# PROBLEMS AND PROGRESS IN MEDICAL CARE TWELFTH SERIES ESSAYS ON CURRENT RESEARCH

# **Mixed communications**

FOUR ESSAYS

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## Contents

#### Foreword Gordon McLachlan

vii

# Towards better practice and teaching of communication between doctors and patients

#### CHARLES FLETCHER

Introduction, 3. Practice and teaching of the interview, 4. Evidence of doctors' lack of interviewing skills, 5. The importance of interview failures, 7. Why are doctors' interviews so often faulty? 7. Doctors' attitudes to their patients, 7. Practical problems, 10. What can be done to Inappropriate training, 8. improve the interview? 10. Improved undergraduate teaching, 10. Pre-Postgraduate interview training, 15. consultation questionnaires, 14. COM-MENTARY, 15. Practice and teaching of the exposition, 19. Evidence and consequences of failures in the exposition, 19. Why are doctors' expositions so often inadequate, 20. Doctors' attitudes, 20. Patient attitudes, 21. What can be done to improve the practice and teaching of exposition? 23. Doctors' attitudes, 24. Patients' attitudes, 26. COMMENTARY, 29. Communication with patients with fatal illnesses, with those who are dying and with the bereaved, 31. COMMENTARY, 33. Some conclusions and proposals, 34. COMMENTARY, 37. References, 39.

## The structure of hospital in-patient costs

43

#### J. R. ASHFORD AND M. S. BUTTS

Summary, 45. Introduction, 45. Method of approach, 46. A survey of theoretical models, 48. The construction of an empirical model, 50. Numbers of beds or numbers of patients? 50. Variations in efficiency, 51. Economies of scale, 52. Grouping of specialties, 52. The model building process, 54. Results, 55. Uses of the model, 58. Comment, 60. Acknowledgements, 62. References, 63.

1

vi Contents

# Handicapped children and their families. Their use of available services and their unmet needs

# JOYCE RUBISSOW, JUNE JONES, FREDERIC BRIMBLECOMBE, AND DILWYN MORGAN

Description of the population, 67. Identification of handicapped children, 68. Description of handicapped children, 69. Classification of functional handicap, 69. Comparisons with other studies, 72. Control group of children, 73. Relationship between birth and subsequent handicap, 73. Use of primary health care services, 73. Family doctors, 73. Health visitors, 75. Use of hospital services, 76. Out-patient clinics, 76. Admissions, 78. Use of laboratory Use of accident emergency department, 78. Child abuse, 79. Parents' views of hospital services, 79. Child health clinics, 80. Child guidance clinic, 81. Speech therapy, 81. Preschool education, 81. Social services, 82. Voluntary agencies, 82. Realities of life with a handicapped child, 83. Parents' problems, opinions, and suggestions, 83. Summary, 84. Discussion and description of action initiated, 86. Lack of family support, 87. Family support service, 87. Social services, 88. Education, 88, Conclusion, 89. Acknowledgements, 89. References, 89.

#### Progress and problems in participation

#### JACK HALLAS

Introduction, 93. DHSS: some problems and priorities, 94. Current concerns of hospital management, 96. Sector and functional management, 98. CHCs and the operational level of the NHS, 103. Introduction, 103. Commentary on the pattern of working group formations appearing in Appendix I, 104. Mothers and children, 105. The elderly, 109. The normally healthy and acute services, 112. Preventive medicine, health education, and a glance at the great fluoridization debate, 117. Re-examination of the original hypothesis, 120. Current texts and future problems, 122. References, 125.

Appendix I. Working groups of selected CHCs

127

91

65

## **Foreword**

When the Problems and Progress series was first launched experimentally in 1964, the objective was broadly to present the results of research in progress and it was envisaged that the reports would be of two kinds. These were preliminary communications of results which it was possible could become the subject of longer works, or final reports of research not requiring greater elaboration than the essay form provides. While the objectives have remained the same, during the fifteen years that have elapsed, circumstances have sometimes made it possible to put together in the same volume essays on roughly the same subject, but the major aim has continued to be to provide an occasional forum for essays covering a wide spectrum of health affairs mostly embodying the results of health services research, including the exploration of concepts about health.

There have been one or two critics who seem to assume that collections of papers disparate in genus and tone must fail because they lack some common theme, but the paramount policy is to provide a platform for serious observations through the medium of essays of a length too long for many of the periodicals concerned with sociomedical matters, in the hope that their value will be to illuminate dark corners of the complex field of health, and sometimes lead on to yet more important feats of exploration. Thus, there have been many complimentary reviews of the Trust's Rock Carling series. Particularly in recent years the monographs Effectiveness and Efficiency (Cochrane, 1971), The Role of Medicine (McKeown, 1976), and The End of an Age of Optimism (Dollery, 1978) have been commended and written about, almost as a series on their own. Yet, all of these commissions can be traced to the stimulation of Trust interest in prevention and in examining the scientific evidence in medicine. originating in the commission to Dr (now Professor) George Knox, which resulted in the essay 'Cervical cytology' published in 1966 in viii Foreword

the second Problems and Progress collection and begat the screening seminars, which resulted in the seminal Screening in Medical Care published in 1968. It may be that some of the 114 essays which have appeared in the series until now, have been more important than others which have been perhaps of ephemeral interest, but health problems and their solutions run deep and it is practical policy to cast bread upon the waters.

This collection includes Professor Charles Fletcher's report on the follow-up to his Rock Carling publication Communication in Medicine which raises many questions requiring practical answers. of interest not only to the medical profession but to the community of potential patients. Mr Hallas's essay is concerned with the development of Community Health Councils as participating bodies without direct power in the NHS, and gives some insight into what they can effectively do. Professor Ashford's and Dr Butts's paper deals with the use of statistical models and methods to determine the structure and magnitude of costs of hospital in-patient care. Above all it has a practical application, since it explores the implications of such studies in the context of current procedures for monitoring, planning, and resource allocation within the NHS, topics likely to perplex the 1980s. The essay 'Handicapped children and their families' from the multidisciplined group in Exeter, is based on a study of all children born within the city of Exeter between the years 1967 and 1971 and which identified all those who during their first years of life developed a handicapping condition of prenatal and perinatal origin. It shows what can be done as a practical exercise by any authority in the health and welfare field, to identify the unmet needs of handicapped children and their families as a preliminary to social action.

There is thus no common theme running through the collection; but again such essays illustrate the highly complex nature of the NHS and a further selection of its problems for which there are no simple solutions. Together with those in the previous eleven collections, they indicate the wide range of interests which must be served and utilized in the development and improvement of health services in all their aspects, which is a prime purpose of the Trust.

GORDON MCLACHLAN

Nuffield Provincial Hospitals Trust, April 1979

# Towards better practice and teaching of communication between doctors and patients

# **Professor Charles Fletcher**

With commentaries by participants in a special meeting held at the Nuffield Provincial Hospitals Trust to review the report

# Towards better practice and teaching of communication between doctors and patients

#### Introduction

Concern about unsatisfactory communication between doctors and patients has been growing in recent years owing to many reports of patients' dissatisfaction, to the increasing influence of psychiatrists and general practitioners in medical schools, to proposals for more attention to behavioural science teaching in the Todd report, to publications by the Nuffield Provincial Hospitals Trust (3, 18) and to Patients' Associations which ask for greater participation by patients in their own management as consumers of a service rather than as supplicants for help.

The report of a Working Party of the Royal College of General Practitioners (53) has explicitly emphasized the need for practitioners to acquire skills of communication and has dealt in some detail with methods of teaching them, and this emphasis is seen during the three years of vocational training which all practitioners must now have before they become principals. Yet it has seemed that many, if not most, clinical teachers in British medical schools have remained aloof, confident in their own untutored skills and in the ability of good students to emulate them without any specific training.

In 1976 I was invited by the Trust to make an appraisal of the present state of this teaching in British medical schools and to attempt a 'conceptualization' of the issues, and to this end between March and September 1977 I visited all the Scottish medical schools, nine English provincial schools, and eight London schools. I also had discussions with several individuals unconnected with medical schools who had a special interest in the subject.

I cannot claim to have made a complete assessment. It is difficult

to discover who, in any school, is actively interested in teaching communication. In few schools did I have much opportunity to talk to uninterested teachers and I spoke to students in only one or two schools. For these reasons I cannot present a quantitative report of, for instance, how many hours are devoted to teaching communication in different British medical schools and can only provide qualitative impressions.

The consultation, the 'essential unit of medical practice' (46) consists of two distinct parts: the *interview*, in which the doctor seeks to discover why the patient has come to seek his help, and the *exposition*, when he informs his patient of his conclusions and diagnosis, and what treatment and advice he considers the patient needs. Since the skills of communication required in these two parts of the consultation are in many ways distinct they are dealt with separately. For each of them I shall first summarize the errors that may be made and their consequences and I shall then consider what is being done and what more could be done to avoid these failures of consultation so that medical students could, in their turn, be taught how to avoid them.

I shall deal separately with one special aspect of consultation which presents special problems and in which failure in communication is particularly common, namely communication with patients who have fatal disease or are near to death, and shall finally summarize the conclusions of some who have already seen this report as to how to further the performance and teaching of better communication between doctors and patients.

Many doctors are highly skilled communicators and are successful in both the interview and the exposition. Nevertheless, failures in both parts of the consultation are common, and since there is no doubt that their frequency could be much diminished by measures that are now available, it is on failures and their avoidance that this report inevitably concentrates.

# Practice and teaching of the interview

The term interview is used in preference to 'history-taking' which implies that the doctor's job is simply to ask questions in order to extract information from an unwilling patient rather than to facilitate an unwilling or hesitant patient to tell him all about the problem for which he seeks his doctor's help.

#### Evidence of doctors' lack of interviewing skills

In her study of people's views of their GPs Cartwright (12) found that most of their spontaneous complaints were about doctors being too busy to talk to them. In response to more specific questions less than half the patients said they could discuss family problems with their doctors.

Byrne and Long (10) analysed recordings of 2,000 GP consultations in the early 1970s. They considered that the interviewing behaviour of their doctors fell into two main types: doctor-centred behaviour consisting chiefly of closed questions about physical symptoms, their nature and times of occurrence, and patient-centred behaviour consisting chiefly of listening to, facilitating, and interpreting information offered by patients about their problems in response to open questions. A single consultation may of course contain examples of both types of behaviour, but in an analysis of some 3,000 units of behaviour in one group of GP trainers it appeared that doctor-centred behaviour tended to predominate. Seventy-seven per cent of these items were doctor-centred and only 21 per cent were patient-centred.

These observed doctors tended to make predominant use of one or other type of behaviour fairly consistently. Both types of consultation are liable to particular errors; the doctor-centred behaviour tends to overlook social and psychological problems which are of major importance in general practice while patient-centred behaviour may miss physical illness. In this context of general practice the doctor-centred type of interview is more likely to fail in its purpose but is more often used, presumably because this is the type of interviewing which has been predominantly taught in medical schools.

The outcome of interviews in medical consultations in hospital outpatients seems good. Hampton et al. (19) found that the final diagnosis was reached after taking the history in 83 per cent of medical out-patients. But a psychiatric study of medical in-patients in the wards at one of the teaching hospitals concerned in Hampton's study showed that one in five of medical in-patients were psychiatrically ill, predominantly with depression. No mention of this aspect of their illness appeared in the case-notes (36). It is possible, of course, that these personal problems were known to the medical staff, but the house physicians seemed to be predominantly concerned with the physical well-being of their patients and were reluctant to ask about psychological responses to physical illness, particularly in patients

with malignant diseases. The authors quoted previous findings of a similar kind and suggested that this 'hidden' morbidity was both clinically important and that much of it was remediable. While this may be debated, for this point has not been established, the study seems to indicate that orthodox history-taking in medical wards may easily lead to overlooking personal and psychiatric problems which, if not curable, might at least be helped by discussion, and should certainly be recorded in the case-notes.

No detailed report on the techniques used by hospital doctors in out-patient consultations appears to have been published, but Professor Byrne in Manchester told me that some audiotapes which he had made of consultants' interviews were 'not much better than' those of the GPs he had recorded. It may be assumed from this, from the way in which history-taking is generally taught in medical schools and from my own experience of watching a few consultant physicians at work, that most of their consultations are doctor- or disease-centred. Psychiatrists' consultations are, of course, quite different. A high proportion of their patients have problems rather than organic disease and they have now usually been trained in patient- or problem-orientated interviewing.

In general practice and psychiatry there is often no sharp distinction between the interview and the exposition, when the interview itself constitutes a form of counselling by its analysis and discussion of what the patient's problem really is. In general practice, good interviewing may often reveal that the patient's apparently organic symptoms are due to anxiety, depression, or to some domestic or social problem. The interview in this case may help the patient to cope and no further exposition is needed.

When this happens the interview really takes the form of counselling. And when this is required the doctor may wish to refer his patient to one of the many counselling organizations (a directory of these is available from the Standing Conference for the Advancement of Counselling, 36 Bedford Square, London WC1B 3HO). The doctor should be able himself to deal with many personal and domestic problems, but if he is to do so he would be helped if he had learnt the art of counselling. Teaching doctors how to counsel might best be done after graduation for it is an activity that requires a degree of maturity which few medical students, at the time of their final examinations, have yet attained. Such training is, in fact, part of the postgraduate training of general practitioners and psychiatrists. This is

perhaps where it should remain, but undergraduate medical students should be introduced to the elementary principles and techniques that are involved.

## The importance of interview failures

The main consequence of faulty interviewing must be inadequate or even wrong diagnosis leading to wrong treatment. The commonest error is diagnosis of physical disease when the real problem is psychosocial. Estimates of the proportion of primary care patients whose main reason for seeking their doctors' help is psychosocial vary widely but they are certainly a large proportion. This can also be true in hospital. At one provincial medical school I was told that such problems were prominent in about 40 per cent of both paediatric and general medical out-patients. Apart from these failures making a major contribution to wasted drug prescribing with its enormous financial consequences, they must also leave many unhappy and dissatisfied patients who, had they been enabled to present their real problems to their doctors, might have been helped by counselling. It is not only patients who feel dissatisfied after doctor-centred interviewing. Doctors also find more satisfaction in their work when they have learnt improved techniques.

# Why are doctors' interviews so often faulty?

Doctors' attitudes to their patients

Doctors are inevitably tempted to adopt a dominant attitude towards their patients. They, after all, have the knowledge which gives them the power, if not always to cure, at least to explain or alleviate their patients' diseases. Although many patients expect and accept a submissive relationship to their doctors, and do not wish to be involved in any decision-making about their treatment, there are others, probably a majority, who would find it easier to communicate with doctors who adopted a co-operative rather than a managerial role in many aspects of their care.

The doctor's dominant attitude has various origins. One is a feeling of insecurity, often unconscious, in their daily work. They cannot always diagnose their patients' symptoms and they often have to make critical decisions for their patient's welfare or even survival on incomplete evidence supplemented by 'hunch' derived from experience. They have to learn to steel themselves to make such decisions, but unconscious anxiety may remain (51).

Doctors also have to maintain a discreet and proper emotional

distance from their patients; for, if they do not, it could be difficult to discuss the intimate matters which are commonplace in the consulting room but taboo in social conversation. If they were to allow too close a relationship they would also be burdened with anxiety about their gravely ill patients in their leisure hours. Careful discussion and guidance is essential if young doctors are to learn how to combine this necessary emotional aloofness with expressions of courtesy, warmth, and friendliness, yet few students are explicitly taught about this matter.

Another source of anxiety arises from doctors encountering personal problems and attitudes in their patients which arouse feelings of hostility or guilt. 'Unfortunately' it has been pointed out 'many experienced doctors have, throughout their entire career, avoided direct confrontation with any patients' emotional life. They were not helped to deal with the anxiety created in themselves while training, nor were they given simple instructions on how to proceed and what to expect' (45). In the absence of such training and instruction, it is not surprising that many doctors tend, in their interviewing, to concentrate on organic disease, and fend off any mention by their patients of their emotions.

This difficulty is compounded by the triumphs of modern therapeutics, both medical and surgical. With physical treatments so effective, and with so much technical detail to be learnt about their scientific basis and effective practice, it is easy for doctors to turn away from the problems that patients present as people and to see them as deranged biological machines. Preoccupation with techniques can divert attention from patients' fears and hopes, problems and perplexities which arise from or may cause their illnesses, and which must be appreciated if treatment is to be effective and acceptable to them. No matter how much doctors avow their concern with the 'whole patient' many of them communicate the superficiality of this concern to their patients by the way they deal with them, and students may follow their example.

# Inappropriate training

Doctors have, until fairly recently, received their professional training almost entirely in hospitals where it has been assumed that the doctors' main job is to diagnose physical disease. For this he is taught to 'take a history' using repertoires of questions on symptoms and the techniques of physical examination. The teaching is usually

given in short 'introductory' courses at the beginning of the first clinical year which consist of a few lectures and demonstrations together with 'hand-outs' of conventional instructions. Few of these are so informative or comprehensive as that described by Maguire and Rutter (39), and usually make only passing mention of the need to appear kindly, interested, and sympathetic with the patients' problems. Little, if any, attention is given to the inhibiting effect of a stream of questions on a patient's ability to say what he wants to say. 'If the doctor asks questions in the manner of medical history-taking he will get answers—but hardly anything else' (2). Nor is the importance of listening adequately emphasized. 'The ability to listen is a new skill necessitating a considerable, though limited, change in the doctor's personality—he must be able to notice and to tolerate emotional factors active in the patient and accept them as worthy of his attention' (2).

Conventional teaching has been shown actually to cause deterioration—or at least to prevent any improvement—in students' interviewing skills in the course of their clinical training (4, 20, 23, 38). In their first year they have not yet learnt a battery of formal questions and so listen with interest to what patients have to tell them, but by the time they qualify they have learnt the orthodox inquisitorial technique which inhibits or prevents simple listening. One student said: 'The natural instinct of a student at the beginning of his course to treat people as human beings is gradually destroyed by being taught to treat them as examples of disease'.

Students also realize that in their final clinical examination they will only have to take a history from one patient with major organic disease—and that this is all they will be expected to diagnose. One teacher said that it was getting more difficult to teach communication because the elaboration of the curriculum keeps students from spending time with patients. A pre-registration houseman at a medical school in London told me that several of his contemporaries had passed their final examination without ever having talked to a patient alone. Even when they have had real experience in interviewing this has often been only in the unsatisfactory condition of crowded outpatient departments or behind screens in a ward where neighbouring patients can overhear what is said.

It is remarkable that despite this sort of teaching as students many doctors do discover in the course of their clinical experience how to listen to as well as how to interrogate their patients.

#### Practical problems

Shortage of time is the reason most often advanced for poor interviewing in general practice where the average time of each consultation is only 5-7 minutes. But GPs who have learnt patient-centred interviewing say that this time is sufficient for them to distinguish the minority of patients whose problems require lengthy counselling from the majority who do not. They point out that half an hour specially allocated to one of this minority may save five minutes every fortnight for a year or more which they would otherwise have needed. One doctor who had been on a postgraduate course in Professor Byrne's department had originally an extremely doctorcentred type of consultation style. But after the course, tapes of his current interviews showed he was now listening to his patients more and talking less. He said that although some of his consultations did take longer it was worth it because he had begun to identify and deal with the real problems of patients he had previously regarded as a recurrent nuisance. In some cases effective psychotherapy appears to be possible within a series of very short interviews (25). In the longer consultations of specialist practice efficient interviewing can also save much wasted time.

In hospitals the consultation often takes place not in a quiet consulting room but in the out-patient department. There may be several doctors interviewing patients in a single room, and in the wards screens may just be drawn around a bed and both doctor and patient know that what is said may be overheard.

# What can be done to improve the interview?

Improved undergraduate teaching

James Spence (46) commented on the difficulty of teaching the art of consultation in his day. He said, 'It is best taught in the rooms of out-patient departments. It is not easy in these places to arrange a form of out-patient consultation in which the students can share. We do what we can in our department to demonstrate its methods and purpose, hoping that the students will learn from example, but they can get no more than a glimpse of the art and skill because of the paradox that in most cases it is impossible to conduct a satisfactory consultation in the presence of a third person.' This difficulty has now been overcome by excellent videotape recordings of interviews of various kinds which can demonstrate many of the difficulties that doctors may encounter and how to overcome them, by one-way

mirrors which enable students to observe consultations without the patient or doctor being bothered by their presence, and, most useful, by the facility which videotape recordings now provide for students to see themselves interviewing patients and, with the guidance of a tutor, to see what mistakes they are making so that they can correct them.

Students (and doctors) who have never seen themselves talking to patients remain unaware of how they may be hindering a patient's freedom of expression by interruption and by non-verbal indicators of boredom, disinterest, or impatience, and how they may be missing clues which their patients give of hidden emotions. This educative self-monitoring can also enable students to divest themselves of the idea, encouraged by conventional teaching, that the doctor is in full control in the consultation, and to see how the patients' responses may influence the doctor's handling of the interview as much as the doctor's attitude and responses influence the patient.

At present many doctors first become aware of these interactions through videotape after qualification. When they first see themselves interviewing patients as trainees in general practice or psychiatry they are often horrified by what they see. Such doctors may have the right attitude to patients but realize for the first time that their faulty interviewing technique gives the wrong impression.

When videotape has been used to teach students it has been demonstrated (37, 38, 48) that these students improve their skill at interviewing patients much more than those taught only in the conventional, didactic way. It has also been shown that actors can faithfully simulate real patients with both physical disease and psychological problems, and their use avoids placing undue strain upon real patients in this sort of teaching. Students who have been given actors to interview without knowing it are unable to detect that they are not real patients (22).

I found that few clinical teachers were aware of the value of these methods even if they did know of their existence. Even fewer have read the literature about them. The techniques are well-known in Departments of Psychiatry where the interview is almost the sole method of diagnosis and also in Departments of General Practice where good, time-saving interviewing is essential for effective patient care. Indeed this sort of teaching, where it is being used at all, is virtually confined to Departments of General Practice and Psychiatry, and may therefore be looked on by students as relevant only

to those branches of practice. It should be used in all clinical departments.

To learn skilful interviewing a student must learn something about the psychology of personal interaction so that he can more easily recognize and deal with emotional tensions which may arise in himself or his patient in the course of an interview. This teaching should so far as possible be given in a clinical context: lectures by non-clinical behavioural scientists are frequently felt by students to be irrelevant or even impertinent. They must be given a fairly concise structure to guide them in the course of the interview. In both these aspects of learning they can be considerably helped by appropriate illustrations of various types of interview on film or videotape. It is also desirable that they should come to realize how much more satisfying patient-centred interviewing can be both to patient and doctor.

They must then be enabled to see their own performance in interviews with patients (real or simulated) and be guided by a tutor in detecting and correcting mistakes. They may need simple counselling to enable them to handle any awkward emotional reactions against patients which they may develop. Videotape teaching should begin at the time of first contact with patients and be repeated on appropriate occasions throughout the clinical years. It was suggested to me by one Professor of Psychiatry that when students pass their final exams and become 'real doctors' their attitudes harden towards their patients, who are now 'cases' whom they can manage and no longer people for whom they should care. This indicates that training in communication should continue into the pre-registration years and beyond.

This sort of teaching need not use up much more curriculum time than is already used by less effective didactic teaching. In two American studies it has been reported that simulated patients could be trained to coach students in interviewing from the patients' point of view (21, 48, 49). If anything they did it better than doctors who tended to deviate off into discussing technical matters of diagnosis and therapy instead of concentrating on interviewing skills. These paraprofessionals were less expensive than doctors in terms of salaries.

In one school where videotape teaching was given during a month of psychiatry in the second clinical year, two pre-registration housemen said that after they had spent their third year concentrating on the factual knowledge required for their final examination they had forgotten what they had learnt about interviewing and had had to start discovering how to talk to patients all over again. It seems unlikely that there is really no persistence in this teaching. Studies are planned at Manchester and Birmingham to see whether students who have not had videotape training in their middle year are better during their pre-registration house appointments than those who have not had it.

Videotape teaching can indeed be used for postgraduates and can be very effective at this stage, but the distress it may cause them may lead to considerable resistance which could have been avoided if they had been accustomed to its use as students.

