

# Counselling following diagnosis of a fetal abnormality: the differing approaches of obstetricians, clinical geneticists, and genetic nurses

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## Abstract

**Women receiving a positive diagnosis of an abnormality during pregnancy may be counselled about a termination by one of several types of health professionals including obstetricians, geneticists, and genetic nurses. There is anecdotal evidence to suggest that these groups differ in both their approaches to counselling and their attitudes towards abnormality. The aim of the current study is to document how genetic nurses, geneticists, and obstetricians describe their own counselling of women following the diagnosis of specific fetal abnormalities.**

**Obstetricians reported counselling in a significantly more directive fashion than did geneticists, who in turn reported counselling in a more directive way than did genetic nurses. The extent to which the groups differed in their reported approaches varied across conditions. The most marked difference was evident for Down's syndrome: 94% of genetic nurses, 57% of geneticists, and 32% of obstetricians reported counselling non-directively. Future research needs to focus on what these different groups see as the objectives of counselling in this situation, how they actually counsel, and with what effects.**

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It is generally agreed among health professionals that decisions concerning termination of a pregnancy following diagnosis of a fetal abnormality should be made by the woman and her partner, with the support, but not the influence, of health professionals.<sup>12</sup> Non-directiveness is considered an important feature of any counselling provided.<sup>3</sup> The extent to which health professionals agree with or follow these guidelines is not known.

Women receiving a diagnosis of a fetal abnormality may be counselled by members of several health professions including obstetricians, clinical geneticists, and genetic nurses. There is indirect evidence to suggest that some counselling may be more directive than guidelines suggest. Following abnormal AFP results, some women reported feeling encouraged by their obstetricians to undergo amniocentesis and to terminate affected fetuses.<sup>4</sup>

In a small uncontrolled study of 40 cases of sex chromosome abnormalities it was found that 78% of parents who saw obstetricians underwent terminations, in contrast with 50% who saw geneticists.<sup>5</sup> One possible explanation for this difference is that these groups of health professionals conducted consultations differently, giving parents different descriptions of the conditions, or using differing counselling styles. If this interpretation is correct, it suggests that whether a pregnancy is terminated may depend upon which type of health professional a woman consults.

The aims of the current study are, first, to determine the extent to which health professionals involved in counselling women following the diagnosis of a fetal abnormality endorse the guidelines of non-directiveness, and, second, to compare self-described counselling approaches of the three main professional groups conducting counselling: obstetricians, clinical geneticists, and genetic nurses.

## Methods

### SAMPLES

#### *Clinical geneticists*

This sample comprised all consultants and senior registrars employed in the main genetics centres in England and Wales (n=85). The response rate was 80% (68/85). The respondents comprised 32 men and 36 women, with a mean age of 41.7 (range 30-64); 30% were regular church attenders.

#### *Genetic nurses*

This sample was contacted via the mailing list of the Genetic Nurses and Social Workers Association. Out of the membership of 88, 40 responded (45%), of whom 39 were female. The mean age of respondents was 41.8 (range 28-65); 18% were regular church attenders.

