

Decision-making after ultrasound diagnosis of fetal abnormality

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Abstract During the last few decades, the use of ultrasonography for the detection of fetal abnormalities has become widespread in many industrialised countries. This resulted in a shift in timing of the diagnosis of congenital abnormalities in infants from the neonatal period to the prenatal period. This has major implications for both clinicians and the couples involved. In case of ultrasound diagnosis of fetal anomaly, there are several options for the obstetric management, ranging from standard care to non-aggressive care and termination of pregnancy. This essay explores the context of both clinical and parental decision making after ultrasound diagnosis of fetal abnormality, with emphasis on the Dutch situation. While normal findings at ultrasound examination have strong beneficial psychological effects on the pregnant woman and her partner, the couple is often ill prepared for bad news about the health of their unborn child in the case of abnormal findings. This is, in particular, true in settings where ultrasonography for the detection of fetal abnormalities is offered as an integral part of antenatal care without appropriate counselling. An important question is to what extent the couple should be supported in decision making when a fetal abnormality is diagnosed. In this context, the parental perception of having a choice varies markedly. When parents consider end-of-life decisions, they experience both ambivalent and emotional feelings. On the one hand, they are committed to their

pregnancy, while on the other hand, they want to protect their child, themselves and the family from the burden of severe disability. These complex parental reactions have implications for the counselling strategy.

Keywords Fetal abnormality · Prenatal detection rate · Ultrasound · Parental decision-making · End-of-life decisions

Congenital abnormalities

Congenital abnormalities are the main cause of infant death in industrialised countries [1, 2]. Congenital abnormalities are frequently diagnosed before birth, as many of the major fetal abnormalities can be detected by a prenatal ultrasound examination [3–5]. From data derived from a routine ultrasound screening setting of an unselected population in Oxford [6], the estimated birth prevalence of infants with abnormalities is 2.2% (Fig. 1). Just more than half (55%) of them were diagnosed with abnormalities that were identified prenatally. Currently, ultrasound scanning is considered the most important tool for prenatal diagnosis of fetal congenital abnormalities. It detects the majority but certainly not all of the fetal abnormalities [6]. In specialist centres for prenatal diagnosis, detection rates of fetal abnormalities range from 80 to 95% [4, 7]. Detection rates in screening settings are probably lower. The detection rates also depend on the nature, type and numbers of abnormalities. For example, prenatal detection rates of neural tube defects approximate 98% while those of congenital heart defects are about 38%. Apart from the nature of the fetal abnormality, maternal obesity has a considerable impact on detection rates [8].

The study in Oxford also addressed the overall impact of prenatal ultrasound diagnosis in terms of numbers of infants

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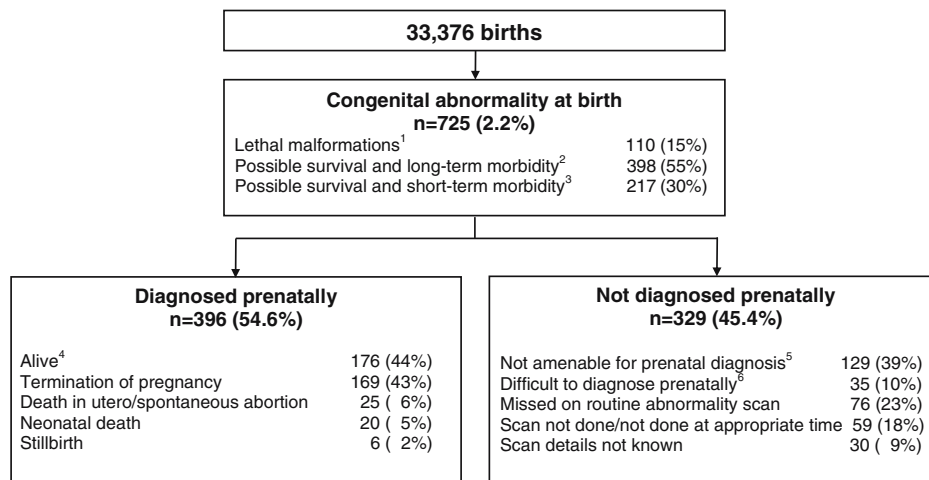


