

PATIENTS: RECEIVERS OR PARTICIPANTS?

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Unlike the retail trade, where an old dictum declares 'The customer is always right' in the professions he is only right when his professional adviser tells him so. The supremacy of knowledge and the monopoly of information which accompanies them has led the professions to the top of the social status and reward structure. It has also allowed them until recently to take an unquestioned dominant role in relation to their clients, who accept that the quality and integrity of their work is ensured by training, ethical standards and the corporate conscience of their professional associations. Despite the slings and arrows of a few assailants, even those as long ago and as witty and perceptive as Bernard Shaw on professions in his preface to 'The Doctor's Dilemma', little effective criticism has emerged. Until recently the professional-client relationship has remained in all its essential features in its traditional form.

Students of the professions have never been in doubt about the inclusion of medicine in this category. Indeed they have tended to put its practitioners in a special position as archetypes, embodying all the essential attributes. Thus the conventional interpretation of the doctor's professional and social position is one of wide autonomy and control over circumstances. The literature is a testament to this view. It goes back to Carr-Saunders¹ on this side of the Atlantic and Everett Hughes² on the other. The flow of studies since the war, whilst becoming increasingly radical in its commentary,³ has maintained the division between an altruistically motivated provider of services and an ill formed but grateful receiver. If anything, the more polemical writings have tended to further

spell out and reinforce the popular view.

Re-assessment of the doctor-patient relationship has nonetheless begun. A number of changes within health care itself supply indicators of what is to come, whilst social scientists have now assembled a body of research and interpretation which casts new light on both the traditional and the new situation. The traditional view of the patient is one which casts him (or her) in the role of a receiver of expert services of a sort which he is incapable of evaluating and must therefore take on trust. Characteristically the patient is a suppliant whose main active involvement in diagnosis and prognosis is to provide information which is requested by the doctor. Judgements about his welfare and statements about his health are made by the doctor with some background knowledge of the individual, but with little or no discussion about their acceptability or appropriateness.

This construction of the consultation process in general practice is not a statement of the invariable manner of its conduct, but a broad generalisation against which recent thinking and movements can be set. In doing this attention will be given to two seemingly related developments. The first is to be found in sociological studies of illness behaviour which during the past decade have given increasing attention to providing detailed accounts of actual behaviour at all stages of illness episodes. A shift in approach amongst some medical sociologists has provided a different level of analysis and fresh insight into how people think about illness and how they act out their perceptions of the situation before, during and after seeking medical help, if indeed they do so at all. Even the seemingly deferential role adopted by many in consulting their doctor can be seen as a calculated form of behaviour rather than mere passivity.

The object of this review of the sociological literature will be to show

that the doctor-patient relationship is much more of a bargaining and interactive process than is commonly thought. This will lead on to discussion of the significance of the trend towards consumerism and greater knowledge and assertiveness amongst the consumers of goods and services. Part of that movement is the increasing sophistication of ordinary people in medical - as in other professional - matters. Amongst the manifestations of these changes is the strengthening of patient pressure groups and the emergence of community health councils as a real force in the health care field.

Thus, if there exists a long established pattern of bargaining between patient and doctor which has frequently influenced or controlled medical management of illness, then in a climate of demand for greater consumer involvement, our traditional medical models clearly need re-examination. Health professionals will need to recognise these changes and respond to them in creative ways, if they are to maintain medicine as an effective service and retain the standing they have so long held in society.

SOCIOLOGICAL CHANGE

Sociological thinking which was dominated until the early sixties by the school of 'structural-functionalist' or systems theories and in Britain by empiricism, has expanded into a heterodox situation where several 'brands' of sociology uneasily co-exist. The structural-functionalist view of the status of the professional is a clear reflection of the predominant accepted view of its time. Parsons⁴ and Merton⁵ in their writings on the medical profession and on socially appropriate behaviour of the sick person, delineated a set of precepts. The theory of the 'sick role' set out by Parsons twenty-five years ago states that illness is a deviation from normal functioning which affords the sick person temporary exemption from certain social responsibilities on the grounds that he cannot be expected to look

after himself or dispose of the illness through willpower. As corollary to the exemption from normal duties the patient is expected to want to get well, obliged to seek competent medical help and co-operate with prescribed treatment. This construction is rooted in a view of society which defines all social positions within a set of institutionalized expectations which generate both rights and obligations.

Thus the role of the medical profession in the illness process is defined and reinforced by the ways in which doctors behave; and the universalized expectations of patients are conditioned by what they believe the doctor expects of them. This neat reciprocal arrangement is transmitted to the student physician by his teachers who are so convinced of its authenticity that they have enshrined it in codes of professional practice. A number of studies of medical education have drawn attention to the importance of learning to think and act as a doctor should and have spoken of the primary learning experience as that of socialization into the values and practices of medicine.⁶ Such writers conceive of the doctor-patient relationship as one in which technical knowledge is exercised by practitioners with 'affective neutrality' and who exercise the right to 'functional autonomy'. This means nothing less than that doctors should have no emotional involvement with the patient; will be merely applying scientific knowledge and techniques; and because of their training must always be right. Such a view is less widespread now than hitherto, but the assurance with which it was felt, not so very long ago, is well illustrated by the words of Lord Thomas Horder, royal physician through five reigns, who said: 'Only the doctor knows what good doctoring is'.⁷

Ever since these propositions about illness and about doctors were put forward they have been the object of criticism. At an early stage Becker and colleagues⁸ set out detailed evidence on the negotiative and uncertain

processes of medical training from observations of student culture and behaviour. Through participant observation studies and interviews, they built up a picture of the medical school career as one where the student had to drop any ideal concept he might have had in favour of techniques which got him through exams and kept him in favour with his professors. Boys in White illuminated the small scale processes of the social action of medical school life⁹ - what Strauss called 'status passage' - and in so doing led others to look closely at the acting out of the professional role and at the realities of behaviour in medical consultations. In summing up a paper on nurse education - which he described as 'doctrinal conversion' - Fred Davis¹⁰ captured the essence of this alternative sociological focus.

