Management of Chronic Illness

edited by
Mark McCarthy and Peter Millard

Foreword by Donald Acheson

King Edward's Hospital Fund for London

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Papers from a Seminar

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Foreword

King Edward's Hospital Fund for London decided some two or more years ago to hold a small number of seminars to debate important issues in the assignment of priorities in health care. The papers which have been collected in this volume relate to the third of those seminars, which was centred upon the management of chronic illness. This publication comprises the papers which were given by the various authors, revised in the light of the discussion which took place at the meeting. It will be apparent to the reader that most of the professions who help to care for the chronic sick were represented in the discussions and that during the two days of the meeting a number of problems were identified. By deciding to publish this collection, the King's Fund intends to make a contribution to the general debate and hopes that this volume will stimulate further discussion about ways to improve the management of the care of those who suffer from chronic illnesses or disabilities.

Donald Acheson

1978

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Issues in the management of chronic illness

J GRIMLEY EVANS

Chronic illness is not a homogeneous entity and a comprehensive consideration of its management could take us over an immense field. None of us can claim to be expert in more than a small area and it is necessary to resist the temptation to assume that the issues we face in our particular activities necessarily apply elsewhere. Most of what I have to say concerns the elderly, but in choosing particular topics I have been guided by conversations with colleagues concerned with psychiatric disorder and with the care of young disabled patients in the hope of identifying some problems which affect more than the elderly.

Organisation

Chronic illness is found predominantly in the following groups of patients: mentally ill and mentally handicapped people, disabled children and young adults, the elderly and alcohol and drug addicts. The elderly differ from some other groups in that the younger disabled patient or the addict can in most cases be regarded as suffering from a single disease with or without associated complications, whereas most disabled elderly have several pathologies and this may lead to difficulties in coordinating the efforts of several specialties and professions. However, the organisation of our health and social services is such that, even where there is a single pathology, similar problems arise if community care is relevant because of the multiplicity of agencies involved.

The organisation of agencies concerned with people suffering from chronic disease is a patchwork of history and politics, and owes little to the pattern of needs among the population revealed by specifically directed research. The multiplicity of autonomous agencies causes difficulties in the prescription and administration of individually appropriate 'packages' of care for patients whose needs form a continuum not reflected in the administration of the services to be provided. Sometimes unnecessary discontinuities arise due to failure of cooperation at a personal level, but this merely underlines the basic fault in the management structure. Too often, no one carrying personal responsibility to the patient has executive control of all the resources needed. This may prevent optimal care for the individual patient and it precludes any coherent policy of allocating priorities between patients, thus leading to inefficient deployment of resources. Furthermore, contemporary health and social services suffer from gross deficiencies in most parts of the country and this leads to additional breakdown in cooperation since the agencies involved are not necessarily aiming at the same objectives. Where resources are scarce, hospital services will inevitably be more consistently committed to community care than will the general practitioner or social service teams.

In addition to these troublesome discontinuities in administration, there are discontinuities in what should be a continuous spectrum of provision available to the disabled and disadvantaged patient. Some of these discontinuities occur in the provision of housing which most of us accept as being the fundamental axis of care for the elderly. The incontinent patient may be cared for in hospital or in her own home, but not in the supposedly intermediate *milieu* of residential care. There is an important loss in the status and rights of an elderly person passing from her own home to residential care. Except in the most enlightened areas, she has to give up her furniture and most of her savings and she is given no statutory right to her place in the residential home; she may be sent on a one-way trip to a geriatric hospital whether she wills it or no—something which would not happen to an old person nominally in her own home.

A number of workers have alleged an under-provision of sheltered housing. There are undoubtedly people in residential care, or awaiting residential care in hospital, who could manage in sheltered accommodation were this available. There is also evidence that a high proportion of people in sheltered accommodation are too disabled for their placement there to be regarded as appropriate. We lack a coherent and explicit social policy linking sheltered accommodation with other provision in terms of admission criteria and what degrees of disability should be catered for. There are dangers in visualising sheltered housing as a normal stage in progressive care of the elderly, for it may interpolate a disturbing change of environment on an elderly patient, perhaps at a particularly vulnerable period in the evolution of disability such as following bereavement or other family crisis. There are also ethical issues in setting up procedures for removing old people from their sheltered accommodation yet this might have to be part of such a policy. Two essential aims of sheltered accommodation are an undemanding environment and adequate surveillance; there may be potential in pursuing more energetically the provision of these facilities in a patient's own home as part of housing and social policy.

