THE ROUTINE USE OF ULTRASOUND IN ANTENATAL CARE: IS THERE A HIDDEN AGENDA?

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Synopsis – The development of high-resolution real-time ultrasound has given us the opportunity of identifying fetal congenital anomalies. When this technique is made part of a screening activity, it has to be based on the belief that early identification and early care will have a favourable impact on the natural history of the disease. This is not the case when pregnant women are screened in second trimester to detect malformations. On the contrary, in Norway this might lead to the elimination of 300 desired fetuses yearly. Some of these would otherwise have had a longer intrauterine life, some might have benefited from postnatal medical treatment, and some might otherwise have been born as healthy children but were eliminated due to misclassification.

The fetus inside the womb will not only give rise to bodily sensations but will also produce vivid pictures in the mind of the pregnant woman. The fear of carrying a child which is *marked*–as having a defect or a malformation – plays a special part in this process. What does the fetus look like? Is there anything wrong with it? The woman's inner picture of the fetus will be painted by her past and the emotions of the conception, while it will also be nourished by the daily occurrences during the waiting period.

She might seek reassurance from the medical profession, bringing her fears into the antenatal clinic. Up until quite recently it was the woman's own concepts and ideas about the fetus that formed the basis for these types of consultations. Although her worries might be interpreted and acted upon by the health system in a way that might alienate her from her own experiences (Oakley, 1984; Young, 1984), she has been the prime messenger between the fetus and the health service. The visual image of the fetus brought into antenatal care by the use of high-resolution real-time ultrasound has changed this profoundly and created a new go-between the fetus and the outside world.

This is how leading international obstetricians see the issue:

> With the introduction of high-resolution real-time ultrasound in obstetric practice, the concept of prenatal care has changed profoundly. Whereas once the obstetrician was primarily concerned with diseases affecting the mother, the scope of antenatal care has expanded to include a broader range of fetal diseases . . . The feasibility of identifying congenital anomalies before birth has created an entirely new field in obstetrics. (Romero, Oyarzun, Sirtori, & Hobbins, 1988)

While a woman might seek reassurance from the ultrasound image of her fetus in an attempt to combat her own frightful illusions, the medical reasons for screening are quite different. What implications the routine examination might have for her fetus are

hidden in the information given to pregnant women: "Around the 17th week you will be given the choice of having an ultrasound checkup in order to see if everything is as it should be" (Abrahamsson, Adrian, Celander, Nordenskar, & Rybo. 1990). This formula appeals to the deeply ingrained fears of carrying a marked fetus. But when examined the woman can no longer choose the questions she wants the go-between to ask her child. In a screening program the health services have their own obligations to follow, and in this case, they are hidden from the woman.

THE SCREENING PROCEDURE'S QUALITATIVE DIFFERENCE FROM CLINICAL APPLICATION

In Norway, a consensus conference concluded that all pregnant women should be offered an ultrasound checkup. This conclusion was not reached on the basis of scientific evidence that screening with ultrasound during pregnancy would improve the perinatal results. Rather, the conclusion was based on a belief that the number of ultrasound examinations should be restricted (Backe & Buhaug, 1986). In spite of this, proponents of the procedure within the health service have referred to this offer as a screening program. Therefore, a screening program has in fact been established and 96.6% of all pregnant women participate (Backe et al., 1991). When proponents in the health service describe the examination in terms of its being a screening program, women must take it as given that the offer is the best for their future child and who then can say no? The woman's autonomy is strongly restricted when a routine procedure is introduced, particularly in the perinatal field. This is well described by other feminist scholars such as Henfin, Hubbard, & Norsigian (1988).

In the following I will limit my discussion to ultrasound technique applied in a screening program, excluding clinical situations such as when a woman asks to have her fetus examined because she already has a malformed child. That the life circumstances of some women would make them inclined not to carry a malformed baby to the end of pregnancy is understandable. In such situations, the new developments in diagnosis are employed in accordance with the mother's wishes. The task given to the go-between is clear and definite. But, even in these situations the woman might feel inclined to seek a prenatal diagnosis for other reasons than her own. A feminist perspective of the Scandinavian legal aspect of a woman's right to choose has been discussed in a recent article (Aasen, 1991). It is also necessary to explore the cultural and social norms surrounding a woman's right to choose. In our Western societies, the process of childbearing has been put under strain to adapt to criteria for production. The social norms encourage the woman to "produce" the "right" number of healthy children at the "right" time (Kauf-man, 1988). I also agree that the information from an ultrasound examination may be of great help in the event of a clinical problem, as when bleeding occurs or the baby is suspected of having growth retardation, etc. This kind of application of the technique is not included in the discussion below.