'It remains for sociology to generate models of professional socialization that are far more faithful to this picture of thinking, feeling, ever-responding and calculating human actors . . . models, in other words, which in their sociological richness and complexity transcend the dominant one available today - that of neutral receptive vessels into whom knowledgeable, expert members of a profession pour approved skills, attitudes and values'.

It is to a selection of the studies which share Davis's concern for more 'transactional' accounts of human behaviour that attention now turns, for it is there that we shall gain some insight into the way medicine is already much modified both by its clients and by the ways doctors and nurses in particular have changed their own practices.

ILLNESS AND PEOPLE

Much of the relatively short history of medical sociology has been taken up with a re-examination of the nature of illness, how individuals respond

to it and the way it is resolved or coped with. In proceeding with this analysis of the position of the patient in medical care it is possible to summarise this work under headings which relate to two questions (i) Is illness really a clearly defined entity? (ii) How do people behave when they think they are ill?

Definitions of Illness

The 'systems' model of illness as advanced primarily by Parsons gives no real attention to the ways in which morbid conditions are defined. It is taken for granted that universal definitions exist which are shared by doctors and patients. Yet this consensus, although encouraged by that practice of medicine where all symptoms are assumed to be part of a disease entity, is clearly a mirage.

Aubrey Lewis¹¹ wrote:

'Anyone who has reflected on the many definitions of health, and of mental health in particular, will I think, conclude that there is no consensus, and he will see that when moral or social values are invoked there are scarcely any limits to the behaviour which might be called morbid.'

In the definition and labelling of physical illnesses there are historical, cultural and economic factors involved. Fundamental to any notion of illness is that it causes impairment of normal fulfilling of work and family tasks and for this reason Parsons' observations have been attacked as being ethnocentric, being defined only in terms of American values and habits.¹² But conditions which are admissible as illness in the U.S. may be seen as normal or unproblematic in less technological and medically sophisticated societies e.g. rheumatism, migraine, hallucinations.¹³

Mechanic¹⁴ reports an interesting case of this conflict between culture and the medical stage a particular society has reached. He describes a tribe of South American Indians most of whom have blue spots over their bodies which the tribesmen consider cosmetically desirable. Indeed men who have none of these spots are marked out as deviant and unmanly, thus losing their right to marry. American medical scientists diagnosed the blue spots to be symptoms of the dietary deficiency disease, dyschromic spirochetosis. Thus the majority were declared sick and the deviant minority the only healthy ones. There is no system of evaluating the relative rightness or goodness of trans-cultural differences of interpretation. Whether the Indians or the medical men have the superior explanation depends on the criteria you choose to apply.

The situation raises important if equally thorny issues. Is it possible that the majority of a population will ever define themselves as ill even when they have manifestly degenerated? It seems unlikely and historical experience such as in pre-war Germany bears testimony. Samuel Butler¹⁵ in Erewhon, a cruelly ironic parody of Victorian health and morality illuminates the human ability to countenance and legitimise the evil and the ridiculous as long as those in power are prepared to live with it. He depicts a fictitious land where illness is treated as a crime and crime as an illness. He points up the farcical nature of many of our legal and medical beliefs through characters like Mr. Nosibor who was just getting over a bad attack of embezzlement, but receiving visitors and condolences. Through a long and detailed description of the trial of a man in his twenties for 'persistent offences of pulmonary consumption and aggravated bronchitis', the reader witnesses a horrifying catalogue of prejudices and value judgements. It was the technique of parody which uncovered the unpleasant truth of Victorian double standards for rich and poor. Not surprising it made the establishment of the day quiver with rage. In a very different way

Roger Bastide¹⁶ was raising the same questions in examining the concept of mental illness. Following a discussion of the ways in which mental illness is defined and finding them to be either normative or relativist (i.e. by comparison with some other man made standard) he asked the telling question: Can a society go mad?

Statistical prevalence has long been one of the bases of definitions of health and normality and as these vary from society to society there is no agreed set of interpretive rules. Sociological studies have well established how personal, social and cultural differences occur in responses to what appear to be the same symptoms. Zborowski¹⁷ and Zola¹⁸ have both described the different responses of Irish, Italian and American men to pain and illness, explaining these differences in terms of traditional beliefs, ethnic optimism or pessimism, societal demands of physical fitness in order to succeed and of family structure. Petrie¹⁹ also looked at pain responses, but at the different ways individuals within a culture behave and think. Her researches led to the construction of a personality-linked continuum of 'augmenters' who amplify painful stimuli and 'reducers' who accommodate stimuli without apparent concern.

Illness, then, may be defined in one way, according to medical criteria but, in another way, the social evaluation of the importance of the condition is the significant factor in action both from patients and from doctors. Yet, as will be seen, in both cases there is a great deal of negotiation involved in the process of definition.

