et al 253 of the 3893 women that were referred to their fetal unit with severe malformations were offered LTOP and 191 accepted LTOP.[1] At Steve Biko Academic Hospital, Pretoria 100 LTOP were performed between January 2010 and January 2017. Detection of most congenital abnormalities can be made earlier in pregnancy but some structural malformations and genetic syndromes are diagnosed later in pregnancy and this results in a need for late termination of pregnancy.[2]

The Royal College of Obstetricians and Gynaecologists Working Party on Ultrasound Screening for Fetal Abnormalities and the National Institute for Clinical Excellence (NICE) Guidelines for Routine Antenatal Care states that pregnant women should routinely be offered an ultrasound scan to screen for structural anomalies between 18 and 21 weeks gestation.[3,4] In resource poor settings congenital abnormalities are detected at an advanced gestational age due to late booking or missed abnormalities during an earlier scan. LTOP is offered in many countries but it poses an ethical dilemma both to the expecting mother and the treating physician. The expecting mother receives unexpected news about severe malformations in her baby and has to make major decisions about her pregnancy. The clinician has to deliver bad news, counsel about time of delivery, counsel about future pregnancy risk and provide support to mother and her family for their psychological recovery.[5] Many medical providers have difficulties coping with these unpleasant issues and this may hinder their ability to provide empathic care and support. A multidisciplinary approach is needed for managing a pregnancy affected by severe fetal malformations.

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Ethical Considerations

Advances in perinatal medicine bring new ethical dilemmas for parents and clinicians. Like all medical disciplines, the clinical practice of perinatal medicine should be guided by an ethical framework. The professional responsibility model of perinatal ethics provides a transnational, transcultural and transreligious ethical framework that should guide perinatologists in responsibly caring for pregnant, fetal and neonatal patients.[6]

Chervenak and colleagues have proposed the professional responsibility model as an alternative to the rights-based reductionism model.[6] The abortion debate clearly illustrates the main-features of fetal rights-based reductionism. Here, fetal rights always override the rights of a pregnant woman and termination of pregnancy at any gestation is ethically impermissible. By contrast, maternal rights-based reductionism holds the view that the pregnant woman's rights always override those of the fetus. Termination of pregnancy is ethically permissible at any gestational age: the pregnant woman has unconditional right to control what happens to her body. Both forms of rights-based reductionism are appealing because of the simple 2-step reasoning that is invoked: a) one either has rights or one does not; b) if one does have rights then others must always respect and implement them. However unacceptable clinical simplification of perinatal ethics occurs when the overriding ethical consideration is either the rights of the pregnant woman or the rights of the fetus.[6] This simple dichotomy does not withstand clinical ethical appraisal.

Rights are based on many factors, including cultural, political and religious beliefs. There is therefore deep, centuries-old controversy about the nature and limits of both the fetus's and pregnant woman's rights. The reductionist model does not consider that professional integrity sets justified limits on preferences of patients.

Consider the following case: a distraught 34-week pregnant woman requests a termination of pregnancy as soon as possible because her partner has deserted her. Professional integrity requires the obstetrician not to implement this request because feticide is ruled out by the obstetrician's beneficence-based obligation to protect the life of this fetal patient. This is an example of a clinical situation in which a pregnant woman's request for termination of pregnancy should not be granted. Similarly, there are problems with fetal rights-based reductionism which holds that the fetus has unconditional right to life or to complete gestation. The presence of a fetal anomaly incompatible with life exposes this view as lacking scientific and clinical foundation.

Unfortunately, perinatal medicine has no capacity to correct such anomalies. It is therefore clinically unrealistic to insist on unconditional right to life or to complete gestation. The professional responsibility model of perinatal ethics includes the pregnant woman's right to control her body but also, unlike the maternal rights-based reductionist approach, includes limits on these rights originating in the pregnant woman's beneficence-based obligations to the fetal patient. The model also includes ethical obligations to the fetal patient.