Is the agenda of the go-between a sound one – in the sense that overall it is beneficial to the mother-to-be and her fetus? The feasibility of identifying congenital anomalies before birth has created an entirely new field in obstetrics. It is this field I will question as part of a screening procedure in antenatal care. I will use general established medical criteria for a screening program as an analytic tool as described by Mohide and Grant (1989). The underlying idea of all screening procedures is that early discovery and treatment can either cure the patient or lead to the disease being milder than if it had not been discovered before the disease has progressed so far that the symptoms bring the person to the physician.

ARE CONGENITAL ANOMALIES A SERIOUS HEALTH PROBLEM?

In order to recommend a screening program, the condition(s) the procedure should cover must be recognized as a public health problem. An attempt to answer this question immediately reveals problems with screening congenital anomalies. Malformations do not constitute one disease, but cover a number of highly different conditions. Some have minor impact on the future health of the baby, such as having extra toes or the like, but other conditions may be incompatible with life. The significance of the problem is therefore dependent upon definition. I will first look at the most serious of the conditions: In Norway we calculate that approximately 8 babies in 1000 are stillborn. Approximately 25% of these deaths are attributable to congenital defects (Norwegian Government Reports, 1984).

The estimate of the percentage of babies born alive with defects depends upon the extent of the postnatal diagnosis. Comprehensive diagnostic procedures give very high figures. The total percentage of babies born with malformations is estimated at 15%, while those with serious malformations are given a 2% (Romero et al., 1988). But these estimates do not give a valid picture of the magnitude of the health consequences. For instance, a child with a major congenital anomaly such as pyloric stenosis (a narrow upper part of the stomach) will undergo surgical correction and later become a healthy child. In order to examine the magnitude of the health consequences, it is therefore more appropriate to look at other figures. An American study shows that 5% of admissions to children's wards are due to conditions which are attributable to congenital factors (Romero et al., 1988). There are many reasons for mental retardation, and malformations are a contributing factor with estimates varying from 14 to 30% (Grimsmo, 1990). Chromosomal disorders which result in Down's Syndrome are the main single cause.

We can use economic indicators to show what effects congenital defects have on each family. A child with spina bifida represents a total cost in its childhood years that is a little more than double the amount it would cost to have a normal child (Arnler & Dull, 1987).

Together, the figures give a rough estimate of what congenital anomalies represent as a public health problem. There is no doubt that if we look at all these conditions as a cause of illness in and death of children we can recognize the important challenge that faces the health service. But is this problem such that we can consider solving it with a screening procedure? Which of these conditions can be discovered before they manifest symptoms in pregnancy or are being discovered at birth, and at the same time are such that the discovery can give the baby a better chance?

WHAT CAN BE DISCOVERED BY MEANS OF ULTRASOUND EXAMINATION?

In principle there are five different ways that a diagnosis for anomalies is evaluated during an ultrasound examination: (a) absence of normal anatomic structures; (b) deviation in contour, form, localization, sonographic quality, or the size of normal anatomic structure; (c) presence of abnormal structures; (d) abnormal biometric dimensions; and (e) abnormal fetal movement (Romero et al., 1988). Romero et al. list as many as 180 faults that they feel are the most important conditions that can be identified by means of ultrasound. The most important anatomic structural faults which can be discovered are obstructions either in the intestines or urinary tracts. Malformations of the heart and nervous system are also important groups of disorders, in addition to diaphragmatic hernia and defects in the abdominal wall. With the help of supplemental

diagnostic tests, the fetus can be examined further. Amniotic fluid or fetal blood can be sampled by amniocentesis or umbilical cord puncture and analyzed biochemically or chromosomally. One-third of fetuses with structural anomalies have chromosomal disorders. In addition, DNA probes of specific genetic diseases might be applied.