Illness and Behaviour

One of the most coherent criticisms of the Sick Role theory was put forward by Mechanic²⁰ who pointed out that it took no heed of what David Robinson²¹ later called the process of becoming ill. Mechanic called this

process 'illness behaviour' and defined it as 'the way in which given symptoms may be differentially perceived, evaluated and acted (or not acted) upon by different kinds of persons'.

People with symptoms do not automatically declare themselves ill and take to their beds, nor do they necessarily consult a doctor. As Mechanic suggests there is a wide range of responses which themselves are derived, for example, from experience, folk law, the need to complete tasks, or to earn money. In fact, examination of actual illness defining behaviour makes one realise immediately that there is an enormous pool of tolerated illness in the population at any one time which has been ignored, normalised or left to develop. This submerged part of the iceberg of disease is also, as the metaphor suggests, the great bulk of it.

Successive studies have indicated that almost everyone is experiencing symptoms of physical or mental discomfort at any given time. Wadsworth, Butterfield and Blaney²² in their study of 2,153 adults in Bermondsey and Southwark confirmed earlier findings. Only five per cent of the people interviewed said they were free from symptoms or ailments of any kind. The other 95 per cent reported complaints occurring during the two weeks prior to the interview. 19 per cent of these took no action and 76 per cent were taking action of various kinds. Of the total survey population the investigators, using their own criteria, considered that over half needed further investigation which would possibly lead to medical treatment.

Mental illness, though notoriously difficult to define, also exists in far larger quantities than that which is reported to doctors. One estimate using World Health Organisation criteria, put the level of psychiatric illness at more than half of the population.²³ More restrained definitions employed by psychiatrists at the Maudsley Hospital²⁴ put the figure of

emotionally disturbed people at about one in eight. Yet it is well known that people who are disturbed rarely take their condition to the doctor except when disguised as part of a more 'acceptable' physical complaint. Resulting from this reluctance there is again a substantial submerged iceberg.

If a visit to the general practitioner is not the first line of defence, what action normally follows the emergence of symptoms? In fact there is no simple answer to this question. People respond to symptoms mainly as a way of coping with them until they recede and vanish, or reach a threshold of tolerance where the condition becomes threatening in some way. Typically, the first line of defence for all but the immediately serious and traumatic is self-medication. Dunnell and Cartwright²⁵ found that 41 per cent of their national sample had taken pain killers during the preceding fortnight; 14 per cent indigestion remedies, 14 per cent skin ointments or antiseptics; 13 per cent throat or cough remedies, and many others including gargles, alcohol, embrocation, rejuvenators and suppositories.

Over the counter sales of pharmaceutical and other preparations are big business. Brian Abel Smith²⁶ in examining the ethics and economics of the drug industry, comments:

'Throughout the world patients also buy a wide range of medicines without a medical prescription. In the United States, the average citizen spent \$21.52 for prescribed drugs and \$14.14 for other drugs and sundries in 1971. In more developed countries, aspirin and its derivatives, vitamin preparations, tonics and laxatives represent substantial shares of the non-prescription drug market. In many developing countries people incur heavy expenditure on traditional herbal remedies.'

In Britain the bill for drugs prescribed by general practitioners came to £272 million in 1974, whilst the amount spent on over the counter medicines was approximately £95 million, or one third of the amount spent on NHS prescriptions. The 1973 Family Expenditure Survey reports that in a sample two week period 58 per cent of households bought some kind of over the counter medicines (including dressings). The average amount per week for each household was 20 pence.²⁷ In interpreting these figures it should be remembered that the most expensive drugs are not available without prescription and thus the number of occasions on which self-prescribed medication was taken may well rival those prescribed by doctors.

In addition to the now conventional consumption of drugs to assuage symptoms there remains a substantial amount of traditional healing practices in common use. In Africa there is a syncretization of modern scientific medicine with magical and folk remedies.²⁸ Sociologists and anthropologists have given much more attention to this predictable phenomenon, than to its counterpart in developed societies. Nonetheless Coe²⁹ in reviewing the still slender American literature, demonstrates the variety and magnitude of non-medical approaches to illness ranging from homeopathy to full-blown magical rituals. In teasing out the magical elements in modern medicine Tina Carmeli³⁰ heightens our awareness of the important place metaphysical beliefs and symbolic rituals have in the whole gamut of 'getting well' behaviour.

Successors to the Carboloc Smoke Ball are to be found widely advertised in Sunday newspapers and periodicals. Miracle cures appear to continue to thrive despite the Trades Descriptions Act; but there is also a growth in consultation with practitioners of non-medical healing like osteopaths, chiropractors and acupuncturists. Hard information about the actual size of this market and the number of practitioners is hard to come by. Hewitt and

Wood³¹ produced figures in 1975 of some categories of heterodox practitioners who are registered with the semi-official bodies which represent them. There were 61 acupuncturists, 167 naturopaths, 116 homeopaths (medically qualified), 75 chiropractors, 296 registered osteopaths and 60 non-registered. They go on to suggest that 'On available evidence it would seem that something like two hundred thousand people consult an osteopath or chiropractor during the course of a year'. Later estimates suggest that both the number of practitioners and the number of people who consult them is much underestimated by these figures. Nonetheless they indicate a very substantial field of healing activity outside of orthodox allopathic medicine.

In a similar way self-care in illness and disability has in recent years become a much more organized affair. Mutual self-care groups exist for many specific conditions like, Alcoholics Anonymous, Weight Watchers, British Diabetics Association, The Phobics Society, Royal National Institute for the Blind and hundreds of others which exist to help sufferers cope better alone, by drawing on the experience of others. David Robinson³² has pointed out that many of these groups, far from establishing a separation from medicine, become extensions of prescribed medical regimes and engage medical advisers to formulate policy. His argument is convincing in some cases and especially when the condition is mainly physiological. However, within this range there are many groups and movements which have adopted homeopathic and naturopathic approaches based on the rejection of orthodox medicine.