#### *Obstetricians*

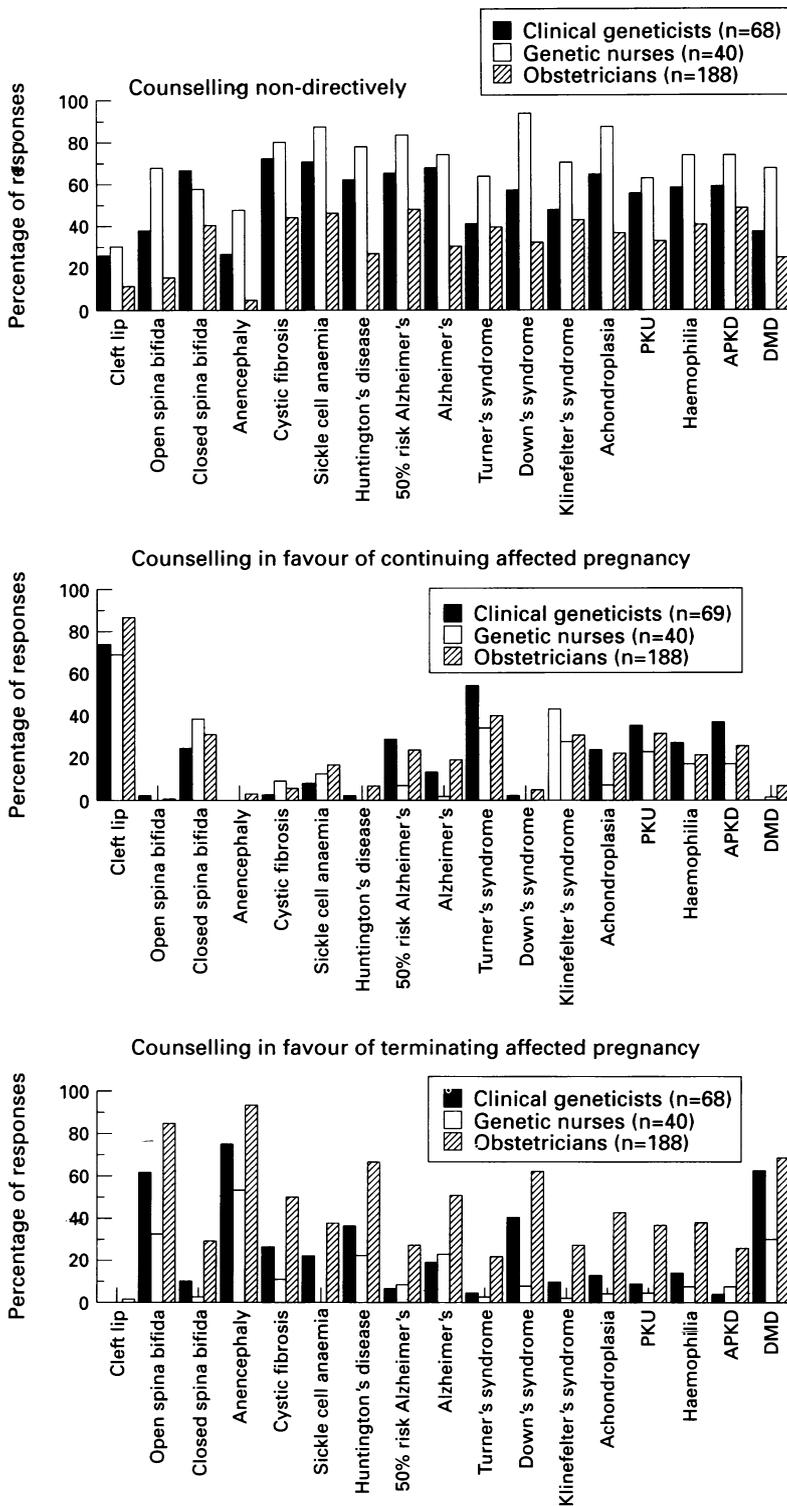
A random sample of 700 members of the Royal College of Obstetricians of England and Wales were sent questionnaires. Questionnaires were returned from the family and colleagues of 29 members who had died. A further 188 questionnaires were completed and returned, giving a response rate of 28% (188/671). A total of 127 respondents were male, the rest female.

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Proportions of clinical geneticists, genetic nurses, and obstetricians approaches to counselling for different conditions. (Top) Proportions of respondents using response option (3) "try to be as neutral as possible, covering both positive and negative aspects". (Middle) Proportions of respondents using response options (1) "encourage parents to carry to term" or (2) "try to be as neutral as possible but overall convey more positive than negative aspects of the condition". (Bottom) Proportions of respondents using response options (4) "try to be as neutral as possible, but overall convey more negative than positive aspects of the condition" or (5) "encourage termination".

Their mean age was 48.3 (range 32–77); 27% were regular church attenders.

MEASURES

Approaches to counselling were assessed with a questionnaire based upon one developed by Wertz and Fletcher, but not yet used by them (personal communication). Respondents were

asked to state how they would counsel women found to carry a fetus with one of 17 conditions, varying in severity, age of onset, and type of disability. The list is reproduced in the figure. Response options covered non-directiveness and varying degrees of directiveness. The five response options were: (1) encourage parents to carry to term; (2) try to be as neutral as possible, but overall convey more positive than negative aspects of the condition; (3) try to be as neutral as possible, covering both positive and negative aspects equally; (4) try to be as neutral as possible, but overall convey more negative than positive aspects of the condition; (5) encourage termination.

Responses to these questions were used to derive two scores.

**Directiveness.** A scale of directiveness was derived to provide a summary score for each respondent based upon their responses to all 17 conditions. A score of two was given when a non-directive stance to counselling was reported for any of the 17 conditions. Stating a tendency to emphasise positive or negative aspects of a condition was accorded a score of one. Encouraging termination or the continuation of a pregnancy was accorded a score of zero. The total possible score for each respondent across all 17 conditions was therefore 34: the higher the score, the more non-directive the counselling approach.

**Direction of directiveness** was determined by deriving a mean score of counselling approaches across all 17 conditions for each of the health professionals. A score of zero was given when a non-directive stance towards counselling was reported for any of the 17 conditions. Stating a tendency to emphasise positive aspects of a condition was accorded a score of +1, while stating a tendency to emphasise negative aspects of a condition was accorded a score of -1. Encouraging continuation of an affected pregnancy was accorded a score of +2, while encouraging termination of an affected pregnancy was accorded a score of -2. A mean score of zero suggests a tendency to counsel non-directively; a score above zero suggests a tendency to counsel towards continuing affected pregnancies; a score below zero suggests a tendency to counsel towards terminating affected pregnancies.