The processes of historical and political accretion which have produced fragmented administration and disjointed provision have also produced an irrational multiplicity of professional groups within the separate departments. An old person needing community support may be visited by nine or ten different people providing different bits and pieces of care. Such fragmentation is being fostered by the current impulse towards professionalisation coupled with older and darker social forces separating 'professional' tasks from the 'menial'. It seems conceivable that a study of the distributions of tasks required by disabled people might lead to more rational job designs for community personnel. One would also like to see some exploration of more sophisticated means of allocating limited resources between patients than the prevalent 'waiting list' approach. In particular, it would seem beneficial to consider what indications could be established for the withdrawal of services from someone who no longer needs them as much as others.

A further consequence of growth by accretion has been the overt or covert process of redeployment of professional groups. This has led to some personnel doing tasks for which they were not recruited or trained, and has caused some loss of morale through disappointed career expectations. One sees these effects among health visitors and doctors faced with the unforeseen, though eminently foreseeable, growth in the old and disabled population. It has also been seen in the community services attempting to cope with the burden of chronically disabled patients who, until recently, would have been institutionalised.

Specialisation

The characteristic reaction of the medical profession to a new challenge is to create a new specialty. A charitable interpretation (and there are others) of the thinking behind the creation of geriatric medicine as a specialty is that it provides elderly patients with doctors with special training and expertise in their problems. But this approach, however well intentioned, brings problems of its own. The separation of a group of people and those who care for them from the rest of the populace can never be neutral; it inevitably creates or consolidates attitudes based on comparative perceived worth or on fears of compromised status.

These attitudes become more extreme when priority for allocation of resources becomes an issue; the creation of the geriatric specialty was not an integrated policy, and it was not associated with appropriate redistribution of resources or educational facilities. Most important, the creation of a specialty implicitly gives professionals the right to regard problems presented by patients beyond their perceived specialty boundary as someone else's responsibility. There is still a tendency in current thinking towards dubious fragmentation in planning for chronic disease. One sees this where rehabilitation facilities for the young disabled are being set up without responsibility for the services for the young chronic sick, or where hospices for the dying are being advocated as a service provision. Without in any way detracting from the achievements of those who, by concentrating in specialist units on particular care problems, have greatly advanced our knowledge, I think we should not accept too readily that corresponding specialisation in our service design will necessarily be in the public interest.

There is a fundamental dilemma here which has been sharply focused in the discussions arising from the Royal College of Physicians' working party report on medical care of the elderly.[63] The answer will not necessarily be the same for all groups of patients; some relevant factors will be the prevalence of the problems, the degree to which costly capital plant is involved in care, the degree to which facilities and skills are shared with other groups of patients, together with aspects of manpower recruitment and education. Clearly there must be some grouping of resources and some specialisation of practice but, as a tentative general principle, I suggest that specialisation should take place in the context of an integrated policy which, as far as possible, does not transect the natural history of chronic illness.

Improving community care

It is possible to identify a further dilemma which is likely to preoccupy many of us over the next decade. For some time the avowed objective of our health and social services has been for disabled people to live as long as possible in their own homes. For the younger disabled (aged under 65) this policy has probably been implemented with some success, for the proportion of younger people in institutions has fallen in recent censuses. It is equally clear from census data that the same is not true for elderly people; indeed, institutionalisation ratios among people aged 75 and over have increased in the last three censuses.[20] This increase has been almost entirely into residential homes and so represents permanent rather than temporary institutionalisation. (It is not explicable in terms of a shift in the age structure of the 'open-ended' age group of the over-75s.) This may partly have been an inevitable consequence of the decline in family support consequent on a number of demographic factors over the last 20 years[38], but conceivably our emphasis on community care has been less than wholehearted and less than wholly appropriate. Certainly our expenditure on domiciliary services is unimpressive in relative terms. A recent estimate[76] is that only 2.7 per cent of public expenditure on the elderly was devoted to domiciliary services, which is only 0.5 per cent more than was spent on residential care. Could this partly be an attempt to fulfil a false prophecy that community care will be cheaper than institutional care? Recent work[58] suggests that this will only be true at trivial levels of care, otherwise economy can only be achieved by neglect. Similar misgivings are raised in a review of day hospital care for psychiatric patients.* There may be a general misapprehension about the cost of managing chronic illness. The evidence suggests that adequate hospital care for the elderly will be much more expensive than administrators have so far been prepared to budget for, and here again the separation of geriatric services from those of general medicine may have allowed this misapprehension to be current longer than it deserved. Looking into the short-term future, with increasing transport and salary costs it is unlikely that the costs of high-intensity community care will move favourably relative to those of institutional care where capital expenditure on new building is not required.