HOW WELL DOES THE ULTRASOUND EXAMINATION DISTINGUISH BETWEEN HEALTHY AND SICK FETUSES?

The evaluation of ultrasound examinations as a screening test for malformations has seldom been the object of scientific evaluation – "it is essentially unknown," according to Romero et al. (1988). With such an evaluation one must register the number of fetuses with a tentative diagnosis from a routine examination and the number which later prove not to have the condition. In addition, all aborted fetuses and babies born must be examined in order to find out how many had the condition without it being indicated in the fetal period (Neilson & Grant, 1989).

A few studies have been conducted and as an example I will look at a relatively large study carried out in England which dealt with urinary tract problems by Livera et al. (1989). A urinary tract defect is one of the conditions where the assumption has been that early intervention can affect the baby's kidney function later on.

The study covered over 6000 randomly chosen women. They were all examined by ultrasound with the aim of discovering kidney problems. This was carried out around the 26th week in the pregnancy. This indicates that no fetuses were aborted because they had kidney problems. The evaluations based upon ultrasound concluded that 92 fetuses were ill. After birth all the babies were subjected to a special examination. Fifty of the assumed sick babies proved to have healthy kidneys. These babies had been wrongfully suspected of having a kidney disease in the fetal life. Seven other children were born with urinary tract problems, without any problems being indicated during their fetal period.

But did early discovery of kidney failure have any consequences? Among the 42 children who indeed were born with kidney changes only 23 were treated. Twenty-one babies either had an operation or were placed on a waiting list for an operation, and two babies received antibiotic treatment. This means that for three-fourths of the fetuses picked out during pregnancy the examination had no positive significance. Perhaps it had the opposite effect because the mothers were unnecessarily distressed. Of all the 30 (23 + 7) mothers who had a baby needing treatment, approximately one-fourth had been wrongly told in their pregnancy that everything was allright with their baby.

Even though these are the results from only one study and one organ system, this points out that there is a high degree of inaccuracy with the ultrasound examination as a screening test for malformations.

DOES EARLY DETECTION HELP?

Whether or not we are to accept the inaccuracy of a test in relation to a screening procedure must be considered in light of how important it is to discover the condition for those it applies to. Burdening some women with unwarranted worry might be defended if it can give other women's fetuses a better chance. What does it mean to discover such an abnormality in the fetal phase? How many of the 23 babies who had an intrauterine diagnosis had or would have had symptoms just after the birth and as a consequence received treatment anyway? The authors say nothing about this. But they answer the question about the possible benefit to health in another way (Livera, Brookfield, Egginton, & Hawnaur, 1989: p. 1423):

> The impact that early diagnosis of abnormalities of the fetal renal tract and subsequent intervention may have on the incidence of symptomatic renal disease later in life – for example, acute pyelonephritis and recurrent urinary tract infection remains unknown.

As this is only one organ system, are there more promising reports about other organ abnormalities? With diaphragmatic hernia, gastrointestinal abnormalities, and cardiac abnormalities, it is suggested that the conditions for operative treatment after the birth would be optimized. Until now, the effect appears to be that early indication of the abnormalities makes genetic mapping possible in order to determine the fetuses that have a poor prognosis. By terminating these pregnancies we are in fact practising a preoperative genetic selection that necessarily influences the survival of those who have the chance of having an operation (Hughes, Nyberg. Mack, & Pretorious, 1989; Allan, 1989; White, 1990; Fadel, 1989).

Attempts have been made to perform intrauterine treatment of the fetus. This includes an attempt at inserting a catheter into a cranial cavity in order to release pressure in the brain (Fadel, 1989). The same method is used for the kidneys (White, 1990). But none of these procedures have proven successful. Attempts have also been made to operate on fetuses, but there have been great problems selecting those suitable for an operation and the operations have been totally unsuccessful. Open fetal surgery continues to be performed at some centres in the United States. The pessimistic conclusion by Evans, Drugan. Manning, & Harrison, (1989) is that fetal surgery is experimental treatment and at the moment it is not viable for normal practice.

