enough to review and summarise the available research: the challenge is to get it used in practice as the basis for clinical guidelines and as information to users.

The case study shows that different stakeholders react differently. There was resistance from ultrasonographers, who raised a number of difficulties, including questioning the credibility of the evidence presented. They also expressed concern about increasing women's anxiety, reducing the uptake of ultrasound scans and perpetuating negative attitudes. The leaflets were welcomed by midwives and access to the information seems to have been appreciated by the 26 women who took part in the pilot study. Interestingly for all concerned, the uptake of ultrasound scanning was maintained in this small group, despite worrying evidence that 1 in 200 abortions are carried out on fetuses with no major abnormality.

Research evidence shows that the information provided about antenatal screening tests is limited¹ and that women want more detailed and reliable information on these procedures so that they can make an informed decision about whether they will be carried out.² In a study in north Essex a representative sample of 800 women was asked to list the reasons given to them for having a scan. Only 60% selected "to look for abnormalities/problems" from a multiple choice list, and it is a recurring theme that some women are upset to discover for the first time when they receive results that their scan had been carried out for this reason.³

Research on women's views of the usefulness of different kinds of information in pregnancy suggests that the leaflets produced by the Midwives' Information and Resource Service are valued because they are

generally seen as being unbiased and reliable.⁴ However, the leaflets for women do not explain the methods used, and some of the participants in focus group discussions wanted to know the basis for the conclusions drawn.⁴ They had some understanding of research and sampling issues and were interested to see, for example, the list of references on the paired leaflet prepared for health professionals.

Our concern is that providing pregnant women with information on evidence based outcomes is not being considered a priority by purchasers or providers. Fifteen of the 21 maternity units surveyed in the West Midlands region had decided not to buy the "Informed Choice" leaflets of the Midwives' Information and Resource Service, and none reported money available from the purchaser for this purpose.⁵ Furthermore, at the "But will it work, doctor?" conference held earlier this year (22-23 May, Northampton), which focused on involving users of the health service in outcomes research, John Swales, director of the national research and development programme, implied that government funding for the "Informed Choice" initiative would be only short term.

1 Marteau TM, Slack J, Kidd L, Shaw J. Presenting a routine screening test in antenatal care: practice observed. *Public Health* 1992;106:131-41.

2 Dodds R. *Women's experiences of antenatal screening*. London: National Childbirth Trust (in press).

3 Greedy M, Newburn M, Dodds R, Gauge S. *Birth choices: women's expectations and experiences*. London: National Childbirth Trust, 1995.

4 Greedy M, Newburn M. *Report of the second phase of the choices project*. London: National Childbirth Trust (in press).

5 Henderson C. Prioritising the priorities: Is there a choice? *British Journal of Midwifery* 1996;4:117-9.

Commentary: Evidence based practice and antenatal ultrasonography—the need for more studies

Paul Chamberlain, P A Boyd

An attempt to introduce evidence based practice and informed choice for pregnant women is a worthy aim. Women deciding whether to have screening for fetal abnormality, either by ultrasound scanning or biochemical serology, should be given adequate information to allow them to understand fully the advantages, disadvantages, and limitations of the available tests. The separate information leaflets produced for patients and carers, as described by S Oliver and colleagues, are generally good. However, they presume that the evidence on which they are based (primarily randomised controlled trials) is appropriate. This presumption may not be correct.

For example, in the largest randomised controlled trial (RADIUS: routine antenatal diagnostic imaging with ultrasound) the end points used to evaluate ultrasound screening performed in the second and third trimesters included the overall perinatal mortality rate and the incidence of intrauterine growth retardation.¹ No beneficial effects in either of these end points were noted. In the Helsinki trial a lowering of the perinatal mortality rates in the screened population was noted if termination of pregnancy resulted from the identification of a major structural congenital abnormality.² Are these the correct end points to judge the effectiveness of ultrasound screening? The presumption should not be that ultrasound screening is appropriate only for women who would opt for termination if a serious abnormality were identified. For some women it is helpful to know in advance that major (or minor) abnormalities are present.³ In this context, a more correct end point to

judge the effectiveness of ultrasound screening might be the accuracy of sonographic assessment of suspected fetal abnormality and its correlation with findings noted after delivery. If judged in this manner ultrasound screening performs well.^{4,5} Similarly, to expect a single ultrasound examination performed in the early third trimester to reduce the incidence of intrauterine growth retardation ignores the complexity of the pathophysiology of this condition.^{1,6}

The negative views expressed by the few ultrasonographers reported on by S Oliver and colleagues warrant comment. They found it shocking that 1 in 200 fetuses aborted as a result of the scan were in fact normal or had only a minor abnormality.⁴ In simplifying information for the leaflets some of the evidence has become misleading. One of the two fetuses in question had gastroschisis (not omphalocele as suspected) while the other had large bright kidneys in the scan but subsequently normal kidneys on histology.⁴

We emphasise, however, that, although examination of the fetus after termination is extremely important, it cannot always provide answers about structural normality, let alone about function. The dissection and fixation processes themselves may sometimes disturb anatomic relations noted prenatally. The decision to terminate a pregnancy is occasionally taken on a probability (not certainty) that the baby will be seriously handicapped. Given the natural history and subtlety of certain serious congenital abnormalities, ultrasound scanning should not be expected to detect all anomalies prenatally. Some conditions—for example, micro-

cephaly and the Dandy-Walker malformation or variant—may develop late in pregnancy and may not be diagnosed from a scan at 18-20 weeks.