Fig. 1 Overview of prenatal detection of congenital abnormality when prenatal screening is offered routinely in an unselected population in Oxford, 1991–1995; births included all births over 20 weeks and all pregnancies terminated because of fetal abnormality detected at any age of gestation. 1, e.g. anencephaly, trisomy 13, trisomy 18, hypoplastic left heart, renal agenesis, Meckel Gruber syndrome; 2, e.g. spina bifida, hydrocephalus, Down's syndrome,

complex cardiac malformations, diaphragmatic hernia, abdominal wall defects; 3, e.g. non-complex cardia malformations, facial clefts, club foot, hypospadias; 4, two infants died after the neonatal period; 5, e.g. skin abnormalities, hypospadias, congenital dislocation of the hip, cleft palate, atrial–septal defect; 6, e.g. tracheo-oesophageal fistula or fistula, coarctation of aorta, polydactyly, ambiguous genitalia

born with conditions that result in mortality or severe morbidity (Fig. 1) [6]. In fact, when severe congenital abnormalities are detected prenatally, termination of pregnancy is an option for the couple involved. In the majority of end-of-life decisions in the prenatal period, suspicion of fetal abnormality was first aroused after ultrasound scan [6]. Hence, the practice of ultrasound scanning is closely related to that of end-of-life decisions.

Developments in fetal ultrasound

Since the early sixties, when the first ultrasound images of the fetus were made, ultrasound has evolved into the most important diagnostic tool in fetal medicine [9]. First, only static images of the fetus were available. In 1977, real-time scanning was introduced, which allowed for moving images of the fetus. Soon thereafter, ultrasound became widely available in clinical practice. In a short period of time, a myriad of reports on both normal and abnormal anatomy of the fetus appeared in the medical literature. Nowadays, routine ultrasound examination during pregnancy is an integral part of antenatal care in most industrialised countries [9–11]. Routine ultrasound examination typically includes a dating scan in the first trimester of pregnancy and a fetal abnormality scan at approximately 18–20 weeks' gestation [9].

In countries with a routine ultrasound screening policy, more than half of all congenital abnormalities are diagnosed prenatally, including 74% of the major abnormalities (i.e. abnormalities that have implications for the infant's health)

and 46% of the minor abnormalities (i.e. abnormalities that have no implications for the infant's health) [6, 12].

Ultrasound screening

From the perspective of public health, the potential benefits and limitations of ultrasound screening for fetal abnormalities have been debated extensively [4, 9]. To date, reports on the benefits of ultrasound screening for the detection of both lethal and non-lethal abnormalities among unselected populations are inconclusive [13]. Randomised controlled trials have been done but have used perinatal mortality and morbidity as outcome variables. Moreover, in research settings, there was a wide variation in expertise levels of sonographers. The interpretation of the research findings is further impeded by the time period of the studies being conducted; ultrasound nowadays is more advanced than in former days [10]. These methodological problems are reflected in an enormous variation of reported overall sensitivity of the detection of congenital abnormalities, which ranges between 14 and 96% [3–5, 13]. Apart from these methodological flaws, the use of perinatal mortality and morbidity as the most important outcome variables is questionable [10]. Other outcome variables, such as improved information of pregnant women about the health status of their offspring, enhanced care for the affected neonate, better fetal–maternal bonding, the potential prevention of a 'wrongful life' are relevant as well [13]. These issues warrant additional questions about the aim of screening. The answer to these questions should not only

pertain to medical data but should also incorporate moral choices [10, 11, 14].

In The Netherlands, the implementation of ultrasound screening into clinical practice has been a matter of strong debate [11]. Initially, the government decided that ultrasound is only to be offered for ‘genetic’ indications, i.e. targeted at women at increased risk of congenital abnormalities in offspring [11]. This policy should be seen within the Dutch sociocultural context. Dutch law typically bans population screening, unless certain conditions are fulfilled, such as the availability of effective treatment for the outcome of interest [11]. In the context of prenatal screening for fetal abnormalities, abortion is not considered as an “effective” modality. Furthermore, there were concerns about the implications of prenatal screening in terms of medicalisation of the pregnancy and regarding the position of handicapped people in the society at large [11]. Only recently, Dutch law became more compliant, which resulted in a trend towards offering all pregnant women an ultrasound examination at 20 weeks’ gestation.

The government’s initial decision not to incorporate routine ultrasound screening into clinical practice resulted in large practice variations, i.e., some women having no ultrasound examination at all, while others having a two-scan policy or a ‘pleasure scan’ in a commercial setting. The latter may give false reassurance as these ultrasound examinations are not intended for the detection of fetal abnormalities [11, 15]. Until recently, there were neither formal guidelines for the timing of the ultrasound and counselling nor for qualifications of sonographers. So even if women have had one or multiple ultrasound examinations, potentially detectable major fetal abnormalities were still missed.

