A developing role in genetic counselling

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SUMMARY The valuable contribution made by nurses and social workers employed in genetic services in Britain was recognised by a Clinical Genetics Society Working Party. A recent survey has examined their role in the service and a selection of findings is presented in this paper. Their introduction to the clinical team facilitates the process of counselling and promotes a more comprehensive service for families.

The introduction of nurses and social workers as an adjunct to genetic services is a relatively recent innovation in the United Kingdom. As a specialist group they are still few in number, widely scattered, and often working in isolation, as the only non-medical member of the clinical team. In 1980 they formed an Association* which offers a forum for matters of mutual concern. One member has been elected to the council of the Clinical Genetics Society as a non-speciality representative.

In North America the employment of nurses and social workers in genetic units is a much more widespread and long established practice1 and since 1969 training has been provided for another non-medical health worker, the Genetic Associate.2 3

The Working Party on Regional Genetic Services of the Clinical Genetics Society4 indicated that “…genetic services employing nursing staff have found them invaluable…” and went on to discuss the recruitment of suitably experienced nurses and their need for additional training in medical genetics. Recognition was also made of the valuable contribution from experienced social workers, particularly in genetic disorders with considerable social impact.

In the absence of any formal training or preparation for work in genetics and with a variety of backgrounds there are likely to be considerable differences in a person’s interpretation and execution of the role. In order to identify similarities and differences, a survey was undertaken in 1986 among members of the Association: an exploratory study by means of a postal questionnaire. Some of the issues examined were their role in the service, the organisation of work, the responsibilities undertaken, opportunities for extending their knowledge base, professional qualifications, and demographic characteristics of the group. Twenty-nine completed questionnaires were returned, a response rate of 74%. A selection of findings is presented here.

Only three respondents were not nurses and their background was related to a clearly defined role within the genetic services. Nurses were assigned a large assortment of job titles. This lack of consensus reflects the novelty of the role in the United Kingdom and the absence of a recognised preparation. Two-thirds of these posts have been created since 1980, the first in 1959, the second in 1971. Subjects in this sample, all female, had been in post for between two months and 14 years (median = three to four years).

Twenty worked full time. Part time hours ranged from 15 to 30 hours. Among the first and intermediate degrees held by respondents, only two were in genetics. One non-nurse had obtained a Masters degree in genetic counselling in the USA. Nurses had acquired a wide range of post basic qualifications, 20 out of 26 holding a health visitor certificate.

Before taking up a post in genetics, 14 were working as health visitors, 11 were employed in a variety of nursing roles within the health service, two were in social work and two in research.

Eight of the sample, all nurses or health visitors, worked alone with one or two geneticists. Their work pattern and responsibilities did not appear to differ significantly from others working in units with a complement of two to six nurses/health visitors/social workers. However, it was clear that they lacked the resources of an infrastructure enjoyed by larger units and were deprived of peer group support.

*Genetic Nurses and Social Workers Association

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Work with families

PRE-CLINIC
Pre-clinic visits to newly referred clients were undertaken by non-medical staff in the majority of units (table).

The average number of visits undertaken in a month was 12, the maximum 30. Less than 10 visits were made by 15 respondents, and these included three whose average was one or less per month.

Clearly, the extent of pre-clinic visiting will depend not only upon the attitude of the geneticist in charge of a unit but also upon the size of the catchment area and the resources available.

The need for a pre-clinic interview was established as a joint medical/nursing/social work decision in more than half the cases. Criteria generally adopted in assessing the need were:

Need to compile comprehensive information on pedigree, medical background. Investigations, for example, CK levels, karyotype.
Bereavement: TOP, stillbirth, infant or other death.
Clarification of referral.
Evidence of particular social/psychological problems or anticipated non-attendance.
Physical or mental handicap.
Anticipated communication difficulties, for example, language, impaired hearing.

Respondents were asked what their own objectives were when undertaking pre-clinic visits. They agreed that the prime purpose of the visit was to gather pedigree and medical data relevant to the family’s genetic consultation. This facilitates the process for both the client and the counsellor. They also identified the following.

Explanation of clinic procedure and establishing rapport with the family.
Assessment of practical/social difficulties and motivation to attend clinic.
Assessment of attitude to genetic condition and client’s objectives in seeking counselling.
Assessment of stage of grieving and appropriate timing for genetic counselling, bereavement counselling.

The achievement of these additional objectives can be viewed as a preparation for genetic counselling. Families may be unaware of the reason for their referral to the service or what to expect at their consultation. Many basic misconceptions and anxieties of clients can be dealt with in the relaxed atmosphere of their homes, for it is now well recognised that anxiety inhibits communication. Feelings of guilt and other matters of concern are often raised which require counselling of a general nature. This preliminary meeting with a representative of the service enables families to understand their need for consultation and to approach the encounter with a more positive attitude. It also offers an opportunity for families to clarify their ideas and articulate questions on a particular genetic condition before their appointment with the geneticist. It often prompts the verification of additional family data.

CLINIC
The number of clinics organised weekly within the respondents’ units ranged from one to five (mean=three). Only seven worked in units which did not operate satellite clinics and where these did feature they were within a range of 12 to 100 per annum.

The main role of respondents in the clinic was identified as observer of client response and comprehension with a view to assessing the need for follow up visits. The interview sometimes elicited new areas of concern for families with which help would be needed. Their presence as client advocate and support in a potentially stressful situation was felt to increase a family’s confidence. Additionally, the nurse’s traditional role was exercised in clinical assistance at the clinic appointment. In some units this session was used by non-medical staff for the initial interviewing of families to obtain pedigree information. In this way and through pre-clinic visiting the sample were responsible for obtaining up to 30 pedigrees a month. Only eight undertook none or fewer than 12 per year. Among the remainder an average of 17 per month was undertaken.