Law on late termination of pregnancy

In South Africa, late termination of pregnancy is permitted and granted by the CTOP Act of 1996, The Choice on Termination of Pregnancy Act, 1996 (Act No 92 of 1996) which states the following[7]:

A pregnancy may be terminated after the 20th week of gestation if a medical practitioner after consultation with another medical practitioner or registered midwife, is of the opinion that the continued pregnancy:

i) would endanger the women's life;
ii) would result in a severe malformation of the fetus; or
iii) would pose a risk of injury to the fetus

In the United Kingdom, late termination of pregnancy is permitted by law and is lawful when two registered medical practitioners are of the opinion, formed in good faith, that the grounds for termination of pregnancy are met, when there is a serious handicap. An assessment of the seriousness of a fetal abnormality is considered on a case-by-case appraisal as they find it unrealistic to produce a definitive list of conditions that constitute a serious handicap.[8]

Definition of severe malformation

There is no legal definition of what comprises 'severe' malformation. Whether a malformation is severe depends on factors such as the nature and severity of the condition and the timing of the diagnosis as well as the likelihood of the event occurring. The World Health Organisation (WHO) defines 'disability' as: 'any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.[9] The WHO further defines the severity of disability by the following 2 categories:

- **Assisted performance:** the need for a helping hand; that is, the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person
- **Dependent performance:** complete dependence on the presence of another person; that is, the individual can perform the activity or sustain the behaviour but only when someone is with him or her most of the time.[8] The Royal College of Obstetricians and Gynaecologists advise doctors to weigh up the following when considering termination of pregnancy for a fetal abnormality:
- The potential for effective treatment, either in utero or after birth
- On the part of the child, the probable degree of self-awareness and of ability to communicate with others
- The suffering that would be experienced
- The probability of being able to live alone and to be self-supportive as an adult
- On the part of society, the extent to which actions performed by individuals without disability that are essential for health would have to be provided by others.[9]

Indications for LTOP

It is ethically impermissible to offer LTOP for viable foetuses without anomalies or with less-than-severe anomalies such as Down's syndrome or achondroplasia. Less-than-severe anomalies do not involve a high probability of death or a high probability of absence or virtual absence of cognitive developmental capacity.[10]

A late termination of pregnancy is indicated when the maternal condition or treatment of such a condition results in increased risk to the pregnant woman's health or life should she continue with the pregnancy. LTOP is also indicated if a severe malformation has been diagnosed.

Psychological aspects

The diagnosis of a fetal anomaly triggers intense distress in the expecting mother regardless of the severity.[11] Many women are completely unprepared for the diagnosis and the uncomfortable silence during the examination. Delays in delivering news, specialist referral and insufficient information all amplify stress and anxiety.[11] For many patients lack of access to services necessitates traveling long distance to get to a referral centre. Many women perceive providers' moral qualms about LTOP as the basis for referral amplifying their distress and anguish. A subset of women experiences long-term psychiatric morbidity including persistent pathological levels of posttraumatic stress symptoms, depression and anxiety disorders.[12] Korenromp and colleagues looked at predictors for adverse and psychological outcomes of 147 women who had LTOP for severe fetal malformations. Four months after LTOP 46% of women showed

pathological levels of posttraumatic stress symptoms, decreasing to 20.5% after 16 months. For depression, these figures were 28% and 13% respectively. Outcomes at 4 months was the most important predictor of persistent impaired psychological outcome.[13] This emphasizes the need for a multidisciplinary team which includes psychologists and psychiatrics in order to deal with the psychological impact of LTOP on the woman. These women need ongoing counselling even after the LTOP has been performed.

Counselling and management

Counselling of expectant mothers of foetuses with severe malformations should be non-directive, non-judgemental and supportive.[9] It should be offered by a multidisciplinary team which includes genetic counsellor, psychologist, obstetrician, social worker, neonatologist and paediatric neurologist.

When counselling, focus should be on five key questions that are the basis for understanding the fetal prognosis. These questions are challenging but it is the health care provider's professional responsibility to address them and these are[14]:

i. What is the diagnosis and how certain is it?
ii. What is the likelihood of survival beyond the new-born period if life-sustaining treatment is provided (e.g. Mechanical ventilation or surgery)?
iii. What is the likely duration of survival if life-sustaining treatment is provided?
iv. What is the range of possible physical or cognitive impairments if the new-born survives?
v. What is the burden of treatment required to keep the baby alive?

To respect the patient's autonomy practitioners need to acknowledge the limits of available data and genuine uncertainties in prognosis.

Practical and ethical approach in management of expecting women[15]:

