THE PATIENT'S POINT OF VIEW 1

Patient participation

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SUMMARY. As two patients we describe the formation, range of activities, and organization of our Practice Association, which provides patient participation for one group practice. Despite some problems, especially communication with potential members, we are convinced of the value of such a practice association.

Introduction

PATIENT participation is a new but growing development in primary health care. We write as patients who have been involved with one group since it started five years ago and we hope in this account of our group, which is known as the Practice Association, to show the strengths and the limitations of what has been achieved.

The practice

The practice, based since March 1975 in a health centre, is in a predominantly middle-class inner city area where the houses are mainly large and Victorian, many of them converted into flats and bedsitters. There are a higher than average number of elderly patients and a fairly large number of children and young adults. There is mobility of between 15 and 20 per cent per annum, mainly among young adults.

There are four partners, all in their thirties and early forties: the three men are full time and the woman does full consulting hours only. No deputizing service is used. The practice, which is long established, has grown rapidly in the last 10 years from about 3,500 to 10,000—mainly through the closing of single-handed practices in the area. When our association started in 1974, the practice list was about 8,000.

The Association

The idea for starting a patients' association came from Dr T. Paine (1974) who as a member of an Open University course on systems behaviour had been impressed by the stress laid on the importance of feedback. He wrote a letter for patients which was left at the surgery during a period of several months and about 1,000 copies were taken and read in that time.

The result was a meeting in February 1974 which was attended by about 40 patients, followed by a further meeting in April 1974, open to all patients, at which the first committee was elected.

Membership and constitution

The Practice Association is open to all patients and staff in the practice. By 1977, it was felt that our brief early constitution needed to be replaced by a more detailed one. At the same time the committee discussed the possibility of a small annual membership fee. Some felt this would give a greater sense of commitment, but most were against this, arguing that all patients should be free to take as great or as small a part as they wished without any formal membership requirement. So all members of the practice are entitled to come to the Annual General Meeting and vote for the committee.

The committee consists of chairman, vice-chairman, secretary, treasurer, and eight members. The chairman and vice-chairman can hold office for only two years. Two ordinary members who have served three years must resign each year, but can stand for re-election after a year's absence. Co-options can be made. The community care co-ordinator, a member of the suggestions and complaints group, and the publicity organizer are always on the committee, which meets monthly. We are fortunate in having a receptionist and a health visitor on our committee. By mutual agreement no doctor serves on it, though doctors are invited in turn to attend.

We have always wanted the staff to feel part of the Association, and the quarterly lunchtime meetings between the committee and the staff have helped considerably. There have also been talks at our evening meetings from the nursing team, and—while we had them—from the health centre social workers.

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Aims

The aims of the Association are as follows:

1. To give patients a voice in the organization of their care.
2. To allow the expression of dissatisfaction and resolve the problem if possible.
3. To provide education and discussion on topics of interest.
4. To give voluntary community care help.

Work of the Association

The Association has been active in the pursuit of its aims.

Aim 1

Giving patients a voice in the organization of their care has been done by various means: through a suggestions box at the reception counter; through a suggestions and complaints group; through quarterly lunchtime meetings of the committee, doctors, health care team, receptionists, and administrator; and through annual evening meetings when all the doctors have answered questions from patients (Weightman, 1977).

Suggestions from patients have resulted in such innovations as a letter-box at the health centre, a ramp for wheelchairs, and notices about the slow working of the lift and the need to report to reception on arrival. We have been consulted by our doctors about changes in surgery hours and we have been able to get some improvement in the several months' waiting time for chiropody. After representations were made to the District Administrator an extra session at the health centre was arranged.

Aim 2

In order to allow any dissatisfaction to be expressed and resolved, at the beginning a liaison sub-committee was set up consisting of three members. This was later called the Suggestions and Complaints Group. All the doctors, health care team, and receptionists accepted this aspect of the Association's work and it was clearly understood that it would not deal with any matters involving medical judgement. Notices were put up and a section included in our annual card asking patients if they had a complaint to telephone a member of the Suggestions and Complaints Group or the chairman, or to make use of the suggestions box.

There have been only about four or five complaints a year, and a questionnaire prepared by the group and completed by 363 patients in one week in March 1976 showed that the large majority of patients were satisfied with all aspects of their care at the health centre. Some anonymous complaints put in the suggestions box have been so lacking in detail that nothing could be done about them.

We find that some patients who ring, however annoyed or angry, do feel considerable anxiety about letting the doctor know about their feelings, however well justified they feel them to be. Such complaints have tended to centre on the doctor's manner, that he has behaved in a brusque, insensitive, or peremptory way, so that the patient has felt unable to express his needs. Having a member of the association available to listen to such problems seems to relieve the patients' feelings and gives the doctors some feedback.

Recently a patient stated that she had not received adequate warning about the side-effects of a drug she was taking. As a result our doctors have produced a small leaflet to be given to patients receiving a drug which might affect their alertness and another leaflet advising about the correct taking of antibiotics.