POST-CLINIC
The average number of post-clinic visits undertaken in a month was six (range 0 to 24). Thirteen undertook less than 10 visits and three undertook none.

Increasing workloads overall were said to account for a reduction in this area of activity. Where possible and appropriate, follow up to the consultation might be accomplished by telephone.

The need for a post-clinic visit was established in the main as a team decision. The criteria generally used were:

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**TABLE** Pre-clinic visits undertaken by non-medical staff.

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certain categories of new referrals only</td>
<td>11</td>
</tr>
<tr>
<td>50 to 100% of new referrals</td>
<td>10</td>
</tr>
<tr>
<td>Less than 50% of referrals</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>29 (100%)</td>
</tr>
</tbody>
</table>
Difficulties in a family's understanding of genetic information and an apparent need for reinforcement and further discussion. Evident need for emotional support following clinic appointment. Further information or investigations required or involvement with other relatives indicated. Specific requests by counsellees. Family's placement on long term register.

In the vast majority of cases the nurse/social worker who made the initial contact with a newly referred family attended their consultation and undertook any follow up visits or long term support. They considered this continuity of great importance, because (1) it developed the client's confidence in the service and improved two way communication; (2) it ensured that they were fully aware of the genetic counselling process for each family and were thus better qualified to reinforce the counselling and offer support; and (3) it offered greater job satisfaction for respondents.

Teaching

Increasing awareness of the genetic component in many disorders and recent developments in molecular genetics have led to greater demands on genetic units for information. The majority of respondents are called upon to talk about the genetic service and their role in it to colleagues in the health and social services and to lay groups. This is an important public relations exercise for a relatively new service. Eighteen in the sample undertook formal teaching sessions and seminars in pre- and post-registration courses, on study days and in service programmes for qualified staff, in schools, and among handicapped groups and their supporters.

Research

Four-fifths of the group had participated in research projects related to genetics. They had been involved in various stages of the research process and four subjects had undertaken their own projects. While declaring interest in this activity they clearly saw their priority as patient service needs. The view was expressed that they should avoid being used as a 'pair of hands' for others' research which would be detrimental to their role. However, there were suggestions that the group should consider undertaking research which evaluated the supportive aspects of the genetic counselling service and that they might also contribute to publications on the psychosocial aspects of genetic counselling.

Counselling

The nurse or social worker generally gives genetic information only as reinforcement following consultation. She may, in certain circumstances, be delegated specific genetic counselling responsibilities by a geneticist when clients fail to attend, for example, to the extended family where the diagnosis and inheritance pattern of a genetic condition has been clearly established. Twelve persons were delegated authority for primary counselling in this way. Two had specific counselling responsibilities in relation to the preconceptional vitamin study and three were involved specifically with amniocentesis counselling.

Numerous references were made throughout the questionnaires to the extent of their responsibility for supportive (psychotherapeutic) and bereavement counselling of families, a need which Fraser identifies. “Exploring these feelings may be far more important than providing a statistical estimate of the risk, and somewhere during the counselling process there should be an opportunity to do so, but in practice this aspect of counselling tends to be neglected”.

Attitudes to work

Twenty-five reported that they were satisfied with most aspects of their work. Most were able to participate in unit/departmental clinical meetings on a weekly or monthly basis and had access to hospital seminars. It is generally accepted that this group of staff needs a good working knowledge of genetics in order to function effectively. Only nine felt their working day allowed sufficient opportunity to update their knowledge. Four-fifths wished to pursue specific areas of interest which would allow them to develop knowledge or skills related to their role.

Funding for their attendance at study days/conferences was not readily available for increasing numbers in the group. One nurse is reimbursed by the health authority for only one day annually. She pays her own expenses for others. Attendance at such sessions during the previous two years was between one and five days for just over half the sample (mean=four).

Increasing awareness of the need for a more structured approach to their professional development both as individuals and as an identifiable group has led to the setting up of a working party among members of their Association. This group is currently considering a number of issues.

The knowledge and skills necessary to perform their role.
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The additional training required by personnel on appointment.
Their continuing educational needs.
How provision can best be made for both initial preparation and ongoing development.

Discussion

As genetic services continue to expand, more nurses and social workers are entering this area of work. Their introduction to the team contributes to the provision of a more comprehensive service for families. In their preparation of documentation for clinic appointments the process of genetic counselling is facilitated, thereby using geneticists’ and families’ time more effectively. In preparing clients for consultation, potential barriers to communication can often be reduced and the geneticist alerted to areas requiring special attention. Nurses and social workers are available to follow up families to assess their comprehension and reaction and to respond to their practical needs. Families may rely upon them to translate difficult concepts and medical terminology into language more easily understood. Clients know they can be reached by telephone and that they will intercede on their behalf. As non-medical members of the service nurses and social workers may be perceived as less threatening. Another important aspect of their role is liaising with other members of hospital and community departments and the public.

The recent application of principles of general management to the health service will require specialist groups to justify the allocation of resources for their work. This survey paves the way for that exercise. It has also helped members of the Association to examine their role and educational needs and to consider ways in which their role might develop in the future. Finally, it contributes towards an awareness of their group identity, separate from, but complementary to, other members of the genetics service.

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References


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