

*Contemporary Themes***Attitudes of patients after "genetic" termination of pregnancy**

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Abstract

Twelve of 15 women who had had abnormal fetuses agreed to be interviewed after termination of the pregnancy. The survey showed that persistent adverse psychological and social reactions may be much commoner in patients undergoing termination of pregnancy for genetic rather than "social" indications. Adequate information and counselling before, and support after, termination of an abnormal pregnancy are essential if these women are to cope with the experience.

Introduction

Several studies¹⁻³ have shown that early termination of an unwanted or unplanned pregnancy is rarely accompanied by severe or persistent psychiatric or adverse social sequelae. Evidence is much more scanty concerning the much rarer termination of pregnancy performed after prenatal diagnosis of fetal abnormality. These "genetic" terminations, although greatly outnumbered by the "social," are very different, especially since genetic terminations end planned, or at least wanted, pregnancies. They are also preceded by a period of intense anxiety accompanying the process of prenatal diagnosis at a time when fetal movements are often already apparent. The surgical techniques in genetic terminations are more radical, and the abrupt end of a pregnancy is obvious to friends and relatives.

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Patients and methods

During 1976-9 15 pregnancies were terminated in the university unit at St Mary's Hospital, Manchester, after prenatal diagnosis of fetal abnormality. With the co-operation of the general practitioners, these patients were approached by one of us (NC) to arrange an interview in the patient's home. At this stage NC knew only the name of the general practitioner, the name and address of the patient, and that she had had a termination after prenatal diagnosis of fetal malformation. The interview was deliberately unstructured and was as long as was necessary to allow the patient full opportunity to communicate. NC gained access to the case records only after she had submitted a detailed report on the patient's reaction to termination.

Results

All 15 general practitioners contacted agreed to their patients being interviewed, and 12 patients subsequently co-operated. Table I shows details of the three patients who declined. Table II shows details of the 12 patients who were interviewed and the indication for termination. After confirmation of the diagnosis the patient and husband were interviewed, the nature of the abnormality explained, and the termination performed.

After termination the care in hospital was described as satisfactory by 10 patients, but two patients had had distressing experiences;

TABLE I—Details of patients who refused an interview

| Patient | Age | Parity | Fetal diagnosis | Method of termination of pregnancy | Possible reason for refusal |
|---------|-----|--------|--|------------------------------------|---------------------------------|
| A | 23 | 1+0 | MSAFP I Anencephaly | Extra-amniotic prostaglandin | Immigrant—poor English |
| B | 30 | 1+2 | Duchenne muscular dystrophy (carrier) (male fetus) | Hysterotomy | Third termination of male fetus |
| C | 40 | 1+2 | Maternal age Trisomy 18 | Extra-amniotic prostaglandin | Toddler twins |

MSAFP I = Serum screening without previous fetal defect.

TABLE II—Details of patients who accepted an interview

| Patient | Age (yr) | Parity | Indication for tests | Fetal diagnosis | Method of termination | Fetal diagnosis-termination interval | Gestational age at termination (weeks) | Termination-interview interval (months) |
|---------|----------|--------|----------------------|------------------|-----------------------|--------------------------------------|--|---|
| D | 40 | 1+1 | MA | Trisomy 18 | Hysterotomy | 24 hr | 19 | 3 |
| E | 39 | 1+0 | MA | Trisomy 21 | Hysterotomy | 48 hr | 20 | 4 |
| F | 30 | 1+0 | MSAFP I | Spina bifida | EAPG | 24 hr | 21 | 7 |
| G | 28 | 1+0 | MSAFP I | Anencephaly | Hysterotomy | 24 hr | 18 | 10 |
| H | 40 | 2+3 | MA | Trisomy 18 | Hysterotomy | 24 hr | 18 | 10 |
| I | 20 | 0+1 | DMD | DMD (male fetus) | Hysterotomy | 24 | 21 | 12 |
| J | 30 | 1+0 | MSAFP I | Anencephaly | EAPG | 9 hr | 20 | 14 |
| K | 29 | 0+0 | MSAFP I | Spina bifida | EAPG | 24 hr | 17 | 16 |
| L | 30 | 0+0 | MSAFP I | Anencephaly | EAPG | 2 weeks | 23 | 18 |
| M | 22 | 1+0 | MSAFP II | Spina bifida | EAPG | 24 hr | 27 | 30 |
| N | 29 | 0+5 | MSAFP II | Trisomy 21 | Hysterotomy | 24 hr | 22 | 40 |
| O | 27 | 0+0 | MSAFP I | Anencephaly | Hysterotomy | 5 days | 23 | 49 |

MA = Maternal age.