Those who have used videotape teaching find that some students—about one in ten—fail to benefit from it, apparently because they have natural difficulty in relating to patients. Yet, when asked, they do not say they intend to become laboratory workers, but that they want to go into clinical practice. No student should be allowed to enter a clinical branch of medicine until he has shown himself competent at the art of consultation. Those who are unable to learn the necessary skills might be directed into non-clinical branches. This would require clinical deans to assume a greater responsibility for career guidance of their students than most of them do today.

At present students pass their final examinations without any adequate test of their ability to interview. They do 'take a history' from a patient in their 'long case', but they know that they will not be watched as they do this and that they will be marked only on the number of items of information about physical disease that they elicit and on how they interpret them. They know it doesn't matter how they get their information, nor whether they miss information about accompanying social factors, fears, and worries. Any part of the medical curriculum which is not tested before qualification is inevitably neglected by students as being manifestly unimportant. Yet these untested skills of interpersonal relations and communication may, in the long term, be at least as important for the students' ability to help their patients as the skills and knowledge which are tested. Videotape, or at least audiotape, should most certainly be used to assess their competence at conducting a consultation before they qualify to practice medicine. Valid and repeatable methods of assessment of interviewing skills are already available and it should not prove difficult to develop satisfactory scales for assessing giving of information and advice.

To carry out this test in the final examination would not be impossible (15), but it would be unrealistic to expect students in the stress of their examination to be sufficiently at ease to interview skilfully. They should be tested by videotape—using actors if necessary—at some time in their final year and should not qualify for clinical practice until they have shown themselves to be competent communicators.

An alternative possibility would be to test interviewing skills after the pre-registration year, for it might be difficult for students to develop adequate skill until they have had experience of dealing responsibly with patients as doctors. Dr Donald Irvine, Secretary of the Council of the Royal College of General Practitioners has noted:

We find it necessary to spend much time on teaching the processes of consultation in our vocational training schemes because of the deficiencies of the pre-registration year, when we believe that young doctors who are taking clinical responsibilities for the first time in their lives should have special instruction in this subject based on their own clinical work with patients, but do not. The College's membership examination does not include a formal examination of consultation skills, but they are giving active consideration to a clinical test which would have this aspect as a major aim.

In the Newcastle region the College is trying an experimental line of observing the doctor at work with patients in his own practice. They are trying this out with paediatricians as well as Camily doctors. It would be worth watching this experimental technique to see whether it could be applied to hospital doctors during their pre-registration year.

## Pre-consultation questionnaires

One method of obtaining information more easily from hospital out-patients has been to send them simple questionnaires on symptoms, and sometimes other problems, to complete at home before the consultation (18a). This can not only save time spent on routine questions on symptoms which may be irrelevant, but may allow tongue-tied patients to disclose information which they might not mention in a hurried interview with an awe-inspiring doctor.

This technique undoubtedly merits further study. Apart from any formal questionnaire, patients should certainly be encouraged to bring notes of special points to which they want to draw their doctors' attention but might forget in the fluster of confronting the

doctor. At present some doctors look on this sensible procedure as a form of 'maladie du petit papier' described by Charcot as an index of hypochondria. No means should be neglected by which shy patients may find it easier to communicate with their doctors.

## Postgraduate interview training

General practitioners and psychiatrists use modern methods for teaching postgraduates how to interview, but other branches of medicine and surgery appear to do nothing about it. It appears that many medical registrars, for example, have acquired inadequate skills of interviewing or giving information, because those who enter general practice or psychiatry are usually found to perform unsatisfactorily. Consultant skills are not tested in the membership examinations of either the Royal Colleges of Physicians or of Obstetricians and Gynaecologists, nor in the examination for the Fellowship of the Royal College of Surgeons. It is not mentioned in any of the specialist training schedules of the Royal College of Physicians. It has never been considered as something which should be taught at the Royal Postgraduate Medical School at Hammersmith.

Means by which a change might be brought about are difficult to define. The essential thing is to provide doctors with feedback about how they talk to their patients. This might be promoted by a study of consultants' interviewing skills similar to that carried out in general practice by Byrne and Long (10). If consultants were influenced by such a study or by the proposed conference (see p. 36), or by demands made in revised curricula of medical schools, they might one day be moved towards developing more sophisticated skills and techniques. Eventually, if today's students do become better educated in communication, they may well insist, when themselves consultants, that the topic should become a recognized part of postgraduate education.

#### COMMENTARY

Conflicting opinions were expressed on interviewing skills of clinical teachers in medical schools. Too much emphasis could be given to the arrogant or insensitive attitudes of a few teachers so that the excellence of the majority was overlooked. But students now often complain to Deans and Professors of Psychiatry or General Practice about the former. While this presages well for the future these complaints add to the extensive anecdotal evidence that many hospital consultants treat their patients as specimens rather than people.

Some participants thought that interviewing skills were now much better than they used to be. A comparison of the sort of information recorded in old hospital notes at one hospital showed that they were concerned solely with organic disease. More recent notes recorded much more information about personal and social problems. Others thought that taking account of the changed expectation of patients today, communication was relatively worse than it used to be. One physician after listening to final-year students taking histories particularly noted what a small proportion seemed to have developed the skill of listening to what the patient said. Very often they actually rejected clues which the patient offered, because they were so busy thinking up the next question to ask, so there had been a failure to teach these students how to listen to patients. Being quite good at talking, they went on to entirely irrelevant questions before the main substance of the patient's complaint had been dealt with.

Some participants made the point that while there was clear evidence about the deficiencies of interviewing skills in many entrants to general practice and the majority of established general practitioners, there had been no study of the skills of hospital consultants who teach students. Some indeed asked for the production of hard evidence before any suggestion was made of a lack of skill. But this request was looked upon by others as a delaying tactic or expression of anxiety. The debate illustrated lack of agreement about the present effectiveness of patient interviewing.

It was stressed that the most important factor which inhibits doctors from recognizing defective interviewing skills is that they so seldom get any feedback. This can now be provided by audiotape or videotape (which is discussed in the next section). Before this development no doctor could ever see or hear himself as his patients heard and saw him, so that even the most well-intentioned doctors could develop serious faults without ever realizing it. Not only is there no feedback about the doctor's own skill, but few doctors ever see a colleague interviewing a patient. There has therefore been an inevitable lack of appreciation of the sort of insensitivity to patient's feelings about which many of them complain.

There was general agreement on the faulty concept of the interview which conventional teaching of history-taking induces in many students. Asking strings of questions pre-empts free communication.

Another problem, seldom explicitly recognized and discussed with students, is the basic peculiarity of the clinical interview in which

17

matters are frankly discussed that are never admitted to normal social intercourse. This may lead students, as they become more and more adept at the specifically clinical aspect of the interview, to forget that they still need to use their normal social skills of courtesy and politeness in talking to patients.

With regard to method, there was general agreement that videotape teaching for interview training was essential. Although some participants questioned the artificiality imposed by interviewing in the presence of a camera, those with experience of the method said the camera should be concealed but was anyway very soon forgotten about. In any case, the clinical interview is inherently rather artificial because of its very nature, at least for students. The need for obtaining hard evidence on the persistence of the effects of videotape training, given in the undergraduate course, was emphasized and the planned Manchester and Birmingham studies were welcomed. Several participants emphasized that the technique is expensive in time and resources, particularly if every student is to have individual tuition. One way of reducing this difficulty is by group teaching. Some who had had experience of groups found that students were soon bored by watching their fellow students interviewing. Others had found that this difficulty could be overcome by getting the students in a small group to act as tutors themselves, each scoring other students' interviews so that they were actively engaged in appreciating the problems each interviewer was encountering.

In relation to the question of when, in the course, video training should be given, consultants at one medical school had insisted that it could not be used till the end of the third year when students had learnt enough medicine to be able to take a history.

However, one participant pointed out that medical schools require students, in taking histories, to learn not only how to interview but what the content of 'medicine' is, and these two purposes cannot easily be served by the same experience. This does not mean you cannot learn medicine by taking histories and gaining experience of patients, but that you do not improve your interviewing by taking that kind of history. The opportunities in the process of medical education about communication seem to occur, first, in the pre-clinical phase during a behavioural science course, second, in a course introductory to clinical medicine and third about six weeks into actual clinical work. There is a particular point when the student suddenly finds himself up to his neck in all the things which he has wanted to be involved in but he finds it extremely painful.

Some of them retreat into the format of history taking they have been taught. Some only ask the questions they expect the consultant to ask them. Some just feel inadequate. This is the time to give them guidance and help.

The general feeling was that there should be continuing teaching on the nature of the interview, starting in the pre-clinical period, and that tuition, where possible with videotape, should extend through the clinical years and continue into the pre-registration year and into vocational training.

There was some discussion of 'sensitivity training', much used in industry for communication training. This is a process which does at least teach—if you are capable of learning it—not only how to listen but how to pick up things which are not said. This, it needs to be emphasized, is not just listening, it is seeing as well as hearing, picking up non-verbal clues. The other part of it, which is very important, is helping people to be aware of themselves, of their own emotions and feelings, and of the way that they impact upon other people. For a doctor to understand how frightening he is because of the way he behaves is a very important thing for him to learn. In relation to this patients should not be allowed to regard their doctors as omnipotent. They must be made to feel free, and indeed encouraged, to ask doctors as many questions as they ask them.

It was agreed that students must be given more time and opportunities to listen to patients.

It was also necessary that students should appreciate, not only the emotional, but also, intellectual, cultural, linguistic and sociological barriers between doctors and patients which inhibit free mutual understanding.

Pre-consultation questionnaires were reported to have been found helpful by two participants, in particular for gathering essential factual information, for instance about menstrual and obstetrical histories in O & G departments. One study was reported in which hospital doctors were asked to list the routine questions which they regarded as essential to ask all patients from whom they took a history. When their interviews were subsequently recorded it was found that they actually only asked from 20 to 60 per cent of them. So 'essential questions' are very often omitted, but could readily be covered by a questionnaire.

There seemed to be no doubt that this technique could be valuable, but that it required further study and evaluation.

The topic of postgraduate interview training received no detailed discussion. It was admitted that little attention has yet been paid to how teachers should be taught. Courses on this topic are offered by the Postgraduate Medical Federation. They had a slow start but attendance is now improving.

# Practice and teaching of the exposition

Whatever the failures or successes at interviewing, there remain the considerable difficulties of 'explaining the situation to the patient; of persuading him of the necessity for treatment; of inducing him to change his way of life; of breaking bad news and perhaps confessing the inadequacy of therapy while at the same time retaining his confidence' (46). It is hardly surprising that failures in the second part of the consultation are more frequent and better documented than failures in the first part. This part of the consultation continues beyond the surgery or consulting room into the hospital ward and all its associated departments of special treatment and investigation, for in all of them patients may seek to obtain the information they want, and may be given false and possibly alarming hints about their diagnosis, prognosis, and treatment.

# Evidence and consequences of failures in the exposition

The difficulties that patients find in getting information about their illnesses are well attested in both hospital and general practice, and are the basis of the commonest complaints that patients make about their doctors (1, 12, 14, 31, 41a). We all see patients who seem to have been told nothing about the treatment of previous illnesses. Quantitative evidence is available from general practice, where only 18 per cent of social class 1 and 6 per cent of social class 5 patients said that their doctors were good at explaining things to them (12), and from hospital studies where dissatisfaction about information given has ranged in various studies from as little as 5 per cent to as much as 65 per cent of patients (31).

There is also the serious problem of patients failing to take their prescribed treatment, even when it may be essential for their recovery or even survival (5, 42). Non-compliance rates vary in reports concerned with various kinds of medication from as low as 20 per cent to as high as 80 per cent. Even life-saving insulin for diabetics has been found to be taken by half of them in the wrong dose. It is remarkable that this serious problem continues undiminished twenty

years after its importance in therapeutics was first recognized.

# Why are doctors' expositions so often inadequate?

The reasons for inadequate exposition are complex and not at all well understood (51). Among many contributary factors that are known some, at least, could be remedied.

#### Doctors' attitudes

The effects of doctors' attitudes towards their patients in interviewing has already been discussed (p. 7). They are even more important in relation to giving information about which there are wide variations in attitude. Not all doctors accept the need to inform patients about their illnesses. The hospital patients studied by Cartwright (11) complained: 'doctors just jump down your throat if you ask them questions'; 'You were treated like a child, as if it were nothing to do with you if the medicine were changed. No reason was given.' A sociologist in hospital for investigation put on her dressing gown on a hot morning and walked towards the ward balcony. 'You mustn't do that', said a nurse, 'you might catch cold' (17). Where else in human society could one adult say that to another? Some patients complained of being put off by meaningless reassurance: 'I asked my specialist what was the matter. He said, "You will be all right". I might just as well not have asked.' They were put at a disadvantage, as they lay in bed, by doctors standing up as they talked to them. 'The supine position is an important element in the established notion of order' wrote another sociologist about her experience in an antenatal clinic (13).

The patient, regarded as a consumer, is probably less well-informed and less able to judge the value of the service he receives from a doctor than that from any other professional or commercial service. The patient is thus in a position of uncertainty which gives his doctor a special sense of power. The more information he gives his patient the more his dominant role is changed to a co-operative one. He loses power which may give him a sense of insecurity. This problem of uncertainty and of power is discussed in some detail by Waitzkin and Stoeckle (51).

The dominating attitude that doctors have normally had towards patients in respect of the advice they give is shown by the phrase 'doctor's orders' and by the way in which patients who do not comply are described in some publications as 'liars, unco-operative, negli-

gent, deviant, disobedient, etc.'. This attitude causes resentment by sophisticated patients and regression to a childish attitude by the more submissive patients. Both of these attitudes inhibit recollection of instructions and acceptance of advice. At one medical school a videotape is shown to students in which a doctor apologizes to a patient about an error in diagnosis. The invariable reaction among students is that no doctor should apologize to any patient. This attitude does not appear to have been overtly taught. Another clinician who uses actors to simulate angry or dissatisfied parents in teaching paediatrics confirmed that his students start with the same resistance to apologizing. It seems that medical students rapidly come to realize that dominance and a pretence of infallibility will protect them from anxiety.

#### Patient attitudes

That patients are 'lousy receivers' was said to me by a professor of medicine and by a lecturer in surgery, because of their experience that even when special care is taken to give patients a simple explanation of what is wrong with them and why the treatment should be what has been decided, they have been found to remember almost nothing of what they have been told. I had a woman on steroids for rheumatoid arthritis who had come in for gastrectomy because of repeated haematemeses. She was told about the operation by my houseman, my registrar, myself, and the professor of surgery. When my rheumatological colleague came to see her he ended his note, 'I think someone should tell this patient she is going to have an operation'.

Little research appears to have been done on how and why these patients' receivers are switched off, nor how the barrier, if it is one, can be overcome (51). One reason for poor recollection emphasized by Cartwright (11) is that patients are so diffident in the presence of doctors that they don't like to ask for clarification. This failure perpetuates the doctors' inability to communicate for he gets no feedback. Some patients, of course, don't want to know anything about their illness (30 per cent in Cartwright's study). But the majority who do want information often fail to take it in.

The effect of anxiety and its relief may be one reason why few doctors realize how anxious many of their patients are during a consultation. Doctors themselves do not experience this when they consult a colleague and have seldom been taught about it. I have

learnt about it mostly from lay people I have advised to see friendly colleagues, and I discover they are as anxious as if they were to have an operation. Anxiety certainly inhibits learning, as may its relief. If a patient comes to a doctor fearing cancer and is told he has some curable condition, he may be so relieved as to stop listening to his doctor.

A number of other doctors' faults can be recognized:

Jargon. Few doctors, as I learnt especially during the various television programmes which I have introduced, talk naturally about their job in monosyllabic English. A speaker when asked a question about diet in a recent Nationwide programme replied: 'Yes, dietary factors can be of considerable significance in the causation of migraine' when the reply might have been, 'Migraine may be caused by something you have eaten'. Until doctors have learnt how little most patients know about human anatomy and physiology, or about (to doctors) commonplace words like 'mid-line', 'diagnosis', 'factor' and how to talk simply and clearly to their patients or to use more effective methods of teaching, they will continue to make it difficult for patients to understand them. Simple dictionaries to assist translation from medical jargon could help here.

Time and talk. Shortage of time is usually given as the main reason for doctors' failure to give adequate information and advice. But this shortage only inhibits verbal communication. If time is too short, other techniques must be developed, but few doctors do this: all tend to rely solely on time-consuming talk. In teaching students they give hand-outs, encourage note-taking, and use many audiovisual aids. They also realize that a seminar in which questions are asked is usually more effective than a one-way lecture. Yet when it comes to teaching patients they stick to unillustrated lectures.

It is not surprising that with this verbal technique the number of statements made by doctors which are forgotten by patients increases in proportion to the number that he gives them (32a). It has been shown that patients recall best the first thing they are told regardless of its importance (32). Many doctors leave advice on treatment until the end and thus discourage recollection of it, although it can be also improved by 'explicit categorization', which is telling the patient the sort of thing you are going to tell them before you actually give the information (34).

Inappropriate prescription. Compliance with therapy remains poor even when patients recollect what they have been told. This may be due to the prescribed treatment being seen by the patient as inappropriate (50). When a patient goes to his GP with a minor physical complaint, hoping to discuss an emotional problem which the doctor fails to deal with, the patient is unlikely to use a prescription for the physical complaint (32), or to take a prescription against which he has an irrational prejudice unknown to the doctor.

Conflicting information. In hospital there are many sources from which the patient may receive conflicting information (physiotherapists, radiologists, social workers, ward maids and so on), apart from nurses and doctors. This inevitably causes confusion and dissatisfaction.

Lack of teaching of students. The whole question of how to inform patients is so beset by ignorance and prejudice that students get taught little about it. They get little experience themselves because of their scanty knowledge of medicine which inhibits them from talking to patients with any confidence, and few doctors realize how great the problem is for they seldom, if ever, ask patients at the end of the consultation to repeat the information and instructions they have given, let alone asking them how much they recall later on.

# What can be done to improve the practice and teaching of exposition?

Thirteen years ago, in a delightful lecture on 'The bedside manner', Bodley Scott (43) concluded: 'The art of communication between doctor and patient is basic and self-evident in importance and I hope I have convinced you that it deserves more time and study than it has been accorded in the past.' That was thirteen years ago. Since then, while much effort has been devoted to developing better interviewing skills, and methods of teaching them to students little has been done to develop better practice and teaching of exposition.

I heard of few examples of students being asked to explain medical matters to patients under supervision. (One of these was in a Department of Physiology where students were asked to explain what they had learnt, for instance, about glucose metabolism, in terms that a diabetic patient might usefully understand.) By and large patients' failure to understand or comply with what they are told seem to be regarded as a form of original sin—sad but inevitable.

Though many studies of factors affecting compliance have appeared, I did not get the impression that the problem concerned clinicians as much as might be expected. This attitude in one medical school was exemplified by the advice given by his chief to a registrar who had done a study of non-compliance by patients after discharge from hospital. He had found that compliance was directly related to patients' satisfaction with the information they had been given. He was advised to publish it in a journal of public health so that it would not be read by, and thus give offence to, the consultants whose patients he had studied. This he did (40).

Various faults, which I have already outlined, and which are thought to affect compliance have been studied. A recent lengthy review of the topic (42), concluded that, apart from the obvious factor of complexity of therapeutic regimes, the main factors which have been shown to reduce compliance were inadequate supervision, dissatisfaction by the patient with his doctor's attitude and inappropriate beliefs about drugs. I discovered only one Department of Clinical Pharmacology where definitive studies had been made and even here they had faltered for lack of financial support. With ignorance and disinterest prevalent in our medical schools it is not surprising that there is, as far as I could discover, little clear teaching on this topic. One Professor of Clinical Pharmacology said: You can't teach students about non-compliance, they have got to find out about it when they qualify.' In a few departments however promising attempts at providing better information are proceeding and though untested may turn out to be valuable.

It is worthwhile listing again the various causes for failure of exposition and to suggest what might be done to correct them. Few of these methods have been evaluated but all of them could without great difficulty be submitted to controlled trials. In view of our present ignorance of this art one of the best methods of discovering how to improve it and to teach it could be to encourage students to make definitive studies of one or other of the possible ways of improving exposition in their elective periods.

# Doctors' attitudes

If, as has been suggested (51), doctors' dominating attitudes to their patients are in some way based on a need for a feeling of power over them to counter the anxiety they might otherwise feel in relation to the difficult and crucial decisions they so often have to take in their

clinical work, and if giving information lessens this sense of power, the dominant attitude may prove hard to change. But this hypothesis may not be generally valid and most of the failures may be due to unawareness of patients' desire and need for information, of their anxiety and of the doctors' own inadequate techniques of communication. In this case improvements should not be difficult to achieve and could be combined with more effective teaching. What would be needed to bring this about would chiefly be to increase doctors', and in particular teachers', awareness of the problem so that more effective research would be carried out into solving the failures of communication.

Students are now, as several participants pointed out, more willing than they used to be to criticize the way they see their mentors handling their patients. They are even encouraged in a few schools to do so. They should also be encouraged to conduct studies, which could be fairly simple, of the amount of information patients need, receive, and recall. More detailed investigations could be made by registrars and research fellows into the value and application of the sorts of explanatory techniques that have been found to increase recall and compliance (42). At present very little such research is being done. More of it would help to arouse teachers' interest.

Feedback. More attention might be paid to the topic if more feedback were available to consultants. To this end audiotape recorders should be available in all teaching hospitals for consultants to use in their clinics so that they could listen afterwards to what they had said to their patients and how they had said it. The mere presence and use, if only occasionally, of such recorders might produce an immediate improvement, and students could be encouraged to use them.

Quantitative monitoring (not necessarily continually but at least regularly occurring) of compliance and of satisfaction, recollection and understanding of information and advice should be a routine in all therapeutic clinics in teaching hospitals and in academic departments of general practice. Students should be encouraged to take part in these studies and to develop and test means of correcting failures. In this way they would enter on their professional career at least aware of the problems and of some means by which it may be dealt with.

Jargon. Control of jargon could also be attained by use of tape

recordings of expositions by both doctors and students with discussion of how simpler words could have been used. The exposition could then be repeated and listened to again to see how much it had been improved.

#### Patients' attitudes

I have suggested that a patient's anxiety (or elation) may be a common inhibiting factor for recollection of information and acceptance of advice. As far as I am aware little research has been done into this hypothesis nor into how best to identify and relieve the anxiety. One first step would be for all students to be taught to recognize anxiety and to give routine assurance when it is necessary. At two medical schools arrangements have been made for students at the beginning of their first clinical year to accompany out-patients from their homes, through their consultation and investigation. In this way, I was told, they come to appreciate the almost universal anxiety that such patients experience and of which most hospital doctors are unaware.

A sister tutor at a Scottish school pointed out how much anxiety can be caused by conventional consultant ward rounds. She regularly takes her nurses on post-ward-round ward-rounds to teach them how important it is for them to ensure that these iatrogenic anxieties are relieved. She had not conveyed her findings to the anxiety-inducing consultants lest they should stop her ward teaching. This sister also said that the best way to discover what ward patients are worrying about is to visit them just after the lights have been turned out. Patients are especially liable to worry at this time, are more ready to talk about their anxieties and quiet reassurance may be effective. One houseman at the same medical school reported how valuable he had found this tip to be.

All clinical teaching in out-patient departments and wards should include a discussion of what the patient wants and needs to know and how this information should be given. Students should be asked to report back afterwards on how much their patients had understood and recalled what they had been told. Reasons for success or failure should then be discussed and failures corrected.

Time and use of verbal information. The inevitable shortage of time in routine consultations makes it essential for doctors (though they have not hitherto so regarded it) to increase their efficiency in giving

information and advice. One way is by careful arrangement of the information (34) and of the way in which it is given (27) (and see p. 22). Another obvious thing to do, but unnecessarily time-consuming for common prescriptions, is to get the patient to report back to the doctor at the end of the consultation all that he has been told. One professor of pharmacology said he always got the patient to write down his own prescription at his dictation. In hospital patients a check on any unanswered questions by the houseman before discharge can increase satisfaction (33). Patients are also more satisfied if the ward sister and doctor both answer the patients' questions than if only one or the other answers them (11). Sheets of paper given to patients on which to write their questions can help to remind them what to ask the doctor when he visits them.

Informative pamphlets and tapes. Brief pamphlets about drugs or 'Patient package inserts' could be developed (26, 35). 'People get much clearer instructions when they buy a camera or a transistor radio than they do when they are given a life-saving antibiotic or cardiac drug' (47). A pharmacist told me that he frequently had to tell people coming from their doctors with prescriptions what they were for, what side-effects they might have, and whether they were worth taking. It should not be difficult to produce brief, simple pamphlets giving essential information about common drugs. Doctors could keep files of them on their desks ready to hand to patients, or pharmacists might issue them with their prescriptions. This technique is now being developed in the USA and should be started here (30a).