ULTRASOUND EXAMINATIONS AS CREATOR OF CONTACT BETWEEN MOTHER AND CHILD?

In Norway, we have become used to articles in newspapers and weeklies that display satisfied mothers attending the ultrasound examinations. The few scientific studies of the psychological effects have also been carried out on women who have been told that "all is as it should be." But this does not prove the contention that there is a long-lasting calming or positive affect on parent-child bonding (Green, 1990).

The natural anxiety that occurs during pregnancy goes in waves. It is greatest in the first stage of the pregnancy, ebbs in the middle part, and then rises again near the end of the pregnancy (Sjøgren, 1989). This anxiety grows out of reality: The majority of conditions that threaten the fetus can not be indicated with an early fetal diagnosis. Growth retardation and premature births – not abnormalities – are the most important reasons for fetal illness and death.

There are no studies that address what happens to women who are given wrong information. How has this bad news affected their pregnancy? Conversely, how do women react if they have a deformed baby that went undiscovered during the pregnancy and they had thought all was OK? Nor has the effect of information about a baby's abnormality been studied. How does such information affect the experience of pregnancy? Is information always beneficial?

INFORMATION ABOUT LESSER OR INVISIBLE ABNORMALITIES

By lesser abnormalities I am thinking of such conditions as lip-palate cleft, clubfoot, or too many fingers or toes. These can be treated after birth and have minor impact on the later health status of the child. Of these, a greater number is discovered with new technical developments. But is there a benefit in being informed? Most likely the anxiety may be greater than necessary and the mother-to-be will have a pregnancy that is unnecessarily

negatively coloured by the information given. The ultrasound-induced inner picture might be much more frightening than seeing the baby herself when it is born. At birth she will be able to touch, smell, and handle the baby, and actively participate in the child's welfare. Coping with information about these types of conditions is likely to be easier then.

Due to the misclassification problems, the wrong information might produce frightening images that may persist even after birth. Even though the mother is told after birth that her baby is as sound as any other baby, the ultrasound test provoked fears that might be overwhelming and difficult to get rid of.

A subgroup of anomalies would remain undiscovered without the use of ultrasound. I am thinking here of organ variations such as variation of kidney shape, which does not have any definitive effect on future health. Receiving this kind of information must be considered an unwanted side effect of a screening procedure: A comparative situation occurred in a Swedish screening program when parents were informed after birth that their baby lacked Alpha 1-antitrypsin. This is a condition that can cause lung infection. The conclusion drawn from later studies of the psychological consequences was that the disadvantage of burdening the parents with information from which no clear conclusion could be drawn outweighed the advantages and the program was stopped (McNeil, Sveger, & Thelin, 1988).

INFORMATION ABOUT SERIOUS ANOMALIES

Suddenly finding out that the fetus a woman carries has a serious illness is undoubtedly a very difficult situation. How sick will the baby be? Will it be seriously handicapped, physically or mentally? Up until now there is little to indicate that early discovery improves the fetus' chances of survival. From this point of view it appears that bad news could wait. Bearing such a burden does not improve the pregnancy experience. But information that the baby is seriously malformed makes it possible to terminate the pregnancy. This is the basis for offering fetal diagnosis to groups of women who already have considered termination as a possible outcome of the consultation. An entirely different situation arises when the health service, without any preparation, throws this dilemma upon the parents. They can not then choose not to know. The basis of the information that the parents are given for their choice may also be uncertain. An examination of fetuses that were aborted (induced) after an ultrasound discovery showed that 53 of 133 fetuses were evaluated differently after the abortion than before it. The revisions of the diagnoses were so significant that they might have affected the advice given before the abortion and definitely altered the genetic counselling. In 25 cases, the risk of recurrence was considered less after posttermination diagnosis than before. This study included only fetuses which were received from clinicians wishing to use the special service of a regional genetic centre (Clayton-Smith, Farndon, McKeown, & Donnai, 1990). One would expect the accuracy of the diagnosis to be even less if all aborted fetuses in the region were included.

