Generic outcome measures cannot be specified in rehabilitation—therapists rightly concentrate on their patients' individual goals

contract performance they need to determine with providers a small number of meaningful measures that are capable of being routinely collected. These must reflect the concerns of users of health services and also be measures by which clinicians would be content, on scientific and practical grounds, to have the quality of their service monitored. Such measures may not necessarily be outcome measures. They may well be measures of process of care, such as the time between onset of symptoms and the provision of thrombolysis. The fact, however, that thrombolysis is cited on so many occasions as an illustrative example, shows the difficulty of finding other measures that truly reflect the quality of patient care.

Importance of trust in provision of non-elective care

We think that there are great difficulties in writing a contract for many professional services. Our service specification for stroke may be one which commissioners and providers find helpful when jointly planning local services. A contract should in theory influence the quality of the service provided,⁵ but we question the

value of a contract in addition to a service specification. We argue that it is unlikely a contract can ever be written for any clinical activity other than the most elective procedures. Using the example of stroke as a model, all that a commissioner can realistically do when planning a non-elective service with his or her local community and hospital trusts will be to say: "Here is £x million—do what you can for patients with stroke within that sum, using the attached service specification document. In particular, we expect to see the appointment of a clinician with particular experience of and interest in stroke care who will be responsible for coordinating the many professions involved in the provision of good care." The amount of money may improve with time and with better accounting mechanisms, but it can never be more than a broad estimate. With regard to planning a local service, the situation remains similar to that before the health service reforms. A block of money is provided and health professionals are expected to provide the best care they can for patients within the available budgetary limits.

The past 20 years have seen a breakdown in the traditional relationships of trust between various sectors of society. This breakdown is reflected in the demands of users and potential users of health services for greater accountability of the medical profession. Yet one has to consider that the very basis of medical individual practice since the time of Hippocrates is that physicians provide their knowledge and skills to individual patients, with the implicit promise that they will do their best for them. The implicit contract is based on trust. We acknowledge that it would be totally unwise to trust a poorly educated or out of date doctor, and it is right that since the health service reforms, the profession has laid increasing emphasis on evidence based medicine, continuing medical education, and clinical audit. In the final analysis, however, we believe the contract to be a paper tiger that cannot ensure good care. We argue for renewed emphasis on trust and mutual respect.

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- 1 Langhorne P, Williams BO, Gilchrist W, Howie K. Do stroke units save lives? *Lancet* 1995;342:395-8.
- 2 Royal College of Physicians. *Stroke audit package*. London: RCP, 1994.
- 3 NHS Executive. *Clinical involvement in contracting: a handbook of good practice*. Leeds: NHS Executive, 1995.
- 4 NHS Management Executive. *Improving clinical effectiveness*. Leeds: NHS Executive, 1993. (EL (93)115.)
- 5 Hopkins A, Maxwell R. Contracts and quality of care. *BMJ* 1990;300:919-22.

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Continuing with pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendations for management

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In the genetics clinic we meet many parents whose pregnancy has been complicated by the unexpected finding of a serious fetal malformation. Many of these couples terminate their pregnancy but some continue and allow nature to take its course. We summarise the experience of five couples and highlight various aspects showing the inappropriateness of routine obstetric care for these women. These were five consecutive couples (see table 1) known to the genetics department who agreed to a semistructured, tape recorded interview at varying intervals (one week to eight months) after their pregnancies.

Discussion of options

Three of the five women thought that the options of termination and continuation of the pregnancy had been adequately discussed from an early stage. One commented that it had been made clear that there were "different choices for different people." Another couple (case 5) were not aware that continuation of the pregnancy was a real option until they reported to the labour ward for "induction" at 21 weeks. Up to that point the word "termination" had not been used. "It was like we were in a tunnel and there was only one way

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Table 1—Summary of case histories in the five cases

Case No	Age (years)	Parity	Relevant history	Diagnosis	Method of diagnosis	Outcome
1	40	1+0	Infertility 11 years	Twins, one with trisomy 18	Amniocentesis at 16 weeks	Twin 1 intrauterine death at 34 weeks, twin 2 alive and well
2	31	1+1	Nil	Twins, one with trisomy 18	Scan at 18 weeks, then amniocentesis	Twin 1 neonatal death at 6 hours, twin 2 alive and well
3	24	1+0	Nil	Anencephaly	Scan at 18 weeks	Stillbirth at 37 weeks
4	29	1+0	Nil	Multiple abnormalities	Scan at 18 weeks	Intrapartum death at 35 weeks
5	39	1+2	Nil	Triploidy	Scan at 18 weeks, then amniocentesis	Intrauterine death at 28 weeks

out. I just didn't think that I had any choice but to go with what was suggested. I don't understand why they didn't discuss all the options. I don't think that we thought of the consequences of what we were doing. I went in to have the baby induced—that was the word used. It didn't register with us that they were going to terminate the pregnancy." Once the couple realised what induction meant they decided not to proceed and returned home.