As another method of dealing with criticisms we are hoping to adapt the 'Speak-up' sheet used by another association. This allows the patient to remain anonymous but ensures that the complaint and the response to it are written down in some detail. The Association committee member acts as 'postman'.

Aim 3

In order to provide education and discussion on topics of interest, we have had about nine evening meetings each year. We try to keep a balance between specialist subjects (heart disease, arthritis, acupuncture, marriage counselling) and more general preventive medicine (eating and health, problems of old age, knowing your pills and potions). The attendance varies considerably from 25 to over 100. This year (1978/79) we are planning two self-help groups, one on stopping smoking and one on losing weight, and half a dozen talks on other topics. It will be interesting to see how effective a more extended approach is.

As the result of a talk on yoga, we have had weekly classes for members of our practice in a local hall for the past three years, and these have been much appreciated.

We have a monthly morning group for mothers of young children, and they have a programme of talks of particular relevance to their needs.

Aim 4

Voluntary community care help is achieved by means of a co-ordinator, who is always on our committee, who receives calls from a doctor or other member of staff when there is need for such help as fetching prescriptions, shopping, transport, baby- or granny-minding, doing some regular visiting to a housebound person or some practical job such as gardening. Balancing about 50 volunteers with demand is not always easy and at times we may have lost volunteers who did not feel sufficiently used, but perhaps typical of the general feeling of volunteers is the remark: "I've been glad to show in a practical way my appreciation of the care and help I've received at the health centre."

During the past three years a fortnightly—and now weekly—lunch club for about 30 elderly and often housebound patients has been very successful. We are fortunate in having the use of a room and kitchen at the local Friends' Meeting House for a small fee. The lunch club also has outings in the summer and theatre visits. We have set up a working party to look at provision for the elderly in our area and to see where the gaps are and whether we can do any work to close them. About twice a year the co-ordinator sends a newsletter to all volunteers, and we are now developing this to cover most aspects of our work and it will be made available to patients at the health centre.

A welfare rights group has been meeting at the health centre one morning a week for the past year and a half, but there has been only a trickle of referrals. It appears that the need for this is not being perceived, is not great, or is being met by other bodies.

We have compiled a list of patients belonging to various national associations concerned with aspects of health. These patients are willing, when asked by a doctor, to explain to another patient the information, advice, or support their particular association can give.

Publicity

Local

From the beginning, communication was seen as a major difficulty, particularly as the health centre is shared with another practice which does not have a patient participation group and all wall publicity has to be in the entrance lobby and not in the waiting room.

In July 1974, we sent a letter to all homes in the practice so that at least at the beginning all patients should know of our existence and aims. Subsequently we have had to rely on other, less demanding, methods.

Cards setting out the year's meetings and the Association's main functions are available at the reception counter and have been in use for three years; they have proved a useful innovation. At the beginning of each year we have delivered over 1,000 cards to patients in selected groups of roads and last year we printed 4,000 in all. Previously we had had to rely on slips of paper distributed about three times a year.

Publicizing meetings outside the health centre has not proved easy because we are only one practice in a densely populated area served by many doctors.

National

There has been more widespread publicity in national papers and periodicals, and on local radio (Lyall, 1977). Several community health councils in other parts of the country have written asking for information. One patient represents our interests on the local Community Health Council, and we have taken part in community health council conferences on health centres and on the future of the health services in our area.

One of our doctors and several committee members have spoken to various interested groups and we are now one of the 14 groups who make up the National Association for Patient Participation in General Practice, which aims to circulate information, discuss ideas and problems, help new groups get started, and hold conferences or meetings about twice a year (Paine, 1978).

Finance

Finances have not presented any big problems. In the first two years we held raffles at evening meetings, but this has not been necessary recently. Our main outlay is the printing of the cards. Coffee at our meetings gives a small profit. Patients needing transport quite often make a donation (we pay volunteers 5p a mile). The luncheon club makes a reasonable charge for soup, sandwiches, and coffee to cover its expenses. With only one fund-raising effort this year (a cake stall at a local fair), we have a healthy balance. Donations are sometimes received from patients, or their relatives, when they are especially grateful for help given by the staff.

Conclusion

We hope that this account gives some indication of what can be achieved by a group such as ours. During the last five years we have gradually discovered ways of co-operating with the primary health care team to—we hope—the mutual benefit of patients and staff.

References

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Paine, T. F. (1978). Inaugural meeting of the National Association for Patient Participation in General Practice. *Journal of the Royal College of General Practitioners,* **28,** 377-380.

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Addendum

Copies of the Newsletter can be obtained from Mrs J. M. Whatmore, 26c Downleaze, Bristol BS9 1LZ, on receipt of a stamped addressed envelope.

Life expectation in Scotland

Based on the 1971 Census of Population and on the mortality experience during the three years to 1972, the expectation of life at birth in Scotland is 67·30 for males and 73·65 for females.

Reference

Scottish Information Office (1979). Press release.