For some sufferers these and other unorthodox healers are the last resort after medical failure, as Cobb³³ has shown for cancer cases. Yet for many they are positive commitments to the kind of alternative medical system prescribed by Illich.³⁴ Ideologically they represent the distant polarity from modern medicine, adopting healthiness as a base for living. Michael

Wilson's book Health is for People³⁵ deserves attention for its sensitive and passionate exposition of the healthy non-medical life. In it he explains the nature of health in many ways, but two of them put his case: 'There is no way to health through the cure of illness'. 'Health is not for the rich to give to the poor. Health is a quality of life they make together.'

Those in the natural health movement view orthodox medical practices as health polluting and monopolizing and thus have no or only minimal contact with it.³⁶ Others hesitate about seeking the aid of a physician for diverse reasons. The literature has come to term this as 'patient delay'. Early studies adopted the Parsonian paradigm of behaviour and thus tried to explain why sick people should behave in apparently irrational ways. As a result inquiries like Goldsen's³⁷ on cancer patients defined 'delayers' as those who waited more than three months before seeking a doctor, and who were more likely to be rural residents and to have lower levels of income, occupation and education than non-delayers. This type of classificatory approach has given way to studies of the social, psychological and economic reasons for non-consultation, focussing on accounts of actual behaviour and analysis of the thinking which gave rise to the actions. Irving Zola³⁸ identified five 'triggers' in patients' decisions to seek (or not to seek) medical care; summarized as Interpersonal Crisis, Social Interference, The Presence of Sanctions, Perceived Threat, and Nature and Quality of the Symptoms. Mechanic³⁹ set out an even more elaborate scheme based on ten key variables which precipitate doctor consultation. These and other studies have centred on closer analysis of individual behaviour rather than on establishing the explanatory potency of socio-demographic factors. This type of work has led to recent and current small scale studies which seek to uncover the meaning of commonsense and everyday life as it impinges on illness and illness on it. Una Maclean's⁴⁰ study of 32 heart attack patients

has led her to challenge the medical belief that infarction is an instantaneous and dramatic event and that patient delay is therefore frequently an inappropriate and wrong-headed label. Her evidence, based upon detailed reconstructions by coronary patients, indicates that the pains were frequently passed off as indigestion and not of the sort which produce paroxysms of pain.

Extended attention has been given to the way people think and behave prior to going to see the doctor because although no one clear simple picture emerges, it is material to the argument that patients have a great deal more control over illness situations than is commonly thought. The choice about whether to seek medical attention or not is a real if problematic one for most people. And if the evidence is to be believed, very few consult without due thought and consideration about the significance of the symptoms to them nor without some clear idea as to what they want from seeing the doctor. Attending a surgery is therefore the culmination of one process and the beginning of another; for, as the author wrote once before

'... the individual must first perceive his condition, then evaluate its seriousness. Given that these two processes have been gone through and he finds it needful of professional attention, he must present his problem to an appropriate agency and be sufficiently articulate to allow proper diagnosis.'⁴¹

Thus having mapped out the area of illness defining behaviour and noted that it encompasses the majority of symptoms without medical aid, it is essential to look at the way illnesses referred to a physician are handled by both parties.

In his performance of the classic sketch 'The Blood Donor', Tony Hancock prefaces the business of giving blood with a string of pleasantries that verge on the obsequious. Having had a pin-prick test taken and in full readiness for his tea and biscuit, he is alarmed to find a whole pint of his blood is required. The doctor says that what he has given is 'only a smear', to which Hancock retorts 'It may be a smear to you mate, but it's life and death to some poor devil'. Although the circumstances are peculiar, the scene represents an important dilemma in all doctor-patient relationships. The consultation process is commonly accepted as one in which the deferential patient acts as a passive receiver. In reality the deference is frequently only the acting out of a traditional role. Indeed by his very presence there the patient has, at least in general terms, already decided what he wants out of the encounter and has chosen to consult his doctor in the belief that his needs will be appropriately supplied.

In the structural-functionalist model the patient behaves according to expectations which are socially agreed and upon which the physician has come to rely. He therefore projects them onto the patient. There can be no doubt that medical practitioners do frequently continue to hold to the views of doctors' and patients' roles set out in this model and still taught in medical schools. But increasingly this sort of behaviour only serves to heighten the conflict of which Freidson⁴² has spoken, rather than to perpetuate the controlled interchange which the medical student was also taught to expect. Freidson commented: '... the separate worlds of experience and reference of the layman and the professional worker are always in potential conflict with each other'.