Appreciation was expressed by other couples about the positive aspects of their care. Time given for decision making in a relaxed atmosphere seemed of particular value, and the offer of a second appointment for further discussions was also welcomed.

Experiences in the antenatal clinic and ward

NEGATIVE EXPERIENCES

The inappropriateness of routine antenatal provision for these women was frequently highlighted. "Queuing up with the other women and hearing them talk about their children—that was one of the hardest things. I stood in the queue and when I got to the front the receptionist said something about signing for the bounty bag and I just ran out of the door and cried all the way home" (case 4). "I came out from seeing the consultant and sat there crying. And everyone looked at me. You're put with the rest of the women while you wait to have a scan and obviously people wonder what's wrong with you" (case 2). "I said to the midwife that I hadn't turned up for the class [antenatal exercises] because I didn't want to be with other mothers. I didn't want them to say when is your baby due?' or 'are you looking forward to it?' But the midwife said, 'well, it [labour] is something you've got to go through anyway, so here's a leaflet on breathing'" (case 4).

One particular difficulty which arose from the lack of any special antenatal provision was a feeling in three women that many staff were ill informed about their condition. "It was unfortunate that I couldn't talk to the same doctor all the time. I saw the consultant just once, but that was after the baby was born. No doctor knew what the other one had told me. There was a real lack of communication" (case 3).

Three women had periods of inpatient care before delivery. Comments and questions from other mothers in the antenatal ward often caused problems. One patient (case 4) in an antenatal side room missed meals because she "couldn't face" the ward; the staff did not offer to bring food to her. Another patient spoke of her postnatal experience. "I had been given a special side room. The next day I was asked if I wanted to go back to the ward. But all the women in the ward had got babies. Why would I want to go back in there with them?" (case 2).

POSITIVE EXPERIENCES

In the two cases in which special antenatal arrangements were made these seem to have had a very beneficial effect. In one case the consultant obstetrician saw the woman regularly outside normal antenatal

clinic hours. The other woman had regular follow up appointments in the fetal medicine unit.

Only one couple spoke of their overall experience in generally positive terms. In particular, this couple had found the compassion and sensitivity of the midwifery staff noteworthy. "They were all really understanding. I felt they were trying to learn from my experience. They talked to me a lot about how I felt" (case 1). This couple had little experience of routine antenatal care, partly because of periods of inpatient care and partly because the pregnancy was monitored in the fetal medicine department.

Another couple who had extremely negative feelings about their antenatal experience at their local hospital were transferred to a hospital with specialised neonatal facilities before delivery. At that point their experiences were transformed. Communication—both interprofessional and between the couple and the staff—was of a high standard. Multidisciplinary case meetings about the couple's situation were organised. The couple were consulted antenatally about their feelings regarding the use of any special neonatal facilities. This allayed fears caused by the absence of any preparation for the birth by the local hospital. The delivery was handled with great sensitivity and the couple had ample time with their baby. They reported that "even the cleaner" acted with understanding. The staff understood the woman's wish to avoid other mothers, and it was made possible for the couple to have a great degree of privacy.

Seeing the baby

Some couples expressed concern about seeing the baby after delivery. Three, however, did so, one couple bringing relatives in as well. One couple expressed great relief at seeing the baby as they had misinterpreted the ultrasound findings. One woman whose son lived for a short time saw her baby but felt deeply resentful that he had been taken to special care shortly after birth without adequate consultation. "They said, 'we'll take him away and you can go and see him in a minute.' And I thought, he'll probably be dead by the time I get there. Why take him away from me?" (case 2).

Retrospective feelings about knowing

Parents unanimously reported that being prepared for the outcome of the pregnancy was beneficial. "I was glad I knew. I had prepared myself . . . that made it easier in the end" (case 4). "I think I went through the grieving period before she was even born. I went to the cemetery to choose a plot. I went to see my priest to see if he would come and bless her. We were prepared. Had she been stillborn without any warning we would have been devastated, whereas we had time to come to terms with it" (case 5).

The decision to continue the pregnancy allowed the parents to avoid some feelings of guilt, regret, and doubt. "We saw him. If I had had a termination we would have had nothing to remember. And I would always have wondered if the scans were wrong. I would have had that termination on my conscience for the rest

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of my life" (case 4). "I'd 99.9% accepted that the baby wasn't going to live. I was always holding out a little hope. But if the pregnancy had been terminated I would have had guilt. Now I feel no guilt or remorse" (case 5).

One couple who had a twin pregnancy said that, though they would not have changed anything about their decision or having prior knowledge of the lethal condition, they would probably have chosen to terminate if the baby had been a singleton; they might also have made a different decision if the condition had been associated with a viable handicap such as Down's syndrome. One husband disagreed with his wife's decision to continue the pregnancy even after delivery.

Four couples said that in future pregnancies they would want early prenatal diagnosis to detect a recurrence. The fifth, who had been given a high recurrence risk (15%) on genetic grounds, said that it was enough to forewarn them that they were at risk. They did not, however, regret the early warning which they had in their first pregnancy.

