Patient participation in primary health care

JONATHAN P. GRAFFY
Medical Student, University of Birmingham.

SUMMARY. Patient participation groups have been established in about 20 practices, six of which were visited. They did not conform to a particular model but each had adapted to local circumstances. As well as giving patients a say in the practice, they were involved in health education, voluntary work, and campaigns for better secondary care facilities, although these activities were influenced by the way the groups were elected. The emphasis was on participation rather than patient power and their constructive approach to improve services made patient participation a valuable innovation.

Introduction

DOCTORS have established patient participation groups for a variety of theoretical and practical reasons (Pritchard, 1979). However, one concept which underlies all aspects of participation is that health is as much the responsibility of the individual and the community as it is of the medical profession. But do patients want the right to participate, or would they rather hand over all responsibility to the professionals "who know best"? Woods and colleagues (1974) found that 62 per cent of respondents at a health centre felt that "patients are the best people to say what services they would like in the centre". These views were supported by a recent opinion poll in which the NHS was found to be the public service most in need of a consumer watchdog: one third of those interviewed were willing to serve on such a body *(Market and Opinion Research International,* 1979).

Aims

This study was designed to investigate the background, organization, and activities of six patient participation groups and to assess their impact on primary health care.

Method

The study was based on published and unpublished material, interviews with patients and staff, and attendance at group meetings to see participation at work.

Results

Berinsfield, Oxon — 'The Community Participation Group'

Berinsfield claims to have had the first patient participation group in Britain. Built in 1970, the health centre serves 7,000 patients, divided evenly between Berinsfield, (where 90 per cent are council tenants), and the surrounding villages. All community services are based in the centre and this has helped the development of teamwork.

The group is composed of representatives of local bodies including the Community Association, Women's Institute, and Parish Council, but has no directly elected patients. Effective feedback depends on the extent to which these representatives consult their particular groups before meetings.

The main role of the group is to act as a forum for discussion of practice policy, but individual suggestions and complaints are also considered. Other concerns have been the voluntary car service for patients coming from outlying villages and work with the community health council which won an improved chiropody service.

Sand (1978) commented that doctors raised twice as many issues as patients: this is not surprising, given the concentration on long-term policy and the fact that the group meets only three or four times a year. While the group's role may appear limited, it has kept the interest of representatives whose prime allegiance is to the organizations which have elected them.

Aberdare — 'The Patients' Committee'

Aberdare Health Centre serves about 11,000 patients in a Welsh mining valley. The Patients' Committee was established in 1973 with the joint aims of making doctors accountable to their patients and spreading medical knowledge in the community.

The 27 committee members are representatives of the two practices in terms of age, occupation, interests, and the villages they live in. Although clinical matters are recognized as beyond the scope of the group, they have been forceful advocates for patients' concerns. Their

role has been largely constructive, but there is scope for friction as the doctors vary in their enthusiasm for the committee.

Patients and doctors share a common interest in relation to secondary care. For example, they persuaded a psychiatrist to hold regular clinics in the health centre, saving patients a 15-mile journey to hospital.

They have arranged 130 health education meetings attended by 20 to 80 people and even made their own videotapes to show in the community. The programme has promoted an awareness of the need for screening and a meeting on hypothermia led to the establishment of a network of voluntary street wardens for the elderly. These examples illustrate how participation can co-ordinate health care.

Whiteladies, Bristol — 'The Practice Association'

Whiteladies Health Centre accommodates three independent practices, one of which set up the group in 1974 to encourage feedback from the then 8,000 patients.

The committee of 12 are elected annually and are mainly middle class, reflecting the practice population. They meet the doctors quarterly to discuss matters relating to the practice but organize most activities independently. These include a weekly lunch club for the elderly, a monthly mothers' discussion group and co-ordinating about 50 volunteers who collect prescriptions and do other errands for the elderly.

Health education has proved popular, mixing talks on specific illnesses with fringe medicine and preventive topics. Recently a working party of patients and staff has produced a report on facilities for the elderly in the area.

Co-operation with staff is good because the volunteers supplement rather than replace the professionals, but the emphasis on providing services contrasts with their role as representatives. To keep in touch with patients' opinions, they have distributed two questionnaires, on the appointment system and the doctors' way of working. They also hold an annual brains trust for patients to question the doctors on health and the health service.

Lee Bank, Birmingham — 'The Patients' Association'

The Lee Bank Health Centre serves a mixed population of 5,000, drawn from high-rise council flats and middle-class Edgbaston.

