

People and Health

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Patients: a health care resource

On the basis of experience and research at a community health centre in Belgium, the authors discuss the merits and difficulties of encouraging patients to assume increased responsibility for primary care.

The idea that the general public should work for the maintenance, promotion and recovery of health is accepted in most countries. Such participation can favourably influence the efficiency and quality of care and can stimulate self-reliance (1).

In Western Europe, most participation consists of such activities as attending talks, reading health education leaflets, working in self-help groups, and doing voluntary work, e.g., calling on people who are unwell (2,3). Lay people may involve themselves in policy-making, but this is very difficult to develop because of obstacles on both the professional and lay sides. Patient participation groups, of which there are about 10 in the Flemish part of Belgium, 110 in the Netherlands, and 70 in the United Kingdom, are often attached to general practices or community health centres. Experience gained in one of these groups is described below.

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Patient participation in the community health centre of Ledeborg

Ledeborg is a poor, densely populated suburb of Ghent in which 20% of the people are over the age of 65 years, 70% have received only primary education, there is a high unemployment rate, most houses are in bad condition, and there are very few green areas.

In 1981 the group practice of three general practitioners became a multidisciplinary community health centre aiming to achieve integrated primary health care with the participation of the inhabitants. The present team consists of four doctors, two nurses, a social worker, a dietitian and an administrative worker.

Consumer participation

This involves:

- distributing a quarterly newsletter to 400 subscribers, providing them with health education and information about the centre's activities;

- attending exhibitions on healthy diet and drugs, and reading leaflets in doctors' waiting rooms;
- participating in information evenings for specific groups of patients, e.g., hypertensives and diabetics;
- participating in courses, e.g., on relaxation, low-fat cooking, pre- and postnatal exercises, and smoking cessation.

Citizen involvement

Citizens and health care workers cooperate in health-orientated activities.

- The production of the newsletter.
- With the support of a staff member, a group of patients develops a topic four times a year and produces posters and a leaflet, the subjects already covered including child abuse, educational problems, contraceptives, parasites, diabetes and hypertension.
- Attempts to develop voluntary work, e.g., transporting people to hospital, have not yet been successful, partly because of inadequate professional support.
- Patients occasionally help with the redecoration of the centre.

Participation in policy-making

Citizens are involved in such matters as the determination of surgery hours, road safety in the vicinity of the centre, and measures related to the financing of health care.

An annual meeting is held at which some 50 patients discuss matters such as alternative medicine, acupuncture, relaxation groups, voluntary work, and financial policy, and an advisory committee of some 15 patients formulates suggestions on the basis of what is said.

The centre is run by an executive committee that includes six patients and two health workers, and an annual general meeting is held at which patients are in the majority. Furthermore, there are a number of channels for indirect participation, e.g., a suggestion box and complaints procedure. The patients and health workers meet on an equal footing to discuss problems of health care; there is no question of conflict or confrontation between them.

What do patients want?

In May 1985 the advisory committee decided to set up an investigation into patients' views on participation (4).

The aims were to:

- assess the general state of awareness of the patient participation group and its function;
- ascertain attitudes towards patient participation;
- provide feedback on the value of different kinds of activity.

A questionnaire was designed to obtain information on:

- identification;
- knowledge of health care and participation activities;
- views about patient participation;
- priorities in patient participation;
- prospective participation of the respondents.

Between 15 August and 15 September 1985, 200 patients filled in the questionnaire, usually when in the waiting room. There were higher percentages of women and of people aged 20–40 years in the study than in the population at large.

Only primary schooling had been received by 17% of the respondents; 38% had attended secondary schools and 44% had received higher education. The last group was clearly over-represented, probably because of a greater willingness among these people to take part in the research.

A third of the research group had 0-3 contacts annually with a health care worker in the centre, 27% had 4-6, and 18% had 7-12. In the latter group there were relatively high proportions of people aged over 60 and of people who had received only primary education.

Slightly more than a quarter of the respondents had a perfect knowledge of the services offered at the centre. A similar proportion gave three or more incorrect answers to the questions on this subject. The highest proportions of incorrect answers were given in respect of dietetics (42%), social work (40%) and nursing (33%). Knowledge in this sphere tended to be poorest among the old and among people who had attended primary school only.

People with fewer than three contacts annually with the centre had poorer knowledge than the others, and those who had been visiting the centre for many years had a better knowledge than those who had begun attending recently. People who subscribed to the newsletter had significantly better knowledge than people who did not.

It was stated by 58% of the study group that they knew of the advisory committee. This figure may be unreliable because a positive answer was perceived as desirable, given that the questionnaire originated from the committee itself. The proportions of people who took part in activities and subscribed to the newsletter were 13.5% and 37.5% respectively. Subscribers were slightly over-represented in the study group. There

were significantly elevated numbers of subscribers among people aged over 40 years, among people who had more than six consultations a year, and among people who had been visiting the centre for more than five years.

The advisory committee was seen as nonpolitical and of particular value to people confronted by illness. On the whole, the respondents favoured participation in decision-making and cooperation between patients and health workers in order to advance primary health care. The respondents were firmly of the view that patient groups should seek ways of improving the activities of the centre.

