

Patient Participation

Birchfield Medical Centre Patients' Association

BIRCHFIELD MEDICAL CENTRE PATIENTS' COMMITTEE

The idea of patient participation caught our imagination. None of us had heard of it before, yet it brought together 10 patients—almost all strangers to each other—on a blustery February night to discuss ways of turning that idea into practice. The Birchfield Medical Centre Patients' Association originated in a discussion between a patient and one of our three doctors. The practice was about to move from an old terraced house to a new health centre, and this seemed an ideal time to seek patients' views on the operation of the centre and the facilities offered there.

A notice posted in the surgery led to the initial meeting of the nine founder members, seven of whom are still active. Our committee meetings in the spring and summer of 1979 were primarily concerned with identifying and tackling problems that faced the patients who were using the health centre. In addition to drawing on the experiences of committee members, we got some proposals and ideas from patients through a suggestions box. Patients got to know of the committee because of the success of several small schemes—ensuring that an intercom, clock, and printed appointment cards were provided and finding teenage helpers for the mother and infant clinic. This gave us the confidence to tackle bigger projects.

The practice had for several years published a small magazine called *Declare*. We thought that this was an important way for both the practice and the patients' group to reach more of the 7000 patients, but that the magazine could be improved. The committee has organised an increase in print run, submitted articles, and organised a mailing service. A member, who is a design teacher, takes responsibility for artwork and graphics. The design skills of patients have been combined with the doctors' medical knowledge to produce a booklet of cartoons about health education for patients aged over 65. We intend to produce a series of such publications, which reflects a health education role for our group. We have also collaborated with the doctors to produce an experimental tape library of exercises to overcome common ailments, and prototypes cover relaxation techniques and preventing night cramp.

Other roles

Health education is often cited as the main role for patient participation groups, and indeed in practice it is usually the central activity. Our group is no different from others in the concern for preventive medicine, but we also seek eventually to monitor the operation of the health centre. The suggestions box and two very successful social evenings for staff and patients have enabled us to identify gaps in services, some of which can be filled by patient-organised self-help schemes. Members of the committee attend surgery and clinics to talk to patients,

Birchfield, Birmingham
Birchfield Medical Centre Patients' Committee

receptionists, and other staff, and this has led to campaigns directed at patients—for instance, on missed appointments—and to proposals for changes in the clinic organisation. But our major achievements in this area, in response to a doctor's suggestion, is to devise a questionnaire to be sent to a sample of patients to discover attitudes to the services offered at the centre, to the consultation itself, and to the wider health service. With the co-operation of the doctors, the patients' group is therefore moving into the area of review and audit.

It is in our formal relationships with the doctors that we differ from many patient participation groups. Committee meetings are attended only by patients, and it would be exceptional for health centre staff or doctors to be invited. This is not common among patient groups, where doctors who have initiated patient groups regularly attend meetings. In Birchfield we have been left to determine our own future, though ideas are exchanged at formal and informal meetings between committee members and the doctors. We have therefore been forced to come to our own understanding of patient participation and to rely on our own resources in identifying and meeting patients' views and needs. Although our definition of patient participation may not be far removed from that of the doctors, at least it was developed by us as patients, in our own way. If doctors are too closely involved in the meetings of a new group, however well-intentioned those doctors are, there may be a tendency for their ideas and definitions to be imposed on patients. Doctors are often unaware of the definition of patient participation, and because the philosophy of patient participation contains a belief in equalising the doctor-patient relationship the doctor must be prepared to permit the patients' group to gain the knowledge and confidence to enable this equality to emerge. Without this willingness, patient participation will remain something that doctors do for patients, rather than something that patients do with doctors.

Wider issues

Our experiences in Birchfield raise a number of issues of wider concern. Firstly, our practice does not really need patient participation. The doctors are keen to develop and improve services—for example, they have a comprehensive monitoring and screening system for certain groups of patients and conditions and also provide a regular series of health education talks. The activities of our group therefore support an already progressive practice, and this is true for the majority of patient participation groups. The problem, however, is how to disseminate the idea, practice, and benefits of patient participation more widely, particularly to practices where there is a greater need for it. To an extent this depends on the medical profession accepting it as "good practice," for although individual patients, groups, and the National Association for Patient Participation in General Practice can do a lot by way of publicity, ultimately the doctor has discretion. Yet such professional legitimacy must

conditions of unemployment and full employment with associated disharmony. I find it ironic that stress and marital disharmony are often seen where husbands are separated from their wives because of full employment in, for instance, the oil industry off-shore.