The Patients' Association was established in 1977. It has an annually elected committee of eight, mainly young professionals who recognize that they are atypical of local residents. Although their relationship with the doctors is good, involvement in policy making is difficult as other staff were unhappy that patient representatives should attend practice meetings.

Practical activities are important and include a successful slimming club, outings for patients, and collecting toys and comics for the waiting room. However, attendance at monthly health education meetings depends on the subject; while 'Breast Cancer' might attract an audience of 50, only a dozen might come to hear about 'The Crisis in the NHS'.

When consulted about plans for a new health centre, the group supported the doctors' appeal to the area health authority. This is noteworthy as it is clearly in the doctors' interest to be able to say: "Our patients are demanding better facilities."

Many of their difficulties stem from the area's lack of any sense of community but they have managed to get some local involvement and to extend the role of the health centre.

Limes Grove, Lewisham — 'The Management Collective'

The Limes Grove practice was established in 1976 and it is considered by some to be the most radical in the participation movement. In their attempt to break down professional barriers, the doctors and staff, whose skills include acupuncture, massage, and psychotherapy, are paid equally on a sessional basis. There are weekly workers' meetings but policy is decided at the monthly management collective, which is open to all patients participating as equals with the staff. Although few of the 2,000 patients now attend, in 1977 100 of the then 700 patients met to discuss a crisis in the staffing of the practice.

The meetings lack a formal structure and as the patients' role is not clearly defined, staff have usually tended to take the initiative. To combat this, they are changing to a more cohesive 'management group' with less frequent open meetings. In addition, a women's health group, a massage group, and a practice newsletter are being started.

A notice in the waiting area invites patients to inspect their own notes and the guide to the practice suggests that they are "against the kind of control that doctors usually have over their patients" and hope that by discussing problems "people will learn about health and how to maintain it". From talking to patients, it was clear that they felt that their doctors were more approachable than most.

Kentish Town — 'The Centre Users' Group'

The Kentish Town health centre represents the triumph of the trend to concentrate all primary care services in one building. With 25,000 patients, 14 doctors, and 70 staff, there is a danger of professionals becoming unresponsive to patients' needs, and the Centre Users' Group was formed to counter this possibility.

The group brings together staff, individual patients, and representatives of voluntary agencies such as Task Force, the Camden Association for Mental Health, and the local law centre. Although members from such groups tend to identify with the professionals, they counterbalance this by sitting in the waiting room once a month to chat with patients.

The Centre Users' Group is fully consulted on all aspects of the health centre and relations with the staff are good, partly due to the support of the previous centre administrator. They have developed slowly as they had difficulty starting a health education programme and there are already many groups doing voluntary work in the area. They appear successful in their main roles of channelling patient feedback and co-ordinating services through contact between staff and local agencies.

Discussion

Representation

Whether a group is representative or not is crucial to its effectiveness. If it is able to voice the concerns of ordinary patients, it will gain the respect of staff and patients, but if not, it will lose that respect and inevitably fade away. Fortunately, groups with less grass roots support appeared to recognize this and either tried to represent the interest of all patients or directed their energies to practical activities.

The opinions of patients attending surgery and their attendance at health education meetings give an indication of their knowledge and support. Activists' other interests and stated perceptions of their role are a further guide. These matters were explored for each group.

The older groups appeared more representative than the newer ones, which suggests that they may attract more support with time. An alternative hypothesis would be that those involved in the earlier groups were more enthusiastic than later converts.

Primary health care issues

Despite the differences between the groups studied, their concerns were remarkably similar. Grouping issues into various categories indicates the range of patient concerns (Table 1).

It is more difficult to assess the outcome of discussions because few of the issues were clear cut and they varied from specific complaints raised by patients to topics put forward by the staff for discussion. However, one can generalize that there was either an improvement in the service, or a better understanding of the problem and why an improvement was not possible.

Activities

Health education and community care work were important to three of the groups studied (Aberdare, Bristol, Lee Bank). It was apparent that they do much to sustain the activists' enthusiasm for participation as well as directly involving many other patients.

The link between participation and health education is a natural one and they reinforce each other. Meetings feed ideas to the activists, who on their part encourage others to take an interest in health education.

Similarly, community care work is effectively organized by a patient participation group, recruiting volunteers for a range of activities which have imaginatively supplemented statutory services to meet local needs. Indeed the volunteers may gain as much as those they help. Although it has been noted that this can modify the consumer role, the groups benefit from greater staff respect.