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* Dennis H Gath in a paper delivered to the Toronto Symposium, 1977, 'Partial hospital care for the elderly'.

Even if community care becomes a relatively expensive option, it may still be preferable on humane grounds. Apart from present statutory services, three other approaches to supporting community care can be considered. As various studies have shown, the family remains the single most important resource for looking after the chronically ill. Is enough being done to foster and encourage family support? One demographic factor likely to reduce family care for the elderly is the high proportion of women aged from 25 to 64 who are returning to work. A constant attendance allowance of about £14 per week (after a six months' qualifying period) is unlikely to be sufficient inducement to persuade women to give up the financial and intellectual rewards of employment to return to their traditional role of supporting elderly relatives. If a policy of rewarding family support for the elderly is to be pursued, it will have to be costed more realistically than this. Is there scope for modifying service provision from knowledge of those particular aspects for the care of the disabled patient which are most likely to lead to a breakdown of family support? Some of these specific factors for elderly patients and for schizophrenics being looked after at home have been identified in the literature.

The voluntary agencies are also an area worthy of more study. The statutory services have always had a somewhat ambivalent attitude toward the voluntary sector, seeing it perhaps as a mute reproof of their inadequacies. One central problem with the voluntary services has been the difficulty of integration, since it has always been accepted that one of the privileges of the voluntary sector is to determine what shall be its range of responsibility. In the case of institutional care for the young disabled, this sometimes leads to 'creaming off' the more sociable patients into voluntary homes, leaving the statutory institutions to cope with the more severely disabled and personally disagreeable patients. At a local level, the role of the voluntary services needs to be seen in the context of an inherent tension in the organisation of our health and social services between the centralist desire to use the opportunity presented by a nationalised system to provide uniform services throughout the country and the contrary impulse for services to be more locally responsible and locally responsive, capitalising on local initiative and resources. It may be that the Royal Commission on the National Health Service will take these up.

A third area for exploration is comprised of the broad aspects of prevention. The primary prevention of the diseases of old age form an unlikely option for benefit in the short term, although clearly any opportunities here must be pursued energetically. There are many unsolved questions with regard to secondary and tertiary prevention—in particular the identification of the most appropriate points for intervention in the course of chronic illness. Many of us working among the elderly inevitably feel disappointed in the poor progress made here and in the present difficulties in funding adequate research. Yet now, more than ever, advances in this field seem to offer hope of release from a stultifying spiral of service inadequacies.

Discussion note

Prevention

It was pointed out that several of the chronic illnesses are also the major diseases of premature mortality in our society—particularly cancer, stroke and heart disease. Community programmes for prevention through control of smoking, hypertension, alcoholism, immobility or loneliness offer a way toward reducing the burden of chronic illness.

Information

Many surveys have shown the extent of un- or under-treated chronic illness in the population. Three agencies are in contact with a significant proportion of these people: social services, general practitioners and community nurses. There might be some benefit if these agencies were able to pool their information at a local level, helping to meet the requirements of the Chronically Sick and Disabled Persons Act 1970[36] and leading to better care.

Management

Local management in the health service can offer leadership in three ways. First, there can be policies to limit unnecessary long-term care of elderly people in institutions, releasing resources for community provision. Second, better cooperation between health and social service departments in the assessment of any person who might need institutional care would help to ensure that each received the most appropriate services. Third, many of the problems of community care can be helped where good neighbourhood networks exist; there would be health benefits if local workers (health visitors and social workers) could form and encourage good neighbour and other voluntary schemes.

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The elderly patient with dementia

COLIN GODBER

A psychogeriatrician is involved in the whole range of psychiatric illness in the elderly, and places great store on the curative aspect of the work, particularly with regard to depressive illness. The extent to which such recoverable disorders are left unrecognised or under-treated is a tragedy in itself. This paper, however, deals predominantly with the problems posed by the chronic psychiatric disease of the elderly par excellence—dementia.