Psychological effects of normal ultrasound

Normal findings at ultrasound examination have strong beneficial psychological effects on the pregnant woman and her partner. For couples, ultrasound is a way of ‘meeting’ the unborn child¹ [16–19]. The personalisation of the fetus enhances both maternal–fetal bonding and bonding of the pregnant woman and her partner [18, 20, 21]. A normal ultrasound reassures parents about their pregnancies [20, 22–25]. The positive effects of ultrasound are stronger when more feedback is provided, such as showing images on an additional monitor and explaining what can be seen [20, 24].

¹ A couple’s reaction to a normal ultrasound: ‘The baby becomes more real... once you see the scan, that all changes. It’s no longer your imagination at work, but you have this real image of a baby. You can see so much detail... it is amazing, his little fingers and toes, his eyes, oh, everything. It is magical, so awe inspiring to see’ Puddifoot JE, Johnson MP. The legitimacy of grieving: the partner’s experience at miscarriage. *Soc Sci Med* 1997;45:837–45.

In fact, fetal ultrasound is highly appreciated by pregnant women and their partners [19, 25–27]. Most women consider ultrasound examinations as an integral part of antenatal care [26]. However, frequently, women lack information about the purpose of ultrasound examinations and its technical limitations. As a result, women are often unprepared for adverse findings [27, 28].

Psychological effects of abnormal ultrasound

The news of abnormal findings of the ultrasound examination frequently comes unexpectedly and is often intensely shocking for the would-be parents, in particular, when major congenital abnormalities are encountered [27, 29]. Pregnant women and their partners may have several emotional reactions when fetal abnormalities are revealed. Firstly, they may have negative feelings typically associated with psychological traumas in general, such as anxiety, grief, anger, loneliness, hopelessness, prostration and guilt [28–30, 32, 33]. These feelings may be aggravated by the loss of the imagined future, as the pregnancy may end in the daily reality of having no child or a severely handicapped child, requiring readjustments of the entire family. These negative feelings can be enhanced by the confrontation with reality, when having to decide about very pragmatic issues ‘should I furnish the nursery?’, ‘should I make arrangements for the funeral?’, and ‘what should I tell my other child?’. Finally, some parents experience a loss of reference. The news of a fetal abnormality in an apparently uneventful pregnancy usually comes so unexpectedly, and is in such contrast with the pleasant experiences that often goes along with pregnancy, that parents have severe difficulty with grasping the facts. It seems so unreal that the child, who is kicking inside the womb, is severely disabled and will perhaps die, thereby making life meaningless. When parents consider pregnancy termination, the ambivalent feelings they experience may enhance this loss of reference. On the one hand, they are committed to their—desired and intended—pregnancy while on the other hand they want to protect their child, themselves and the family from the burden of severe disability [34].

End-of-life decisions after ultrasound diagnosis of fetal abnormality

With the burgeoning of ultrasound, questions around the appropriate obstetric management in case of sonographically established fetal abnormalities have arisen. Should we apply all means to keep alive a fetus with a very poor prognosis? Do medical professionals in the field of perinatal medicine agree on fetal prognosis after ultrasound

Table 1 Studies evaluating determinants of parental decision-making after ultrasound diagnosis of fetal abnormality

Author	Population	N	Method	Outcome variable	Results
Determinants					
Grevengood et al. [52]	Isolated neural tube defect identified <24 weeks GA	50	Analysis decisions in case of anencephaly Analysis decisions in spina bifida lesions >T9 Analysis decisions in spina bifida lesions <T9	TOP	Anencephaly :23/ 23 TOP Spina bifida > T9 : 5/ 5 TOP Spina bifida < T9 : 16/ 22 TOP
Pryde et al. [53]	Normal karyotype Abnormalities identified <24 weeks GA No abnormal karyotype	159	GA stratified into early (<14 weeks GA), mid (15–19 weeks GA), late (20–24 weeks GA) diagnosis Prognostic severity of abnormality stratified into mild, uncertain, severe	TOP	Severity of abnormality GA Maternal age Gravidity Parity
Sheiner et al. [54]	Abnormalities incompatible with life or severe enough to significantly interfere with normal living in Arab	188	63 cases GA>24 weeks 125 cases GA<24 weeks	TOP	GA Previous uncompleted pregnancies Central nervous system abnormality Maternal age Gravidity Parity
Schechtman et al. [55]	Bedouin population Abnormalities identified <24 weeks GA	53,630	Severity of abnormality stratified on scale 1–5, as evaluated by sonographer	TOP	Previous perinatal death Congenital abnormality in family Educational level parents Severity of abnormality Chromosomal abnormalities Central nervous system abnormality Maternal age

TOP Termination of pregnancy; GA gestational age; n.s. not significant

diagnosis of fetal abnormality? How should obstetric and neonatal management be attuned? How do parents view end-of-life decisions concerning their unborn infant? These and other issues have opened a new field of research: end-of-life decision-making after ultrasound diagnosis of fetal abnormality. End-of-life decisions are decisions about medical interventions at the end of life, which certainly or probably hasten death [35].