PROCEDURE

Questionnaires were posted to each of the groups, together with stamped addressed envelopes for replies. No reminders were sent.

Results

Two aspects of responses were considered: the extent to which responses were directive, and the degree of consensus between and within groups.

DIRECTIVENESS

Two aspects of directiveness were assessed: the extent to which counselling was directive, and the direction that any directiveness took, that is, whether this was towards continuing or terminating affected pregnancies. The re-

Proportions (numbers) of clinical geneticists, genetic nurses, and obstetricians reporting counselling non-directively

	Clinical geneticists (n = 68)	Genetic nurses (n = 40)	Obstetricians (n = 188)	
Cleft lip	25 (17)	30 (12)	11 (21)	**
Open spina bifida	37 (25)	68 (27)	15 (28)	***
Closed spina bifida	67 (45)	58 (23)	40 (75)	***
Anencephaly	26 (18)	48 (19)	4 (8)	***
Cystic fibrosis	72 (49)	80 (32)	44 (83)	***
Sickle cell anaemia	71 (48)	87 (34)	46 (90)	***
Huntington's disease	62 (42)	78 (31)	26 (50)	***
50% risk Alzheimer's	65 (43)	84 (34)	48 (90)	***
Alzheimer's	68 (45)	75 (30)	30 (56)	***
Turner's syndrome	41 (27)	63 (25)	39 (73)	***
Down's syndrome	57 (39)	93 (37)	32 (60)	***
Klinefelter's syndrome	47 (31)	70 (28)	42 (79)	***
Achondroplasia	64 (42)	88 (35)	36 (68)	***
PKU	56 (37)	63 (25)	32 (60)	***
Haemophilia	59 (39)	75 (30)	41 (77)	***
APKD	59 (38)	75 (30)	49 (92)	*
DMD	38 (26)	68 (27)	25 (49)	***

Significance of  $\chi^2$  values (df=2): \* p<0.05, \*\* p<0.01, \*\*\* p<0.001.

sponses of each of the three groups to the study question are shown in the figure and the table.

From this figure it can be seen that for none of the conditions was a non-directive approach to counselling always taken. The extent to which respondents reported counselling non-directively varied across conditions, and between health professional groups. So, for example, respondents in all three groups were more likely to report counselling non-directively for sickle cell disease, than they were for cleft lip or anencephaly.

For each condition, there was a significant difference between the three groups of health professionals in the proportions that reported counselling non-directively, assessed using  $\chi^2$  tests (table). So, for example, 32% of obstetricians reported counselling non-directively for Down's syndrome, in contrast with 57% of clinical geneticists, and 94% of genetic nurses ( $\chi^2 = 54.75$ , df = 2, p<0.0001).

All three groups of health professionals were compared on the scale of directiveness, derived from responses to 17 conditions. Mean scores (standard deviations) for obstetricians, clinical geneticists, and genetic nurses were: 17.0 (7.0), 24.9 (6.5), and 28.4 (4.6) respectively. Using one way analysis of variance and TukeyB contrast tests, each group is significantly different from one another ( $F(2,281) = 66.63$ , p<0.0001).

To determine the direction that any directiveness took, groups were compared on a composite score denoting direction of directiveness. The mean scores (standard deviations) for obstetricians, clinical geneticists, and genetic nurses were: -0.32 (0.6), 0.0 (0.3), and +0.01 (0.2) respectively. Obstetricians were significantly more likely to counsel towards termination of affected pregnancies than were genetic nurses or clinical geneticists, who did not differ (one way analysis of variance:  $F(2,281) = 14.83$ ; TukeyB procedure: obstetricians differ from clinical geneticists and genetic nurses, p<0.5).

#### CONSENSUS

Consensus on approach to counselling between the groups, defined as agreement between 70% or more of respondents,<sup>6</sup> was evident for just one of the 17 conditions, cleft lip: the majority of each of the three groups reported counselling

parents in the direction of continuing with the affected pregnancy. Clinical geneticists and genetic nurses held a consensus on three conditions: cleft lip, cystic fibrosis, and sickle cell disease, the consensus on the latter two conditions being to counsel non-directively.