It is perhaps appropriate, in a seminar whose participants are mainly deliverers rather than consumers of services, that we should discuss a disease which is characterised above all by the dependency it produces. The size of that burden epitomises the problems our society faces with its changing age structure, and some facts and examples of this follow. Also outlined are certain clinical points which must be considered if we are to avoid total pessimism at the sight of a patient with dementia, or, worse, an elderly person whom we might superficially write off as being demented. Consideration is then given to some of the options open to those planning the care of people with dementia and to the larger scale organisation of services which is necessary if there is to be any choice between or availability of such options in the future. Finally, mention is made of one or two of the ethical problems involved.

Differential growth—the caseload and the resources

The elderly population

There is an abundance of figures on the increase in size of the elderly population of this country. Their impact is often diluted by considering the over-65s as a whole, since it is the over-75s and particularly the over-85s in whom the future expansion will occur. It is among these that the chronic illnesses of old age are most prevalent, and yet they are age groups least able (by virtue of bereavement or equal frailty of spouses, geographical mobility or advancing age of children, and financial disadvantage) to muster the support necessary to cope with them.

The prevalence of dementia

A community survey in Newcastle, backed up by similar figures from other studies, estimated a prevalence of moderate or severe dementia in 5 per cent of the population over 65 years, a figure rising to nearly 15 per cent in those over 75 years.[45] A later Newcastle study estimated the incidence of new cases of dementia as 1.5 per cent per year among those over 65.[44] Dementia of mainly vascular aetiology is spread throughout the older age groups but the more common non-vascular (senile) dementia is predominantly an illness of the 75–85 year age range, probably running an average course of 5–6 years. Thus projections for the future incidence and prevalence of dementia should parallel those for the over-75, and not the over-65, population.

Where are they all?

In the Newcastle study only 1 in 5 of the patients with moderate and severe dementia was in an institution, and this proportion dropped very much lower among the 4–5 per cent of those with milder forms of mental impairment. Follow-up studies on this sample showed, however, a very heavy usage of hospital and residential beds by the group with dementia. This coincides with practical experience of the various nursing and social factors which underlie not only the acute hospital admissions, but also the high proportion among long-stay geriatric patients and the rising numbers among those entering residential care. This growth is not currently matched by capital expenditure in health and social services, the norms of which are themselves arbitrary and still expressed in terms of the over-65 (as opposed to the more relevant over-75) population. The average ages of entrants to Part III* and long-stay geriatric/psychogeriatric beds in a study in Southampton in 1976 was 81 years.† Our unpreparedness for growth is compounded by the long waiting lists which already prevail for most forms of accommodation for the elderly, by the unsatisfactory staffing levels of most such facilities and by the heavy burdens recognised as existing within the community.

Some points on clinical management

Because of the prognostic connotations, it is important that the diagnosis of dementia is not reached lightly. With current resources we cannot test for the array of disorders which enter the differential diagnosis. A careful history and examination of the physical and mental state, however, can eliminate the reversible confusional states accompanying physical illness, and the mimicry of dementia which can occur with emotional and environmental upsets, depression, deafness and other disorders of communication, and will in some cases offer pointers to further investigation.

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[*] Part III of the National Assistance Act 1948[37] concerns local authority services.

[†] From a paper by John Alexander, lecturer in statistics, department of community health, University of Southampton.

Even with the diagnosis established, the objective of clinical management must be to keep the patient's disabilities down to the basic features of that dementia. Thus, at the outset and subsequently, assessment must be a search for complicating reversible factors. From the physical point of view, these include intercurrent infections and cardiac dysfunction; mundane but vital disturbances such as constipation, malnutrition and anaemia; problems of mobility, vision and hearing; and side effects of or failure to take medication. Depressive illnesses are common complications at any stage, and paranoid or other symptoms may cause great difficulty to the patient and his carers.

Declining competence or difficult behaviour may trigger off anxiety or resentment in relatives, or may become the scapegoat for longer standing or extraneous difficulties. Such feelings may initially be masked by a reaction of guilt but, in the absence of an outlet or adequate support, will build up to a state of rejection which will bring out the worst in patient and carer alike. Another aspect, particularly with the solitary patient, will be the extent to which the structure of his environment supports or exaggerates his disabilities.