Evidence from medical sociological studies is tantalisingly conflicting. Large social surveys are almost unanimous in telling us that patient

satisfaction with doctors is very high. Smaller scale studies are equally in agreement that doctor-patient interactions are problematic and conflict ridden. Therefore to look at a small selection of this work is necessary if the argument is to be advanced a step further. This examination will be mainly confined to studies of general practice because it deals with the vast majority of physician treated illness and because the environment of the hospital places peculiar constraints on the ability of patients to manage their contacts with health professionals of all types.⁴³

Ann Cartwright's study of 1,397 patients and their 422 general practitioners, is one of the major contributions to this area of interest.⁴⁴ From her respondents only 4 per cent of patients were thoroughly critical of their doctors, all the rest finding complimentary and understanding things to say about him. 18 per cent said he was friendly and approachable, 24 per cent thoughtful, considerate, understanding or sympathetic, 19 per cent that he visited promptly and without grumbling, 12 per cent thorough or conscientious. There were criticisms of course. Yet, by contrast, only 5 per cent felt he did not always listen, 5 per cent criticised his manner, 2 per cent thought he did not go into things properly and 3 per cent thought he gave unsatisfactory care. At the end of the book she concludes:

'If a plebiscite was held on whether patients wished to retain the general practitioner service or change to a system in which front-line medical care was based on specialists and hospitals, there is little doubt that the result would be overwhelmingly in favour of the present arrangement. But behind the satisfaction of most patients there lies an uncritical acceptance and lack of discrimination which is conducive to stagnation and apathy'.

Patient satisfaction surveys in hospitals reinforce the image that is

retained of the Cartwright study, giving a sense that all but the disputatious minority are contented with the medical care that they get.⁴⁵ Even the very latest gargantuan cross national study lends its massive statistical weight to this view. Based on interviews with an unprecedented 47,000 people in twelve study areas spread over seven countries, the editors conclude that satisfaction with physician contact is high everywhere, irrespective of the nature of the health systems. Only 5 per cent of the interviewees said they were dissatisfied.⁴⁶

It appears inevitable that social surveys which are primarily about consultations and the medical conditions which gave rise to them, will provide reassuring conclusions when the evaluative questions are tacked on at the end. What is interesting is the way such studies produce such a watertight view of the situation. In the quotation above there is reference to patient apathy and passiveness. In fact she wrote 'Most doctors agreed that a good general practitioner could train his patients not to make unnecessary or unreasonable demands on him and two-fifths of all consultations, 57 per cent of follow-ups and 64 per cent of home visits were felt, by the patient, to have been initiated by the doctor. Raphael writes in much the same terms as did Cartwright⁴⁷ in an earlier study of hospital care, where lack of information was the main cause of anxiety. It is indeed true that official complaints against the GP and hospital services are few, but as will be observed later on, these represent only the tip of another iceberg of which American surveyors like Koos⁴⁸ and Freidson⁴⁹ have given us forewarning.

Smaller scale studies offer an alternative view, Julius Roth's participant observation study of TB patients in hospital⁵⁰ and Fred Davis's account of how families cope with the situation where a child contracts polio⁵¹ have provided models for other researchers. In the case of the TB patient, the search for information upon which a scale of progress and time-

tabling can be constructed is a dominant theme. Roth shows how the sick person is starved of the facts and the progress reports he needs, and therefore resorts to elaborate consultations with other patients so as to build up from that lay referral system a set of expectations about the time of recovery and the benchmarks along the way. Davies also gives much attention to the negotiation which goes on between doctors and patients. In the nature of the polio disease there is little basis for medical prediction yet there is a great hunger for information which is mainly denied.

The reciprocity in the doctor-patient relationship implied by the surveys of patient satisfaction, begins to look very flimsy when examined at close quarters. Bloor and Horobin⁵² suggest that fundamentally the relationship is one of conflict rooted in the expectations that doctors have of patients, so clearly expressed by Cartwright. Doctors expect patients to use their own judgement about when it is appropriate to seek medical advice; but later expect them to defer to superior judgement when undergoing medical treatment. On the one hand patients are assumed to be their own diagnosticians (as indeed they must be to present their symptoms in the first place) but then accept the professional view however much it may differ from their own assessment. Lee and Gunawardena⁵³ make a similar point about the way in which people who present themselves at Accident and Emergency Departments not only self-diagnose but decide positively against going to the GP. This way of getting primary medical care is often considered an abuse of the hospital service, but it can also be seen as well calculated patient behaviour.

This 'double-bind' of patient independence and professional control produces no problems at all for some patients who have learned to accept such paradoxes as normal. But for a few it produces disagreements which result in the patient seeking a new GP - a theoretically possible but difficult procedure under the NHS. More commonly patients who disagree take matters

into their own hands outside of the consulting room. As we have already seen lay and unorthodox advice is widely sought and acted upon and this frequently leads to the disregarding of medically prescribed treatment regimes.⁵⁴ But predictably no single mode of behaviour forms the response to dissonant interpretations of symptoms. The range extends from complete acquiescence to outright rejection. Yet whenever differences do occur which the patient finds unacceptable, he may adopt a number of available strategies for re-negotiating previous diagnoses and treatments.

As Bloor and Horobin point out, most consultations are only one of a series and thus harmony may emerge over time as each encounter brings doctor and patient closer to an understanding. Indeed the dialogue over the interpretation of each set of symptoms might be seen an individual experience to which expectations of the doctor are attached, rather than there being a set of generalized expectations for all situations. Robinson provides a number of very clear examples of the special requirements patients attach to conditions and situations, in his study of fourteen families in South Wales who recorded health diaries for him.⁵⁵ Reading these accounts one is made acutely aware of illness as a process and a process which has dramaturgical forms and properties. Following through accounts of illness episodes, it becomes clear that they have dialogue, form and even plot. The negotiation between the central actor - the symptomatic person - and his significant others (his family, friends and acquaintances) is in itself drama.⁵⁶

In their study of the consultation process in general practice Stimson and Webb placed major emphasis on the way this process is managed as a social activity.⁵⁷ And in order to see the face-to-face contact within the context of the whole process, they also paid attention to what, for the patient, goes on before and after the consultation. Once the often elaborately

formed decision to consult has been made it leads to more or less conscious planning of the next stages.