Little use is made of simple booklets about common illnesses to help patients understand them. Most of the 120 or more Patients' Associations produce them. The Arthritis and Rheumatism Council have some outstanding ones. But it seems that this sort of literature is not widely used. It is true that many diabetic clinics hold classes for patients, but the effectiveness of this teaching is not very great (41). The contrast between the interest of hospital consultants in the technical aspect of the treatment of their patients and their relative lack of interest in the extent to which their patients understand and carry out their instructions is striking. At one teaching hospital patients discharged from a coronary care unit had been instructed to get back to their normal working activities as soon as possible. A study by a psychiatrist interested in psychiatric effects of heart

attacks showed that they were not doing this. Many patients were ignorant of their diagnosis and of what they had been told to do. Their wives knew that their husbands had had heart attacks and that this meant that they must rest. When a simple booklet was prepared for them (and their wives) to read, while they were in the ward, compliance, satisfaction, and morale were found to increase considerably.

At a respiratory unit in a Scottish hospital and at a similar unit at a London hospital visits by students to discharged patients revealed many were quite unaware of their diagnosis (and angry that they had not been told), or of why they should take the drugs they had been given. This ignorance persisted after making special attempts to give full information verbally. In the Scottish unit written instructions are being found to be much more effective (16a).

In the Orthopaedic Department at the Leeds Royal Infirmary audiotape recordings have been prepared for both in-patients and out-patients explaining the nature of their lesions, what is going to be done to them and why; describing, for instance, the sort of discomforts and problems that patients, say, on a Thomas's splint may encounter. They also indicate when a doctor or nurse should be informed of any discomfort. The patients appear to enjoy and appreciate this sort of information which they can listen to slowly, repeatedly if they wish, and at their leisure. They are encouraged to discuss it with the doctors and nurses in wards or clinic if they wish to. No formal assessment of the value of these tape-recordings has been made, but there seems to be little doubt of their value (50). Their use is spreading very slowly to other departments despite some opposition.

At the Mayo Clinic audiotape recordings of patients' consultations have been made and given to them to listen to afterwards at home. Ninety-one per cent found this helpful especially when listened to with their spouses (9).

I have been told that in Denmark in both hospitals and general practice coloured videotapes are widely used for group instruction for patients with coronary heart disease, dyspepsia, and other common diseases.

Preparation of these sorts of material can be costly and takes time and trouble. Its potential value in improving satisfaction of patients and their compliance with and understanding of their treatment is well established, but little is done about it. Some organization should be set up to prepare informative catalogues of available material and of new material as it appears. Some of it is, and would continue to be, of poor quality so that careful assessment by experts would be necessary. It seems logical that this should be a responsibility of the Department of Health and Social Security, but the 'gobbledegook' used in the circulars they send to doctors leaves some doubt as to their capacity. Perhaps an *ad hoc* Committee of the Nuffield Provincial Hospitals Trust could undertake this, or the King Edward VII Hospital Fund for London.

Role-playing. Some departments use this technique—one student is asked to play the part of a patient who has a particular disorder, often a serious one, and another student to play the patient, before a group (35a). It is usually found that the student who acts the patient learns most and this can be a valuable way by which students can learn how difficult it is to provide information with empathy and clarity.

Conflicting information. This is predominantly a problem of hospital practice. Different doctors as well as other professionals are often responsible. One way of avoiding it could be to have an 'information sheet' in all case-notes on which questions asked by patients and answers given could be recorded. A registrar of mine once tried to introduce this on our wards, but failed, probably because of insufficient preparation and persuasion of other staff members. Such a sheet is a routine part of the case-notes at St Christopher's Hospice where it is regularly used and found invaluable. Further trials in general hospitals are needed.

#### COMMENTARY

# A participant from industry commented:

We started working on this a bit sooner than you did, and the difficulty we found was to get people to recognize that there was a problem. The technology for helping people to communicate better—the training method, instructional parameters and so on—have become reasonably well understood in the last ten or fifteen years. The difficulty is to get people to learn. I think your problem will mainly lie in trying to raise the anxiety level in the profession because we have exactly this problem with managers in industry to get them to realize that their communication processes are much poorer than they think they are.

A typical managerial reaction to this subject is that they do not have any communication problem. Their subordinates, colleagues, shop stewards,

bosses, understand what they say. In any case, if there are any problems in their area they can deal with them themselves so they do not need any help, thank you very much. Goodbye!

It was emphasized that one of the things that makes communication more difficult nowadays is the increasing pace of life in hospitals and increasing technology. Technical achievements do not help communication or pastoral care; they make it very difficult, particularly when patients are passed from one specialized unit to another. It was also mentioned that it is often difficult to get information across to quite intelligent people.

A number of highly intelligent patients at the top of their academic profession—sometimes in the sciences—do not want to know about their illness. They say, 'You are the doctor, I have got my life to lead. Will you deal with this complaint telling me as little as possible about it.' It is generally accepted that there are such people and that they should not be burdened with information they do not wish to receive. It should not be difficult to identify them.

One other comment was that non-compliance is not always due to poor communication. Patients may understand very well what the doctor has suggested they should do, but may not wish to follow his instructions. In such cases there must have been poor communication from doctor to patient, if not from patient to doctor, resulting in misunderstanding of intent.

While it was generally agreed that little was being done to investigate and teach improved exposition some valuable developments were reported. One participant said:

Something we have been doing recently has led to a great improvement in exposition to the patient, which is auditing. For the last nine months, on the medical unit, which has five consultants, we meet once a week, and we randomize patients' notes from other consultants, and we sit round with all the students, junior staff and so on there, at lunchtime over sandwiches and coffee, and we monitor the notes. We monitor all aspects of the medical care, the investigations which have been carried out, etc., but a very important aspect of the monitoring is what is recorded about what was told to the patient and the relatives and the result was that within one week—the very next meeting we had—there was an improvement. Immediately doctors began to record what they were telling the patient in the notes, and in the discharge letter and in the discharge summary. We still have the meetings once a week and there is very little to criticize because the improvement has been dramatic. Monitoring is effective if we want to improve this kind of communication, because doctors know that their notes are going to be monitored, therefore they will be asked what they told the patient, and therefore they have to tell the patient something. This does work. It has the added by-product that everybody knows what has been said to the patient and the relatives: the nurses and social workers can pick up the notes and there it all is. Auditing is not impossible, and if we introduce audit sheets we shall improve communications with the patients.

The effect on patient satisfaction and recall had not yet been studied.

#### Another participant reported:

The climate is changing. We have recently been commissioned by our colleagues to audit the notes of all out-patients looking for those recorded as having hypertension and seeing what happens to them. At our three teaching hospitals all the clinicians have agreed for their work to be audited in this way. I strongly suspect that if we set up an auditing process for relations between patient and doctors you would find much more cooperation than you might expect to get at first. The GPs have shown us the way but I cannot believe that this route is barred to other professional groups.

#### A surgeon said:

In trying to improve the exposition, what is required is a series of simple moves. Surgery provides a good example. The consultant must go and see his patients regularly on his own: that is the first rule. The second is that he must always sit down and there must be a stool under each bed for that purpose. Thirdly, at the end of the operation he must make arrangements to telephone the relatives; and fourthly he gives a patient when he leaves hospital a piece of paper with the name of the operation on it and, if it is a complicated operation, a diagram.

By following these rules he had found himself embarrassed by the never-ending gratitude shown by patients who had been treated in this way.

It was even suggested that attitudes were changing so fast that it might not be long before the consultant Royal Colleges might come to recognize the need for their members and fellows to have some training in communication.

# Communication with patients with fatal illnesses, with those who are dying and with the bereaved

This important aspect of medical practice received no mention in the recent Nuffield/GMC survey of medical schools, and in the schools I visited there was either no formal training or at best an occasional seminar or lecture, usually in the introductory clinical course, or

during the teaching of psychiatry or general practice. It was certainly not a formal part of any curriculum. In discussion at one Scottish school a contrast was drawn between the formal, routine teaching that ministers of the church and policemen receive about talking to the bereaved (usually through role-playing sessions) and how seldom such help is given to medical students. At a few schools 'bad news' sessions are held in which, before a group of students, a registrar gives bad news (about serious illness) to an actor (or a student) playing the role of the patient. This is an excellent means of starting a group discussion of the problems that are raised. The supervisor of such a session must be someone who has himself learnt how to handle these problems.

At several London schools, students go for ward-rounds (usually voluntarily) to St Christopher's or St Joseph's Hospices. I was told at more than one medical school that no formal teaching could be given because the teachers themselves did not know how to talk to dying patients and differed—even angrily—with each other about how much should be told. Dr Kubla-Ross in her account of the seminars on dying patients which she held at the University of Chicago Billings Hospital (29) comments: 'The hospital staff reacted with great resistance, at times overt hostility, to our seminars. At the beginning it was almost impossible to get permission for the attending staff to interview one of their patients. Residents were more difficult to approach than interns, the latter more resistant than externs or medical students. It appears that the more training a physician had the less he was ready to become involved in this type of work.'

Failure to help these patients, whose ranks we shall nearly all have to join one day, leaves much severe, but often remediable, distress unrelieved. There is indeed ample evidence of the distress that patients with fatal illness suffer as much from their doctors' embarrassed evasion of the issue as from their occasional brutal frankness.

One professor of medicine told me he had only learnt of his colleagues', and thus of his own, inadequacy in this field of communication when he developed symptoms wrongly diagnosed at first as due to a fatal blood disease. He found his colleagues were extremely unfeeling and tactless in the way in which they told him about their fears. This led him to realize his own faults and he hoped he had managed to correct them. It seems that much of doctors' inadequacies in handling the issue of life and death are due to their not

having faced up fully to their own mortality. I discovered no evidence of students being taught how to do this.

In spite of the uncertainties and disagreements among medical teachers on this question, those who have devoted much thought to it are in broad agreement on the guiding principles that should be followed (6, 8, 16, 24, 44). This is not the place in which to elaborate on them. I suggest it would be helpful if a small group of doctors experienced in this matter should meet and produce a succinct outline of the principles that should be followed, with case-history examples, to illustrate their application. They could also describe the various techniques that are already being used to good effect in several schools: a videotape of an experienced doctor talking to dying patients about death: role-playing sessions: 'bad-news' sessions in which a registrar breaks news of a fatal disease to a simulated patient behind a one-way mirror or with a videotape recorder so that what he did 'rightly' or 'wrongly' can subsequently be discussed. None of these valuable methods are at all widely used.

No doctor entering a clinical branch of the profession can avoid having to deal with dying patients. It is cruel to them and to their patients to allow them to do this without any teaching or practice except of the orthodox kind. For instance one first clinical year student in a London school was told to go and take the history from a woman who had just realized, without being told, that she had disseminated cancer.

In every medical school there must be several staff members who, perhaps helped by the outline of the principles which I have suggested, would be ready and able to give seminars on this topic for both senior and junior staff. These might indirectly help and encourage more hesitant colleagues to join in and increase their own understanding.

It is essential that this topic should receive formal mention in the curricula of all medical schools, and that clinical Deans should ask for volunteers to undertake and guide its teaching.

#### COMMENTARY

It was agreed that medical students are getting more and more concerned about the problems of talking to dying patients and what to tell them. They tend to polarize into the 'Yes, we always do' and the 'No, we never do' attitudes. There was a tendency to such polarization among the participants while some admitted that they were

themselves quite uncertain about how to talk to the dying. Most agreed with the philosophy of the experts (to whom references have been given). One participant expressed this as the principle adopted at St Christopher's Hospice: 'Not to lie and not to thrust. It is so much a matter of picking up the clues from patients about how much they want to know, and how much they have grasped rather than trembling over the abyss of: Is this the vital question coming up now or is it going to be put off?' Another participant said: 'If you wait long enough then you can just take their hand and they will know, but you do not need to say anything to them. They have encapsulated the knowledge so that it is not a shattering destructive verbal confrontation.' Or again:

If anything must be negotiated about, surely it is bereavement and death, and negotiation does not start with implacable rules. If you have implacable rules you cannot negotiate. Medical students ask for certainty and this is worrying. We must show them that this is a matter for negotiation, which I believe it to be, and that the bargain you strike is one between your personality and the patient's personality, so that what I do will not necessarily be what other doctors who are trying to help the dying will do, but the philosophy will be the same.

Several anecdotes were told to show how unwise it is, even in apparently desperate situations, to state that an illness is certain to be fatal, thus confirming Brewin's insistence on the need to maintain the morale of people with grave disease (8). The practice of telling the patient or the family about the prognosis as if it were factual and certain was condemned. The general view of good teaching was well summed up by one participant:

It is important to get the students to learn to listen to patients. If you are sensitive to this you can pick up the kind of clues that tell you what the patient wants to talk about, very often it is not this huge 'Yes' or 'No' question—Am I or am I not dying?—but domestic and personal matters. The idea of telling gradually is a good one because it gives time for these anxieties to come out without actually having to face up to the truth.

## Some conclusions and proposals

If it is accepted that at present many doctors are failing to achieve satisfactory communication with their patients and that these failures often seriously impair their diagnostic and therapeutic ability, we have to decide what can be done both to improve the skills of today's doctors and to ensure that medical students shall be given more effective teaching on this matter. A variety of methods that could be used to this end have been described. It remains to consider why they are not more widely used and what could be done to accelerate their application.

The two main reasons for neglect of these teaching methods are unawareness of their existence and value and opposition by some teachers to the change in relationships between doctors and patients which improved communication may require.

Ignorance is due first to the inadequate teaching about communication that today's teachers themselves received as students, and secondly because most of the recent advances in understanding of this subject, and its basis in the scientific analysis of personal interactions, has appeared in books and journals that are not normally read by medical teachers. If they were to read this literature they might be put off by the verbose and obscure jargon in which much of it is written. For these two reasons these teachers are also unaware of the extent of their own failures in communication and of the ways in which they might be remedied. At the same time, of course, they are keenly aware of the rapid advances in medical technology, and of the importance of understanding them and maintaining full understanding of their scientific basis. Some teachers in medical schools where much more time is now spent by students on behavioural sciences recognized that this could lead them to develop an interest in the psychosocial consequences of illness but that could also lead to neglect of physiological and biochemical sciences. In other schools, however, this conflict was denied.

Some professors of general practice and psychiatry told me that their teaching of a co-operative rather than an authoritarian attitude to patients aroused hostility from their consultant colleagues (more from physicians than from surgeons). This hostility may be deepseated, based on the anxiety that they might feel if they had to face up to patients' emotional problems arousing antipathy or anger which they could not be sure of controlling. But I doubt if serious hostility is widespread. It may be like the derision poured by conservative surgeons on Lister's ideas on antisepsis eighty years ago and will gradually give way as better information about the clinical value of improved communication spreads among more receptive colleagues.

I believe we have to contend predominantly not with deep and irremovable prejudice but chiefly with ignorance. Prejudice there

certainly is, but I believe it chiefly affects the more senior teachers whose conservative influence will not last for many more years. That change is possible is shown by the very considerable advances that have taken place among leading general practitioners and psychiatrists and this gives firm ground for optimism. They have led the way because, while concerned with the physical mechanisms of organic disease, they have to discover and deal with their patients' behavioural problems and this demands skilled interviewing and counselling. Interview training now forms a large part of postgraduate teaching in both these divisions of medicine.

Another favourable sign is the great expansion of communication training in British industry. Although much of this is concerned with the sort of communication that is required if large organizations are to function efficiently, the techniques by which this is taught are like those used in teaching communication in medicine. To encourage self-awareness of any defective skills in relating to people both industry and medicine can use videotape for self-monitoring and 'sensitivity training' (see p. 18) to improve defective communication skills. These methods have gradually been adopted in many industries during the past decade. At first, as in medicine, they were ignored or ridiculed by senior executives but since their value has become clear opposition has subsided.

What then might be done to accelerate the change that in any case is likely to take place spontaneously but slowly? Since the aim is educational the proposal put forward at the Nuffield meeting in 1976 of a carefully structured conference could be a valuable first step.

I would suggest inviting to such a conference equal numbers of medical teachers who are interested in and well informed about teaching communication and influential teachers who are unaware or only superficially aware that the necessary skills can be taught.

There could be a series of 20–30 minute communications reporting on what has been and is being done by various methods in various schools with ample time for discussion after each paper. Final summarizing papers could include proposals for wider use and development of teaching methods which have been described and perhaps suggestions for research. Such a conference would need skilful planning for which a small working group might be formed.

The provision of practical means to facilitate exposition and to improve patient compliance requires additional measures. Many brochures and pamphlets are already available. Some are excellent but many are of poor quality or out of date. Simple accounts of the purposes, use, dosage, and possible side-effects of drugs are not available in any form suitable for most patients. It seems desirable that somebody should catalogue acceptable material that is already available and investigate problems of production and distribution. They should also be empowered to commission new material, including scripts for tape-recordings for local hospitals to edit and record, preferably in local idiom and speech. The DHSS (or perhaps the Medicine's Commission) might be asked to set up a small working party to investigate the need for such a body and report on details and cost. They would certainly have to look at the work of many patients' associations which are the main source of this sort of material today. Ultimately some central agency should be set up to organize revision and renewal of the material and to promote controlled trials of its value.

Another approach might be to discover and encourage individual doctors with special talent in writing and illustrating such material and to provide support until they had developed their techniques to a stage at which it would be profitable for one or more medical publishers to take on the production of this material.

Lastly, there is the crucial influence of the GMC with its responsibility for ensuring high standards of competence of doctors at the time of qualification and registration. If the GMC were to insist that no doctor should enter clinical practice without demonstrating adequate skills of interviewing and speaking to patients (with special mention of the dying) it would surely follow that medical schools would have to improve their teaching in this field.

At the 1976 Nuffield meeting it was proposed that an annotated bibliography of worthwhile publications on the science and teaching of communication between doctor and patient should be prepared. Such a bibliography could be most valuable to those developing an interest in the subject and wishing to start teaching it. It would be an onerous task, but if a suitable scholar could be found it should be commissioned.

#### COMMENTARY

The final discussion was concerned with the road ahead. In the course of the meeting there had been no dissent from the view that clinical excellence required clearer and more efficient communication between doctors and their patients than is commonly achieved today,

but the scarcity of quantitative studies of the clinical consequences of failures of communication allowed differences of opinion on the urgency of the problem. It was recognized that impaired communication was often due to imperfect training so that many clinicians (and, most important, many teachers) remained unaware of the faulty techniques and inhibiting attitudes, implicit or explicit, shown by many doctors in their consultations. Progress was inhibited by lack of recognition of the opportunities given by new teaching methods and by the low priority in academic departments of research into the causes and effects of patients' failures to understand the information and to follow the instructions that they are given.

The question was how best to widen understanding and appreciation of the problem and of how it might be tackled. The proposal for a conference to which influential teachers should be invited was felt to be important. It was suggested that such a conference should involve teachers whose views were sufficiently pliable to undergo change rather than those who were set in their ways. Contributions should be structured so as to encourage rather than to demand changes in attitude. Over-emphasis may reinforce attitudes which might yield to more gentle persuasion.

It could not be expected that a single conference could immediately change the current medical culture in relation to problems of communication. It should be looked on as a potentially useful first event in a longer-term strategy continuing over two or more years. Other activities would involve the collection and publication of more information about the whole problem in readable and concise forms to satisfy those who seek for more hard data; encouragement of more research by clinicians, not only by psychologists and sociologists, into the techniques and effects of improved communication; development of improved technical means of communication with patients such as pamphlets and audiotapes or videotapes; and simple guidance on communication with the dying.

With regard to possible sponsors of these activities, apart from the Trustees of the Nuffield Provincial Hospitals Trust, the General Medical Council, the King Edward's Hospital Fund for London, the Association for the Study of Medical Education, the Council for Postgraduate Medical Education in England and Wales, the Higher Training Committees of the Colleges and the various Medical Groups were mentioned.

It is hoped that this report will be helpful to these and other

bodies concerned with medical education and may also attract the attention and stimulate the initiative of individual teachers.

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# The structure of hospital in-patient costs

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## The structure of hospital in-patient costs

## **Summary**

This essay is concerned with the use of statistical models and methods to determine the structure and magnitude of the costs of hospital in-patient care. Following a review of cost models based upon conventional economic theory, it is shown that resources rather than services are the main determinants of hospital in-patient costs. On the basis of the costs, resources, and activities of 402 non-teaching hospitals in the four Thames RHAs for 1975/6, an empirical model is derived, which is capable of accounting for some 95 per cent of the total variation in in-patient costs. According to this model, the total hospital cost may be expressed as the sum of the costs of the beds provided in each of six groups of specialties, together with the costs of treating patients in excess of the prevailing average number per bed in the acute specialties. Economies and diseconomies of scale in terms of bed provision were found in the medicine, psychiatric, and maternity specialty groups. The implications of studies of this type in the context of current procedures for monitoring, planning, and resource allocation within the NHS are discussed.

## Introduction

Hospital in-patient care is the most expensive and one of the fastest growing components of the National Health Service. For many years, information has been available about the total costs of particular hospitals and about functional sub-divisions of hospital costs, such as medical and nursing salaries, laundries, pathology services, and out-patient services. Such figures are undoubtedly of

value, but since no two hospitals have exactly the same case-mix, it is important that due account should be taken of workload when one hospital is compared with another. What is required in order to obtain an understanding of the way in which hospital in-patient services are being used is to relate costs directly to patient care. The increasing emphasis which is being given to the efficient management of resources and in particular to the introduction of systematic procedures for monitoring and resource allocation (2, 3) means that this topic is of immediate practical interest. The objective of this paper is to compare various approaches to the analysis of the structure of hospital in-patient costs in the context of a substantial and representative body of up-to-date information. At the same time, a method for calculating the expected cost of meeting any defined hospital in-patient case-load will be derived.

## Method of approach

Ideally, all that is required to relate the financial inputs to the patient care outputs is to compile for every hospital in-patient a detailed record of all types of service provided. Given an accounting system by which the unit cost of each type of service can be determined, the calculation of the costs associated with each particular in-patient is then merely a matter of arithmetic. Procedures of this kind are essential in health care systems which involve direct payment for services rendered. In the NHS, patient billing is not a requirement and it is hardly surprising that the elaborate and expensive data systems necessary for the direct calculation of the costs of care for individual patients do not exist. It follows that progress can be made only by indirect methods, as described below.

For all NHS hospitals, a summary of in-patient activities is available in the form of the SH3 return, which is prepared annually. The return shows for each specialty within the hospital the numbers of available and occupied beds and of in-patients treated during the year, together with the average length of stay. This summary of resources and activity can be matched against the total in-patient cost for the hospital, which forms part of the standard annual hospital cost returns. As with all accounting procedures, arbitrary conventions for the allocation of costs of shared resources between different headings, such as salaries between in-patients and outpatients, cannot be avoided, but nevertheless the total costs attri-

buted to in-patient care in any particular hospital reflect a reasonably accurate view of the true position. The analysis of the structure of hospital in-patient costs consists essentially of the determination of the relation between resources and activity on the one hand and total costs on the other. This involves the construction of a mathematical model in which variations in total costs between hospitals are 'explained' in terms of corresponding variations in resources and activity.

There are two main ways in which the construction of a model can be approached, which may be termed 'theoretical' and 'empirical' respectively. The theoretical approach involves reference to some particular economic theory about the composition of the structure of in-patient costs. A variety of such economic theories, centred upon the assumption that costs can be divided into two components, the 'fixed' costs of providing and maintaining resources and the 'variable' costs of treating individual patients, have been put forward. This point of view reflects the tacit assumption that the system has been developed in a way which is optimal at least in some sense and has been advocated by economists such as Deeble (1), Feldstein (5), and Hurst (7). In contrast, the empirical approach specifically rejects a priori assumptions about the structure of hospital costs based upon any particular economic theory. Total hospital costs are expressed as a function of all aspects of resource provision and utilization about which information is available. Statistical methods, based upon stepwise regression analysis, are then used to determine which particular items of information about resources are relevant in accounting for variations in total hospital costs and which are not.