The objective of management should be to reduce these complicating and irritating factors to a minimum. In most cases dementia is a disease of loss of skills and not of florid behaviour disturbance; appearance of the latter should initiate a search for precipitatory factors and attempts to remedy them. In some cases, of course, such changes will signify development in the dementia itself or the imminent breakdown of the patient's present situation, and thus the need for a new chapter in the planning of his care. Such planning should, of course, ideally be a few steps ahead of the development of the disability, though our present facilities seldom encourage this.

Options of care of patients with dementia

In planning the care of the individual, or the services we need to back this up, it is perhaps best to divide our clientele into those who are living with or are closely supported by their families and those without such reserves. The latter group impinges very heavily on our statutory resources and, because of these pressures, we tend to neglect the former. We do so, however, at our peril, not just in terms of burden and unhappiness which accrue, but because we cannot afford to have the families opting out.

Supporting the patient in the family

The strains on the family here fall into three main phases. Initially, there is the impact of the progressive disability and the change in the role within the household and the personality and behaviour. There is then the period of increasing burden and restriction of the social and financial life of the household. Finally, there is the stage in which that burden becomes too much, often because the spouse or child cracks up rather than just through the patient's deterioration.

In the first phase, the thoroughness of the assessment and the sensitivity with which the family is counselled will be crucial. Some outline is needed as to the prognosis, the sort of adaptations to be made and the help which can be made available. Proper management here will help in the second phase, where the vital aim must be to prevent the family becoming acutely or chronically overloaded. This support will need to include help to the relatives in coping with their workload (for example, attendance allowance, home help, incontinence laundry service) and ways of relieving the monotony of the task (relief visitors, day centres, temporary admissions to hospital), and must be tailored to the family's needs and the progress of the illness. If this support is satisfactory, the third phase may be postponed until a very advanced stage of disability is reached.

Providing for the patient living alone

The aim here should be to anticipate the patient's decline and to endeavour to provide an environment which minimises physical risk while maximising independence and self-esteem. Sheltered housing (especially if staffed adequately to offer real supervision) is a useful option provided entry takes place early enough in the illness to permit the patient to get his bearings. Residential care will be necessary if such supervision is not possible and the patient is at risk from accidents in the home or self-neglect. With the increasing proportion of confused entrants to Part III homes, there is a strong case for the specialisation of certain homes to cater for those whose adjustment will be impaired by such confusion or disturbed behaviour. The hospital services would then deal with the very disabled who need nursing care. In the case of moves to sheltered housing and residential care, the adjustment to the new setting will be better if it comes while the patient has the adaptability to adjust to the change. The fewer moves that need to be made the better. These points raise certain dilemmas in the planning for such supervision.

Integration of services

Hospital care

Responsibility for the care of elderly people is least clearcut in the case of those with dementia. Many patients will need discrete episodes of care from specialists (eg, surgery, ophthalmology), just like other individuals. Others, however, will require help mainly on account of their need for supervision or nursing care (rather than clever doctoring) and may come under the care of physicians, geriatricians, psychiatrists or psychogeriatricians, depending upon which specialist has beds available at the time.

Because geriatricians and psychogeriatricians (and their teams) develop particular expertise in diagnosis, prognosis, treatment and rehabilitation of the frail elderly, it would be desirable for them to take the responsibility for the services. Because of the extensive clinical overlap and similar approach to these two specialties, I would like to see them merge into one department with a responsibility for both acute and longer term supportive care to the frail elderly. The vital feature of such a department would be the shaping of its services to the demand from the community, and thus the rationing of its long-stay care to provide sufficient short-stay turnover to meet the demand for emergency hospital admission of its range of clientele. This would then leave the 'general' physicians (and psychiatrists) to take those patients (many of them nevertheless elderly) who needed their specific skills.

Such a joint department would greatly reduce the number of referrals from one specialist to another, and would enable the geriatric specialties to combine their resources under joint operational policies. This would in turn enable them to do away with the present two-channel system of geriatric v psychogeriatric care with its artificial boundary, setting up instead a three-channel system (medical–geriatric, mixed and psychiatric–geriatric) operating at every level of care (outpatient, day patient, short stay and long stay). Such amalgamation should also increase the impact of the 'geriatric' specialties on the total care of the elderly in hospital, as well as giving a better base for liaison with the services outside the hospital.