WHEN THE FETUS HAS A LETHAL CONDITION

The most serious congenital anomalies are incompatible with life and the fetus will either die intrauterinely or shortly after birth. Some feel that the obvious solution is to "get rid" of such fetuses as soon as possible (Saari-Kemppainen, Karjalainen, Ylöstalo, & Heinonen, 1990). But is it really better for the woman to be exposed to a late abortion – which is not a real birth, but rather induced pains that lead to the expulsion of a fetus? Many studies indicate that a late abortion after a diagnosis of an anomaly is a very traumatic

experience. After such an abortion the parents often feel responsible for the death of the fetus. They had to make the decision and therefore wonder if perhaps the baby would have survived if it had been given a chance (Jørgensen, 1985). Perhaps it is better to be allowed to give the baby the time it is given on this earth, even if it is only that period it spends in the womb – and then experience a normal birth. Perhaps it is best not to know that the fetus will not survive to be a baby. If the health service can find no other good reasons for exposing a group of women to this knowledge, then why do it? To be able to give oneself away is a perfect expression for the quality of life in many of its areas such as love and sexuality. The same is true about giving oneself away to a pregnant state which is released at birth – without burdensome information!

A DIAGNOSIS OF ANOMALIES – AN UNINTENTIONAL BYPRODUCT OF A SCREENING PROCEDURE WHICH HAS OTHER USEFUL EFFECTS?

During the 1980s, a number of controlled studies were conducted on the benefits of ultrasound screening. The general idea was that screening would lead to reduced perinatal morbidity and mortality. The mechanism for this was believed to be that screening would lead to early identification of growth retarded fetuses and that by subsequent intervention their development would improve. Another expected effect was a reduction in mortality in multiple pregnancies. Until recently, the conclusion was that screening with ultrasound did not improve the outcome of the pregnancy (Ringa & Breart, 1989; Thacker, 1985).

However, in an autumn 1990 issue, Lancet published a controlled study which showed an effect of ultrasound screening (Saari-Kemppainen et al., 1990). Over 9000 women participated in the study. The authors concluded that ultrasound screening reduced the number of deaths related to birth by half, but that this reduction was largely due to the fact that 11 malformed fetuses had been removed before they had a chance to be born (p. 391);

> We believe that our findings justify systematic one-stage ultrasound screening of all pregnancies for the detection of major congenital anomalies under circumstances in which their elimination by induced abortion is acceptable.

To sum up the *benefits* of ultrasound screening program: No benefits are shown for the normally formed babies. And if only fetuses with lethal fetal anomalies are eliminated, the only thing accomplished is that the time of death is moved forward. The long-term benefit that the Finnish authors refer to is more the possibility of preventing fetuses from being born as babies in need of treatment. The premise for this as a beneficial service is that the women do not – in the words of the Finnish authors – "refuse an abortion." On the basis of the Finnish figures concerning cases where termination is appropriate, approximately 5 per 1000, the number of eliminated fetuses because of ultrasound detection will approach 300 per year in Norway. Some of these would otherwise have had a longer intrauterine life, some might have benefited from postnatal medical treatment and some might have been born as healthy children but were eliminated due to misclassification. For the woman, the offer of a fetal checkup as it is presented to her today is something she can not refuse. She is mislead to believe that it is a great improvement also for her to see her child. Seeing that her baby has 10 fingers and two arms and legs, has strong appeal. The technique is presented as a true image that displays the baby as it really is, and not as a method with inherent errors resulting in uncertainties and bluntly wrong information. The result might be intrusive

images worrying the mother-to-be even after the baby is born.

This is what screening with ultrasound today can offer for mothers with fetuses who have congenital anomalies. For mothers of normally formed babies it is only a hazard to their baby's health as the future child might risk being misclassified and aborted. And for all women there is a danger of being invaded by intrusive persistent images destroying the pregnancy experience. No wonder this is an agenda that can not be spoken openly about!

CONCLUSION

The first condition in the debate is to clarify the obligations of the proponents of ultrasound screening. Because it implies the abortion of some fetuses as a premise for the beneficial effects on public health, society must be willing to accept a eugenic ideology. In Norwegian society this is very unlikely to happen. The logical conclusion must therefore be to stop the early detection of congenital anomalies as a screening procedure in antenatal care.

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