In principle, an analysis which embodies a valid theory is to be preferred to one which rests solely on empirical evidence. A realistic representation of the process by which revenue is allocated to hospitals is thus of prime importance. When the NHS was first established, responsibility for meeting the expenditure of the wide variety of existing hospitals was assumed. Since that time, there has never been any formal mechanism for the calculation of the funds to be allocated to particular hospitals in terms of the existing resources or the expected workload, expenditure during the previous financial period, together with any new activities, being taken as the main criteria. This process is in no sense one in which the providers of care are responding to market forces under competitive conditions and there is no reason to suppose that conventional economic

theory must apply. Furthermore, as an increasing degree of standardization has evolved in staffing levels and other major determinants of costs, expenditure is being tied ever more closely to resource provision, particularly that of hospital beds. For these reasons, we believe that the empirical approach to model building is to be preferred, notwithstanding the fact that as time passes and methods of management and the balance between different components of costs change due to general inflation and other factors, the structure of the model may also vary.

The main sources of empirical data used in this analysis are the hospital cost returns (HCRs) for the financial year 1975/6 (April 1975–March 1976) and the SH3 returns for 1975 for 402 non-teaching hospitals in the four Thames RHAs. The hospitals are grouped by the DHSS on the basis of the general nature of the care provided into nineteen standard classes, although there are large variations in the distribution of beds between specialties within each class. It is thought that this body of data is sufficiently large and diverse to provide an adequate foundation for model building and one which is certainly more satisfactory than could be obtained from a single region or a single class of hospital.

## A survey of theoretical models

The main impetus for the study of hospital costs was generated by Feldstein (5), who was concerned with the HCR and SH3 returns for a group of 177 'large' (annual expenditure greater than £50,000) hospitals in England and Wales for 1961. Feldstein made the assumption that the total hospital in-patient costs may be represented in terms of the numbers of patients treated in each of nine groups of specialties. According to his model, the total cost of in-patient care at a hospital consists of the sum of the products of the number of patients and the average cost per patient taken over each group of specialties. This model does not involve any component which represents expenditure not directly related to the number of patients treated. Nor is any allowance made for variations between hospitals in efficiency as manifested by differences in bed occupancy, length of stay, and other factors. The grouping of specialties was chosen on the basis of 'the medical character of the cases treated' rather than of the costs of such treatment. The data used to validate the model comprise large hospitals only and are

clearly unrepresentative of the full spectrum of NHS hospitals. In the event, Feldstein was able to account for only just over one-quarter of the total variation in in-patient costs within the selected group of hospitals with which he was concerned. The comparatively poor performance of his model points to an inappropriate structure and to the exclusion of items of information which have an important bearing upon total costs.

Further studies of hospital costs were carried out by Gibbs (6), who put forward a model involving three components: treatment costs, hotel costs, and overheads. The first factor was quantified in terms of numbers of cases, the second in terms of the numbers of bed-days and the third in terms of the numbers of available beds. The Gibbs model makes no allowance for possible differences between specialties, despite Feldstein's firm conclusion that 'biased and possibly misleading results may be obtained if case-mix differences are not taken into account'. Bearing in mind this reservation, it is interesting that Gibbs suggested that the cost per case is made up of 42 per cent for overheads, 25 per cent for hotel costs, and 33 per cent for treatment costs.

Later work by Hurst (7) was based upon a combination of the Gibbs and Feldstein models. Total in-patient costs at a hospital were expressed as the sum of hotel costs and the treatment costs in each of the specialty groups defined by Feldstein. Hotel costs were themselves expressed as the product of the total number of cases at the hospital, the average length of stay and a parameter representing the per diem hotel cost. Treatment costs in each specialty group were expressed as the product of the number of cases in that specialty group and a parameter representing the average cost per case. This model assumes that hotel costs are equal in all specialties and that specialty-specific treatment costs vary directly with the number of patients treated. On the basis of HCR and SH3 returns for some 360 acute hospitals (Types 1, 2, and 3 in the DHSS classification) for 1969/70, Hurst's model accounted for three-quarters of the total variation in in-patient costs within this group of hospitals, a considerable improvement upon that of Feldstein. Hurst has stated that his results are, with the addition of an hotel cost, virtually identical to those of Feldstein. The same comments therefore apply. In the first place, the analysis has been restricted to a selected and homogeneous set of hospitals which are certainly not representative of all NHS hospitals. Secondly, specialties with very different average

lengths of stay and treatment patterns, and therefore with very different costs, have been grouped together in the analysis. In the third place, no allowance has been made explicitly for costs which are not directly associated with the treatment of patients. Finally, and somewhat paradoxically for a model based upon conventional economic principles, no provision has been made for concepts such as economies of scale, which are emphasized in the classical economic folklore. It is hardly surprising that as large a proportion of the total costs as 25 per cent could not be explained by the model.

In his paper, Hurst concluded that:

A rough picture has been provided of how these factors (i.e. length of stay and specialty) affect cost per case in some specialties. Further work is needed, however. First, because the marginal cost of varying length of stay in various hospitals remains uncertain. Secondly, because some specialties have not been covered in the analysis and the results for others are shaky.

Although the precise basis of the cost estimates quoted in the Report of the Resource Allocation Working Party (3) is not revealed and no reference is given to any supportive work, it can be inferred that the Hurst model was used. In view of the importance of making proper allowance for cross-boundary flows in resource allocation calculations, particularly at the sub-regional levels, we have applied the Hurst model to the more up-to-date and representative data for the Thames regions. In marked contrast to Hurst's analysis of the 1969/70 data, the only explanatory variables which were found to be significant at even the 10 per cent level were the hotel costs (which dominated the relationship) and the treatment costs for the surgery and convalescence specialty groups.

## The construction of an empirical model

NUMBERS OF BEDS OR NUMBERS OF PATIENTS?

The studies described above have involved the explicit or implicit assumption that the cost of a specialty in a hospital is the sum of the costs of treating each individual patient in that specialty and hospital. Thus, the cost of the specialty is assumed to be directly proportional to the number of patients treated and no provision is made for those costs which do not depend directly on the treatment of patients. On general grounds, this may not be appropriate, since these assumptions do not reflect the implied mechanisms by which the funds were

allocated. It is evident that staff salaries account for the greater part of the total costs, with the nursing component making the largest contribution. Rightly or wrongly, it has been the practice to base nursing establishments on the numbers of beds in particular specialties rather than upon the numbers of patients treated. Since there is considerable variation between hospitals in lengths of stay and bed occupancy (and thus in the number of patients treated per available bed), numbers of patients and numbers of beds are not exactly equivalent. A model based upon numbers of patients does not account for the sometimes significant proportions of beds assigned to a specialty which are staffed but not occupied. The extent of this factor varies between specialties and between hospitals and as a result it is reasonable to expect that an effective model should take account of the distinction between numbers of beds and numbers of patients in an explicit way. Staffing costs of other grades of staff, such as cleaners and auxiliaries, as well as other categories of expenditure, such as heating and routine maintenance, would also be expected to be related more closely to numbers of beds rather than to numbers of patients. Furthermore, the revenue consequences of new capital schemes are commonly calculated in terms of the numbers of beds.

Since it may be argued that the majority of components of costs are better explained by numbers of beds rather than by numbers of patients, there are strong a priori grounds for including the former rather than the latter at the first stage in the development of a realistic model. This observation was confirmed empirically since the proportion of the variation in costs between hospitals explained in terms of available beds was found to be greater than the proportion of variation explained in terms of numbers of patients.

#### VARIATIONS IN EFFICIENCY

Although we have argued (and confirmed) that beds rather than patients treated are the dominant element, it is also clear on general grounds that there must be some costs in some specialties at least which are directly associated with the treatment of patients, as opposed to the support of beds. In theory, it would be possible to include both numbers of patients treated and numbers of beds in each specialty in a cost model. However, despite the existence of variations between hospitals in bed occupancy and length of stay within a given specialty, the numbers of occupied beds and of

patients treated are highly correlated. Inclusion of both quantities explicitly in a model involves a large and undesirable element of redundancy. This problem can be overcome by including in the model the number of 'excess' patients, rather than the total number of patients. The excess is calculated as the difference between the actual number of patients treated and the expected number based upon the average throughput per bed in the specialty and the number of beds, in the specialty in the particular hospital.

#### ECONOMIES OF SCALE

On general grounds (and according to classical economic theory), economies of scale may exist within some production systems. Unit costs within a given specialty may be expected to vary according to the size of the unit. Both the efficiency and the case-mix (and thus the unit costs) may differ between larger and smaller units. The existence of economies (and diseconomies) of scale was confirmed by the application of the model to groups of hospitals of varying total size. Further investigation showed that the effect was associated with the size of specialties within a hospital rather than with the size of the hospital as a whole (the two quantities are highly correlated). The model was therefore expanded to include a cost component varying with the square of the numbers of beds in a specialty as well as a term which varies with the number of beds. A negative coefficient associated with the squared term indicates the presence of economies of scale, whereas a positive coefficient indicates diseconomies of scale.

#### GROUPING OF SPECIALTIES

On general grounds, it is clear that costs may differ between specialties and ideally a model of cost structure should take account of each specialty separately. There are, however, about forty different recognized specialties in NHS hospitals and a model which takes account of each separately must inevitably be very complicated, so much so that in order to fit such a model, the demands made upon the empirical data would be impossibly severe. Some compromise is necessary and various groupings of specialties were explored before the system set out in Table 1 was adopted. The specialties were divided first into two broad classes, acute and long-stay. The acute specialties were further subdivided into four sub-classes, medical, surgical, regional, and maternity, whilst the long-stay specialties

Table 1. Specialty groupings

	Acu	te	
Medical	Surgical	Regional specialties	Maternity
General Medicine Paediatrics Infectious Diseases STD: Special Clinics  Orthopaedics Opthalmology Plastic Surgery Dental Surgery Orthodontics Gynaecology OSU: Other Specialist Unit		Neurology Cardiology Radiotherapy Urology Thoracic Surgery Neurosurgery	Obstetrics SCBU GP Maternity
	Long-	stav	
	Geriatrics.	siuy	
con	valescent, and GP	Psychiatric	
Chest Diseases Rehabilitation Rheumatology Geriatrics Younger Disabled GP Other Pre-convalescent Convalescent Staff Wards		Child Psychiatry Mental Handicap Mental Illness Adolescent Psychiatry	

were divided into two sub-classes, geriatrics, convalescent, and GP on the one hand and psychiatric on the other. Various elaborations and alternative groupings were tested, but none of the variants proved capable of explaining a significantly higher proportion of the variation in total costs than the classification chosen. For example, when paediatrics was separated from the other medical specialties, the fit of the model was not significantly improved.

The specialty grouping listed in Table 1 was applied to the parts of the model concerned with the number of beds. For all specialty groupings except maternity, the number of available beds was taken. For the maternity group, the number of occupied beds was found to be a more appropriate measure. This reflects the fact that many maternity units are now working at well below their full capacity, with wards or complete floors closed in some cases. For the parts of the model concerned with excess patients, a broad grouping in which all acute specialties are taken together was found to be adequate.

#### THE MODEL BUILDING PROCESS

The basic model used in this study involves the representation of the total costs as the sum of a 'structural' element, made up of the sum of a number of components corresponding to the resources of the hospital and the way in which they are used, together with a 'random' element (or error) which corresponds to the part of the costs not explained by the structural part of the model. In the initial statistical analysis the error was assumed to be a random variable following a normal distribution which has a constant variance for all hospitals. This is the standard general linear model as used in many branches of applied statistics.

The validity of the structural part of a model of this type may be assessed in terms of the proportion of variation explained by the particular set of explanatory variables which have been included. Different cost structures were investigated by changing the composition of the structural variables and the benefit (or otherwise) of such change was assessed in terms of the improvement, if any, in the proportion of variation explained. In the initial development of the model, all hospitals were included in the analysis. The data were then subdivided in terms of hospital size and the results obtained pointed to the existence of economies and diseconomies of scale.

In order to explore the validity of the assumptions about the random element of the model, the data were subdivided into eight groups, each containing about forty hospitals, in terms of total hospital in-patient costs. As expected, it was found that the variance of the error term did tend to increase with increasing hospital size. This indicated that the standard, unweighted, estimation procedure used to fit the model was inadequate and that a weighted procedure was necessary. A non-linear function was fitted to the data in order to obtain an estimate of the relationship. This function was then applied to 'weight' the individual observations in order to stabilize the error variance and the final analysis was carried out using weighted least squares, a procedure which takes proper account of the properties of the data. The exploration of the structural part of the model was repeated using a weighted regression procedure and it was found that the general conclusions of the initial analysis were unchanged. Having fitted the model, the expected total costs for each hospital based upon the structural part of the model were compared with the actual costs. The differences between the two quantities, denoted the residuals, were found to follow a normal distribution. Results 55

thus confirming the assumption made when the model was fitted. This rigorous investigation of the form of the random element in the cost model is in contrast to the studies described above. These authors worked in terms of a model of average cost per case (rather than total hospital cost) but provide no evidence to show that the error term is normally distributed with constant variance as is implied by the procedures which were used to fit their models.

#### Results

The model which finally emerged from the building process may be summarized as follows:

#### Total hospital

in-patient costs = Sum over all specialty sub-classes of cost per bed × No. of beds (in specialty sub-class)+Sum over medical, psychiatric and maternity specialty sub-classes of cost per (bed)<sup>2</sup> × (No. of beds)<sup>2</sup> (in specialty sub-class) + Cost per 'excess' acute patient × No. of 'acute' patients+Random Error.

The first term corresponds to the costs of providing beds, the second covers economies and diseconomies of scale, the third corresponds to the costs associated directly with patients and the fourth to local departures from the overall trends. The random error was found to follow a normal or Gaussian distribution with zero mean but with variance which increases with increasing hospital size. Several types of function were fitted to the relationship between the residual variance and the total number of hospital beds. The most effective involved the representation of the residual error as proportional to the (0.8)th power of the total number of beds.

In the analysis of the Thames RHAs data, one further factor must be taken into account—the effect of the 'London weighting' to salaries. For hospitals within the so-called 'London Zone', employees were in 1975/6 paid an annual allowance of £312, whilst employees in the 'Outer London Zone' were paid an annual allowance of £141. Approximately half of the hospitals in the four Thames RHAs were in the London Zone. The data were analysed both separately and together using the weighted least squares procedure and model described above and the results are shown in Table 2.

Perhaps the major feature of the results is the fact that 94-95 per cent of the variation in total hospital in-patient costs has been

Table 2. Analysis of hospital in-patient costs, Thames RHAs 1975/6. Cost (£) per bed per annum (and standard errors).

Component	London Z	one	Elsewi	here	Both	42
Number of hospitals	210		192		402	
Percentage of variation explained	95.5		93.7		93.9	
Medical beds	7,481 (1,034)	1,034)	10,959 (1,470)	(1,470)	9,535 (576)	(276)
(Medical beds) <sup>8</sup>	9.39 (	3:0)	-12.9	(16·3)	su	
Medical unit (50 beds)	7,950	575)	10,314	(750)	9,535	(276)
Psychiatric beds*	5,167 (	(772)	3,439	(366)	4,073	(362)
(Psychiatric beds) <sup>2</sup>	-1.5 ((	)-56)	-0.25	(0.49)	69.0-	(0.41)
Psychiatric unit (100 beds)	5,017	525)	3,414	(375)	4,004	(350)
Maternity beds†	) 077,61	1,302)	12,047	(1,193)	15,877	(945)
(Maternity beds) <sup>2</sup>	-129	31-9)	-35.8	(32-3)	-63.6	(23·8)
Maternity unit (50 beds)	13,320	1,150)	10,257	(920)	12,697	(875)
Surgical beds*	8,631 (	193)	7,184	(410)	7,771	(337)
Regional specialty beds*	16,323 (	(1861)	9,565	(1,349)	12,011	(1,204)
Geriatric/convalescent/GP beds*	5,075	223)	4,213	(201)	4,646	(160)
'Excess' acute patients‡	) 6.66	32-4)	150-5	(29·4)	116.8 (22.6)	(22.6)

<sup>•</sup> Available beds. † Occupied beds. ‡ Cost per 'excess' patient.

Results 57

explained by the model, a real improvement over the 'economic' models for much more heterogeneous data. This degree of success is not solely the result of including a much wider range of sizes and types of hospital than in the previous analyses. Indeed, when homogeneous sub-sets of the data have been analysed separately, levels of explanation considerably in excess of 90 per cent were reported. Secondly, diseconomies of scale were detected for the medical specialties in the London Zone, as revealed by the positive coefficient for the squared term. This implies that cost per bed tends to increase with the size of the group of medical specialties. Possibly this reflects a different (and more expensive) case-mix in the larger units or alternatively the efficiency of the larger units may be lower than that of the smaller units. In contrast, outside the London Zone there were economies of scale in the medical specialties, possibly as a result of the different influence of the London teaching hospitals upon the more distant non-teaching hospitals. On the other hand, the psychiatry and maternity groups of specialties show evidence of economies of scale in the London Zone which are small for the former and large for the latter. In other words, the cost per bed in the larger units is lower than that in the smaller units. For the psychiatric specialties this is consistent with general experience. Amongst the maternity specialties, however, the trend is surprising since it implies that the cost per bed in the smaller (and generally worse-equipped) maternity units is higher than that in the larger (and generally better-equipped) units, even when account is taken of differences in levels of throughput by means of the 'excess' patients variable. For the three specialty groups in which there are economies and diseconomies of scale, the cost per bed has been calculated for a unit of a standard size: 50 beds for the medical and maternity specialty groups and 100 beds for the psychiatric group.

The relative magnitudes of the estimates of the costs per bed are for the most part consistent with experience. The highest costs were reported for the regional specialties, particularly in the London Zone. The next most expensive are the maternity beds, for which the cost is the same as for the regional specialties outside the London Zone, and considerably higher than for the medical and surgical specialties. The results for medical specialties are believed to be diluted to some extent by the classification of geriatric beds as general medicine in some units. The lowest costs per bed were associated with the psychiatric and geriatric/convalescent/GP

specialty groups, which reflects the lower levels of service which are provided. The costs per excess patient are low in comparison with the costs per bed. Assuming that there are as many as ten excess patients per bed per annum (a very high figure), the total cost of £1,000–1,500 at most amounts to one-fifth of the costs of an acute bed.

Reference to Table 2 shows that the costs per bed in all specialties except the medical group were higher in the London Zone than elsewhere in the four Thames RHAs. The fact that the medical specialties show the converse trend may well be due to a misclassification of some geriatric beds in the London Zone as general medicine. On the assumption that the London Zone allowance would account for at most a differential of 10 per cent in salary costs, the differences between corresponding unit costs suggests that other factors are involved which increase London Zone costs. It is, however, interesting that the cost per excess acute patient is lower in the London Zone than elsewhere, although the difference is not statistically significant.

Table 2 also shows the standard errors of the estimates of the various parameters involved in the model. For the most part, these are between 5 and 15 per cent of the corresponding estimates. Thus, in spite of the high proportion of the total variation explained by the model, the parameter estimates are subject to an appreciable degree of error. This is a reflection of the fact that the method of approach is an indirect one involving the analysis of data from groups of hospitals which vary widely in terms of size and case-mix. The most accurate estimates were obtained for the long-stay specialties, which are more commonly catered for in single-specialty hospitals than the acute specialties.

#### Uses of the model

A model has been described whereby existing sources of data, routinely collected, can be analysed to produce estimates of specialty costs and a hospital cost equation. Such an analysis calls for the use of a computer, but nevertheless could be undertaken at regional or national level using existing NHS data processing facilities. In many instances SH3 and HCR data are already available in computer-accessible form for other purposes and results such as those described could be produced routinely on an annual basis as soon as the previous year's data becomes available. Given that this

information could be readily obtained, there are two immediate uses to which it might be put.

There is no clear guidance from the DHSS concerning the costing of strategic plans (4). Many regions and areas are, or will be, going through periods of unparallelled change in hospital provision as a result of policies of resource redistribution. If plans are to be consistent with financial constraints, an appropriate method of costing plans, in particular those relating to the most costly sector of hospital in-patient provision, must be available. We believe that our approach provides an improvement on the methods promulgated nationally. The results derived from the model correspond to the existing patterns of expenditure of the hospitals included in the analysis and therefore form a firm basis for projecting future unit costs. In the absence of any information to the contrary, the results could be applied unaltered, or in the light of these results policy decisions about specific changes in cost structure could be taken and the costs modified accordingly. Thus, the expected revenue cost could be calculated for any defined in-patient provision. In formulating its strategy, each individual area or region must be concerned that appropriate unit costs are used, and rightly so if financially feasible plans are to be constructed.

As an alternative to using the results from the analysis directly, which in some sense represent 'average' costs for the set of hospitals included in the analysis, the results may be used to estimate expenditure on individual specialties and thus total expenditures at individual hospitals. Based on the bed distribution in the particular hospital, the theoretical expenditure in each specialty group can be calculated from the regression equation; the actual hospital total in-patient expenditure may then be broken down to the separate specialty groups in proportion to the theoretical expenditure. This assumes that any factors which inflate or deflate the actual cost of the hospital are common to all specialties, such as higher than average staffing levels or the expense of heating old buildings. It is a matter of judgement and agreement as to which particular set of costs should be applied. However, we believe that this use of the model will improve the quality of information and consequently the costing of any particular strategic plan.

The model and results may also be used to assist financial monitoring. Given the bed distribution at a particular hospital, the theoretical revenue expenditure may be calculated from the regression equation. If the actual expenditure is significantly different, then this would indicate a case for further investigation. It has been pointed out that the funding of hospitals has been, to date, based largely upon historic levels of spending. It would not be surprising, therefore, if examples existed of hospitals which have always enjoyed high levels of funding with no apparent justification or, equally, instances where hospitals have persistently managed on a lower than average budget. The rectification of anomalies revealed in this way certainly conforms to the spirit, if not the letter, of the current movement away from the status quo and towards a more equitable distribution of resources within the NHS.

#### Comment

Since the NHS was reorganized in 1974, increasingly formal management procedures are being introduced for planning, resource allocation, monitoring, and other functions. In the initial approach to these problems little attention was given to financial matters, but as experience has accumulated there has been a growing awareness that the costs of providing particular items of patient care must occupy a key position in the armoury of information at the disposal of the manager, Recent guidance on planning (4), provided by the DHSS to regions and areas has dealt specifically with this problem. but the solutions offered by central government have been gravely handicapped by the lack of an appropriate methodology and by the absence of relevant and up-to-date data in an accessible form. Failing a more acceptable alternative, the DHSS has recommended that the costing of services should be based upon arbitrary and simplistic working assumptions, many of which are manifestly unrealistic when applied to particular local situations. This approach is recognized as being inconsistent with the procedures for resource allocation to RHAs which are being implemented by central government, which must surely constitute the focus of managerial activities at lower levels within the system. It is self-evident that real progress towards more effective and efficient use of resources within the NHS calls for a managerial strategy based upon a coherent and co-ordinated appreciation of entities such as patient care-related costs.

The approach described in this paper does offer real prospects of progress towards a proper understanding of the way in which Comment 61

hospital in-patient resources are being used. The basic mathematical models relating total hospital costs to resources and activities associated with in-patient care are useful in pointing to which elements are important in determining costs. They are also capable of providing a convenient and relatively simple summary of what is often a very complex set of activities. We have shown that it is indeed possible to fit all types of in-patient care, ranging from small hospitals covering a wide range of acute and long-term care, within the same logical framework. Bearing in mind how the NHS is financed and run, it is not surprising that classical economic theory does not provide the best available explanation of in-patient costs. Our empirical models have been further tested in the light of information from the Trent RHA for the financial years 1973/4 and 1975/6 and have been found to be adequate and superior to the 'economic' models advocated by other students in the field. The next logical step is to extend the analysis to an even wider and more representative set of data and a study based upon the SH3 returns and hospital cost returns for all hospitals in England and Wales for 1975/6 is currently in hand.

Although the models account for the greater part of the variation in hospital in-patient costs between hospitals, there are still discrepancies when the actual expenditure at particular hospitals is compared with the expenditure expected for the given resources and case-load under the model. Preliminary studies suggest that such discrepancies are due at least in part to local variations in classification and nomenclature. For example, the general medicine specialty tends to include varying proportions of old people who might equally well be assigned to the geriatric specialty. It is also very probable that differences in case-mix within the same specialty may also be important. For example, our studies of the Inner and Outer London areas suggest that the effect of the teaching hospitals on the structure of the cases treated in the non-teaching hospitals may differ very widely between different geographical areas. The age of the buildings and the general standard of the amenities in a hospital are also likely to have some effect on cost levels, particularly in respect of the new district general hospitals. Further study of these problems is required. In the meantime, however, a reasonable policy for monitoring hospital expenditure would call for the specific justification of departures from the expected total in-patient costs produced by the model.