MSAFP I = Serum screening without previous fetal defect.

MSAFP II = Serum screening with history of previous fetal defect.

EAPG = Extra-amniotic prostaglandin.

DMD = Duchenne muscular dystrophy (carrier).

patient H had a hysterectomy, and patient L developed septicaemia and was transferred to a medical intensive care ward. Eight patients (D, E, G, I, J, K, N, O) commented at interview that the support from the family and relatives was good but in four instances (F, H, L, M) family support was reported as poor. When interviewed by NC, seven patients (E, G, J, K, M, N, O) were considered to have made a good emotional recovery from the experience of termination. In three cases (D, I, L) the recovery was considered to be fair, and in two women (F, H) the experience had continued to be associated with a disturbing and distressing reaction. It was noted at the interview that all the patients showed signs of emotional strain while relating the circumstances of their termination. Although 11 of the patients did not express feelings of guilt, recognising that termination was appropriate, one very distressed patient (H) thought pregnancy should have continued, even though the fetus was known to be abnormal.

Discussion

Although this is a small series of patients, it has been possible to identify several points during the processes of prenatal diagnosis at which special care must be taken whether or not termination of pregnancy is eventually necessary.

It is essential that women understand the nature and the reasons for prenatal tests. While most of the patients in this series understood the reasons for the termination, a minority remained in doubt as to the precise indication. It is desirable therefore to reinforce counselling with a leaflet provided when first attending the antenatal clinic explaining the prenatal tests available. This allows the patient and her husband to discuss the tests in the tranquillity of their own home. When test results suggest the presence of an abnormal fetus, pretermination counselling with the consort present is essential. When counselling, it should be possible to identify the special needs of those patients who, by virtue of their past medical or obstetric history and religion, will require particular care and support during and after termination of the pregnancy.

Having learnt about the nature of the fetal malformation, most women are anxious for termination to be effected as soon as possible. In this series one patient (L) elected to continue her holiday plans and underwent termination two weeks later. She later deeply regretted this delay. Another patient (J) underwent termination within 24 hours and found even this minimum delay too long. For most, however, termination within 72 hours of counselling was acceptable.

The mode of termination should always be discussed with the patient, and in our series six patients elected to undergo hysterotomy, preferring to be unaware of the event. For those patients not wishing to have more children, there may be much to recommend this procedure, despite the greater operative risks. Whether sterilisation should be offered is more difficult to ascertain. Nevertheless, the only patient sterilised at the time of termination (by hysterectomy) was profoundly depressed one year later, although in her case cultural, religious, and social factors also contributed to her depression.

Careful counselling and support for patients undergoing termination are essential, not only at the time of termination but in the weeks thereafter. All 12 patients showed signs of emotional strain during the interview, and five stated that they would have welcomed the offer of a follow-up home visit in the weeks after termination. This could be conducted by a health visitor with experience gained in a medical genetics unit, provided that there is close liaison with the general practitioner. Improved communication with the general practitioner, antenatal services, and community staff are necessary if ill-timed or inappropriate communication with the patient is to be avoided.

Although the number of women interviewed is relatively small they do represent 80% of "genetic" terminations from one obstetric unit over a four-year period. It is reasonable to conclude that the small numbers of women undergoing termination of a planned or wanted pregnancy after prenatal diagnosis constitute a high risk group, vulnerable to depression and social disruption. Considerable care is necessary before, during, and after the event if they are to cope emotionally and socially with this experience.

Because of the small number of genetic terminations, this study is semi-anecdotal. Nevertheless, it has had an important effect on changing clinical practice after the realisation that a high proportion of patients were experiencing difficulty in coping with the termination of a wanted pregnancy, albeit abnormal. We now ensure that a genetically experienced health visitor contacts such women while they are in hospital. Continued support may therefore be offered by an experienced nurse, in the patient's home if necessary. The health visitor, remaining in contact, is in a position to identify the need for further genetic counselling when appropriate. A prospective study is now being planned that will include professional psychiatric collaboration when assessing patients undergoing genetic abortions in order specifically to identify factors contributing to prolonged depression after termination.

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