Coordination of institutional care

Institutional care is the most expensive of our resources for the elderly, with hospitals, residential care and sheltered housing in that order. With these facilities already overloaded in most places and with the caseload expanding, we must envisage more rational use of resources in the three sectors, close coordination between them and joint decisions on the areas into which new developments should be directed. We have not, I feel, yet explored the full potential of sheltered housing. If the numbers of staff working in sheltered housing were increased (though still not by as many as those needed for residential care), the tenants could stay until they reached a greater degree of frailty, their independence could be better harnessed (in contrast to the dependency-creating atmosphere of residential care) and their privacy preserved.[31]

Such a shift in clientele would greatly reduce the need for residential care and thus for beds in long-stay hospitals, so that more temporary support for families could be given. Another important aspect of such a freeing of pressure on the more intensive sectors of care would be that these could more easily come to the rescue when patients became too difficult for their current setting. Lastly, it would mean that more of the people waiting for care in sheltered housing would be relatively fit rather than seriously disabled people in urgent need of residential or even hospital care. It follows from these comments that I see sheltered housing as the main development area, not residential or hospital beds.

Balance and links between community and institutional care

The size of the problem of dementia means that most of the care will be borne by the community. Our aim should therefore be to make sure that we are dealing with as much of the treatable morbidity as possible, and that what remains the least tolerable will be carried by the hospitals. Speedy help in crises, relief admissions and day care are ways in which the psychogeriatric service can help. For a given population we need a certain basic quantity of short-stay beds; over and above that it will be up to the district to decide how many long-stay beds it can afford.

Conversely, we have to count the cost of very intensive support of patients in the community and such schemes as the 'hospital at home'.[11]

Another aspect of this balance is the extent to which the specialist service moves into the community. In the service in which I work we assess all new referrals at home, and find this invaluable. Similarly, I or another doctor from the unit visit regularly the residential homes for old people in which we have patients. I am aware, however, that in the longer term we would probably do far better if we concentrated on working through the general practitioners by meeting at domiciliary visits, or regularly at their surgeries. A key role in the supportive community follow-up in our service is played by the psychogeriatric community nurses who, as members of the community nursing team (nominally health visitors), are independent of the hospital-based service though, of course, liaising closely with it and having access to its beds.

The medical role in the management of the patient with severe dementia

I have placed emphasis on the need for doctors to spot the treatable conditions which might impair performance, suggesting that geriatricians and psychogeriatricians are likely to develop particular skills in that direction. Another important facet of the assessment, however, is that of the general pattern and quality of life led by the patient and those around him. In the case of the individual with severe dementia, presenting with an acute and possibly life-threatening illness, such aspects may be of importance in restraining us from over-zealous treatment. From some of the sad instances of the lack of such restraint which I sometimes have to take over, I am convinced that this is an area of hospital care which should form part of the service of an acute geriatric unit. This readiness to subjugate medical enthusiasm to nursing care and the comfort of the patient is one which applies even more forcibly in the long-stay psychogeriatric ward. We are fortunate that nurses find work with long-stay patients more satisfying on the whole than do doctors. Nevertheless, it is of great importance that medical staff show an interest in and appreciation of the work that the nurses are doing, backing this up with regular meetings to discuss the clinical progress and general aspects of management of the patients. The quality of life and comfort of the patient at the present must always outweigh the quantity that is to come in the future. This makes it very important to pay great attention to the comfort of the dying patient and to ensure that the medical policy on treatment is in harmony with that of the nurses.

Conclusion

Dementia in the elderly is one of the most challenging of the chronic illnesses facing the health and social services in the last quarter of this century. It is a problem which overwhelms us already, and our estimates of the needs for resources in the future are almost certainly too low. More economical use of these resources and cultivation of the non-professional systems of care (families and volunteers) will be vital, as will more objective evaluation of the various options of care. Better coordination of services for the elderly will also be essential, and the cornerstone for this could be provided by joint departments of geriatric medicine and psychiatry. As well as focusing the responsibility for the provision of hospital services for the frail elderly with a team geared specifically to their needs and patterns of illness, this bringing of the two specialties into the 'front line' could also stimulate the better assessment and management of chronic illness in the elderly by other professionals without which the system cannot operate properly.

Discussion note

It was deemed essential that the basis for a coordinated service be cooperation between geriatric medicine and psychiatry. Both of these services throughout the country are short of investigatory and treatment facilities. In many areas there is little cooperation. The problem of getting anyone actually to admit responsibility was discussed. It was agreed that it was all too common for families to be told that there was no resource available or that someone else was responsible. The concept of coordinated care was supported.