i. Respecting the autonomy of the pregnant woman.
Practitioners should acknowledge and carry out the value-based preference of the mother because each pregnant patient's perspective on her interests is a function of her values and beliefs.
ii. Respecting the fetus as a patient.
The ethical principle of respect for autonomy and the concept of autonomy-based rights does not apply the fetus as the fetus has no capacity to generate a perspective on its interest. Beneficence-based obligations to the fetus exist when the fetus is reliably expected later to achieve moral status as a person and child.
iii. The viable fetal patient.
When the fetus is presented to the physician and when it is of sufficient maturity that, given the availability of biotechnological support, it can survive into the neonatal period and later achieve moral status, the fetus is a patient. Gestational age for viability is different in different parts of the world, and in most developed countries, viability occurs at approximately 24 weeks of gestational age. In our unit viability is achieved at 26 weeks gestational age. In a situation where a viable fetus is diagnosed with severe anomalies that have a very high probability of death as outcome or a high probability of irreversible deficit of cognitive developmental capacity the beneficence-based obligation to protect and promote the fetus' health-related interest has reached its limit. Induced abortion or feticide when these criteria have been met in rigorous clinical judgement does not violate beneficence-based obligations to the fetal patient.
iv. The previable fetal patient.
A pregnant woman's autonomy is the only link prior to the fetus achieving moral status. This is because there is no biomedical technology independent of the woman's body that can sustain the life of the previable fetus. In such cases the previable fetus has no claim to the status of being a patient independently of the pregnant woman's autonomy. This means that the pregnant woman is free to withhold, confer, or having once conferred withdraw the status of being a patient on or from her previable fetus according to her own values and beliefs. This is an important clinical implication of respecting the pregnant woman's autonomy.
v. Respecting individual conscience
There is ethical obligation that every physician has to the pregnant and fetal patients. This obligation is based on respecting the pregnant woman's autonomy and respecting the fetus as a patient. Physicians however, also have individual consciences which appeal to sources of morality other than professional medical ethics such as personal experience, family upbringing and religion. Professional conscience governs every physician's obligations to his or her patient. Individual conscience governs whether continuing to serve as a physician to a particular patient obligates that physician to act in such a way as to produce intolerable burdens on his or her individual moral convictions, values and beliefs. Respecting the individual conscience of each individual physician means that some pregnant women cannot become or continue to be patients of a particular physician. Respecting the physician's individual conscience is an indispensable component of the responsible management of termination of pregnancy.

Methods of LTOP

When a viable fetus has a severe malformation offering feticide followed by termination of pregnancy is ethically appropriate. In this case, the beneficence-based obligation to protect life has reached its limit. This means that there is an autonomy-based justification followed by LTOP of a viable fetus with a severe malformation.

The RCOG currently recommends feticide for

terminations over 21^{+6} week's gestation.[16] The only exception to this rule is when the fetal anomaly itself is so severe as to make early neonatal death inevitable irrespective of the gestation at delivery. In cases where feticide is not performed after 22 weeks gestation LTOP could result in a live birth. In such situations the child should receive the neonatal support that is in the child's best interest and its condition managed within published guidance for neonatal practice. If the physician for moral reasons is unable to perform LTOP it is his or her responsibility to refer the patient.

Procedure of feticide: A feticide should be performed in a tertiary hospital in a maternal-fetal unit. Parents must receive sympathetic and supportive counselling before and after the procedure. Feticide should be performed by an appropriately trained practitioner under aseptic conditions and continuous ultrasound guidance. Intracardiac potassium chloride (KCl) is the recommended method to ensure fetal asystole. Although KCl can be administered via the umbilical route after cordocentesis failures have been reported. In a South African study Govender et al reported a 100% rate of fetal demise with feticide by ultrasound guided intracardiac KCl injection and that it was an acceptable, safe and effective method of LTOP.[1] Fetal demise may also be induced by intra-amniotic or intrathoracic injection of digoxin and by umbilical venous or intra-cardiac injection of 1% lignocaine. These procedures are not as effective as intracardiac KCl injection.[1,17]

When LTOP is declined

It should be never assumed that in the presence of a severe fetal anomaly an expecting woman will choose LTOP. When she decides to continue with the pregnancy she must be fully supported.[9] Some women will choose to continue with pregnancy with the option of palliative care after delivery and this decision must be respected, supported and an individualised care plan agreed. Women who decline LTOP for non-lethal conditions will need referral to specialists such as paediatricians, paediatric surgeons or neonatologist and must deliver in centres with these specialities. Antenatal care should continue for these women and their needs must not be overlooked regardless of the nature of the abnormality.

Conclusion

A diagnosis of severe malformation comes as a shock to an expecting woman and it is associated with much of emotional and psychological pain. Health care providers need to be sympathetic, non-judgemental, nondirective but supportive when counselling these patients. LTOP with feticide is permitted by law if the fetus has a severe malformation. Managing these patients should be done by a multidisciplinary team which includes obstetrician, psychologist, social worker, neonatologist, paediatric surgeon or neurologist. Management should be guided by the 3 pillars of medical ethics: respecting the woman's autonomy, non-maleficence and acknowledging that beneficence in the case of the fetus is limited.

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