A major conclusion of our analysis is that it is resources rather than services provided which are the main determinants of costs. In a competitive situation an organization which behaved in this way would not be viable. However, the provision of health care by the state is not competitive. Given the growing pressures towards uniformity and standardization, the resource (typically the hospital bed) has been adopted as the basic vardstick for the provision of funds, rather than a unit based upon service. As existing planning and resource allocation procedures become more effective, this trend is likely to be reinforced, to the detriment of efficiency. What is needed is a re-definition of managerial objectives towards more subtle but more relevant criteria based upon patient care and away from the more tangible and easily measured but illusory criteria based upon resource provision. The effect of the absence of competition upon the responsiveness of the health care system to changing circumstances is underlined by the level and structure of the costs of maternity care. The present situation, in which the average costs of maternity beds are comparable to those of the generally much more exacting regional specialties and where the larger and better-equipped units cost less per bed than the smaller units is surely a reflection of gross inefficiency in resource allocation.

The difference in estimated costs between Inner and Outer London suggests that there may be real variations between different geographical areas in the cost of providing defined services. Our proposed analysis of data for all hospitals in England and Wales will provide further evidence about this point and will in fact enable an estimate of the cost of standard units of in-patient care to be made for each RHA. If (as seems likely) significant variations are revealed, and can be justified, the basis for the distribution of funds between RHAs advocated by the Resource Allocation Working Party must be open to serious doubt. If cost levels per unit of service really do differ, any formula for the distribution of funds based upon equality of service provision must reflect this factor.

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## Handicapped children and their families

Their use of available services and their unmet needs

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## Handicapped children and their families

Their use of available services and their unmet needs

A population-based study has been made of all children born within the city of Exeter between 1967 and 1971, to identify all those who, during their first five years of life, developed a handicapping condition of prenatal or perinatal origin. In addition to the medical nature of their disorder, an attempt has been made in each child to classify the functional severity of their handicap. The purpose of the study was twofold.

- 1. To describe and measure the total use of health, educational, social, and voluntary services by the population of preschool age children with handicaps of prenatal or perinatal origin.
- 2. To identify the unmet needs of these handicapped children and their families.

Each handicapped child has been matched with a control child from the same birth population of Exeter children in order that both the use of services and the unmet needs of the handicapped children and their families could be compared with those of a control population of families.

We present our results with some diffidence. Whilst our data does provide a description of the use made of services and some obvious indications of unmet needs, yet our interviews with parents have left us with increased insight into the difficulties of assessing how far the services provided were appropriate to the extremely varied needs of individual children and their families.

#### DESCRIPTION OF THE POPULATION

Although the Registrar General's classification of social class distribution does not reveal any significant difference between the population of Exeter and the general population of England and Wales, yet Exeter in common with most of the south of England has more favourable environmental living conditions (1) and a higher expenditure on community health (2) than the rest of the United Kingdom. From Table 1 it is apparent that the neonatal and infant mortality rates for Exeter during 1967–71 were significantly lower than those for England and Wales as a whole.

Table 1. Exeter Survey, 1967–71. Population: 95,700. Births: 7,059. Demography and childhood mortality. (Mortality rate per 1,000 children of comparable age.)

Rate	Exeter (1967–71)	England and Wales (1971)
Birth-rate	14.6	16· <b>0</b>
Stillbirths	13.2	12.5
Deaths 0-6 days	7.3	9.9
7-28 days	1.6	1.7
1-12 months	4.5	5.9
1-4 years	0.7	0.7

#### IDENTIFICATION OF HANDICAPPED CHILDREN

Since all our birth population came from the small City of Exeter (population 95,700), our research team had only to make contact with one unified maternity and hospital service, one health care district and only forty-nine general practitioners. Similarly only one local education authority and social services department were involved and each voluntary organization had only a single headquarters from which its service operated. The research team was given free access to all records (with appropriate safeguards regarding confidentiality) from all these services. All hospital records were analysed by medical members of the research team, but due to the limitation of our resources, although all general practitioners had given permission for their patients to be included in the survey, the general practice records were not analysed. Thus, the information now reported about the contact made between handicapped children and their families with their general practitioner has been derived from interviews with the parents of the handicapped and control children. Local health authority (health care district since 1974) records regarding orthoptic, audiology, and speech therapy have been analysed. The child guidance service has given us details of attendances of children but did not disclose confidential information regarding families. We have had access to all special schools and nursery schools serving children under five years of age, as well as much help from health visitors about neighbourhood play groups. Information about use of the social services and voluntary agencies is mainly derived from our interviews with parents. The local authority handicap register, the register of birth defects maintained by the Genetic Counselling Service, and the school health register were all made freely available to us.

#### DESCRIPTION OF HANDICAPPED CHILDREN

This study was restricted to handicap which was considered to be of antenatal or perinatal origin, in order to identify possible relationships between the subsequent development of handicap and the circumstances surrounding birth. Handicaps which were considered to be due to environmental causes occurring after the neonatal period were not included. Since medical diagnoses alone often fail to indicate the extent to which a child is functionally handicapped, an index of the functional severity of handicap was designed.

#### CLASSIFICATION OF FUNCTIONAL HANDICAP

### Group I

In this group were included children with minor congenital defects, such as extra digits, haemangiomata, which later subsided spontaneously, or were inconspicuous, functional cardiac murmurs which required no specialized investigations and which were considered unlikely ever to create medical problems in later life, children born with inguinal or umbilical hernias, phimosis, or minor bone and joint disorders such as minimal varus deformities of the foot or genu valgum which required no treatment or for which treatment was completed before the child's first birthday.

## Group II

This group consists of children who had defects or disorders which caused some degree of functional handicap during the early years of life but which were completely corrected by the child's fifth birthday. These included children with congenital dislocation of the hip diagnosed in the first weeks of life and in whom appropriate treatment with splints effected a complete cure, mild talipes, requiring only physiotherapy, significant delays in motor or speech develop-

ment for which treatment was given, strabismus, which was successfully corrected, minor chronic gastro-intestinal disorders such as lactose intolerance and failure to thrive.

### Group III

In Group III were included all children in whom a handicapping disorder persisted beyond their fifth birthday but in which the handicap, though serious, did not create severe functional restriction at home or at school or was considered likely to reduce life expectancy. This group included children with mild educational subnormality (ESN(M)), mild cerebral palsy such as minor hemiplegia, persisting visual defects, such as strabismus, cataract, or other causes of defective vision which were not wholly correctable, persisting speech or hearing problems, congenital heart disease with the prospect of corrective surgery, and behaviour disorders unlikely to result in mental illness in adult life.

#### Group IV

All children in Group IV had severe handicapping disorders. They were subdivided into four sub-groups IV (a-d) according to the nature of the predominant functional handicap, although in many individual children their handicap was multiple in character.

## Group IV (a)

All children with severe mental subnormality (ESN(S)) were included in this group whether or not additional handicapping disorders such as cerebral palsy, spina bifida, epilepsy, or multiple malformations were present.

## Group IV (b)

Children with predominantly severe locomotor disorders such as severe cerebral palsy or spina bifida but without severe mental subnormality and children with disorders such as muscular dystrophy were included in this group.

## Group IV (c)

This group of children included all those with severe chronic illness such as cystic fibrosis and incurable congenital heart disease.

## Group IV (d)

Children with major disorders of their special senses, such as very

severe hearing impairment or total deafness, severe visual impairment or total blindness, severe language disorders or other severe disorder of communication and severe emotional or psychiatric disorders were included in this group.

Because of the limited nature of this study which extended only to each child's fifth birthday, it will have not identified the group of children who may subsequently be found to be of less than average intelligence or who may develop behavioural or neuro-psychiatric disorders which are considered to be caused by factors occurring during the prenatal or perinatal period. The numbers identified in each Group are shown in Table 2.

The numbers included in Group I are incomplete. For the purpose of this study it was considered necessary to collect details of a sample of children suffering from these types of disorder, so that appropriate comparisons could be made between them and the groups of children with more severe disorders and with the control group of children. Once a sufficient number of Group I children had been collected for comparative and descriptive purposes, no further children who might have qualified for Group I were included in the study. By contrast all children identified from the population of 6,966 live births who had functional handicaps as defined in our Groups II, III, (IV) (a-d) are included in this study.

Table 2. Exeter Survey, 1967-71. Functional classification of handicap. (Population: 95,700. Live births: 6,966.)

Group	Severity (0-5 years of age)		Number
Group I	Minor congenital defect. Disorder corrected single surgical procedure.	by a	81+
Group II	Developmental delay or disorder corrected lifth birthday.	у	45
Group III	Minor or moderate permanent disabling dis causing some limitation in some aspect of participation at school.		105
Group IV	Severe handicap		77
(a)	Mental handicap:	29	,,
(b)	Neuromuscular disorder:	11	
(c) (d)	Chronic illness: Special sensory or language disorder,	16	
.,	major psychiatric or emotional disorder:	21 77	
Total			308+

#### COMPARISONS WITH OTHER STUDIES

Comparisons with other studies reveal numbers similar to those found in other British surveys of the incidence of handicap. The numbers in our own study are summarized in Table 3.

Table 3. Exeter Survey, 1967-71 births. Handicaps of prenatal or perinatal origin detected by the age of five years.

	No. per 1,000 live births
Severe handicap: Groups IV(a-d)	11
Persistent mild handicap: Group III	15
Handicap corrected by the age of five years: Group II	6
Total	32

The Isle of Wight survey (3) identified 11 per 1,000 school age children as severely handicapped. The National Childhood Development Study (4) found 12·7 per 1,000 seven-year-old children to be severely handicapped (in about 9 per 1,000 the handicap was considered to be of prenatal or perinatal origin). The Newcastle-upon-Tyne study (5) found 8 per 1,000 children to be severely handicapped because of severe mental retardation or severe sensory abnormality (our Exeter results indicate 7 per 1,000 children in our Groups IV (a) and Group IV (d)). Kushlick (6) found 3·6 per 1,000 school age children to be severely mentally subnormal compared to the 4·1 per 1,000 children under five years of age in our study. Rather lower prevalences of severe handicap from all causes were recorded in the York Register (7) of 6·1 per 1,000 and the Bristol study by Diana Pomeroy (8) of 6·7 per 1,000.

It is less easy to find comparable figures for the prevalence of moderate or mild functional handicap since most authors refer to the prevalence of individual diseases or particular congenital disorders without identification of the extent of the functional handicap. In France in 1968 (French Sixth Plan) (9) it was estimated that 48 children per 1,000 live births who survived to the age of one year had some evidence of handicap; a figure which may bear some comparison with the total of our Groups II–IV children, which show that 32 children per 1,000 live births will by their fifth birthday have evidence of a functional handicap of prenatal or perinatal origin.

#### CONTROL GROUP OF CHILDREN

For each handicapped child, a control child was selected from the register of Birth Notifications for the City of Exeter matched for sex, birth rank, size of family, and social class. Only children whose birth date was within six months of the handicapped child's birth date were selected. Both the families of the handicapped children and the control families were visited by the research nurse (J.J.); of the 308 families with a handicapped child only one refused to be interviewed; of the 312 control families approached only four refused interview.

Table 4. Exeter Survey. Severe handicap and place of birth, 1967-71. (Birth population: 6,966. N: 77) (percentage.)

Place of birth	All births	Severe handicap
Home birth	12	12
Non-specialist maternity unit	50	40
Specialist maternity unit	38	48
•	100	100

#### RELATIONSHIP BETWEEN BIRTH AND SUBSEQUENT HANDICAP

The main correlations between perinatal care and subsequent in this survey have been described elsewhere (Brimblecombe et al., 1977). The different significance of low birth-weight related to neonatal mortality and to subsequent handicap is clearly shown. Of the total neonatal deaths, 61 per cent came from the 6.8 per cent of the birth population who weighed 2,500 g or less at birth; but this same 6.8 per cent of the birth population accounted for only 21 per cent of the severely handicapped (Groups IV (a-d)) children. Strong support for birth in a specialist maternity hospital is provided by the data shown in Table 4. In our survey less than half the infants with subsequent severe handicap were born in the specialist maternity unit (to which the special care baby unit is attached). It must be emphasized, however, that many of the handicaps were not preventable wherever the birth took place or whether or not the infant was subsequently treated in a special care baby unit.

#### USE OF PRIMARY HEALTH CARE SERVICES

#### Family doctors

All 49 of the family doctors concerned with our 308 handicapped,

and 308 control children and their families kindly gave permission for them to be included in our survey. Unfortunately, the resources of our research team were insufficient to implement one of our original intentions, namely a study of the general practitioner records of the complete survey population, together with an interview with the family doctor about each family. Data from other surveys (10) indicates that in the age group 0-4 years, the average number of consultations is about 4 per annum; the figure is higher in the first year of life but reduces as the child grows older. Most of our information about the children's primary health care is derived from interviews with the parents. We recognize that this may provide a one-sided description of the contact between family doctors and young handicapped children and their parents. The parents were asked to identify the occasions when they had seen their family doctor primarily on account of the handicap or on account of an intercurrent illness (respiratory, gastro-intestinal, rashes, or behaviour problem of early childhood). The number of visits on account of intercurrent illness did not differ between the handicapped and the control children; nor did the number of occasions on which antibiotics were prescribed.

The additional consultations between the handicapped children and their family doctors were concerned with the handicap itself. This number of contacts was in many instances surprisingly small and varied with the nature of the handicap. Even in Groups III–IV, the additional contacts were on average less than double that of the control families. Since each family doctor had an average of only 3–4 Group II–IV handicapped children in this five-year birth cohort within his practice, his experience with young handicapped children is extremely limited if these figures provide an accurate estimate.

It is important in trying to understand the type of service provided by family doctors to families with young handicapped children to appreciate how totally varied and disparate this service appears when seen through the eyes of the parents. Some families could not speak too highly of the support and help that they received from their doctor. Such doctors remained a constant source of strength to the family. This attitude towards their doctor is contrasted with that reported by other families with a handicapped child. In these instances the family did not appear to expect help from the family doctor about the handicap itself but had already come to rely upon a particular hospital resource centre for advice.

The organization of health centres seemed in some cases to militate against an optimal service for handicapped children. Receptionists, seen through the eyes of parents, often seemed to show no insight into the difficulties of bringing a handicapped child by public transport (and often a toddler and a new baby as well) to a health centre at a highly inconvenient hour. Many parents were distressed that they did not see their own doctor either at the health centre (unless the appointment was made for several days ahead) or for home visits when their handicapped child was sick.

A number of parents did not expect management help for children with severe handicaps from their family doctors (children with valves for hydrocephalus, mental handicap, or cerebral palsy) but tended to go direct to the appropriate hospital resource centre with which they had built up a relationship.

#### Health visitors

The same extreme variation of opinion was expressed by parents about the service offered them by their health visitors. Failure to visit and absence of positive advice and practical help were the two main criticisms. As seen through the eyes of the parents some health visitors were not well-informed both about the details of their families on their list or lacked expert knowledge about particular handicaps. Three specific examples must suffice. A mother of a three-year-old boy with severe athetoid cerebral palsy could not bear to go to the child health clinics because she felt it distressed the other mothers to see her child. She felt very isolated and would have appreciated regular visits from a health visitor but these were not made. A teenage mother, separated from her husband, was afraid to go out of the house for months in case her baby daughter with cyanotic congenital heart disease died whilst she was away. She was never visited once by a health visitor during the child's first year of life. The health visitor of a family with a boy with Down's syndrome visited rarely, explaining that it was not necessary for her to visit more frequently because the family were 'coping so well'. On one occasion she heard the noise of a baby playing with a rattle in the next room; she expressed surprise to the parents as she said that she had understood that Down's syndrome babies did not learn to play.

As seen through the eyes of parents, some health visitors often seemed in retrospect to have failed to take opportunities to give practical advice upon the problems affecting the other members of the family of a handicapped child. Failure to offer information about family planning was a common problem in the earlier years of our study (there has been a steady improvement since 1971 when family planning services started to become more freely available).

On the other hand, as with many family doctors a considerable proportion of individual families found their health visitor to be the person they most relied upon for support. No higher testimony can be offered than the experience of 1974, when as a result of reorganization of the NHS, many health visitors had their areas of work changed. This was regarded as a major disaster by many families who had come to rely upon the personal relationship built up with their own particular health visitor as their main source of help and support.

In summary, there was a remarkable variation in the attitudes of families with handicapped children towards both their family doctors and to their health visitors. One is tempted to ask how much of this variation is the result of the type of training received by family doctors and health visitors (in both a positive and negative sense) and how much is the result of their own personalities (in spite of any professional training they have received). It is also practical to ask whether the available resources for primary health care for handicapped children and their families are currently being used in the most effective manner?

#### USE OF HOSPITAL SERVICES

The data regarding the use of hospital services was extracted from the hospital records of all the children in our study born during 1967-9 and includes all uses of services made by them during their first five years of life. The total numbers of cases and controls in the following tables is therefore 180 in each group rather than 308 (which represents the numbers born between 1967 and 1971).

## Out-patient clinics

In contrast with their usage of the primary health care services, young handicapped children made far greater use of the hospital services. Table 5 shows the number of out-patient clinic visits made by the children with each degree of functional handicap compared with the control group of children. These numbers refer to the total aggregate of visits to all clinics (paediatrics 40 per cent, orthopaedics

16 per cent, ophthalmology 14 per cent, general surgery including urology and thoracic surgery 12 per cent, otolaryngology 8 per cent, plastic surgery 3 per cent, neurology and neurosurgery 3 per cent, dermatology 2 per cent, others 2 per cent). It is of interest that the Group II children made the largest number of visits, which may indicate an emphasis upon curable conditions. The control group of children made on average one visit to an out-patient clinic in their first five years of life.

Table 5. Exeter Survey, 1967-9. Secondary medical care during first five years (N: 180).

Hospital clinic visits (per child)	Cases	Controls
Group I	6	1
Group II	17	
Group III	10	
Group IV	14	
Total clinic visits for all 180 children	2,196	185

Table 6. Exeter Survey, 1967-9. Secondary medical care during first five years (N: 180).

Hospital admissions (per child)	Cases	Controls
All groups	1.8	0.2
Hospital days (per child)		
Group I	9	1.6
Group II	25	
Group III	31	
Group IV	117	
Total hospital days for all 180 children	6,511	288

Table 7. Exeter Survey, 1967-9. Use of laboratory services during first five years (N: 180).

Cases	Controls
5	1.3
6.5	
11.5	
28	
2,977	238
	5 6·5 11·5 28

#### Admissions

Admissions to hospital (Table 6), illustrates the expected variation with the severity of the handicap—but shown by the number of days spent in hospital over the five-year period. Only 1 in 5 of the control children required hospital admission during their first five years of life.

### Use of laboratory services

The use of laboratory services as shown in Table 7 reveals the expected trend. It is to be emphasized that the use in Table 7 of 'a test' as a unit of measurement fails to indicate that many of the tests carried out on handicapped children were complex, time-consuming and expensive, tests on the control children tended to be more of a routine nature and were both simpler and less expensive.

## Use of accident emergency department

Visits to the accident emergency department, Table 8, shows only a slightly increased use by handicapped children compared with the control children.

Table 8. Exeter Survey, 1967-71 births. Use of accident/emergency department during first five years of life (N: 308).

Number of visits	Cases	Controls
Number of children making visits	121	94
Total visits	155	123
Visits for burns	12	5
Fractures of upper limbs	7	2
Parental anxiety	21	12
Unspecified	7	2

The use made of the accident/emergency department varied little between children in each of the groups of functional handicap and between the control group of children and the handicapped children as a whole group. Although the numbers of handicapped children who sustained burns and fractures of the upper limbs is only marginally greater than in the control group of children, their numbers are specifically mentioned as the only two conditions for which any trend suggestive of a different pattern of accident emerged between the handicapped and the control group of children.

#### CHILD ABUSE

Of the 308 handicapped children in the study, three were the subject of court orders on account of child abuse; two of these were severely handicapped children, the third had only a Group I handicap. One further handicapped child was placed on the child abuse 'at risk' register. None of the control children were either the victims or were suspected of being at risk of child abuse.

#### PARENTS' VIEWS OF HOSPITAL SERVICES

Criticisms of the hospital service were on all too familiar lines. The highly unsatisfactory situation of a patient seeing a different doctor each time he visited an out-patient clinic was depressingly frequent. This was by far the most common complaint about the hospital service in our survey. A large proportion of consultations were unsatisfactory to the parents in that they felt that they had not been given sufficient information. Attendances at a large number of different clinics placed a considerable strain on parents of children with multiple handicaps notably children with spina bifida.

As seen by the parents, the hospital service failed in its purpose in cases where communication between individual departments was poor. The mother of a four-year-old boy with delayed motor development had become acutely concerned about her child when, following a series of severe convulsions at the age of ten months, his developmental progress had stopped. She was seen by a paediatrician, child psychiatrist, educational psychologist, physiotherapist, and speech therapist. 'Nothing was gained by all those long waits for appointments and evaluations, and when they came to give me the results it was either nothing or something I already knew well.' She felt grateful to the last specialist she saw, an orthopaedic surgeon: 'He finally told me what was wrong-hypotoniaand that it would definitely improve.' Comforted by this, she remembered that she had been told immediately after the episode of convulsions that the boy would improve with time but she could not then accept this advice.

Specialist hospitals came in for criticism that insufficient attention was paid to the total needs of children. Sometimes a child was described as 'too difficult to examine', when the parents felt that this was the result of a long wait in uncongenial and unfamiliar surroundings. It is apparent from the following examples that despite theoretically comprehensive follow-up and examination that

clinical errors continue to occur. A pre-term infant was seen regularly for two-and-a-half years in a special follow-up clinic before his deafness was detected. A child referred to a paediatric out-patient clinic on account of a cardiac murmur went away with his congenitally dislocated hip undetected.

There were very few criticisms of the in-patient care received by children in this study.

It is to be emphasized that throughout the period of this study there was no Comprehensive Assessment Centre (Child Development Centre) in Exeter (although one has since been opened in 1977). In summary as with the primary health care service, the views of the parents of handicapped children support a more unified specialized service for handicapped children which would integrate many of the services which were acting independently of each other during the period of the survey.

#### CHILD HEALTH CLINICS

Handicapped children attended child health clinics less often than did the control group of children; 30 per cent of the parents of handicapped children and 17 per cent of the control group denied ever attending a child health clinic. For those children who did attend, their visits ceased on average at the age of fifteen months both for the handicapped and for the control group. Handicapped children may have attended less often than others because some had already been directed to special clinics or centres at a very early age. It is of great interest that parents of both handicapped and non-handicapped children preferred neighbourhood clinics, where they were seen by health visitors and doctors who dealt with geographical neighbourhoods rather than the clinic organized by the family doctor's practice. With the former arrangement the parents enjoyed the opportunity to meet their neighbours and were often able to form supportive groups among themselves. Attendance at a health clinic based not on a geographical area but recruited from the patients on a particular general practitioner's list did not provide them with the same social appeal. The difficulties which some mothers of handicapped children experienced in attending child health clinics has already been described. Many clinics were illdesigned in the opinion of parents. Two exits on to a main road, through which a two-year-old child might escape were difficult to supervise whilst also nursing a new baby. Access to some clinics

was difficult by public transport for some families (a return to the more conveniently placed neighbourhood clinic would have been preferred).

#### CHILD GUIDANCE CLINIC

The child guidance clinic played a relatively small part in the service for preschool age children in Exeter. Of the 308 handicapped children, 8 per cent attended the clinic during their first five years of life, of the 308 control children, only one attended.

#### SPEECH THERAPY

Many children received speech therapy as part of their multidisciplinary care and education in special nursery schools and special schools. In all, 30 per cent of the handicapped children received advice from a speech therapist whilst 4 per cent of the control children (who were only accepted by us as controls if their speech development was considered to be normal!) had also seen a speech therapist.

Table 9. Exeter Survey, 1967-71. Handicap and use of preschool services (N: 180) (percentages).