Table 1. Typical issues discussed by patient participation groups.

Structural
Waiting/play area
Privacy while making appointments
Wheelchair ramps
Parking facilities
Planning new health centre
Staff
Staffing levels
What is hoped for in a new partner (for example, woman preferred)
Staff roles
Staff attitudes (complimentary as well as critical)
Organizational
Surgery hours (evening/Saturday mornings)
Appointment system
Night calls
Use of intercom to call patients
Services
Preventive and screening programmes
Marriage guidance counselling
Chiropody
Home visiting for the elderly
Community based social work
Health visiting
Policy
Medical student training
Social worker and health visitor training
Videotapes for teaching
Hospital referrals
Drug policy (hypnotics and antibiotics)
Research work

Campaigns and secondary care

Some of patients' concerns relate to matters outside the control of the primary care team and in these, the interests of doctors and patients converge.

Each of the groups visited had some contact with the community health council but liaison was best in Aberdare and Kentish Town where some members served on both. Interestingly, patient participation groups preferred to bypass the community health council on most issues, taking their case directly to the area health authority, family practitioner committee or consultant concerned. They may find a direct approach is simpler or fear that their case might be affected by the poor relationship some community health councils have with the area health authority. Sand (1978) compared the minutes of three groups with those of the local community health council and found that they had a number of shared concerns, from which he concluded

that their efforts were mutually reinforcing. They are able to complement each other as the patient participation group gains an official channel for its concerns and the community health council some grass roots support.

Relationships with professionals

While the doctors who had initiated groups were enthusiastic, other staff tended to judge them on practical activities rather than effectiveness as representatives, unless they were also involved in decision making.

Many doctors fear that participation might lead to conflict, but this was not a major problem in the groups studied although difficulties occasionally arose in relation to staff who chose to have little contact with the patient participation group. The common interest in practical activities and improving services explains the constructive atmosphere. More importantly, most conflicts arise out of misunderstanding and the open discussion which participation allows enables a much clearer understanding of what is possible and desirable.

Organization

Many of the differences between groups could be related to their organization. The three models adopted were observed to have specific advantages and disadvantages as follows:

1. The directly elected committees at Aberdare, Bristol, and Lee Bank were most suited to practical activities. Their activists viewed the patient participation groups as the first priority but needed support to recruit activists in the initial period.

2. In Berinsfield and Kentish Town, the patient participation group was a secondary interest to the representatives of other groups. Although easier to establish, it relied on the practice for long-term support and had few practical activities.

3. The less formal approach adopted by the Limes Grove practice is more difficult to sustain but perhaps better able to respond to crises.

These points need to be considered by anyone planning to establish a new group as its character will be influenced by the model chosen.

Future developments

At present, participation is limited to a small number of practices and it is difficult to predict whether it will become more widespread. The groups' successes could be related to the doctors' enthusiasm and, although not all may share that enthusiasm, developments like vocational training for general practice as a positive career choice may increase their number. The case for participation will also be strengthened as health centres, the extension of the primary care team, preventive medicine, and health education lead people to challenge the view that all interactions between doctors and patients can be dealt with in the consulting room.

The National Association for Patient Participation in General Practice has recently received financial support from the Department of Health and Social Security, and the study day on participation organized by the Royal College of General Practitioners (Pritchard, 1980) has encouraged more doctors to consider establishing a patient participation group.

Ultimately, participation is a matter for individual practices and although it is unlikely to gain the widespread support that some of its more vocal advocates might wish, it will continue to play an important role in primary care at a local level.

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Addendum

Further information on other groups is available from Mrs Joan Mant, Central Information Service, 14 Princes Gate, London SW7 1PU.

Since this article was accepted the author has qualified and is working as House Surgeon at the General Hospital, Burton-on-Trent, Staffs.

Depression in family practice

Somatic pain, functional, and anxiety complaints of 154 depressed patients were followed during the course of their initial depression and were found to parallel the depression: these complaints increased in number just prior to diagnosis of depression and decreased to normal levels after one year's treatment of the depression. Persistence of these types of somatic symptoms after one year's treatment predicted eventual chronicity of the depression. Older patients were also more likely to develop chronic depressions, and there was some indication that those individuals who had an initial remission of a depression followed by a second depression which then became chronic had longer first depressions.

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