'Anticipating the encounter may begin long before the person is seated in the waiting room. It is, in fact, difficult to divorce this anticipation from the decision-making involved in perceiving a problem as an appropriate one for the doctor's attention . . . This anticipatory period may also include a mental construction of the encounter in terms of how such consultations are usually conducted, how events might proceed in this instance, and the possible outcome and the ways of achieving certain desired ends. Such a construction may also involve the person in considering the likely and probable reactions of the doctor. The person then plans what to say if the doctor follows one course rather than another. For instance, one woman whose doctor had earned the nickname 'Two-minute Todd' reflecting the supposed speed with which he conducted his consultations, intended to try to prolong the encounter in order to clarify her problem and was planning ways of counteracting her expected dismissal by the doctor.'

However the consultation goes, and whatever the outcome, it only forms part of the ongoing drama of the illness episode. Most consultations result in a prescription. The usefulness of the drugs is assessed and the medicine is taken or rejected according to experience, prejudice and whim. The consultation is also evaluated against previous expectations. 83 per cent had had an expected outcome and thus were able to weigh it up in these terms. Dissatisfied and satisfied patients tend to talk out the encounter in order to legitimise the experience and to establish expectations of what should follow with relatives and friends. Just to underscore the essentially social nature of the exercise, the study shows how each patient's account of

the consultation depicts him as the hero. The dramaturgical nature of the process is thus drawn out and the meeting of doctor and patient is placed in the context of human biographies rather than viewed with the narrow confines of the consulting room.

CONSUMERISM, DEFERENCE AND THE PROFESSIONS

A latent kind of consumerism has already been discussed. It is the manner in which patients exercise varying degrees of control over the way their illnesses are managed. If this established pattern is placed in a context of changing relationships between customers and clients on the one hand and retailers and service providers on the other, then it is likely that a more equal and participative arrangement will emerge. But before going on to look at the consumer movement, it is worth taking a look at the notion of deference.

Reference has already been made to the tacit agreement in society at large about the deferential nature of the patient role. It remains largely unchallenged because it underpins many of the hierarchical relationships that continue in modern Britain. The nature of class relations has undoubtedly changed even since the war, but there is still a substantial residue of behaviour ranging from the ingratiating to acquiescence in the 'establishment' view. Sociologists and political scientists have done little to dispel the view that deference is a continuing part of, in particular, working class life in the workplace, in voting behaviour, in consumer habits and in all areas of authority despite some their own findings to the contrary.⁵⁸

Howard Newby⁵⁹ has examined the literature on deference and feels that it fails to come to terms with the many discrepancies in expected and real

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situations because it does not distinguish clearly enough between behaviour, attitudes and socially held beliefs. Thus deferential behaviour should not be taken as confirmation of a deferential attitude. It may merely be a useful mode of achieving some desirable end like getting a sick note or time off work to go to a wedding. This is the mode of behaviour that Goffman⁶⁰ calls 'impression management' and one which is used when people are 'on stage'. The metaphor of social drama is again employed here and the term 'on stage' refers to, say, the behaviour of a butler when talking with his employer and who then goes 'off stage' below stairs.

A good deal of deferential behaviour is ritualised and habitual like the soldier's salute and the addressing of customers in shops as 'madam' and 'sir'. Consequently it cannot be used as a reasonable guide to the attitudes it represents. If deference is to be meaningful the behaviour must faithfully represent an attitude and not just be a piece of impression management. Therefore, Newby suggests that 'real' deference occurs only where there is a congruence of behaviour and attitudes, but that deferential behaviour which denies the underlying attitude is calculative and thus in essence non-deferential.

In relations between the providers and consumers of services there has been a clear shift in behaviour in recent years. There is more assertiveness and less passivity. Consumerism has grown up in America and Western Europe in the past decade manifesting itself in nation-wide organizations like the Consumers' Association in Britain and the Ralph Nader organizations in the U.S. Their first concerns were with the re-establishment of the buyers' rights in relation to manufactured goods. Attention later moving to the quality of service provided by retailers and maintenance firms. Nader led a crusade against the power of commercial interests, whilst in Britain, the less emotive response was more directed at ensuring those merchantable

quality and rights which frequently existed in the Sale of Goods Act 1893, but were submerged by time and practise. By the mid seventies consumer protecting legislation had become enormous as had the machinery for its enforcement, though not fully operational to achieve the objectives of the legislation.

Organizations for the better informing and better representation of the 'ordinary' consumer have grown up in many fields of activity. As well as the bodies which advise on the quality of goods and services offered for sale, there is an impressive number of agencies which offer the same service for such 'groups' as the alcoholics, the mentally ill, those receiving social security, the single parent family, the homeless, the old, the physically disabled, and the politically oppressed. Not all of the groups which provide this sort of advice and support are new, but even those which have been in the field a long time (Age Concern in its former guise as the National Old Peoples' Welfare Council; the Councils for Voluntary Service, MIND as its other self The National Institute for Mental Health, serve as good examples) have newly taken on the clear role of social advocate and representative - a theme developed in a less sanguine manner by Ham in his analysis of consumer groups in the NHS.⁶¹

Citizens Advice Bureaux, Housing Advice Centres, Claimants Union stalls, Pregnancy Advisory Service and Family Planning clinics, Legal Advice Centres, CPAG, and Shelter offices are all familiar sources of information on a national scale. Moreover these bodies will frequently help complainants to lodge their complaint and in some cases act as spokesman and intermediary. It is therefore possible to make a case for the emergence of consumerism as a force to be reckoned with. Yet its main thrust has been confined to consumer durables and related activities. Now this emphasis is also to be found in bodies which represent the claims of the poor, sick and inarticulate

to administrations and bureaucracies.

