

Carrier testing for cystic fibrosis: knowledge and attitudes within a local community

ABSTRACT—We report a questionnaire survey of 216 adults (aged 16–68) attending the dental hospital in Newcastle. This was undertaken to provide a representative assessment of the level of knowledge in the community of cystic fibrosis and attitudes towards testing for carrier status. Knowledge of inheritance and symptomatology of the condition was scored and found to be less than previously reported in selected population groups. In the majority the source of information reported was the mass media; only 27 respondents had any contact with an affected individual. The questionnaire provided information about the inheritance and effects of cystic fibrosis. Three-quarters of the respondents accepted the idea of carrier testing for themselves, which included most of those of reproductive age, and all considered that testing should be available to those planning a family. General practice surgeries were the most favoured venue for testing. The implications of these findings for those involved in the planning of population screening programmes are considered.

With the detection of approximately 75% of carriers of cystic fibrosis made possible [1], attention has been directed towards the implications for population screening [2]. Favourable attitudes have been reported among selected groups [3, 4]. Before attempts are made to expand carrier testing it is important to assess public awareness since population acceptance will exert a major influence on the outcome of any such programme.

We have attempted to avoid selection and assess, in a cross-section of the population, attitudes towards screening for cystic fibrosis and the level of background knowledge.

Subject and methods

All adults accompanying children to the outpatient clinic of the dental school at the University of Newcas-

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tle upon Tyne were invited, over a three-day period in 1990, to complete an anonymous two-part structured, self-administered, questionnaire. Since this group were predominantly female, a second group attending the adult clinic were recruited over a four-day period. The child health clinic group (A) comprised 86 females and 25 males (age range 16–67, mean 38 years). The adult clinic group (B) comprised 51 females and 54 males (age range 16–68, mean 42 years). The total study population was therefore 216 adults. Response rates were 112/132 (82%) and 105/115 (91%) respectively.

The questionnaire collected data on prior knowledge before offering factual information on cystic fibrosis, the availability of screening and its limitations. The respondents then offered their opinions on population screening and preferred arrangements for testing.

Results

The findings concerning inheritance and symptomatology of cystic fibrosis are shown in Table 1. The female score was consistently the better. Knowledge of the disease was slightly better in the 27/216 who claimed to have had contact with an affected person (58% of those who had contact knew it could only be inherited, compared with 40% of those who had no reported contact). For the majority of patients who knew it could be inherited, the source of information was the mass media.

After reading the information paragraph the respondents' attitudes to testing were surveyed; 75% of group A and 68% of group B considered that the test would be useful, ie they agreed in principle with the concept of testing, and 75% of group A and 66% of group B would wish to be tested.

Ninety-six per cent would support testing of others at reproductive age and 100% would support testing of others when planning a family. They were offered a choice of locations for a screening clinic (hospital outpatients, family planning clinic, child health clinics, general practice surgeries); 76% of group A and 67% of group B favoured testing in the general practice surgery.

Discussion

As expected, most individuals do not have first-hand knowledge of cystic fibrosis and in this study knowl-

Table 1. Extent of knowledge about cystic fibrosis: Responses (percentages of each group) obtained by questionnaire

| | Males | | Females | | Total | |
|--|-------------------|-------------------|-------------------|-------------------|--------------------|--------------------|
| | Group A n = 25 | Group B n = 54 | Group A n = 86 | Group B n = 51 | Group A n = 111 | Group B n = 105 |
| <i>Genetics</i> | | | | | | |
| Approx. birth incidence correct | 16 | 24 | 18.6 | 25 | 18 | 24.7 |
| 'Inherited' given as a cause | 52 | 61 | 81 | 70.5 | 75 | 65 |
| 'Inherited' given as only cause | 20 | 31 | 60 | 53 | 51 | 42 |
| <i>Symptoms</i> | | | | | | |
| Chest problems involved | 40 | 52 | 61 | 65 | 57 | 42 |
| Digestive problems involved | 16 | 18 | 37 | 23.5 | 32 | 21 |
| Chest and digestive problems involved | 12 | 15 | 32 | 21.5 | 28 | 18 |
| Chest, digestive and failure to thrive | 12 | 11 | 29 | 13.7 | 25 | 12.3 |
| Indicated reduced lifespan | 48 | 35 | 58 | 62 | 56 | 48 |

edge seemed to be at a lower level than others have found.

Accepting the limitations of a questionnaire to assess future behaviour, our findings, even when not liable to subjective bias by use of interview, add further confirmation of those reported in earlier studies showing a relatively high level of acceptance for the development of carrier screening for cystic fibrosis.

Most individuals do not have personal knowledge of the disease and media sources of information will be important in this respect. Curriculum changes for schoolchildren may eventually improve awareness regarding inherited disease but there remains a large proportion of the reproductive population for whom this has not occurred, which would need to be taken into consideration in the planning of any future screening programme.

Whilst the more difficult issue raised by the current inability to detect all heterozygous individuals was not addressed by the questionnaire, the researchers were impressed by the readiness of individuals to participate in this study.

Clarke highlighted the potential dilemmas raised by the availability of screening for inherited disease, one of which was the paucity of community involvement in programme development [5]. Our study suggests that the organisation of population screening services would benefit from the involvement of representatives of general practice and the population at the outset.

A representative sample of 216 adults has indicated

a broad acceptance of the concept of population screening for cystic fibrosis. From our experience there is a clear preference for this to be incorporated into primary health care. Planning of such a service should take account of this opinion and of the general need to involve the population under study at an early stage of the development.

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