Termination of pregnancy when the unborn child has Spina Bifida and/or Hydrocephalus.
An overview on international literature.
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Reviewing the recent literature on prenatal diagnosis of Spina Bifida and selective abortion, we can summarise the articles in four categories: actual practice and policy in different countries, the moral and ethical aspects, the legal aspects and a challenge to the actual practice and policy.

Actual practice and policy

Since 1975 prenatal diagnosis of Spina Bifida became available with routine screening for elevated levels of maternal serum AFP, amniocentesis and in more recent years the widespread availability of ultrasound. The ability to assess the severity of foetal abnormality at an early stage of gestation enables the parents and the physician to discuss prognosis and make an informed decision regarding termination of the affected pregnancy, which is legal in most states until 24 weeks. Some of these diagnoses are not made until after 24 weeks' gestation. At these late gestations, many physicians are unwilling to perform pregnancy termination, partly because of the possibility of producing a "live-born" neonate. Not all parents faced with a foetal anomaly elect to abort. However, in case in which the parents have elected abortion, the intent is to prevent the delivery of a live-born neonate. Some neonatologists believe that once any potentially viable neonate is separated from its mother, it is independent and thus requires resuscitation regardless of maternal intent. With the intention of preventing the attendant medical, ethical, and legal problems arising from the birth of live-born, anomalous foetuses, intracardiac potassium chloride injection is used to assure stillbirth in the setting of medical abortion late in pregnancy.

Medical and ethical aspects
Ensuring a stillborn: the ethics of foetal lethal injection in late abortion

In his article J.C. Callahan argues for the moral acceptability of using intracardiac KCl injection to ensure that a seriously anomalous foetus will not be live-born. He gives moral arguments supporting lethal injections for anomalous foetuses: the safety of the woman and the interest of the anomalous foetus. "Late abortions of seriously anomalous foetuses are undertaken precisely because it is decided that if these foetuses were to survive, their lives would be of an unacceptably low quality."
Legal aspects
Late abortion and the European Convention for Human Rights

National abortion laws usually do not allow abortion when a foetus is independently viable, i.e. from a gestational age of about 24 weeks. Foetal anomalies are sometimes detected only in an advanced stage of pregnancy.

National legislatures who want to allow "late" abortion need to account for the protection the foetus may derive from the European Convention for the protection of human rights. Due to rapidly growing developments in prenatal diagnosis, with which treatment methods do not as yet keep step, an initially welcome pregnancy may become unwanted if a severe, incurable disease or handicap is detected. It then depends on the moment of detection, which for several reasons may be not before the third trimester, whether or not, under the standing Abortion Act in the country concerned, an abortion is still allowed.

European Convention on Human Rights and the law in some European countries.
In France, the law allows for a "therapeutic" abortion to be authorised by two physicians not only if continuation of pregnancy would seriously endanger the health of the woman, but also if it is to be expected that the future child will suffer from a particularly severe abnormality or disease which is considered incurable. There is no limit in terms of gestational age (art L.162-12 code de la Santé publique).
The Belgian code has a prevision which is basically similar. (art. 350,2 code penal)
In the UK not only legislation on abortion for foetal abnormality has been enacted, but also professional guidelines exist. The law is to be found in the Abortion Act as amended by the Human Fertilisation and Embryology Act 1990. Previously, the upper gestation at which abortion for foetal abnormality could be provided was limited.
Under the amended Abortion Act two medical practitioners, acting in good faith, may certify that a pregnancy can be terminated at any gestation if..."there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped". The practitioner notifying an abortion after 24 weeks is required to provide a full statement of the medical condition of the foetus and should also complete a still birth certificate.

Law and practice in the Netherlands
Abortion is prohibited under art.296 of the Dutch Penal Code. Only if the abnormalities are of such a nature that "no extra-uterine survival" can be expected (which means that even after 24 weeks the foetus cannot be considered viable), the law would not prohibit termination of the pregnancy.

A challenge to practice and policy
In a recent article on Prenatal Diagnosis and Selective Abortion, Adrienne Asch argues that professionals should re-examine negative assumptions about the quality of life with prenatal detectable impairments an should reform clinical practice and public policy to improve informed decision making.
Current data on children and families affected by disabilities indicate that disability does not preclude a satisfying life. Many problems attributed to the existence of a disability actually stem from inadequate social arrangements that public health professionals should work to change. This article assumes a pro-choice perspective but suggests that unreflective uses of prenatal testing could diminish, rather than expand, women's choices. This critique challenges the view of disability that lies behind the social endorsement of such testing and the conviction that women will or should end their pregnancies if they discover that the foetus has a disability trait.

In order make testing and selecting for or against disability consonant with improving life for those who will inevitably be born with or acquire disabilities, our clinical and policy establishments must communicate that it is acceptable to live with a disability as it is to live without one and that society will support and appreciate everyone with the inevitable variety of traits. When our professions can envision such communication and the reality of incorporation and appreciation of people with disabilities, prenatal technology can help people to make decisions without implying that only one decision is right.

**Conclusion**

**Our message to the medical world and the policy makers**

The prognosis for children with Spina Bifida anno 2000 is much better than indicated by Lorber. Professionals should change their pessimistic view on long-term prognosis and need to counsel parents about the full spectrum of impairment in addition to the effects of modern forms of treatment on the outcome of unborn infants with Spina Bifida. The pessimistic public opinion has to be changed before we can assure prospective parents that they and their future child will be welcomed whether or not the child has a disability. If the child with a disability is not a problem for the world, and the world is not a problem for the child, perhaps we can diminish our desire for prenatal testing and selective abortion and can comfortably welcome and support children of all characteristics.