In some instances welfare milk tokens have been known to be traded to unscrupulous shopkeepers for cigarettes and other commodities, and the shopkeepers then acquire the milk with the tokens from the welfare clinics and sell this baby milk in their shops. Happily, however, mothers still bring children to the appropriate clinics and immunisation sessions. Antenatal clinic attendances are also high and there is an obvious increase in attendances, but a large proportion of the younger girls are unmarried when they first attend. The older children are displaying other signs of lack of parental control in the increased incidence of delinquency, drug taking, glue sniffing, and other solvent abuses. In their search for drugs some of these young people have now taken to breaking into our cars as they sit in the health centre car park—not only at night but also in broad daylight. Six doctors' cars have been broken into this year.

As a family doctor in these circumstances I feel frustrated because I find it difficult to restore a man's self-respect when he is obviously devalued in his own eyes and in the view of his family. During the recent census the name of any wage earner in the house was frequently placed at number 1 on the list, ahead of the nominal head of the house. Those who provide the most help and support from our practice are the health visitors and social workers, yet, because of this, other services to the practice community must suffer, such as care of the elderly.

When we can do so very little from our own professional base it is perhaps unfair to criticise other professions. We are fortunate in having another psychiatrist who attends our practice meetings and runs groups sessions to which we send patients suffering from stress and anxiety. A clinical psychologist from the district general hospital holds a session each week in the health centre. He is seeing a lot of the behavioural problems, especially children. I think that many of these problems are associated with the present economic problems. We do lack an active, dynamic church that could help bolster the morale of the people of the community in these difficult and trying times. Sadly, religious belief seems to have reached a particularly low ebb. Furthermore, in the 1930s youth organisations and welfare clubs were more prevalent and active than now. The area also contained several allotments, which provided interest for the men and extra food for the family.

The only solution is to restore employment and with it pride, confidence, and dignity to these men and women. The youth of the community should in some way be kept fully occupied and trained so that they can play the part which will be expected from them when the country's economy starts to recover. Meanwhile, surely there is plenty of public work to be done even if only to maintain a reasonable standard of public services. I know that in Govan there is a crying need for this, as our public services continue to deteriorate as a direct result of the economic recession. Surely it would be better for the unemployed husband and father to be earning money repairing roads than wasting social hand-outs in a soul-destroying life of aimlessness and idleness.

Beyond the Surgery

General practitioner in the factory

F J WILKINSON

A regular weekly session as medical adviser to a nearby pharmaceutical factory provides a pleasant oasis in the shifting sands of everyday life in general medical practice. The life of a general practitioner with its frequent changes of pace and direction needs, for me at least, to be punctuated by spells of "one thing at a time" at a reasonable and constant speed. When a two-hour session at the factory is sandwiched between a drive of some eight miles on a good country road the tonic effect is considerable.

There is, superfluently at least, a feeling of ordered purpose about the factory. The hierarchical structure with each section and department fitting neatly with its neighbour to form a whole, guided and directed by the manager and his staff, seems sometimes a far cry from the bustle and turmoil of a busy day in the practice.

The friendly salutation of the security guard as he lifts the barrier at the main gate is echoed by the cheerful, "Hello doctor," as I walk briskly into the medical suite and ask, "What have we got today sister?"

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Examining prospective employees

There are four areas of responsibility in my work as a factory doctor. The examination of prospective employees to ascertain their fitness to carry out the tasks of the particular job for which they are applying could easily become a rote routine. It is often interesting, however, to learn what similarities—or differences—there may be between his, or her, previous and proposed work. Some of the employees have done interesting and exciting things and appreciate a personal interest being taken in them during the examination. The opportunity is taken at this time to explain the position of the factory doctor who, while being responsible to management for ensuring that prospective employees are fit to undertake the work required of them, is also uniquely able to advise the applicant of any possible hazards of the job and the measures taken to protect them from these hazards. The concept of shared responsibility for safety and health, as I believe, a major factor in maintaining a low incidence of industrial disease and injury. It is not enough for everyone to accept the safety rules and procedures; there must be motivation to share the responsibility and there is no better time to stimulate this than in the intimacy of the consultation between the factory doctor and new employee.

Assessing fitness for a job is made not only on physical grounds—confidence, knowledge, skills, and attitude play an

be gained without the loss of a patient-based approach to participation.