Two kinds of end-of-life decisions can be distinguished after ultrasound diagnosis of fetal abnormality. That is, (1) non-aggressive obstetric management and (2) termination of pregnancy. A non-aggressive obstetric management refers to an obstetric management in which interventions needed to sustain fetal life are forgone because of the poor prognosis of the fetus concerned. Chervenak and McCullough [36] first reported the non-aggressive obstetric management approach in 1989. They described 13 cases where such approach was adopted. They regarded a non-aggressive obstetric management as permissible, and even preferable, when there is certainty of death or absence of cognitive developmental capacity as outcome of the congenital abnormality. They argued that, in such cases, the fetus does not benefit from obstetric intervention, while such intervention may harm the pregnant woman and interfere with her autonomy [36, 37]. However, empirical data needed for a balanced professional and societal debate about forgoing fetal life-sustaining treatment are scarce [36, 38, 39].

Termination of pregnancy is a management option, in which the pregnancy is terminated with the explicit intention of hastening fetal death. Termination of pregnancy is done by induction of labour, which may be preceded by fetal intracardial potassium injection. The first termination of pregnancy after ultrasound diagnosis of fetal abnormality was reported in 1972 by Campbell et al. [40]. Their report concerned a fetus with anencephaly. Termination of pregnancy has far-reaching implications for the couple. It bears life-long lasting consequences and evokes strong emotions of the couples involved [41, 42].

End-of-life decision makings after ultrasound diagnosis of fetal abnormality have to take into account both the interest of the fetus and the pregnant woman. Therefore, these difficult decisions are usually made by multidisciplinary teams [43–47]. These typically consist of obstetricians, neonatologists, paediatric surgeons and other paediatric specialists, such as paediatric urologists, paediatric neurologists and paediatric neurosurgeons [43–47]. However, little is known about how exactly decisions are being taken in these teams.

Parental decision making after ultrasound diagnosis of fetal abnormality remains a largely unknown territory. Table 1 shows the studies to date, which evaluate determinants of parental decision regarding termination of pregnancy. Low gestational age, severe abnormality,

involvement of the central nervous system, previous uncompleted pregnancies, low maternal educational level and the presence of chromosomal abnormalities are associated with high rates of women deciding for termination of pregnancy. However, these data are not conclusive and do not reflect why and in what way some factors are important for the parents. Sandelowski and Jones [48] studied parental decision making concerning prenatal diagnosis of fetal abnormality in more depth. She interviewed 15 women and 12 of their partners. Her study showed that women have highly variable perceptions of choice. In fact, women in comparable circumstances feel differently about whether or not they have a choice about the future of their pregnancy [48].

Legal context and current guidelines

In The Netherlands, law prohibits termination of pregnancy at a gestational age of 24 weeks or beyond. However, in case of good clinical practice, physicians will not be prosecuted by the public prosecutor [49–51]. Good clinical practice is described in guidelines that were made by a collaborative group of the Ministry of Health, Ministry of Justice and the Dutch Society of Obstetricians and Gynaecologists. According to these guidelines, when parents persist in their request for termination of pregnancy, this will be granted when fetal prognosis is considered lethal. Fetal prognosis is considered lethal if (1) the infant has no chance of survival and the abnormalities cannot be treated or (2) the infant has a chance of extra-uterine survival but post-natal use of life-prolonging medical treatment is considered futile [50].

In conclusion

In most industrialised countries ultrasonography for the detection of fetal structural abnormalities has become an integral part of antenatal care. In general, women are often ill prepared for bad news about the health of their unborn child. Upon the detection of severe fetal abnormalities, they could be faced with decisions whether or not to continue pregnancy. This essay explores the context of decision making after ultrasound diagnosis of fetal abnormality, with emphasis on the Dutch situation. In the case of fetal abnormalities, perception of choice among pregnant women varies markedly, challenging the counselling strategy.

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