Ultrasound scanning in experienced hands is a powerful diagnostic tool. To maximise its role in clinical practice, appropriate training, good equipment, and access to expert referral when necessary are all required. New knowledge and improved equipment lead to new diagnoses—for example, the many “markers” of chromosome abnormality—which need to be appropriately investigated to find their true importance and to reduce the anxiety caused to parents when they are identified.⁷ The publication of leaflets giving honest information to health professionals and pregnant women about screening tests in pregnancy is a step in the right direction. However, if evidence based practice is to achieve its goal health professionals need appropriate,

up to date evidence to be collected and collated. Such evidence is not yet available.

- 1 Ewigman BG, Crane JP, Frigoletto FD, Le Fevre M, Bain R, McNellis D. Effectiveness of prenatal ultrasound screening on perinatal outcome. *N Engl J Med* 1993;329:821-7.
- 2 Saari-Kemppainen A, Karjalainen O, Ylostalo P, Heininen O. Ultrasound screening and perinatal mortality: controlled trial of systematic one stage screening in pregnancy. *Lancet* 1990;336:387-91.
- 3 Chitty LS, Barnes CA, Berry C. Continuing with pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendation for management. *BMJ* 1996;313:478-80.
- 4 Brand IR, Kaminopetros P, Cave M. Specificity of antenatal ultrasound in the Yorkshire region: a prospective study of 2261 ultrasound detected anomalies. *Br J Obstet Gynaecol* 1994;101:392-7.
- 5 Luck C. Value of routine ultrasound scanning at 19 weeks: a four year study of 8849 deliveries. *BMJ* 1992;304:1474-8.
- 6 Villar J, Belizan JM. The timing factor in the pathophysiology of intrauterine growth retardation. *Obstet Gynecol Surv* 1982;37:499-506.
- 7 Snijders R, Nicolaides K. *Ultrasound markers for fetal chromosomal defects*. London: Parthenon Publishing Group, 1996. (Frontiers in fetal medicine series.)

Lesson of the Week

Who spots the spots? Diagnosis and treatment of early meningococcal disease in children

F Andrew I Riordan, Alistair P J Thomson, John A Sills, C Anthony Hart

Information for parents and doctors about meningococcal disease should emphasise the septicaemic rash, not meningitis

Meningococcal disease can begin suddenly and may kill within hours.¹ Delays in diagnosis and treatment can therefore decrease the chances of survival. The commonest delays in those who die are: parents not recognising that their child is seriously ill; and doctors failing to make a correct diagnosis.²

Accurate information about meningococcal disease for both parents and doctors is therefore extremely important. The information widely available, however, may be misleading, because it tends to focus on meningitis rather than on septicaemia.³ More deaths result from septicaemia, and the proportion of children who present with septicaemia is increasing.⁴

We conducted a prospective study of children admitted with meningococcal disease over a period of 18 months, and we highlight the details of one case in which a missed diagnosis led to the child's death.

Subjects and methods

This prospective study included all children admitted with meningococcal disease over 18 months to four hospitals in Merseyside: Alder Hey Children's Hospital, Arrowe Park, Whiston Hospital, and the Countess of Chester Hospital. Parents were interviewed on admission and were asked about specific features they had noticed, their reasons for seeking medical advice, and the outcome of any contact with a doctor during the illness.

Results

One hundred and twenty six children with meningococcal disease were admitted, 13 of whom died. *Neisseria meningitidis* was isolated from 78 cases. The median age (range) was 20 months (3 months to 14 years). On admission 113 children had a rash and 57 had neck stiffness.

Non-specific features were commonly noted by parents (fever in 122 of the 126 cases, lethargy in 112, and vomiting in 96), and they were often the initial symptoms. A rash was seen by parents before admission in 96 cases, but headache (41 cases) and neck stiffness (14 cases) were rarely noted.

Rash was the commonest reason for calling a doctor (66 cases), followed by fever (41), and lethargy (32). Advice was rarely sought for headache (five cases) or neck stiffness (three).

Parents or relatives were the first to spot a petechial rash in 92 cases. Doctors were the first to notice the rash in 13 children.

RECOGNITION BY DOCTORS OF MENINGOCOCCAL DISEASE

Sixty of the children with meningococcal disease were seen but not admitted by a doctor in the 48 hours before admission—50 by a general practitioner and 10 by a doctor in an accident and emergency department. Thirty two of these children had non-specific signs, six had a petechial rash, and 22 had a maculopapular rash. Four children subsequently died, two who had been seen with no rash and two with a maculopapular rash.

Preadmission parenteral penicillin was given to 22 of the 69 (32%) cases admitted by general practitioners, more often to children who were referred as “meningococcal disease” (18/22, or 82%) than to those referred as “meningitis” (3/15, or 20%).

Antibiotic treatment was delayed after admission to hospital in 15 children. Ten of these children presented with a maculopapular rash: one died. Three children developed a petechial rash after admission and one of these children also died. The other two children with meningococcal meningitis never developed a rash. Delays in treatment on admission thus occurred in those with either a maculopapular rash or no rash.

Case report

A 3 year old boy became febrile overnight. The next morning he was lethargic and vomited. He developed a maculopapular rash and was seen at 1400 by his general practitioner, who diagnosed measles. He remained unwell and was taken to the local accident and emergency department at 1520. A petechial rash began about this time but was not noticed. Meningococcal disease was diagnosed at 1730. Antibiotics were started, but by this time he was in shock. He was intubated, ventilated, and

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