Secondly, there is an assumption built into the current model of patient participation that the individual is an actual or potential recipient of health services. This approach tends to see the cause of ill-health as an accident and the natural degeneration of the body or the individual's failure to lead a healthy life-style, or both. Thus patients groups aim to ensure that appropriate services are available, while at the same time promoting health education programmes to make the potential patient aware of ways in which his or her good health can be maintained—by not smoking, by taking regular exercise, etc. But what the idea and practice of patient participation has largely ignored is that the choices for good health open to an individual are marginal. We may, for example, decide to forego

cigarettes and to eat a high-fibre diet—despite the projected appeal of smoking and convenience foods—but we have little individual choice in deciding whether or not to consume lead that is in petrol and the water supply or the by-products of industrial processes. Many of us also directly or indirectly produce ill-health for ourselves and others because of the type of business and industry we work in and our life-styles.

This poses a central problem for patient participation in general practice. Though valuing the existing activities of groups—from designing and producing a tap-turner for arthritic patients to recommending changes in clinic organisation—we must also consider whether our horizons should expand outside the surgery to consider the man-made basis of health and ill-health and to recognise that our work and leisure activities may cause someone to become a patient.

Unemployment in My Practice

Govan, Glasgow

JOHN MACKAY

Govan is situated up river on the south bank of the Clyde, and Govan Health Centre stands within earshot of what once were busy shipyards and docks. Now the song of the Clyde is mured, and the thronging tenements of old Govan have been largely razed to the ground, creating deserts awaiting the slow and painful birth of a new Govan. The people, who once formed a community with a proud sense of identity as an old burgh annexed to Glasgow in 1911, are scattered throughout the West of Scotland, England, and abroad. This exodus has not been due to the recent problems but to steadily increasing unemployment over many years as the shipbuilding industry declined after the post-war boom. The skilled craftsmen with their own tools have taken themselves to new pastures, and we are left with a less dynamic population. At this point it may be appropriate to say that the size of our practice is about 6600 patients almost entirely of social classes III, IV, and V. The unofficial unemployment figures for Glasgow are: men 17.7%, women 9.5%.

During the shipyard redundancies of the past two years I was appalled at the number of relatively young men who requested medical certification of previous ill health to allow them to qualify for voluntary redundancy. In effect, they were seeking early retirement, and even if alternative employment had been available to them they had no intention of seeking this. Many of them had a history of alcohol abuse, and since becoming redundant some have become alcoholics. The district general hospital, which has a department of psychological medicine, is close by. There is a consultant in that department whose interest is alcohol and drug dependence. He holds a session at the health centre once a week, and we refer most of our alcoholic patients to him. These patients are then followed up as required—either

at the main hospital or at the Charing Cross Centre, which has evening sessions where spouses are also welcome. This centre has all the social and other services that deal with the problem of alcoholism. The main problem is to get a patient to co-operate.

From personal observation and discussion with our practice health visitors and social workers it is clear that women are much more adaptable and resilient in the present circumstances than men. This may be because wives and mothers still have their responsibilities, which they continue to meet.

Different from the 1930s

In the 1930s when Govan faced similar depressing circumstances, the men—small men in cloth caps—could be seen grouped at street corners, shuffling about rubbing their hands in a strange ritualistic fashion, and for hours on end they discussed politics and football. Now their successors of the 80s sit slumped all day in a chair in an overheated living room, smoking endlessly, a can of beer by the side of the chair, eyes glued to the television set, showing animation only when racing is the diet of the day. Even the casual observer can see that there is work to be done about the house. Help is needed with the children, but apathy reigns in the father's heart. Even the presence of the family doctor visiting the sick child arouses no interest. How different the scene from that depicted by our national bard, Burns, in the "Cotters Saturday Night."

In these circumstances the diminished family income is further depleted by the obvious increased spending on alcohol, cigarettes, heating, and gambling. To the overburdened wife the husband about the house is like having another child, almost a handicapped child, constantly around her feet. Stress eventually develops, and the health visitors report increased abuse of the wives, but happily, at least in this area, child abuse has not increased. It is strange that family stress seems to arise in

important part in technical work. It is natural and necessary, therefore, that the medical and personnel departments are closely linked and that the medical staff can discuss various aspects of the job and the calibre of the applicants with the personnel staff. Most applicants are, of course, found fit, but the most important part of the medical examination is the exploration of the employee's medical history. It is rare to find an abnormal physical sign, apart perhaps from a raised arterial blood pressure, without finding some clue to its presence from a history.

Annual checks

Once accepted, the employee undergoes an annual medical check. During the 12 years' association of our practice with the firm we have found more value in the dialogue of the consultation than in the physical examination. A few minutes' questioning and discussion often helps an employee with an evolving or minor medical problem to decide whether, and if so where, to seek further advice. At this time it is usual to ask about his or her work situation and whether there are any difficulties, particularly if the employee is handicapped in any way.