	Cases	Controls
Play group	48	53
Nursery school	16	10
Hospital play group	6	
Peripatetic teacher	11	
Speech therapy	30	4

#### PRESCHOOL EDUCATION

Table 9 provides a brief summary of the use of educational services. The survey period was one of considerable change in the development of preschool age educational services. In particular Honeylands (11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21) was just beginning to evolve as was the peripatetic teaching service for handicapped children provided by the local education authority. Much of the peripatetic teaching referred to in Table 9 refers to the teaching of deaf or visually impaired children. It will be seen that rather more than half the sample of control children attended a playgroup. Since the survey, the number of playgroups has increased con-

siderably. Facilities for special nursery education have also been progressively increased.

#### SOCIAL SERVICES

Parents of handicapped children had had very little contact with social workers apart from the one social worker on special secondment to the hospital paediatric department. Where they had at some time met a community social worker, there seemed to have been little product from the meeting; either the social worker had failed to make a return visit or a second visit had been made by a different social worker, who knew little of the details of the problem. A sad but typical experience is that of a family with twin infants with cerebral palsy. The mother had a stroke and was in hospital for two months. The father refused the offer that his two handicapped and one normal child should be put into care and gave up his job in order to look after them, inevitably experiencing a period of great financial hardship as a result. On his wife's discharge from hospital she needed a bannister rail in order to go upstairs at home. This was promised them by a social worker. Six weeks later a carpenter arrived to take measurements. When it was explained by the husband that he had fitted the stair rail within forty-eight hours of his wife's return home, as it was impossible for her to go upstairs to bed or to the lavatory without it, the social services refused to reimburse him for his expenses.

Table 10. Exeter Survey, 1967-71. Handicap and marital status and severe mental illness of parents (N: 308).

	Cases	Controls
Single parent	26	21
Divorced	10	5
Severe mental illness of a parent	12	7

#### **VOLUNTARY AGENCIES**

There was contact with a voluntary society in 67 instances (44 of the children in Group IV a-d and 16 from Group III). The most commonly consulted agency was the local Spastics Society followed by the National Society for Mentally Handicapped Children. The type of help varied; many children with locomotor problems received therapy from the Spastics Society and a smaller proportion

attended their nursery school. Help from other societies was mainly advisory.

#### REALITIES OF LIFE WITH A HANDICAPPED CHILD

Parents' problems, opinions, and suggestions

In our study, we asked the parents a series of formal questions from which the information given in tabular form in this paper has been derived; we also offered them the opportunity to tell us about other problems, specifically related to their handicapped child and also to the life-style of their family. A similar opportunity was given to the parents of the control children.

In many respects the narrative result of our survey has been more informative than the standardized questionnaire component. Words caused pain to parents, for example, the doctor in a child health clinic who said 'he looks moronic'. Other words allegedly used to parents about their children included 'cabbage' and 'vegetable'. More often how, where and when the initial bad news was broken and the subsequent discussions took place were the subject of critical comment by the parents rather than the actual words that were used. The wide variability of parental reaction was particularly obvious in our group of eight children with Down's syndrome in this study. Although the extent of functional handicap shown by all eight of these children was similar, the variety of reactions shown by their eight families would require a separate monograph to describe them adequately. In summary, the parents needed much more information and supportive counselling in the early months after their child's birth, more advice about the skills which they needed to acquire to look after their child and more informal family support comparable to that now provided at Honeylands. An extended description of their unmet needs would however require to be set against the needs of the control group of families whose children were not handicapped. Among the eight families who provided the control group to the eight families with Down's syndrome infants, there was one mother with severe depression which she explained was the result of her exhaustion from working each night at a bingo hall to pay off the mortgage. Two mothers felt very lonely and said that the child health clinics they attended were unfriendly places and poorly run. Another mother in this group had had persistent anxiety about her child's speech development, although without justification; her need was for reassurance.

Housing problems were common among families with young children, whether handicapped or non-handicapped. Often it was the environment of a particular housing estate as much as the physical crowding that caused distress. Vandalized telephone kiosks, unpleasant neighbours, refusal of credit facilities in stores, or convenient access to services such as chemists' shops and poor public transport facilities were problems common to both groups. Inevitably the presence of a handicapped child accentuated many of these difficulties.

#### SUMMARY

It is apparent from this study that the effectiveness of the services for handicapped children was extremely variable and also very difficult to measure. The quantitive use of services is of itself an inadequate measure of their value. For children with congenital defects or disorders of perinatal origin which were completely correctable either by a surgical procedure or by medical or paramedical therapy, the services were in general more developed than those for children with handicaps that were life-long. This almost certainly reflects the priority given over many years in an evolving health service to acute or incidental illnesses in contrast to the provision of services for individuals with chronic handicaps.

Our investigation indicated to us that families with children with chronic handicaps often found that the services offered to them were inappropriate or inadequate for their needs. Often the service approach to them was predominantly a medical or nursing one when their greater needs were social, emotional, and educational. The result was frustrating both to donors and recipients. The predominantly social nature of a chronic handicapping disorder both to the child and the family has been well described by Gliedman and Roth (22). It was in these respects that unmet needs were most often apparent in the population which we studied. We wish to emphasize that our investigation took place during a period in which a major reorganisation of all services was taking place, including the changes in social service arrangements consequent upon the Seebohm Report (1969), the reorganization of local government (1974), and of the National Health Service (1974) itself. During this period and subsequently both public opinion and central government have shown increasing concern about the care of chronically handicapped people of all ages. The need to provide improved local community-based services as opposed to institutional care for the handicapped has become more widely recognized but has been slow to evolve, not only on account of economic difficulties but because the metamorphosis of institutions, the attitudes of professionals, and the content of professional training has been and continues to be a slow process.

Much more has been written about the need for improvements in the co-ordination of the work of the varied professional groups involved. In our investigation we found many examples of inadequate communication between professionals engaged with one individual family. There were also many instances of failure to provide adequate information about available services to the families of handicapped children. It was encouraging to observe that this aspect improved throughout the survey period, notably in respect of information about the entitlement of families to special allowances.

Our summary of the unmet needs of families with handicapped children as they were described to us must concentrate upon three main areas of service.

- 1. Lack of information about their child's disorder.
- 2. Inadequate opportunities to discuss their problems with their professional advisers.

Parents were frequently left with a feeling of frustration that they had not been fully informed about their child's abnormality. Many doctors and some health visitors had failed to achieve effective communication with parents. Many parents felt that if they had had a better understanding of their child's basic disorder they would have been better equipped not only to cope with the situation, but to have acquired the necessary skills and insights to help their child and their own family to undertake a more active participant role in helping their child to adapt to the handicap. They often felt that the professionals who advised them underestimated their ability both to face the reality of the situation and actively to participate in treatment. This contributed to the creation of negative attitudes on their own part and promoted feeling of anxiety, anger, and even to rejection of their child.

In this paper an attempt has been made to quantify the occasions on which parents received professional advice. If in the parents' judgement these opportunities were inadequate, how much was this inadequacy a matter of quantity or of quality? As far as doctors were concerned, inadequate time was often a major factor. Many parents, and indeed all patients in general, feel constrained not to take up too much of a busy doctor's time. It was our impression that in some cases both doctors and parents of handicapped children were influenced by the conventional pattern of doctor/patient consultations. Both parties accepted the constraints of what they conceived to be the typical consultation which has a strictly limited duration. Yet our analysis shows that, when seen as a component of the total medical work load, the opportunities given to parents by doctors to discuss their children's problems seemed remarkably limited.

#### DISCUSSION AND DESCRIPTION OF ACTION INITIATED

It is difficult in attempting to analyse the reasons for this situation, to know how much this is the result of a failure in the professional training of those concerned, or how much it is the result of the individual personalities of those involved in this work. Conversely many professionals were conspicuously successful in achieving the type of rapport which the family needed so much. Was this a result of their training or their own individual personality? Alternatively the stumbling block may have originated with the parents who saw the professional in a type-cast role from which they refused to allow him to escape?

In the opinion of many parents the help received during medical consultations more than met their expectation. But this does not answer the question of whether it was optimal or even adequate, but can only be a value judgement by each individual. Equally, parents who felt that their opportunities for discussion were inadequate, were also making personal value judgements. Yet in this latter situation the emergence of consumer dissatisfaction is an identifiable factor. Parents complained about their feelings of isolation, the lack of an experienced adviser with whom to confide and of the strain of the constant care of their handicapped child. Lord Moran has written in another context of the varying reserves of courage and endurance which each of us possess to enable us to continue day after day to cope with constant stress. The caring of a handicapped child is an analogous situation; parents vary in their capability and in the extent with informed help that they are able to learn to improve their capacity to sustain this situation with equanimity. Yet all need periods of relief and recreation to enable them to recharge their strength to maintain such responsibilities. It was apparent from our investigation that the lack of this type of help

represented one of the major unmet needs of the families with whom we discussed their difficulties.

#### LACK OF FAMILY SUPPORT

Parents are reluctant to share the care of their handicapped child with others, unless a relationship has first been allowed to develop which enables the parents to feel trust and confidence in those who offer family support. The relationship must differ in many respects from a formal professional service to include a component of partnership. If this type of family support is provided by those who are also involved in the child's specific therapy, it is even more acceptable since it can be accepted by the parents not only as a relief service for themselves but as a directly beneficial contribution to their child's treatment.

The third element of this pattern of family support is the opportunity given to parents to meet other families with problems similar to their own. Parents often learn as much, both in informal discussion and through forming friendships, from each other as they learn from professional advisers. Family support of this kind changes the relationship of the parents and their advisers from one of receiving patronizing expertise and of formal visits to institutions to that of an enabling service designed to give parents the insights, skills, and courage to manage their handicapped child. As well as relief from long periods of unbroken and unrelieved stress at home, there is the opportunity for the development of close relationship between parents and professionals. The parents themselves can determine the extent to which they make use of such a service which must involve both day care and short-term residential care. Many parents like to have a regular arrangement in which for example their child may attend a family support unit for day care two days a week and on alternate weekends on a regular basis and in addition the facility to use the family support unit at any time in emergencies both for day and short-term residential care.

#### FAMILY SUPPORT SERVICE

A family support and treatment unit has been established at Honey-lands, Exeter, as a part of the paediatric unit provided by the National Health Service in Exeter. To be effective as a resource centre such a unit must include not only professional staff representing the unified child health service, doctors, nurses including

state-registered, enrolled, and nursery nurses with close collaboration of health visitors, paramedical staff including physiotherapists, speech and occupational therapists, and clinical and developmental child psychologists but also social work staff and educational psychologists and teachers from the local authority. Invaluable assistance can be obtained from voluntary workers. It is of critical importance that the parents themselves are represented on the policymaking committee of the family support and treatment unit. A unit of this kind can work closely with the comprehensive assessment (child development) centre of the district general hospital. It is believed that such a resource centre can go far to meet many of the unmet needs of handicapped children and their families provided that its relationships with both the hospital and community services are well co-ordinated. Such a unit needs to be open day and night throughout the year.

#### SOCIAL SERVICES

In many areas social service staff find themselves too over-committed to meet all the needs of the elderly, the mentally ill, and disadvantaged families. In our investigation we found that there was often little involvement of community social workers with families with handicapped children. Frequent staff changes inhibited the formation of long-term relationships between social workers and parents. It appears that the most that could be expected was assistance from social work staff at times of crises rather than in a preventative capacity. A resource centre such as Honeylands can provide a nucleus from which information can be disseminated to ensure that community social workers are made aware of the needs of families with handicapped children.

#### **EDUCATION**

The last decade has seen major developments in the provision of preschool educational services for handicapped children. Nursery education and play-groups which accept handicapped children are now more freely available. Peripatetic teachers for visually and hearing-impaired children and for physically handicapped children are becoming more widely established. Their work needs to be closely integrated with that of medical and voluntary agencies who assist handicapped children.

#### CONCLUSION

It has been the purpose of this study first to identify the use of available services made by handicapped children and their families. Secondly to discover as much as possible about their unmet needs including areas where existing services were either inappropriate, inadequate, or totally lacking. Thirdly a brief description is given of the establishment of a family support and treatment unit which it is believed goes some of the way to meet these deficiencies. Such a unit needs further evaluation in order to determine its relationship to each of the professional and voluntary agencies which provide services for handicapped children. It is believed that such a unit may have a catalytic effect in a community of the size of a health care district in improving the services available to a family with a young handicapped child.

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# **Progress and problems** in participation

## Jack Hallas

## Progress and problems in participation

#### Introduction

In July 1976, some two years after the establishment of most community health councils, the Nuffield Provincial Hospitals Trust granted research monies in order to test out the hypothesis that a significant number of councils were beginning to run in parallel with the NHS organization at district level, and that there appeared to be a noticeable paucity of information and lack of contact between councils and the operational levels of hospital, unit, and sector.

This essay is one of the results of testing out that hypothesis. It is nothing like what was originally intended: firstly, because of the normal consequence of concentration, the realization of knowing more and more about less and less; secondly, priorities for investigation suffered a 'sea-change' and the very real problems of workers at sector and hospital units began to demand more consideration than the starvation of councils' information and activities at that level. As a result, this essay is concerned with participation in organizational decision-making, both internally and externally, and even strays into philosophy. To retain a sense of concreteness, particularly in the realm of CHCs, instances and examples will be given, but it should be understood that they represent only a very small selection from a mass of material provided most readily by members and secretaries of councils.

To be as tidy as possible where, necessarily, themes and topics overlap, consideration of the issues raised by the inquiry will follow this sequence. First there is a comment on DHSS policy and its identification of NHS management problems pre-April 1974, followed by a section on a major NHS problem of 1978. Next, some brief consideration will then be given to the current concerns of hospital unit management, followed by a look at the allied problems

of sector and functional management. After examining the anvil, attention will then turn to the hammer. The major part of the essay will be concerned with the work of some councils during 1976–8 that can be related to the operational level below district. For conciseness, the selected areas of council activity are limited to the health care of mothers and children, the elderly, a brief section on acute care, and, finally, a glance at councils that have gone some way towards considering preventive health measures. At that stage, the original hypothesis will be re-examined, amended, and updated. The last section will be concerned with quoting and commenting on some current texts which have relevance to the problems and solutions offered in the earlier parts of the essay. The Royal Commission on the NHS is expected to make its report in summer 1979, so the closing comments are offered as a contribution to the debate that will surely follow on its heels.

Given the constraints mentioned above, this essay has every chance of satisfying nobody and falling ungracefully between two stools. What it is hoped it will do is to remind the reader that, before propounding a final or even tentative solution to a problem, the first and most difficult, and therefore often neglected, task is to really understand what the problem is.

## DHSS: some problems and priorities

When the final draft, printed on grey paper in blunt type, of what later became HRC(74)4 first appeared at RHA level in December 1973 it was apparent that the Secretary of State intended, to use a phrase current at the time, to solve 'at a stroke' a number of problems and ameliorate certain conditions by the establishment of community health councils. Significant proportions of local authority and voluntary organization nominees to councils ensured that, at least on paper, coterminosity and collaboration with local authorities was encouraged, as well as a public platform being created for the well-known consumer groups and voluntary organizations. The proportion of RHA nominees would help to soak up the committed regional hospital board, board of governors, and hospital management committee members who had not been elevated to RHAs or AHAs and who were thought to have something to offer to the reorganized NHS. As a response to the growth of organized consumer complaints which began to burgeon in the late 1960s, along with the

well-publicized scandals of some large psychiatric hospitals, CHCs were expected to be a useful listening post. Along with the Hospital, later Health, Advisory Service, they could be perceived as warning devices sensitive to local conditions. The change in the title of the HAS underlines one of the basic weaknesses of the original DHSS guidance. It was overwhelmingly hospital slanted. This was hardly surprising as almost all the involvement of the Ministry of Health, later the Department of Health and Social Security, with regional hospital boards and boards of governors had been concerned with hospitals, their construction, and their staffing. Other activities in the health field were either the major concern of local authorities or agencies working on behalf of independent contractors, such as GPs. dentists, etc. These were peripheral to the concerns of the DHSS. which made politicians and civil servants very sensitive to the growth of consumerism with regard to the hospital services provided by the NHS. As a matter of deliberate policy the DHSS stance towards CHCs has maintained since then its deist approach of winding the clock up and then allowing it to run along quite nicely without interference, apart from the odd shake of 'Democracy in the National Health Service' and an occasional oiling of the parts.

In those heady days of 1973 and early 1974, the managers were expected to manage, and the participators to participate. There was a basic assumption that a clear division existed and that participation was something that went on outside or external to the system.

How very different the major problems of the NHS appear now. Participation is now a major internal problem of the NHS. The guidance manuals on participative management, published by the DHSS in 1975 (1), are now freely admitted on all sides to have been largely wasted effort. Events had overtaken them, often consequent upon the ancillary workers' strikes of early 1973. Industrial relations at their worst are now a daily feature of life within the NHS. The assessment of the Advisory, Conciliation, and Arbitration Service involvement in NHS Industrial Relations (2), submitted to the Royal Commission on the National Health Service, should be compulsory reading for managers in the Service and members of CHCs. It points up the feeling of 'distance' between management and staff, beginning in the early 1970s and accelerated by the 1974 reorganization which, they say, moved the operational management tier away from the hospital, and placed it at district level. Regarding joint conciliatory machinery, they identify some of the main problems as:

- 1. A need for collective bargaining and consultative machinery at local level.
- 2. Little consistency regarding procedures, which are often inconsistent and ineffective.
- 3. An organizational structure with fundamental weak links in the chain.
  - 4. Poor communications between NHS disciplines.

Their solutions centre around training a substantial proportion of the NHS workforce. Having witnessed the intense efforts currently being put into Industrial Relations training by Professor Dyson of Keele University and Stuart Dimmock of the Nuffield Centre, the enormity of this solution is frightening. One final quote is also relevant: '... the NHS is no longer a unitary "family" organization but must be regarded as one which has many legitimate divergent interest groups. The problem is that many managers have yet to recognize this.'

## Current concerns of hospital management

For the purposes of this section, 'large' hospitals are assumed to be of 500 beds or over, 'medium' hospitals about 150-500 beds, and 'small' hospitals less than 150 beds and/or units where specific health care is carried on, for example, maternity, or a very limited range of services such as the old 'cottage' hospitals.

The removal of the operational management tier from hospital level was noted by ACAS, but some other observations are needed before moving on to a consideration of the problems of sector management.

Drucker (3) is reported as having commented that most large organizations in developed countries are today mainly run for the benefit of the workers. Certainly, large hospitals are big organizations and, in some sense, what we have witnessed in the 1970s is the proletariatization of the workforce of these concerns, not least the junior doctors, and now, fast coming up on the rails, the consultants. This makes life different from the dear old days of the Medical Superintendent or powerful Hospital Secretary, although there are those that would hold that there never was such an animal (4). So the problems presented in running such enterprises are often new, or posed differently, and are currently exercising the minds of professionals and academics.

Perhaps this is the place to suggest that such large hospitals could be ideal placements in an NHS that began to encourage a 'decompression' programme for senior managers. Before going to that even greater authority in the sky, members of area and district management teams over the age of 55 might well have the sapiential authority and dignity to act out a role of tribal chief, overseeing such hospitals' village headmen.

Medium-sized hospitals can, without doubt, make excellent training posts for administrators and nurses. Medical staff are very visible and make their presence felt. In terms of human scale, the middle of the range, say 300–350 beds, seems to be about right as far as patients and staff are concerned. The task of managing this size of hospital is very different from that of trying to cope with the complexity, which increases geometrically, of the larger establishments. They seem not to fit quite so easily into the 'industrial model' approach to health care, and it will be interesting to see what the future patterns of patient and staff behaviour are when the 'nucleus' hospitals begin to come on line.

The 'rationalization' process has cut deepest into the stock of small hospitals, although some CHCs have failed to see much that is rational about proposals for closure made from time to time by certain authorities. Staff working at this level often feel they are under threat and that they will be forced into marriages with new or larger hospitals. Management in these circumstances is much concerned with keeping self-fulfilling prophecies of doom at bay by concentrating on retaining good staff on the books and maintaining a reasonable standard of morale.

These few comments on hospital and unit management are offered so that they will show how futile it is to say, as some now do, that 'strong' unit management is a panacea that will help to rid us of the ills produced by over-complexity, especially by the introduction of the sector concept into the management structure of the NHS. Old solutions to problems, for example, a return to hospital secretaries or medical superintendents, have a certain period charm when new solutions seem to be failing, but simplicity is not sufficient justification for thinking them elegant. The stability that once seemed to exist does so no longer.

## Sector and functional management

There is nothing stable or elegant about sector management. Certain of the functional managers are in a crude position of strength, for example, engineers, but otherwise the entry of the observer into this scene is like an unescorted trip through Dante's Inferno. In the circumstances, it is the best policy, like Dante, to let the tormented souls speak for themselves, so this section draws on the public debate that has filled many pages of the professional and quasi-professional press.

Early warnings of the hellishness of the sector situation were given in 1976 with the publication of the Report on the Role of Unit and Sector Administrators by a Joint Working Party (5). Although weighted heavily towards emphasizing the need for an administrative co-ordinator at unit level, and recommending that practical experience there should be a sine qua non for those aspiring to senior office, the Report did begin to examine the problems of sector management, even if not in great detail. Their questionnaire identified four differing situations that administrators found themselves in:

- 12.1.1. Sector administrator responsible for the day-to-day administration of a large unit, with or without community health services.
- 12.1.2. Sector administrator responsible for the day-to-day administration of a unit and also responsible for co-ordinating activities of other unit administrators, including administration of community services.
- 12.1.3. Sector administrator who has no direct responsibility for the administration of a unit but co-ordinates the activities of several unit administrators, including administration of community services.
- 12.1.4. Sector administrator with responsibility for administrative aspects and co-ordination of community health services only, e.g. immunization and vaccination, home nursing, school health, family planning, etc., and administrative oversight of health centres and clinics.

Whilst having reservations about 12.1.2 and 12.1.3, it was situation 12.1.4 that the Working Party found to be unsatisfactory.

Turning to functional managers, the Report has this to say: In many of the cases where there has been difficulty in developing the right kind of relationship between the administrators and functional managers, this has been in part due to the inability of the administrator to recognize his role as co-ordinator and enabler rather than his former responsibility for the day-to-day management of departments traditionally linked with administration, e.g. catering, domestic, portering, medical records, etc.

A final quote is necessary before moving on to more recent contributions:

The composition and character of sectors and units vary so considerably that the question of formal relationships must be left to local determination. What is clear is the need for definition of the levels at which communication should be made having regard to the nature of the subject, and for this mechanism to be widely known through the organization. There are, it is suggested, two essential ingredients: goodwill and recognized machinery.

In November 1977 the *Health and Social Service Journal* (6) carried a short article by the Chairman of the Association of Health Sector and Unit Administrators which, after mentioning the 'enabling' role of administration, goes on:

The functionalization of many services has done nothing to create a multidisciplinary approach to patient care/training and organization and, just as Salmon tended to set nurses apart from their colleagues, so the extension of functionalization in many other services, both support and professional, has tended to fragment and isolate the local administrator from his colleagues. That is unless his personality and strength of character has enabled him to survive the conflict.

This section commenced by looking at the problems of administrators because it is they who have made most fuss and are in an obviously invidious situation. If sectorization makes sense at all, it is in administrative and functional activities. Doctors and nurses are sometimes surprised to discover that they have been living and working in a 'sector' for over four years. Because of the confusion surrounding this concept, perhaps a few comments at this stage might be helpful.

Ever since the work of Argyris et al. (7) in the early 1960s, the concept of a link-man, or co-ordinator, has been a favoured 'organization man' type of task. Although nobody ever said it was easy, management theorists, almost without exception, saw it as a good solution to many of the problems arising within large organizations.

In an innovatory setting, with new projects or products constantly coming forward, having their time, and then disappearing, the need for co-ordination is self-evident. Perhaps one of the mistakes of the thinking underlying the reorganization of the NHS was the assumption that district and sector management would be innovatory. Overwhelmingly, mainly for extrinsic reasons, novelty of thinking and action are at a low level. In such a situation the co-ordinator ceases to be seen as a person of real value to the organization and, in the words of Mant (8), becomes merely an 'Agent' of the organization and,

ization. In sessions with sector administrators, in groups and alone, the recurring comment is that they become messengers or postmen, moving paper from one place to another. This cry is echoed more mutedly by nurses, and is seldom heard from functional managers. One of the strongest points made in Alastair Mant's polemic is that the tendency in this country to appoint generalists to high managerial responsibility is out of line with other countries in Europe, where the emphasis has always been on specialist managers taking on generalist management as an addition to their original functions. As the years have gone by, we have accrued more and more specialists in personnel, planning, supplies, and so on. The generalist administrator is on a reducing raft and is finding life uneasy. 'When a number of people try a job and none of them can make it work, then it is a "non-job" (9). For such a 'non-job' the rewards are still fairly high. A sector administrator on Scale 18 will earn over £7,000 towards the top of the scale. As a goodly proportion of these posts are occupied by men, and a few women, of about some thirty summers, the trap, to say the least, is fur-lined.