What would have made things easier?

All parents commented on the need to improve communication among hospital staff. Many insensitivities were perceived to have arisen from this problem. As one husband put it, "There was a lack of communication. It's not just a normal pregnancy. Someone should have warned the staff to be careful" (case 5).

The importance of consistency was also highlighted. Seeing many different professionals during the antenatal period was experienced as difficult and demoralising. The beneficial effects of specialised monitoring by and contact with a small group of professionals seemed clear.

The provision of formal counselling facilities was suggested by interviewees as a potential source of help, both in the early stages of diagnosis and discussion of options and as a supportive measure during decision making. The paucity of written information was also mentioned. "If you're told your child has this condition, it's not really easy to find anything about it. I looked it up in an encyclopaedia, but I would have liked some sort of written information" (case 3). The need for educational opportunities for professionals was also mentioned.

Discussion

Most congenital abnormalities occur in pregnancies at low risk, and with the increasing use of routine fetal anomaly scanning more parents may be faced with difficult decisions.^{1,2} Many will elect to terminate the pregnancy but some will continue.^{3,4} Indeed, the grieving process may be easier for those who continue.^{3,5} Comments from our five couples emphasised the need for special antenatal care facilities for women whose fetus has a serious abnormality.

The parents interviewed had suffered high levels of distress, and these emotions (shock, anger, sorrow, etc) can result in heightened awareness of insensitivity as well as misattribution of feelings to the behaviour of staff. These factors may account in part for some of the apparently negative experiences reported. However, it is clear that most professionals are ill equipped to deal with such situations. Many parents in this situation will decide to terminate the pregnancy, thus accounting to some degree for the obvious lack of awareness and preparation of many of the staff with whom they came into contact. That staff themselves often believe that termination of pregnancy is the more appropriate option in these circumstances⁶ may also account for the apparent lack of understanding and sensitivity shown by some health professionals.

Several important issues were highlighted by the interviews (see box). The manner in which news of an

abnormality is conveyed may be important in minimising initial distress. A sensitive, unhurried face to face delivery of such information in privacy was clearly appreciated by the parents in this study. Sadly, this was not the universal experience. When possible special provision should be made for the continued antenatal care of these pregnancies, which should avoid many of the most negative experiences reported. This is not always easy to arrange, but better use of general practitioners and specialised antenatal counselling midwives, when available, could be considered. Continuity of care is imperative, and staff dealing with these parents must be well informed. When inpatient care is necessary separation from normal antenatal and postnatal patients is preferable. Again, in every case all staff should be well informed of the nature of the situation and the parents should be actively concerned in discussions regarding management. The concept of a "case conference" is good from the point of view of both enhancing patient care and providing staff support.

Recommendations

- Give bad news personally and sensitively; if results are to be given by telephone discuss this in advance at the time of the test
- Discuss all the options clearly and honestly
- See patients outside routine antenatal clinic hours when possible
- Ensure continuity of care by the senior doctor and midwife; communicate with the general practitioner
- Provide separate facilities on antenatal and postnatal wards
- Training programmes for health professionals should be made available

Conclusion

Some parents wish to continue a pregnancy given a poor prognosis for the fetus. If counselling was less directive possibly the proportion would be higher. All the parents interviewed found the time to prepare for the death of their child valuable, but many had distressing experiences during that time. These parents need extra support, understanding, and respect for their decision. These are best given by providing special antenatal facilities (box). Health professionals in general have limited experience in dealing with these situations and would benefit from training. Such management may not necessarily apply just to lethal abnormalities but may also apply to any mother in whom a serious fetal abnormality is diagnosed prenatally.

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- 1 Chitty LS, Hunt GH, Moore J, Lobb MO. Effectiveness of routine ultrasonography in detecting fetal structural abnormalities in a low risk population. *BMJ* 1991;303:1165-9.
- 2 Shirley IM, Bottomley F, Robinson VP. Routine radiographer screening for fetal abnormalities by ultrasound in an unselected low risk population. *Br J Radiol* 1992;65:564-9.
- 3 Watkins D. An alternative to termination of pregnancy. *Practitioner* 1989;233:990-2.
- 4 Lilford RJ, Stratton P, Godsil S, Prasad A. A randomised trial of routine versus selective counselling in perinatal bereavement from congenital disease. *Br J Obstet Gynaecol* 1994;101:291-6.
- 5 Hunfield JAM, Wladimiroff JW, Passchier J, Venema-Van Uden MU, Frets PG, Verhage F. Emotional reactions in women in late pregnancy (24 weeks or longer) following the ultrasound diagnosis of a severe or lethal fetal malformation. *Prenat Diagn* 1993;13:603-12.
- 6 Marteau T, Drake H, Bobrow M. Counselling following diagnosis of a fetal abnormality; the differing approaches of obstetricians, clinical geneticists and genetic nurses. *J Med Genet* 1994;31:864-7.

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