It is tempting sometimes to explore a medical problem not directly connected with the person's work because of its clinical challenge. This has to be resisted for it is not part of the remit of a factory doctor to usurp the role of the family doctor. It is all too easy, sometimes quite unconsciously, to become too involved in such problems. Unless one recognises the danger there is a serious risk of impairing the valuable link, mutual trust, and co-operation that can and should exist between factory and family physician. This firm is fortunate in having a nursing sister who enjoys the confidence and respect of the workforce, thus enabling her to guide them where necessary towards a solution to some of their problems. Yes, we are one of the "big jobs" for the employees, able to act in their personal interests when the occasion demands it.

Industrial hazards

The third and perhaps the most interesting aspect of the work at the factory is the particular concern we must have with the possible adverse effect on health associated with certain processes or the use of particular equipment. Although much is known and documented about medical industrial hazards, there is still much to learn, and new dangers and problems are brought to light with each new process or piece of equipment. One of our particular hazards has been the risk of oestrogen contamination—the factory manufactures the contraceptive pill. When production first began in the United States in the 1940s people did not concern themselves much about protection from contamination. The development of breasts in the male chemical and pharmaceutical workers and the impotence and aplasia that were noticed eventually led to the use of masks and protective clothing during some of the stages of manufacture.

In the early days of the factory's existence it was fascinating to hear a list of the gossip in the neighbourhood about the fearful sexual disturbances said to be developing in the operators. Fortunately by the diligent pursuit of our regular screening programme we have, I believe, scotched the rumours and fears. Because it is much easier to recognise oestrogenic overexposure in men only men are employed in the manufacture of the oestrogen-containing pills. Over the years we have in fact had very few incidents of contamination, the effects of which, unless repeated, are fortunately reversible. Most of these incidents occurred, some 10 years ago now, when a new reduced-dose pill was rushed into production and many feverish hours of overtime were worked for a few weeks. By carefully recording both the work being done and the contamination incidents, as well as the symptoms we were able to identify the actual contamination incident in almost every case. As a result of the findings a number

of adjustments in some manufacturing processes were made. One of the pill-pressing machines was modified to reduce the cloud of powder it created; certain analytical procedures previously carried out on the laboratory bench were moved to fume cupboards; and air-ventilated protective clothing was introduced in some areas. Although there has not been a contamination incident for some years, the men's nipples are examined routinely for tenderness and plaques; this seems a pointless exercise, but it maintains an awareness of the risk and a concern for protection. This undoubtedly has a spin-off in other processes where contamination by noxious substances might otherwise occur.

There have been problems of noise in certain areas—particularly from the grinding mills—which, with the help of noise meters, have been identified and eliminated. The co-operation of the engineers in reducing vibration and the operators in wearing earmuffs was essential in dealing with this. The inevitable problem of sensitivity dermatitis in a factory dealing with many possible allergens, some identified and some not, is a continual challenge. Recently with the help of the safety officer we have been searching published papers for the possible visual effects of video data terminals on the operators. Consultations with experts have enabled advice to be given about positioning the terminals, the surrounding and supravit lighting, and also air-conditioning, which, because of the exacting needs of the computer hardware, is not ideal for those working alongside.

From time to time there have been opportunities to work in clinical research projects in the firm. Employees have been generous in their willingness to participate in clinical trials. Some of these trials were mounted to assess some aspect of a proposed modification to one or other of the firm's products before large scale production. We look forward to further opportunities in this field.

Complementing general practice

In many ways part-time involvement in occupational medicine complements the work of a general practitioner. As in general practice, the concern is for the people who may become ill or injured and with the prevention of disease rather than cure with disease itself. The general practitioner as an occupational physician sees men and women like his own patients while they are working. He can appreciate the need for gradual return to full activity in an exacting job after a prolonged absence from work. He sees the difficulties in trying to meet this need during the final stages of rehabilitation, often after the patient is considered fit to return to work by his own doctor. There are many inquiries being made now into the future of primary medical care in relation to other specialties such as obstetrics, paediatrics, psychogeriatrics etc. Industrial medicine subtly invites a similar scrutiny today.

The Brimflit leighthouse has, of late years, thrown great attention to the prevention of infant-blebs, by supporting the founding hospital, St. B. But we will venture to say, if one-tenth part of the funds laid out in supporting that institution, had been bestowed towards promoting the practice of inoculation of the small-pox among the poor, that not only more useful lives had been lived, but the practice ere now routinized quite universally in this island. It is not to be imagined what effort and a little money will have upon the poor; yet, if not to themselves, they would go on for ever in the old way, without thinking of any improvement. We only mean to say as a hint to the humane and public-spirited. Should such a scheme be approved, a proper plan might easily be laid down for the execution of it. (Buchan's Domestic Medicine, 1986)

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