Perhaps they order these things better in Scotland. The Scottish Home and Health Department is noted for sounding a clear note on the trumpet when they issue guidance; for instance, their Circular on the establishment of local health councils was a more stringent document than HRC(74)4. Perhaps the troops do not always hear the call, or are uncertain as to the battle they are expected to fight, but nevertheless the Circular issued by the Scottish Home and Health Department on 4 July 1975 (10) was direct. Some extracts from it will show this to be so.

The first objective of management below district level is to ensure the smooth running of health service institutions and services and thus the day-to-day provision of health care to the public. The managers in all disciplines at this level will have the greatest direct impact upon the public [author's italics]. An effective and economical structure of management is essential to ensure that the community receives the quality of care it needs.

#### Administrative Units

... a sector should normally consist of hospitals, health centres, clinics and related community health services. The exceptions to this type of grouping will be the largest hospitals which may require the full-time services of an administrator and will constitute a sector in themselves.

Pretty straightforward stuff and clear in its intentions. It is sadly the case that unit and sector management problems are not all that easy

to solve north of the border. A series of multidisciplinary one-day seminars were arranged by the Scottish Home and Health Department in mid-1977 to examine the difficulties of management below district level. At the time of writing the results of these and subsequent deliberations have not been made public. Time and again sector staff in England commended the arrangement suggested in the SHHD Circular whereby hospitals, health centres, and community services form a natural sector. After interviewing sector administrators involved with this type of arrangement, their comments demonstrated that this integration of differing types of service resulted in the community element coming into the spotlight quite quickly. The amount of time devoted to collaboration seemed to be rewarding to all concerned. On the other hand, interviews of sector staff involved in sector management teams underlined the sad fact that the creation of teams every time a major problem presents itself only results in more heads being shaken in dismay at the same time, and more often. As mentioned earlier, doctors and nurses do not, as a rule, see the sector concept as anything else but an administrative complication, having small relevance to their day-to-day work. In this situation, when 'cui bono?' is posed, the answer is that it is the administrator who gains the most, and it is not a common experience these days to hold administrators' benefit events.

It is time to consider the other side of the equation suggested in the original hypothesis. Before going on to examine the activities of CHCs at the operational level of the NHS, a general observation should perhaps be made. The major contest at sector is between specialist and generalist managers. The term 'management' is itself suspect. In health care systems which are normally routine, there is a large part to be played by straightforward administration of known rules (11). A simple identification of management as being concerned with innovation, and consequently 'risk' acceptance, is in need of expansion but, in this context, will suffice to remind the reader that it is often not a major element of health care systems. It is at the margin that such innovations take place, normally as a result of changes in the ways in which the medical profession deals with the health problems of individuals or whole populations. If 'administrative' and 'management' activities seem to have created difficulties when presented with problems involving co-ordination, perhaps it is opportune to consider yet another label. The phrase that comes to mind is 'diplomatic skills'. A whole body of literature exists which

provides insights into problems involving understanding of power groups, collaboration, 'balances of power', persuasion, and marginal shifts from bad positions to slightly better ones. The rewards and stature accorded to diplomatic skills are very varied in different organizations. For instance, in the upper reaches of the British Civil Service they are high: in hospitals they are often seen as devious behaviour, 'trimming', or 'playing politics', medical or otherwise. Given the situations outlined earlier, at unit and sector levels they cry out for expertise of a diplomatic nature. This expertise is not easily gained, but it could, in time, become a 'specialism' of the generalist. Currently it would entail, at the very minimum, a broad knowledge of the planning cycles, industrial relations, and participation in decision-making within and from without the system. These three areas of activity involve bargaining, negotiation, collaboration, and 'trade-offs' between interested parties. A change of attitude resulting from a diplomatic approach is that the 'territorial aggression' built into administrative or management activities is lacking, superseded, or suppressed. The most immediately relevant text, although not concerned with health care, is by Desmond Keeling (12). This book is not easy to read, as it is often infuriatingly convoluted, a diplomatic fault perhaps. He begins in Chapter V to tease out the differing activities and attitudes of administrators and managers, and finally moves into the area of diplomatic skills.

'Goodwill' and 'trust', mentioned as key words in the Working Party Report and other comments on sector and unit administration, are in no higher supply in the NHS than in any other multisited organization, and you cannot run a railway on these guidelines. Both have to be worked for, earned, and maintained, even during periods of disagreement, dissent, and disappointment. One of the aims of the diplomatic approach is to ensure that these underlying attitudes of goodwill and trust are built up and maintained whilst retaining credibility. Above all it calls for high skills in anticipation of the consequences of actions.

Tinkering about with solutions arising from first-class funerals, redundancies, staff wastage, shortening lines of command, cutting down on the number of functional managers, etc., will not overcome the basic problems of sector and hospital activities at the present day, which often result from changes of attitude towards professionalism, authority, and work styles within British society (13).

Cold comfort might be taken by closing with a quotation from Dahrendorf (14):

... history proceeds by changing the subject, rather than by progressing from one stage to the next, or even by the dialectical motions of doing, undoing and re-assembling things... the way to solve the problem that kept us awake last night is not to do more or even to do better about it but to turn to something different which may be more relevant, more important perhaps, in any case which permits us to make headway.

## CHCs and the operational level of the NHS

#### INTRODUCTION -

This section is, hopefully in the best sense, provincial, and it is therefore apt that it appears under the aegis of the Nuffield Provincial Hospitals Trust. Although one hears exciting things about the activities of London CHCs, the research concentrated on that part of England north of the Trent. Twenty-five councils were selected, thus allowing those who like percentages to do some simple multiplication; though why we persist in forcing figures into a Roman Army pattern is one of life's little mysteries. The selection was based on the premise that a mix of populations reflecting high density urban, low density urban, and rural areas would best represent one of the basic factors influencing the way councils work and the agendas they arrive at.

There is little mention in what follows of the regular, almost obligatory, public monthly meetings of the whole council. If, in the early days of 1974/5, these meetings were in the foreground, they have latterly tended to become sessions looking at work in progress or stocktaking exercises. Some meetings attended have had little to commend them to the public at large, and the most that could be said is that at least they kept twenty to thirty people off the streets for a couple of hours. Others are presented so well by the chairman, vice-chairman, and secretary that the only analogy that suggests itself is to a performance of a Haydn Trio by the 'Beaux Arts', with themes being passed between the performers and a certain artistry displayed, mixed with good taste and humour.

It is in the working groups that councils come to grips with the day-to-day problems of the NHS in their locality, and are at the closest point to the operational levels of sector and unit. They go under a range of titles: Special Interest Groups; Working Parties; Functional Groups; Sub-Committees; and so on. For the purposes

of this section, the generic title 'working groups' will be assumed to cover that whole range of labelling. Appendix I sets out the groups set up by the twenty-five councils, each of which is given a capital letter reference which allows the commentary to make easy reference to particular councils. Three of the councils do not fit easily into the pattern: 'S' has functional groups concerned with issues and campaigns, a method of working well suited to the locality; 'W' has sub-committees that are often concerned with specialist subjects such as the Ten-Year Planning Proposals of Region and Area, and Operational Plans of the DMT; 'X' never does anything like anyone else and has 'Areas of Concern'. The initial commentary reflects information gathered from annual reports, minutes, seminars, and individual meetings with members and secretaries.

## COMMENTARY ON THE PATTERN OF WORKING GROUP FORMATIONS APPEARING IN APPENDIX I

As was to be expected, the 'Cinderella' services take up the major part of councils' activities in working groups, for example, mothers and children, mental illness and mental handicap, and the elderly. The lumping together of the interests of mothers and children has a certain logic, but 'B' has a working group with a remit covering adolescents, school health, and health education, in addition to the usual spread of topics. 'J' associates the problems of the normally healthy with family interests. Given the very bad figures for infant mortality in this district, for example,

Deaths under one week per 1,000 live births, 1976 'J' District 25.8

National average 17.7

one might expect the group to concentrate on mothers and children. However, this district is going through a period of serious social deprivation, with high unemployment and urban decay. This, in turn, affects the health of the total population so, for this locality, it is necessary to consider the interests of the normally healthy, including mothers and children, in the context of their environment. In the case of 'U', as well as a 'standing' working group on family services, they also joined with other adjacent councils to look into problems concerning hearing aid services for children.

Those councils which merge together mental illness and mental handicap are all very careful to ensure that the differing nature of the problems presented by these conditions is well understood. Although counted as one group, they often subdivide their activities into two sub-groups.

The acute services often come under a label such as 'generally healthy' or 'normally healthy', and it is in these groups that the ambulance service and primary care regularly come under scrutiny.

The chronic sick can take in the physically handicapped, for example, 'U', and, in the case of 'J', this group is also concerned with the elderly.

The remaining groupings are very thin on the ground, surprisingly so in the field of preventive medicine and health education. As usual, 'Miscellaneous' is an interesting rag-bag. 'L' has particular trouble with catchment areas and, in this instance, has had to form a specific group to consider the problems of one community. A 'Complaints' group is unusual, but 'P' have linked in 'Commendations', a nice touch. As well as Special Interest Groups, 'Q' also have 'Ad Hoc' groups concerned with specific issues, and they never seem to be short of 'hot' topics.

Sometimes 'Publicity' is given to a working group, but it was not considered relevant to list them in this particular study.

It will be seen that four or five groups is about par for these councils. The range of membership goes from four to twelve, giving an average of about six council members per working group. Allowing for overlapping membership, this means that nearly all council members in the twenty-five councils are involved in this type of activity. The convening of working groups is not as regular as full council meetings, but the usual practice is for a 'get together' and/or visitation at least once a month. Because of their limited size and lack of public notice, apart from annual reports of CHCs, these working groups are often unknown or discounted. The four sections that follow try to give, by quotation and narrative, a background against which we can then return to the original hypothesis underlying the research.

#### MOTHERS AND CHILDREN

Council 'A' has a very varied topography, embracing urban industrial, suburban, semi-rural residential, rural, and hill-farming areas. During 1976/7, members made twenty-three visits to health service establishments.

When visiting establishments, members try to see conditions and provisions from the patient's viewpoint and to ask questions prompted by their observation. It is helpful to have with them, as they do, the Sector Administrator and other senior staff with whom they can discuss points of interest or concern. It is hoped that such contact may be of some value to those officers.

Amongst documents studied in detail was the DHSS Circular 76/40 on Child Mortality.

The child health services in 'B' came under the scrutiny of council in December 1976, particular criticism being levelled at the school health services, for example, selective examinations having replaced routine checks. In May 1977 the area nursing officer attended a meeting of the council to answer the swelling volume of criticisms from members of the council and the public. The council has an ongoing concern about the service in the district and is continuing to monitor its effectiveness.

The family service group of 'C' allocates special responsibilities to individual members, with a convenor without a specific remit. In 1977 the allocation of interest areas were: child guidance; family planning; primary school age; special schools; children in hospital; maternity; secondary school age; preschool age.

Visits to the paediatric wards of the general hospital led members of 'D' working group to feel concern about the number of immigrant children admitted because they have 'failed to thrive'.

Between June 1976 and March 1977 the mothers and children care group of 'E' made seven visits to hospitals and clinics. To improve a situation where mothers and children most in need do not attend welfare clinics, they commend the use of mobile clinics as a partial solution.

A mention has been made of the social problems of 'J' district, but naturally the picture is not wholly grim. There is a new maternity unit which is the showpiece of the district. Whilst agreeing that it is an admirable building, the working group have continually returned to the theme that, because of under-utilization, one floor might be used for non-surgical gynaecology. The group also entered into hot controversy with some members of the public over the Benyon Bill which proposed amendments to the Abortion Act.

'K' working group commented at length on the Report of the 'Court' Committee and did a fair hatchet job on it.

In the rural setting of 'M' the working group spent a large pro-

portion of their time on reviewing reports. They intend to devote more of their time to visits during 1978, even though the distances involved make this a very taxing and time-consuming activity.

In 'P' district the activities of the working group, and the whole council, were fully occupied with debates and correspondence regarding the closure of a maternity home and a hospital for women.

Two brief extracts are taken from 'Q' Annual Report for 1976/7:

## (a) Genetic Counselling

Members were concerned that insufficient publicity was given to this service amongst general practitioners and members of the public.

## (b) Young Chronic Sick and Disabled

The Council has recently formed a group to examine hospital and community provision for the younger members of society who are suffering from long-term or permanent illness or disability.

The Council has formed itself into several committees with specific briefs and specific time scales within which to study singular aspects of health care. The majority of these are still ongoing and detailed reports are anticipated by 1978.

In 1977 'S' produced 'A Profile of Patients' Problems' reporting on some three hundred problems and containing an assessment of why people complain. Given the district, it is hardly surprising that the volume of problems is very great. This council comes closest in this study to those councils in London concerned with inner city problems. During a discussion with the secretary, it became clear that the work, methods of community involvement, and raising of issues, often in a broader context than just the NHS, gave this council many features similar to those of the Inner London CHCs. One campaign they conducted had home confinements as its subject.

The Council was prompted to produce an information leaflet for women who might be wondering about a home confinement. The leaflet was not intended to convey any clinical information but simply advised women who to approach for guidance and help. If, for example, the family doctor was not sufficiently helpful, we suggested that a local midwife could talk over the pros and cons of hospital and home confinements. We gave a list of midwives' names, addresses, and telephone numbers on the back of the leaflet . . .

Our leaflet, which we considered to be carefully worded and quite innocuous, provoked a storm of indignation from some members of the medical profession. Several months of consultation followed over the content of the leaflet and the right of the Health Council to publish such information. Eventually some minor amendments were agreed; the Health

Authority has withdrawn from the debate and the Council will now publish its leaflet 'Where to Have Your Baby'.

There has been a dramatic decline in the numbers of babies born at home and there is evidence to suggest that this satisfies the organizational needs of the National Health Service rather than the wishes of the mother.

There could be no greater contrast between councils than exists between 'S' and 'T'. The Study Group for Children in 'T' must be one of the few in the country chaired by an earl. The district is totally rural, and one short comment from their Fourth Annual Report points up how this environment changes perspectives.

During the year, visits to all Child Clinics have been completed and there is no doubt that mothers prefer local clinics in village and church halls rather than facing long journeys to superior premises; in which case, the Group feels that local clinics encourage regular attendance and it is suggested that ways are found to improve heating arrangements to enable full examinations to be carried out in all clinics.

Mention has been made previously on the work of 'U' Council regarding the problems of deaf children. After studying reports, and bringing the matter to the attention of the Under Secretary of State for Health and Social Security, the working group made recommendations (too numerous to reproduce here), and some general suggestions, amongst which were:

That Hearing Aids should be available for infants with serious hearing loss so that speech may develop at the correct age. The Working Party wish to stress the importance of this as it affects educational development.

That consideration be given to the system operating in other adjacent districts.

Council 'V', in a Report for 1976/7, gave the recommendations of the council concerning the William Benyon Bill in a line-by-line and clause-by-clause presentation which is a model of its kind. Another topic fully reported is the discontinuation of minor ailment sessions at child health clinics. This is set out in dialogue form of question and answer between the council and the AHA.

Unlike many CHCs, 'W' does not divide the council into special interest groups, but invites members to form ad hoc committees for discussion and arrival at viewpoints which are then presented to the main body of the council. The Annual Reports of Council 'Y' have, for two years, provided an unfortunate and sometimes acrimonious public airing of dissent between the AHA and the CHC regarding content and discretion. This is no bad thing, so long as it remains at

organizational level but, when it descends to personalized comments, then it can make the work of the council very difficult. This council has launched numerous initiatives and is prolific in the production of surveys. One recently produced Report is concerned with patient satisfaction with the maternity service, a survey undertaken under the supervision of Professor Kaim-Caudle.

Because of the horrific Early Neonatal Mortality and Morbidity statistics for 'Z' District (twice the National Norm), the Mothers, Babies, and Children Working Group are examining every case of neonatal death in the district. Improvements for visiting at the maternity unit are claimed to have followed on from the previous Annual Report, although this may be a case of 'post hoc, ergo propter hoc'.

### THE ELDERLY

Four of the twenty-five councils have no specific working group identified totally with the problems of the elderly. In these councils, however, this section of the total population is never overlooked. The work of the Health Advisory Service now comes into the picture. The availability or not of their reports to CHCs was a topic returned to again and again when discussing current issues identified at a recent seminar for CHC members and secretaries. Another generalization unquantifiable because of the varied reporting practices is that complaints to councils seem to cluster around problems of the elderly and their relatives involving, in a significant number of cases, transportation, including the level of provision and quality of ambulance services. Council 'B' makes a note to this effect in their Annual Report for 1976/7. Closures and changes of use of premises also bulk large in this aspect of health care, and it should be at this point that councils and NHS staff at all levels come into close contact. There is little drama in an overview of the care of the elderly, but the individual miseries of old people crop up time and again in the minutes and Reports of councils. Working groups have often used DHSS guidance such as HC(76)32 on Improvements in Geriatric Care in Hospitals as guidelines when making visitations to health care establishments. The following comments by councils are taken mainly from Annual Reports for 1976/7 and 1977/8.

Council 'D' are 'keeping a watching brief on health centres to see that elderly patients get the services they are entitled to receive'. During one year, the working group of 'E' made seven visits to hospitals and homes in the district, and two visits to Part III accommodation provided by the local authority. Their recommendations were mainly concerned with alterations and improvements to available facilities for washing, toilet use, and kitchens. This is an activity carried out by over half the sample councils, but this example will stand duty for them also. An informal visiting group was set up by 'F' to allow visits at any convenient time by direct arrangement with local officers. This cuts out advance notice formalities for, as they say:

... this arrangement could be thought to be too much of a blanket over the situation as it actually occurs (sic). In reviewing hospital geriatric accommodation we have perhaps been pre-occupied with the numbers of beds available. We now intend to devote more attention to the quality of life enjoyed by geriatric inpatients.

This comment by 'F' working group suggests that closures and changes of use issues can sometimes lead councils into debates where quantity overshadows quality. Definitions of 'quality' are notoriously difficult (15), but must always remain a major concern of councils. When discussing the communal problems of 'J', a fairly bleak picture resulted. The DHSS and AHA have agreed that 'J' district should be one of eight in England taking part in a pilot scheme on improving geriatric care in hospitals.

Rural areas often find the benefits of voluntary efforts a great help to the official system, but co-ordination (that word again) remains a problem. 'M' working group were delighted when several educational therapy assistants were employed in their district's hospitals under the Job Creation Programme for a one-year period. This initiative encouraged contact with the community and voluntary efforts for the benefit of the patients. The council thinks this demonstrates how much could be done on a long-term basis by a paid voluntary service organizer.

The NHS hospital service has had a good track record on admission procedures; when it comes to discharges then performance is not so good. The working group of 'P' has been concerned with aftercare problems for some time.

It has been ascertained from the Social Services Department that no less than 10 days' notice of any discharge is required to ensure the provision of Meals on Wheels and, as this may not always be possible, the CHC has negotiated with the District Administrator for arrangements to exist whereby, should the need arise, a mini foodpack can be made available to elderly patients to take home with them.

Some comments of 'Q' working group indicate problems often associated with new units:

Two areas of the hospital's work continue to give cause for concern: the Day Hospital and the minimal care flats. In both cases there is evidence of gross under-use of what are very desirable and expensive resources. The Day Hospital was originally designed to accommodate 90 people at each session: in reality, everyone concerned accepts that the facilities are suitable for only about 50 people. This in itself is a sad loss, but not one for present concern as far fewer than 50 people a day are attending the Day Hospital.

From the beginning, problems with ambulance transport meant that very few patients were brought from the community. Even now, those who do come frequently arrive late and have to be prepared to leave after only a short stay so as to be ready for the ride home. Alternatively, return journeys are often delayed till late afternoon or early evening.

The minimal care flats (where people about to return home may live for a while to accustom themselves to independent living again) are similarly under-used. There is always the likelihood that patients due for discharge may not be the type who would benefit from two or three weeks' stay in the flats, but the Group feel there are elderly people in the community who might benefit. Consideration should be given to other candidates, such as holiday relief patients and those occupying beds in specialties other than geriatric medicine.

'S' mounted a campaign in January 1976 concerned with the problems of psychogeriatric services. They sought flexibility in long-term plans to meet changing patterns and levels of need, making the point over and over again that need must never be confused with demand. The 'undemanding' attitude of the population at large is a feature of this and other inner city councils' Reports. This apathy or 'British phlegm' often results in such councils and/or their secretaries being labelled as 'agitators' by the authorities involved in meeting existing demands.

'T' working group has continued to explore the Day Centre idea, arguing that there can be no clear demarcation between Health Service and local authority provision in a scattered rural District. With public transport declining, an Ambulance Service fully stretched, and increasing difficulty in recruiting volunteers to help with transport, it seems essential to the Group that an elderly person should be able to receive a variety of services when attending a Day Centre.

Council 'V' were involved in 1975/6 in a heated controversy with the AHA arising from what the CHC considered the arbitrary transfer of geriatric patients at a particular hospital. After a joint meeting with the AHA in early 1976, the CHC went to the length of appealing to

the RHA, who set up a Special Sub-Committee to investigate the organization and management of the health services in the area. Their report received national publicity, so comment here is unnecessary. During 1977, the CHC went on record that many improvements had been made to the facilities provided in hospital for the elderly.

CHC 'X' had a number of criticisms regarding the 1976 DHSS Consultative Document on Priorities for Health and Social Services. A quote shows the lines of their approach, not only to problems of the elderly.

This CHC believes that the way in which services are determined is the 'wrong way round'. Perhaps this required change in emphasis can best be summed up by quoting from Michael Bayley's Mental Handicap and Community Care; A Study of Mentally Handicapped People in Sheffield (Routledge and Kegan Paul, 1973):

'It is not a question of the community supplementing official services, it is a question of the official services helping and enabling the community to do better the caring it does already, with more help and less strain on individual members of it.'

The 'Priorities Document' talks again and again about 'volunteers' and 'voluntary organizations' forgetting that the majority of 'volunteers' are relatives, neighbours, and friends.

Although very well off for in-patient facilities for the elderly, the CHC for 'Z' District had this to say about what they call 'Functional Management':

In other parts of this report we have already spoken of the superb facilities available for in-patients but of concern to the Group has been the lack of representation of geriatrics at a senior nursing level. This view is not shared by the nursing management of the District who feel that the present system of sectorization is quite satisfactory and the geriatric nursing service should be included along with other responsibilities of the Nursing Officers.

The Council, however, maintain their opinions on the subject and that is at present where the matter rests.

### THE NORMALLY HEALTHY AND ACUTE SERVICES

This section will be even more selective than the two previous ones. The topic is more amorphous, and any attempt to go into detail could lead to the report on the spread of activities taking up a disproportionate amount of space. The reader should remember this, and not judge on this evidence that councils do not give sufficient attention to problems in this area of concern.

'B' have a 'General Health' interest group covering family practitioner services, acute hospital services, chiropody, ambulance services, occupational health, and items of a general nature. One of the subjects examined by them in 1977 was the service provided to sufferers from strokes, both in hospital units and in the community. In 'C', the General Services Working Group conducted a survey of Primary Health Care in the North Wolds. Transport is a major problem for rural CHCs, and an extract from this survey will perhaps bring this home to the car-using urban reader.

The most urgent problem is for some form of transport to and from surgeries and for the collection of prescriptions.

1a. In 4 settlements there is no bus service whatsoever.

- b. In 16 villages there are 2,000 people out of a population of 6,500—nearly 1/3—without access to a car!
- c. A large percentage of the male population with cars are agricultural workers. When a member of their family is ill and needs to be driven to the surgery they have to take time off work—losing their pay in many instances and the farmer at the same time losing a day's work.

The suggested pilot scheme for a voluntary car service to serve the above villages would be most welcome.