Whilst it might be claimed that professional services have remained relatively free of informed intermediaries, in fact lawyers, doctors, accountants, architects, chartered engineers, and academics have all received adverse media coverage and assaults of a kind of late.⁶² But the knowledge gap and the elaborate self-regulatory defensive mechanisms have so far held client retaliation at arms length. Nonetheless it could be advanced that consumer pressure groups of an effective and radical kind are beginning to emerge as a challenge to these professions. Indeed, in some cases the professions have turned on themselves as in the case of community legal advice centres, and, in the recent questioning by solicitors and barristers of their practices. Yet, self interest groups by consumers are not much in evidence. Indeed one of the salutary facts about the consumers of professional services is that whilst they might complain bitterly (or give praise) about the treatment they receive it is usually done in private. There appears to be little which binds such complainants together, partly perhaps because once they have survived a particular series of traumatic events they have neither the desire nor the energy to relive them with little prospect of recompense. In addition, the professions' reputation for closing ranks and deflecting complaints, whether well founded or not, may itself act as a deterrent.

In consequence, the Patients' Association has been made up mainly of those who have had the necessary stamina and the knowledge to fight for others. In the context of this paper what is important about the Patients' Association has been its refusal to play the conventional role of layman. The Officers and staff have ensured that they are well informed on medical matters though not medically trained. Their strength in argument with the health professions is the combination of this knowledge with a refusal to

accept that doctors necessarily know best. Even the pretence of deference is stripped away and discussion about complaints is grounded in a clear view of what is humane and tolerable, regardless of the technical explanations.

The Patients' Association is not new, though until reorganization of the NHS in 1974 it was the only national organization of its type. With the coming of Community Health Councils in the new NHS the Association considered closing down in the belief that the CHCs would do their job. In fact CHCs were specifically directed away from handling complaints. The reality, though, is that whilst CHCs do deal with a lot of complaints the Patients' Association still finds a role for itself in campaigning, providing information and picking up those complaints which some CHCs fail to hear about or carry through.

Until 1974 there was very little in the way of organised support for the unsatisfied consumer of health and medical services. But aware of the growth of participation at all levels or organizations, the Conservative government had introduced specific and separate consumer representation for the first time. If CHCs are not the vehicle for laying to rest the traditional view of the ever deferential layman, they do appear - at least to this writer - to be the main route through which a gradual transformation of the status of the patient is likely to materialise.

POWER TO THE PATIENT?

This essay has attempted to indicate the mythical status of much that is written about the total subservience and acquiescence of patients, particularly in relation to the GP with whom they have the great majority of contacts. In so doing it is not claimed that 'client control' is now the norm, for this is clearly not the case. But the picture of unrelieved medical

dominance is challenged insofar as doctors increasingly take account of rising patient expectations based on greater knowledge and the public view of what the NHS has to offer.⁶³ Note has also been made of an emergent challenge to the hold that professionals of all sorts have over their territories. The evidence for their dominance is still impressively strong,⁶⁴ but there are good reasons for believing that as in other fields the ideology of consumerism is increasing in medicine. This paper has also attempted to draw out the amount of negotiability which already commonly exists in doctor-patient relationships. Even acknowledging the relative ignorance patients have of medical terms⁶⁵ and the continuing class gradient in consultation time⁶⁶ and quality of care,⁶⁷ there are strong grounds for believing that trends in patient behaviour will and perhaps already have, forced doctors to re-assess their own attitudes and ways of conducting themselves.

Some indications can be offered of this modification of medical attitudes and behaviour, though not all in the direction which the public would have wished. For one thing, although there has been a steady flow into general practice from hospital medicine since the 'GPs charter' of the mid sixties came to fruition, it has not been matched with an equal commitment to full clinical duties. Although GPs are contracted with the NHS to provide 24 hour cover for seven days a week, in reality, and in some ways not unreasonably, many are now prepared to pay out of their own pockets for Deputising Services to cover their night and week-end responsibilities. More surprisingly, perhaps, even in city areas where large group practices exist which could more easily provide rota arrangements, it is increasingly common for GPs to contract into a deputising scheme. Whilst such schemes are not necessarily the best ways of meeting the need, they do relieve general practitioners from a burden of round the clock responsibility which many now believe to be excessive. Expectations of GPs have been enormously

high and one aspect of the current fluid situation may be the downward revision of what the consumer demands and expects of his doctor.

Indeed, it might be speculated that withdrawal from clinical work into other more rewarding fields appears to be one of the hallmarks of present day medicine. The author's current research on the careers of medical graduates suggests that many doctors with established careers - and therefore established expectations - find the contemporary medical scene either too confusing or too threatening. One of the responses to the feeling that medicine is in decline and that doctors are losing their traditional autonomy is to work less and play more or spend more time with the family. Another is to become involved in medical politics, perhaps in order to retrieve some of the lost autonomy.

In the hospital sphere there are similar movements. As both Elston and Dimmock⁶⁹ point out, the growth of bargaining power amongst health workers in hospitals has influenced relationships between doctors and their non-medical colleagues. For some it has become an opportunity to work more effectively in multi-disciplinary teams. But change is not universally accepted and leads to resentment or frustration in some quarters. Symptomatic of these feelings have been their campaigns for more money and the juniors and their seniors have both resorted in an unparalleled way to strike behaviour previously condemned as unprofessional.