Knowledge of patient activities was not very good. It was better among women than men, and was relatively poor among people with only primary schooling.

The respondents were asked to indicate what they regarded as six priorities in a list of twelve activities, as shown in the table. Activities closely related to specific illnesses received high scores. This may reflect a fear of suffering from these illnesses. At the top

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of the list were consumer participation and citizen involvement. Participation in policy-making seemed to be of little interest. It was striking that activities not yet organized in the centre took the first and third places on the list. In second place was

the activity about which the respondents knew least.

It was said by 21.5% of the study group that they would participate in a patient activity during the following few months, but 72% said that they would not do so. Men and

Some politicians are in favour of patient participation only as a means of controlling costs.

women responded similarly, but people aged over 60 gave more positive answers than did younger people, and people who visited the centre over six times a year said that they would participate in greater numbers than less frequent attenders. Those who had participated in the past were inclined to do so in the future and this was also true of subscribers to the newsletter. The most important reason for not participating, cited by 53% of the respondents, was lack of time; 17% said they were not interested, a similar percentage stated that they were not free in the evenings, and 8% indicated that they lived too far away.

It is worth noting that the findings of our study corresponded very closely with those of one conducted in the UK (5).

Problems and constraints

Continuity

Many people are patients for only short periods and therefore are only temporarily interested in participation. However, where chronic disease is concerned, self-help groups may be more stable. Like other areas of voluntary work, that of patient

participation has to deal with poor motivation and involvement among a large part of the population.

Democracy

Participation is more than having a formal say within a fixed decision-making structure. It also involves redressing a power imbalance. Patients should be in a stronger position vis-à-vis health workers and should have more say in the design of local policies. However, it should be borne in mind that patients often adopt very individualistic and emotional positions regarding health care, based on their own cases, whereas health centre policy needs a more general approach.

Patients' views on the importance of various kinds of patient participation

Order of priority	Activity	Percentage ¹
1	Organizing clinics for the early detection of illness	56.5
2	Organizing groups where patients with similar illnesses can exchange ideas and give support	52
3	Visiting and helping the sick, elderly and disabled	51
4	Organizing health education while in the waiting room	51
5	Providing transport for those who cannot reach health facilities	48
6	Arranging first-aid classes	45
7	Organizing information and discussion evenings	43
8	Campaigning for better health services	43
9	Organizing a counselling service for family and educational problems	37.5
10	Actions concerning the payment system	32.5
11	Organizing social events where patients and staff can get to know one another	24.5
12	Providing a child-minding service during surgery hours	18

¹ Percentage of respondents who indicated the activity should be a priority.

Quality

Patients' expectations often conflict with quality objectives. Thus health care workers may wish to spend money on education whereas patients may want more apparatus. Permanent discussion about the goals of primary health care is therefore necessary. In this way, patients can become increasingly involved and acquire growing expertise.

Economic factors

Some politicians are in favour of patient participation only as a means of controlling costs, the idea being to teach patients how to use facilities more rationally.

There is a tendency in most European countries to shift the expenses of health care from the community to the individual. When the professional disappears from the scene, a gap arises that has to be filled by self-care. Patient participation is then used as an excuse for reducing the health care sector, especially the basic facilities of primary care. This is political abuse of self-help and participation.

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As we have described it, patient participation:

- is practised on a small scale, free of bureaucracy;
- is flexible and adaptable to local circumstances;
- permits direct interaction between patients and health workers.

The major problems involved in working towards patient participation are as follows.

- In trying to reach target groups the right methods and media have to be found, especially for underserved and marginal groups.

- Participation implies knowledge and awareness of health care problems and requires certain skills to solve them.
- The development of an appropriate structure for patient participation is a permanent process of trial and error and consumes large amounts of energy.

Is it a good idea to have patient participation? We think so. For patient participation groups can play an important role in health education, support for the unwell, and policy modification. Their involvement in primary care should help general practitioners to become more concerned about health in its widest sense. □

Acknowledgements

This article is adapted from a paper presented at the Eleventh Conference of the World Organisation of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA), held in London on 1–6 June 1986. Extended abstracts of this and other Conference presentations were published in the *Journal of the Royal College of General Practitioners*, 3: 253–260 (1986).

References

1. **Develtere, P. & Nuyens, Y.** [*Community participation in health care in Flanders*]. Leuven, Sociological Research Institute, 1985 (in Flemish).
2. **Patient participation in general practice.** London, Royal College of General Practitioners, 1981 (Occasional Paper 17).
3. **Vuori, H.** *Community participation in primary health care: a means or an end?* In: Vuori, H. & Hastings, J. *Patterns of community participation in primary health care*. Copenhagen, WHO Regional Office for Europe, 1986 (unpublished document ICP/PHC/301/s01), pp. 1–17.
4. **De Maeseneer, J. & Debunne, M.** [What do patients expect from patient participation?] *Huisarts nu*, 15: 429–437 (1986) (in Flemish).
5. **Hutton, A. & Robins, S.** What the patient wants from patient participation. *Journal of the Royal College of General Practitioners*, 35: 133–135 (1985).