As an example of how these enquiries into general health expand, working group 'D' has now formed a sub-group for Community Services and a sub-group to consider resources and their allocation. In 'F' District the Patient-Care/Residential Committee meets as many patients as possible to discuss their feelings and opinions on services provided. This time-consuming effort is considered well worthwhile. Although the vast majority of patients are highly satisfied, when complaints, inconveniences, or plain grumbles are transmitted to the DMT, the group see them dealt with conscientiously and fairly. Waiting lists and their length is a recurring subject in minutes and Reports of councils. In 'G' the working group summarized the local position, and their comments were typical of councils' realization that this is a very complex topic, with 'reasons for increased delays' proving difficult to identify satisfactorily.

Family Practitioner Services and their Committees have been one of the most regular flash-points between CHCs and authorities. A short comment from 'J' District Annual Report for 1977 represents the common CHC viewpoint:

In our last Annual Report we requested the opportunity to appoint one 'non-voting' member to the Family Practitioner Committee; this has still not been granted. If it were, we feel that several misunderstandings could

be cleared up. The 'Deputizing Service' used by many local groups of doctors to provide cover at night and weekend is constantly being criticized . . .

The balance between centralized pharmacies in or near Health Centres and local shops near where people live is another point needing discussion, not attack and counter-attack.

The ambulance service too comes in for a good deal of comment from CHCs. In their Annual Report for 1977, 'K' CHC reported briefly on a talk by an assistant divisional ambulance officer:

He referred to a survey that had been undertaken regarding patients' waiting time. With regard to the Outpatients at the Royal Infirmary it was stated that—

83% were not more than 15 minutes late for appointments,

66.5% were not waiting more than 30 minutes to go home,

91% were on their way home inside one hour.

Occasional complaints have been received regarding delays in providing transport for patients between home and hospital. We understood from the Ambulance Service that efforts are continually being made to provide a satisfactory service. It has been stated that there is an abuse of the service and that transport is increasingly being given on social and economic grounds as well as medical needs.

One of the few overt references to industrial action by health service staffs came in the Report for 1976 by 'N' Council:

Whatever the rights and wrongs of industrial action one inevitable outcome in a Health Service dispute is a worsening of the waiting list situation to the detriment of the patient. This we have consistently pointed out to the parties concerned, hoping to remind them of the need to maintain the age old concept of doing no harm to the patient.

There is light relief occasionally, even in CHC matters, and a snippet from 'P' District's Annual Report for 1976/7 gives this to the persevering reader:

An approach was made to the CHC by a Chief Police Inspector who requested assistance in publicizing a register which he maintains of people with odd sized feet, so that help could be given in 'pairing' when buying shoes. The CHC was pleased to help in this exercise.

It is not always a case of 'stand-offs' between family practitioners and CHCs. 'Q' Special Interest Group reported on a useful dialogue developing with GPs in their district:

Members would wish to record their thanks to the GPs who were willing to receive them into their surgeries. The Group was pleased that a growing number of GPs were not only willing to meet members, but actually expressed a desire to keep in contact with the Council to hold discussions and thereby hope to remedy problems facing both Groups.

To give an indication of the amount of effort involved in visiting establishments, the record of 'R' for 1976/7 is noteworthy. Various groups visited nine health clinics, eight health centres, and fourteen hospitals. This is a district with a very large number of establishments, and this amount of visitation is necessary, but could so easily be overlooked or ducked.

The questions that occur with CHCs when large new hospitals, especially those with teaching responsibilities, come on line, were pugnaciously presented by 'S' Council in late 1977:

The Council has stated in the strongest possible terms that the planning of the Royal XYZ Hospital must be set and can only be agreed in the context of a comprehensive plan for the health services as a whole.

The report on hospital visiting mentions the low morale among staff. It is a cause for great regret that the importance of keeping staff as fully informed as possible does not appear to have been appreciated. A monthly news-sheet following the Authority's meetings would surely do much to allay understandable anxieties.

The problems connected with the current financial crisis and the opening of the new hospital are so many and so varied, and time is so short, that we took an unprecedented step. We informed the Authority that if they would set up a working party representing *all* interests, we would join the party, subject to an understanding that any minority view would be fully recorded and publicized.

The Authority did not accept our suggestion, and it seems now that time will not allow the consultative procedures to be as meaningful or as productive as they should be.

The doctor deputizing service often comes in for some hard knocks from councils. Some comments of 'V' CHC indicate their approach:

We intend to take a closer look and do more research into the problems that the Deputizing Service may be having for some members of the public, and we would welcome comments from members of the public who do not wish to take this matter up with the appropriate authority, in order that we may be able to monitor this service over a six month period. The information given by the public will be treated in the strictest confidence.

The management of hospital visiting can be a problem. The working group of 'W' go about it this way:

The administration of this aspect of CHC work has been altered recently and is now carried out by a series of 8 syndicates of 3 Councillors in each syndicate who live in the same geographical parts of the Health District. Each month every syndicate is provided with a pro forma and tasked to

visit a named hospital or clinic within a period of 28 days. The pro forma provides certain information as to name, telephone number and extension of the person to ring and notify the time and date of their intended visit. Also included in the form are places for visiting syndicates to note their observations and make their recommendations and further space provided for the management concerned to reply to the remarks made by the visitors. This system appears to be working very well at the moment.

Mention car parking to sector administrators and they tend to go grey. Some comments from 'X' CHC demonstrate the enormities of the task when a new hospital complex arrives on the scene:

A 455-space car park is better than no car park, but how much will 455 spaces relieve the pressure on the surrounding roads when a 705-bedded teaching hospital is established PLUS the existing out-patients department? Who will be permitted to use the spaces in the car park—410 medical staff, or 4,000 plus other staff, or day patients or visitors, or a proportion of each group? We await the decision of the AHA.

GPs' receptionists come in for critical comment from time to time. 'Y' CHC took an initiative which had national repercussions.

The following resolution passed by Council in November 1976 was sent to the Secretary of State, Mr David Ennals, to 204 CHCs in England and Wales and to 22 Local Health Councils in Scotland and to the Society of Family Practitioner Committees:

'That XYZ CHC stresses the need for more training of all Doctors' Receptionists, not only in the basic skills of typing and practice administration, but in the psychology and the sympathetic understanding of patients, and urges Government to devote greater financial resources to adequate training of Doctors' Receptionists.'

A summary of the replies received was sent to the DHSS, the RHA, the National Association of CHCs, CHC News, the Society of Family Practitioner Committees, XYZ FPC and LMC and to all CHCs who had replied.

Finally, to end this section on a sweetly reasonable note, the comments of 'Z' CHC's working group represent a commonly found attitude amongst CHCs, that not all health staff are villains and not all complainants are heroes:

Most members of the community work for five days per week and then enjoy a two-day break on a Saturday and Sunday. If a GP is to be working on Saturday and Sunday then surely it is reasonable that he should have two days off during the week and if a patient contacted the surgery for an appointment on let us assume a Tuesday evening, they may well be told that the soonest appointment which can be given for that particular doctor is Friday morning. We do receive complaints from patients on these lines but usually they fail to state that an appointment could have been made with another doctor in the practice either the same evening or the next

morning. We have no wish to stifle genuine complaints, but the Group would make a plea to patients to be reasonable with their doctors—to treat their doctors with the respect that they deserve—and this way the Group feel sure that much better relationships may be enjoyed all round.

# PREVENTIVE MEDICINE, HEALTH EDUCATION, AND A GLANCE AT THE GREAT FLUORIDIZATION DEBATE

Although only three of the sample CHCs have specific working groups for these topics, the subject forms an undertow to surface actions and comments by councils. Sometimes the working groups concerned with the normally healthy take it on as one of their interests. This selection tries to indicate the range of council activities involving an aspect of health care which is comparatively new to the NHS, as well as to CHCs. First, it will look at two of the councils with specific working groups.

'M' CHC has a working group entitled 'Health Education and Preventive Medicine', one of its major concerns being a nutrition campaign. As with most well-mounted campaigns, a large number of troops were enlisted. The editor of the local journal agreed to allot a journalist to do features amounting to three or four articles. Local radio helped and, as a generalization, has proved to be a useful confederate of numerous rural CHCs. Regional television advertisement slots were bought at a total cost of some £80. As the working group mentioned in an earlier Report, they were fully aware that this kind of activity was really the province of a health education officer. Unfortunately, there had been a long-standing vacancy in the area because of the lack of suitable applicants. The working group reported that, as a result of the nutrition campaign, members had become more and more aware of the need for priority to be given to health education, and co-ordination and support to the staff involved. The firm intention of the CHC was that it would act as 'middle man' between the NHS and the media, not offering advice, but finding out those who would, and the local stories to go with them. In rurally situated councils, the Women's Institute plays a very crucial role. Have them on your side and a good publicity campaign is almost assured.

One council that has always taken an interest in prevention and health education, right from 1974, is 'N':

Not content with leaving this important matter to others, in June 1977, the Council organized a week-long health exhibition at the Town Hall.

On each night of the exhibition a talk on health matters was given, followed by a health education film and a display on sport such as fencing, judo, yoga, etc.

Other councils in the sample have not been as publicly committed to prevention and health education as 'M' and 'N'. In May 1977, 'B' CHC supported a recommendation that school tuck shops, in their existing form, be banned. Schools should set a good example by perhaps selling fruit instead. As might be expected, a lively correspondence in the local Press followed. A Dental Health Care Study Group was established in June 1976 by four CHCs in the Northern Region, of which 'L' was a member. Their remit was to discuss, and to keep under review, the whole spectrum of dental health activity with particular regard to surgery, prevention, fluoridization, health education, dental charges, and emergency treatment. In their Annual Report for 1976/7, 'R' CHC welcomed the initiative of the AHA in setting up a working party to make recommendations about a 'health promotion body'.

A sub-group of 'W' CHC scrutinized the AHA 'Review of Health Services and Resources 1976/86' and had one touch of acid about primary care and prevention:

The provision of suitable incentives for the recruitment of personnel for the provision of primary care and prevention are unspecified, the sub committee were curious to know exactly what form these incentives are or are likely to take.

The chairman of 'X' CHC had this to say in his Annual Report for 1975/6:

Finally, our role outside the mainstream of NHS provision. This is the real challenge, as I see it, to CHCs if we are prepared to grasp the nettle. It can be clearly seen that the economic and social policies of successive governments have contributed and are still contributing to poor health, chronic illness, and accidents. The paradox is plain for all to see: we have a society pouring resources both financial and human into an endless cornucopia, the NHS, with one hand, whilst the other hand is busy manufacturing those very products which cause or largely contribute to the illness the NHS is valiantly trying to 'cure'.

The report must be apocryphal that, at a public meeting called by a CHC, a pure water campaigner threatened an area dental officer that he would kick his teeth in, but it gives a heightened impression of the fury generated by the issue of fluoridization of water supplies.

What follows is a brief selection of comments from a few of the

study's CHCs. Voting is not a common feature of CHC activities. In nearly every case where voting on this issue took place, it was a closerun thing, and one or two chairmen were worried that a casting vote would be called for.

Council 'C' published a well-argued paper, by a member, which made these final comments:

We, the public, are trapped between two completely opposite opinions expressed by equally eminent people. Opinion surveys have been made but are they a knowledgeable opinion survey? This is no matter that can be decided upon by a few easy questions.

The experience of Council 'D' was as follows:

The Council held two meetings on fluoride. A representative of the Pure Water Society put the case against. At the following meeting the Area Medical Officer and the Area Dentist spoke in favour. CHC members and the public asked a number of questions at these meetings and the Council, by 11 votes to 9 with two abstentions, decided to oppose fluoride. It regretted that the AHA had taken its decision in principle before consulting the CHC. The Council agreed it was powerless to say much after such a narrow vote.

Council 'K' decided, by a majority vote, not to support a resolution for approval to fluoridization in view of its limitation in value to the public as a whole, its long-term results, and its effect on the freedom of choice of the individual.

Another close-run thing was the voting in 'O' Council, which resulted in approval to the recommendation for fluoridization of water supplies (to a level of 1 ppm) by 8 votes to 7 with 1 abstention!

Finally, 'T' CHC reported that, in their district, the estimated cost for fluoridization would be 36·3p per head per annum, with a capital outlay of £17,000. In two adjacent districts, the estimates were respectively 7·4p and 7·9p per head per annum. They drew the attention of the AHA to the relatively high cost in 'T' District, and suggested that funds could be better used improving other aspects of health care.

This comment completes the major section of this essay, given over to a few selected examples of the thoughts and actions of twenty-five CHCs over a period of two years. Any selective process is conducted by rules imposed externally and/or internally. The internalized rules used in selecting material from councils were:

- (a) Ensure a spread of comment. .
- (b) Avoid too much duplication in reportage.

- (c) Heighten contrasts.
- (d) Emphasize innovatory activities.
- (e) Avoid the trivial.

The external rules were set by the original hypothesis, to which we now return.

## Re-examination of the original hypothesis

In the light of the study so far, how does the original hypothesis stand up? The reader will recall that it ran as follows:

In June 1976 a significant number of CHCs were beginning to run in parallel with the NHS organization at District level, and that there appeared to be a noticeable starvation of information and lack of contact between Councils and the operational levels of Hospital Unit and Sector.

It is immediately apparent that this hypothesis now stands in need of correction, change of emphases, and expansion of content. From the sample studied, it is clear that the working groups do not suffer from starvation of information and lack of contact at the very basic level of operational activities, by which is meant the activities of workers in the NHS who are routinely involved in direct contact with the public. The next correction is to remove the word 'sector' from association with the operational level. Almost without exception, for example, Council 'Z' Annual Report for 1976/7, and the occasional reference quoted above, there is no mention of sector in the whole of the material studied, including the great amount not reported. What has become clear is that sectorization below district level is an internal organizational system which is almost invisible to the outside observer.

Suggestions by councils are regularly directed to the district level of the organization. The 'passing down the line' which goes on after such referrals largely goes unnoticed and unreported. It is this 'invisibility' of the 'organization man' which often lies at the root of the miseries examined in the earlier part of this study. When counselling individuals on career progression, one of the personal strategies that presents itself is how to go about achieving 'visibility' within the organization, especially so in the case of sector administrators and administrative nurses. There exists a sense of longing for 'recognition' that is foreign to the functional managers such as engineers, catering managers, pharmacists, etc. Proof of ability, and thereby ripeness for promotion to the next level of competence, often

lies in high visibility within the organization; for example, an excellent job done during a commissioning exercise. The internal multifarious pressures of day-to-day work exampled by industrial relations problems are seen, on the other hand, as submerging rather than baptizing. And yet, not only is this the very essence of the job to be done in any modern organization, it is also unlikely to reduce in volume during the immediate future. In early 1977, the monthly magazine of the British Institute of Management (16) had this to say in an editorial:

The impact on the contributions reaching Management Today is one measure of the enormous change in managerial thought. Where once articles on management science predominated, now the problems and prospects of participation, of human relations techniques, and of democracy are easily in the ascendant. This new order of emphasis must be a major force in the future of management, irrespective of any institutional changes which are imposed from outside.

This comment preceded a most perceptive article on management by consent by Professor Handy, Professor of Management Development at the London Graduate School of Business Studies (17).

This new order of emphasis is very evident in the National Health Service and, taking what has been said and quoted above, the revised hypothesis reads:

In June 1978 a significant proportion of a sample population of twenty-five CHCs were directing their comments, complaints, and suggestions to District level of the NHS organization. Their working groups were, on the whole, retaining links and maintaining contacts at the basic operational level. A vacuum between these organizational levels became apparent which is presently a subject of concern to those working within the system. The evidence assembled in this study indicates that this internal organizational problem has not seriously affected the performance of CHCs in the period under review. The changing nature of organizations in the late 1970s suggests that one of the immediate problems for analysis in considering the future of the NHS centres around a convergence of the 'participative' approach to problems, internally and externally (18).

This revised hypothesis of convergence of participative approaches bears little resemblance to the original. However, as this whole essay is based on the tetradic schema of Karl R. Popper (19), the shift from  $P^1$  (the original hypothesis) to  $P^2$  (the revised hypothesis) is not only to be expected but also welcomed as a closer approximation to questions of improved significance. This essay is not the place to begin an investigation of the revised hypothesis but, in this closing

section, some signposts can be erected which might lead the reader in the right direction.

# Current texts and future problems

During the last decade, we have become accustomed to governments and authorities setting up, or having imposed on them, bodies representing the consumer. Post Skeffington, this trend has become part of the fabric of life in this country. The long history of experience of consumer representation in nationalized industries was useful in that it suggested that too close an identification with the parent organization, especially if it was concerned with complex technology. was to be avoided. By contrast, worker participation, although growing, is still in its infancy in this country. External participation is now respectable and accepted; internal participation is often linked with some very strange, if not downright bad, company. One of the achievements of the nineteenth century was to create, in the mass of working people, a sense that work was work, and freedom and independence something that happened after work was done. The contract of most workers was heavily weighted in favour of the employer. What we have seen in recent legislation is a gradual readjustment of the balance so that, depending on which side of the fence you are on, there has come about either a 'professionalization' of the workers, giving them some of the benefits previously reserved for the professional classes, or a 'unionization' of the professionals (20). To adapt Maine's classic phrase, there has been a movement from contract to status for most ancillary workers in the NHS, and a move from status to contract, as instanced by the BMA's current (July 1978) negotiations with the DHSS on the part of hospital consultants, and other professionals. These changing emphases entail a considerable amount of debate about 'rights'—democratic, workers', or otherwise. There is a growing literature, particularly in the United States, pitched at a philosophical or legalistic level, investigating what we mean and what the implications are when we say that every individual has rights, some of which seem to be inviolable. There is little talk about duties, and it would appear that, in the NHS, we have to begin to devise frameworks which would bring this side of the equation into prominence. The last sentences of this essay contain a suggestion which might merit future investigation.

What does seem apparent is that there could come about, sooner

or later, a convergence of these trends in the NHS. A favourite topic for the media are the problems of the NHS, but these are problems fundamental within our present society. The service is no longer perceived by the public, as it was in the 1960s, as being above the battle. The three issues tackled by the late Professor Hirsch (21) are directly relevant to the NHS. He calls these three issues: 1. The paradox of affluence. 2. The distributional compulsion. 3. Reluctant collectivism.

In spite of what many commentators say, the NHS has, since the mid-1960s, been comparatively affluent, and the paradox is that we remain disappointed. With an inflationary economy, the question 'who gets what?' becomes sharpened, and the NHS is no stranger to this compulsion. Finally, the above comments on the hospital consultants can also be viewed as a case of 'reluctant collectivism'. Instances can be multiplied but, to use Professor Hirsch's title, it is clear that the NHS's demands on resources are pushing against the social limits of the UK today. Also if, in society at large, more participation in decision-taking is initiated, encouraged, or tolerated, then the NHS cannot hope to evade the consequences.

In casting around for like minds, there were few texts that allowed these participative compartments to merge. One early commentator (22) does relate a participatory theory of democracy, which she examines in the light of the writings and actions of Rousseau, John Stuart Mill, and G. D. H. Cole, to participation and democracy in industry. In a later chapter on workers' self-management in Yugoslavia, she points up the way in which this and other countries in Europe are ahead of us in experimenting with, and experiencing, worker participation. In an unpublished report to the World Health Organization, Professor John Greve of Leeds University reviews the state of consumer participation in Europe. A curious imbalance becomes apparent when it is clear that we are well ahead of Europe in consumer participation in health care matters as represented by CHCs. The trends suggested above should at least be considered when the recommendations of the Royal Commission on the NHS become known. They could have implications for the constitution of possibly swollen RHAs, AHAs (if not deceased), or perhaps a new body of DHAs, and certainly for CHCs or their successors.

In the introduction, a promise to stray into philosophy was made. One of the traps easily fallen into by the observer of any scene is to form phantasms in the mind and then comment as if they were not subject to falsification, so a final quotation now, taken from the most under-rated philosopher of recent times (23):

A useful preliminary is to note that animals know, not mere phenomena, but things: dogs know their masters, bones, other dogs, and not merely the appearances of these things. Now this sensitive integration of sensible data also exists in the human animal and even in the human philosopher. Take it as knowledge of reality, and there results the secular contrast between the solid sense of reality and the bloodless categories of the mind. Accept the sense of reality as criterion of reality, and you are a materialist, sensist, positivist, pragmatist, sentimentalist, and so on, as you please. Accept reason as a criterion but retain the sense of reality as what gives meaning to the term 'real', and you are an idealist; for, like the sense of reality, the reality defined by it is non-rational. In so far as I grasp it, the Thomist position is the clear-headed third position: reason is the criterion and, as well, it is reason—not the sense of reality—that gives meaning to the term 'real'. The real is, what is; and 'what is', is known in the rational act, judgement.

The phantasms we created in the mind whilst studying the NHS before reorganization were numerous; a number are still around, such as 'co-terminosity' and 'consensus'. The reorganization process was often 'idealist' in Lonergan's terms. The major part of this essay has been concerned to show that the working groups of councils do come to know the realities of health care, not as mere phenomena, but as things. The real is 'what is' in their particular locality. The bloodless categories of the mind can dance to our tunes; reality often remains adamantly unmoved. How do we make judgements on what needs to be done in this situation? The rational act would be to practise, in Popper's terms, 'error elimination' before the event. Much hardship results when, as so often happens, we commence this weeding out after the event. Nor are judgements of CHCs and NHS members and officers necessarily good because they are received with acclamation or silence. In the situations exampled in this essay, both from within and without the NHS, there must be a place for, in Professor Handy's terms, 'forums for dissent'. A future investigation might well be to see if some machinery can be devised and tested which brings together into such a forum workers at the basic operational level (ancillary, nursing, medical, and others), and representatives of the locality's public. The councils studied here made little use of co-option of NHS workers, certainly nowhere near the extent that other councils are known to have done. Experiments with such mixed groups would give an opportunity to test out whether certain locations received demonstrable benefits from this convergence of viewpoints. This type of activity would bring into question the correct place of the benthamite legacy of statute-based authorities in the NHS. The anguish of their members' sense of remoteness has been displayed time and again in public comment, and in evidence submitted to the Royal Commission. Perhaps, in the phrase used by Nottinghamshire AHA(T) in its evidence to the Royal Commission, they will have to 'stick to their last', accepting remoteness and the resultant misunderstandings, but warning that their successors may not be thrusting themselves forward for a place on the authority. The foreseen dangers of prematurely anticipating possible fields for future investigation are looming. Of the making of problems there is no end.

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Appendix I. Working groups of selected CHCs

CHC	Mothers		health		Mentally		Chronic	services	ervices and	nedicine	
and	and	Family	inc. acute	Mentally	Handi-		sick and	domestic	primary	health	Other
symbol	children	health	services	III	capped	Elderly	disabled	cat., etc.	services	education	Scoups
Airedale	×			×	×	×					
Barnsley		×	×	X (a)	X (a)		×				
Beverley		×	×	(a) X	(a) X	×					
Bolton	×		×	×	,	×		×			
Bradford	×		×	X (a)	X (a)	×					
Burnley									×		Resid.
:				;	;						services
Calderdale			1	×	×						
Crewe			×	$\mathbf{X}^{(a)}$	(a) X	×			×		
Dewsbury		×	×	$\mathbf{X}^{(a)}$	(a) X	×	×				
Doncaster	×		×	×	×	×					
Durham	×			X(a)	X (a)					•	Geo-
East Cumbria	×			X(a)	$X^{(a)}$	×		×		×	graphical
Grimsby				X (a)	X (a)					×	Patients'
;	;		1								services
Harrogate	×		×		×	×	×				
Hall	×		×		×	×	×	×			C. and C.
Leeds (E)	×		×	X(a)	(a) X	×					Ad hoc
Leeds (W)	×			X (a)	(a) X					×	
Liverpool					USE OF		CAMPAIGNS: ISSUES				
Northallerton	×		×			×	×				
North Notts		×	×	×	×	×	×				
Rochdale	×		×	X(a)	(a) X	×					
Scunthorpe					USE	USE OF SUB-COMMITTEES	AMITTEES				
Central											
Sheffield					ARE	AREAS OF CONCERN	NCERN				
South											
Tyneside	×		×	X (a)	X (a)	×			×		
Wakefield (E)	×		×		×	×					

Σz

O ₽ Q ¤ ∞ F ⊃ > § X

Note: A few overlaps between groups exist which are ignored here for reasons of clarity of presentation. (a)=Linked group. C & C=Complaints and Commendations.