Yet, though the medical profession may have become more vociferous of late it may also have to live increasingly with assaults on its own domain as medicine becomes more publicly accountable. For instance, whilst in their report the Davies Committee on Hospital Complaints Procedure⁷⁰ wrote: 'At the moment, between 8,000 and 9,000 written complaints made by patients or on their behalf are investigated each year by hospital authorities in England

and Wales, which represents a fraction of 1 per cent of the annual total of in-patients', an enquiry they commissioned also showed that approximately 4 per cent of patients interviewed after discharge had made oral complaints or suggestions for improvements during the course of their stay. Complaints against GPs are equally infrequent though they must be made either direct to the doctor or to the little known Family Practitioner Committees. Formal procedures for both have existed for some years, but they require confidence, articulacy and staying power. Moreover the procedures, which are ill-publicised, are all effectively 'internal' in that they are conducted by those who are directly or indirectly responsible for the services concerned.

Consideration of the Davies Committee Report has been long delayed, but recently resulted in DHSS issuing a draft circular on a new Complaints Procedure, to be implemented in 1977. The outcome of the discussions is still awaited, but the prospect is that health workers of all sorts and doctors in particular will become much more accountable to their patients, and that Community Health Councils may come to play an important part in monitoring the system. This will greatly extend their current practice of assisting complainants in informal ways. In addition, the Secretary of State in February 1976 invited the Select Committee on the Parliamentary Commissioner for Administration (who is also the Health Commissioner) to review the arrangements for the independent investigation of complaints which arise in hospitals. This review is to deal with procedures over and above the new Complaints Procedure; so it can reasonably be expected that together they will introduce a complaints machinery which will serve to radically open up discussion about quality of service. The complaints issue tends to crystallise the differences of view between those who provide medical services and those who receive them. But the discussion about creating more equality between the parties is concerned with re-defining the relationship and the processes that the medical enterprise comprises. It is also concerned

with a re-examination of the outcomes which people want from health care. Medical education continues to transmit to student doctors traditional views about patient expectations, which some of the students and some of their educators have themselves begun to question. This questioning must of necessity go further into the established profession as the pressure for patient involvement and consultation about what is to be done for him rather than to him, increases.

Partly as a result of this official widening in medicine's public accountability it is suggested that a new phase in the involvement of patients will begin. But, it follows close on the heels of another. Community Health Councils were established to represent the patient and in varying degree have begun to do that. There is a wide range of performance, as Hallas shows,⁷¹ but a sufficient number of CHCs have made their mark for there to be confidence in their future ability to raise the level of debate in a way which will make doctors, nurses and administrators revise their view of current unsatisfactory services and their priorities for the use of resources.⁷² The common experience of CHCs is accumulating in an impressive way, so that the weak are learning from the strong. There will, of course, remain a residue of Councils which are basically ineffective, but one can only be impressed by the commitment and involvement that characterises much of the CHC world. Their critics continue to point to the lack of formal powers, but some commentators⁷³ have seen this as a positive advantage to be exploited. Additional CHC involvement with the consumer of health care in the context of a more open system could provide for the first time a corporate expression of the individual voices previously muffled by the formality of doctor-patient consultations. People who consult doctors do not go blindly or without some notion of their purpose. Nor are they incapable of judging what they think good and bad medicine might be. Therefore, without placing undue faith and optimism on the impact

of CHCs, they can be seen to represent a crucial stage in the emergence of participative medicine and one which could prove to be a climacteric.

Whether this patient involvement is an expression of consumerism or not is perhaps a semantic debate. Certainly it has every appearance of being part of that movement. Margaret Stacey has expressed doubts about patient consumerism on the grounds that the patient is viewed as more of a 'work object' than as a 'consumer'. However this analysis only defines past and, to a lesser extent, current practices, for if the basis of the relationship can be democratised the patient will cease to have the status of object and become a participant. What is clear is that for sociological analysis there is as yet no appropriate term to describe the patient as 'social actor'. The phrase 'patient as partner, but also as work object' is offered but must necessarily be unusable except as a reminder that new situations are emergent that require not only new attitudes but new language.

Patient demands for participation and their increasing, if modest, use of formal machinery to achieve desired ends along with greater use of personal strategies, has already made its mark on the medical world. Yet, it might be argued that if participation is to take on a real meaning, participant patients, CHCs and other 'consumer' bodies will need to involve themselves further in the politics of health care. If the bodies which represent those who receive health care take their tasks at all seriously, then they must advance a more participative form of medicine. The base for this development is long established in the manipulative devices which patients have employed beneath the flimsy guise of deferent behaviour. In a society with high levels of education and mass media communication it is possible for the ordinary citizen to learn much about the professional preserves of specialist knowledge. Even when he does not have matching knowledge he has become increasingly aware of a network of information providers at his

disposal. The concept of layman is being remodelled so that it incorporates the ability to ask intelligent questions and to expect intelligent and intelligible answers.

In all this excavation of the consumer's emergent identity, the professions' own responses should not be ignored. Participative rights will not be handed out on a plate by doctors or nurses or administrators. They will all fight to preserve their own territories and in so doing slow up the process. Consumers will need to heed the consequences of their assertiveness on the professionals, just as the professionals already have to face a more sophisticated audience for their work. Nonetheless, if the present trend continues patients will no longer be prepared to accept Shaw's diagnosis that all professions are conspiracies against the laity.

CHAPTER FOUR

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professionals. The Patients Association and some of the CHCs have begun to take this line.

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