If the cut off is lowered to 50%, consensus between all three groups was evident for just two conditions, cleft lip and anencephaly, the majority of respondents reporting counselling parents in the direction of terminating the affected pregnancy for anencephaly and against termination for cleft lip. At this level, there was consensus between clinical geneticists and genetic nurses on 13 conditions. Aside from cleft lip and anencephaly, the consensus on the other conditions was to counsel non-directively. Clinical geneticists and obstetricians reached consensus at this level for four conditions: open spina bifida, anencephaly, Duchenne muscular dystrophy, and cleft lip. Consensus between genetic nurses and obstetricians was evident for only two conditions: anencephaly and cleft lip.

#### PREDICTORS OF COUNSELLING APPROACH

A multiple regression analysis, with directiveness as the dependent variable, was conducted to determine whether any of the demographic characteristics of the participants predicted reported directiveness of counselling. The independent variables entered were profession, number of children, age, gender, church attendance, number of years since qualifying, and average number of patients seen each week for prenatal diagnosis. The only predictor was profession, accounting for 28% of the variance in directiveness.

#### Discussion

None of the groups of health professionals uniformly approached counselling for any of the conditions in a non-directive fashion. Obstetricians, clinical geneticists, and genetic nurses differ from each other in how they report counselling following diagnosis for a fetal abnormality: obstetricians are most directive while genetic nurses are least directive. While being more directive than genetic nurses, clinical geneticists' reported style is more similar to this latter group than it is to that of obstetricians. When counselling directly, ob-

stetricians are more likely to counsel towards terminating, as opposed to continuing affected pregnancies, at least within the range of conditions studied. Clinical geneticists and genetic nurses, however, are as likely to counsel towards continuing as towards terminating affected pregnancies, the direction being related to the condition.

We do not know the extent to which these self-reported differences are reflected in actual practice. Two aspects of the current study limit the conclusions that can be reached: the response rate and the study methodology. Response rates differed across the groups, ranging from 80% for clinical geneticists to 28% for obstetricians. We do not know how representative respondents are of their profession and hence, for example, whether the views of responding obstetricians reflect the views of all obstetricians. Concerning the study methodology, we do not know the extent to which self-report reflects actual clinical practice. Self-report will to some extent reflect the collective representations of a profession. Clinical practice for clinical geneticists and in particular genetic counsellors is defined by non-directiveness. The responses of these two groups may therefore reflect a knowledge of this value system, rather than reflecting actual practice.

Bearing in mind these limitations, there is anecdotal evidence to suggest that these results do, to an extent, reflect clinical practice. Observations of obstetricians presenting prenatal screening tests<sup>7</sup> show them to be more directive than geneticists would be in offering similar tests. If, as is hypothesised here, self-report reflects practice, this raises two questions: what are the causes of differences between different groups of health professionals in approaches to counselling, and what are the consequences of these differences.

Differences between the three groups may reflect differences that pre-date choice of speciality. Those attracted to a surgical speciality may feel more comfortable with, and have more practice at, making decisions on behalf of their patients than do geneticists. Training and clinical experiences may also explain these differences. Training in obstetrics, genetics, and genetic counselling emphasises different aspects of the roles of doctors and patients. In addition, patients can perhaps more readily be seen as autonomous in the clinical practices of genetics than in the clinic practices of obstetrics.

We do not know the consequences of different approaches to counselling, either in terms of the decisions made by parents, or in terms of their subsequent emotional well being. The counselling parents receive may affect both of these. Certainly evidence from uncontrolled studies suggests that they have an effect upon the decisions made.<sup>5,8,9</sup>

While guidelines for practice are clear in stressing the importance of non-directiveness for counselling, they fail to acknowledge first how difficult non-directiveness is to achieve in practice,<sup>10,11</sup> and second what the patient may want from consultations after the diagnosis of

a fetal abnormality. When attending for genetic counselling, there is evidence that a sizeable minority want some direction. For example, in a postal survey of almost 800 families who had received genetic counselling, 42% stated that, in addition to the facts, they wanted the counsellor's opinion of what they should do.<sup>12</sup> It is not known what proportion of those facing decisions about termination following detection of an abnormality wish for guidance, nor the kind of guidance that they might want. Preferred roles in decision making seem to be strongly influenced by the severity of the health threat people face. While the majority of people think they would want to select their own treatment if they developed cancer, the majority of patients with cancer want a doctor to make decisions on their behalf.<sup>13</sup> This suggests that when facing a major threat to health, patients are more likely to look to health professionals for some guidance. Following detection of a fetal abnormality, particularly one about which they know very little, parents may actively seek guidance from the health professionals providing counselling. The outcomes of fulfilling or not fulfilling such requests await study.

To conclude, future research needs to focus upon what different health professionals see as the objectives of counselling following detection of a fetal abnormality, why they pursue these objectives, how they actually counsel, and with what effects. Alongside this, there is a complementary need to determine what counselees want. Such information is a necessary first step towards the development and evaluation of systematic approaches to counselling following detection of a fetal abnormality.

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