Discussion also covered the development of friendly neighbourhood schemes, the costing implications of the 'hospital at home', the problems of meals-on-wheels provision at weekends, and how to provide adequate support for people in sheltered accommodation.

3

Nursing patients with chronic illness

MOLLIE L CLARK

The needs of patients with chronic illness and the role of nurses in this kind of care have been much written about in the last decade, but nursing practice seldom approaches the standards promulgated. Few would argue with the principle that the nurse should bring to those in her care the right amount of assistance needed—neither to over- nor to under-help the individual patient. Another reasonable expectation is that, for those tasks which are traditionally 'nursing', standards should be as stringent as for acute work. But, whilst maintaining a high standard of technique in clinical practice, the nurse who cares for patients with chronic illness has to learn to modify her general demeanour and approach, to be able to function in a 'home-like atmosphere'—an environment where patients have a lot of say in what happens to them, where the decor is not clinical and where the nurse fulfils a much wider and more flexible role than in acute work.

My comments refer to the hospital environment, but they are applicable to wherever the patient may be. I use the hospital as an example since it is there that the knowledge which informs nursing practice is learnt and attitudes are acquired.

First, what does a nurse do?

> She 'minds' patients during their waking and sleeping hours. In hospital, nurses maintain a 24-hour presence.

> She supervises, assists or performs those personal daily living activities that the patient cannot do for himself. Sometimes she does these things even when the patient can do them for himself.
>
> She performs skilled tasks associated with his treatment. Some of these things can be done by other people, but in hospital these are 'nursing' components of care and treatment.

Training

Advances in public health measures and in acute treatment and care have, it seems, increased the numbers or proportion of chronically ill patients. Their needs can range from high dependency over a long period to intermittent surveillance. If we are to meet these needs, nurses (and other professions) must have practical experience of the management of chronic illness both in hospital and at home during their basic training.

Until recently, general nursing for the state registered qualification was wholly learnt in acute general hospitals. Except for state enrolled nurses, few qualified nurses (almost certainly none of my generation) learned about or practised care of the chronically ill during training. I cannot make up my mind whether this was an advantage or not because, in those days, nursing care of the chronically ill was a travesty of nursing care of the acutely ill. Unintentionally, the nursing regimen kept patients more dependent than one designed for the needs of the chronically ill would have done. Even today we find that the organisation of institutional care of chronically ill people is still modelled on that designed for the acutely ill.

Practice in acute general care is the acknowledged model for most of the health professions. Priorities of accuracy, technical expertise, physical observations and emergency procedures override the more sensitive interactions between professional people and patients. The acutely ill patient does not usually make choices in hospital; he submits and is normally glad to do so.

Recognition of the needs of the chronically ill has been the essential beginning. We have learnt from the chronically ill themselves; for example, Douglas Ritchie in *Stroke*[62] and the people of *A Life Apart.*[55] Setting aims has not been too difficult for the informed and enlightened. But how to reach the objectives is, in my view, now the central issue. It means not only defining roles for people who give treatment and care, but also their acceptance of and education for these roles. It means re-examination by senior members of all the professions concerned of their contribution and how it should be given. It may mean the abandonment of some of our most cherished professional self images and time-hallowed ways of relating to and working with other professions.

Nursing management

The expectations of the nursing management influence nursing care standards and the nurse's performance of her role. If the management's expectations of nurses who care for chronically ill patients are the same as those for acutely ill patients, adaptation of the nursing role to the needs of chronically ill patients is almost impossible.

The role of nurse managers and teachers is to enable nurses to fulfil their role with patients. Their attitudes and assumptions formed by their own experience as nurses often cause them to have limited or unrealistic criteria against which to measure the nurse's performance. This in turn arouses conflict in the nurse if, because she is close to the patient, she understands that he has wider needs which she could help to meet, given opportunity and appropriate training.

We may summarise the difficulties as follows.

The home-like environment, the clutter. The presence of material which is not essential to clinical practice and hygiene can be seen as untidy and out of place in hospital.

Nurses doing non-nursing things; for example, apparently doing nothing, just sitting with a patient and/or his family, playing draughts or not 'helping' a patient who is taking uncertain steps on his way to independence.

Observation. A reduction in visual surveillance can create anxiety although it is inevitable where independence is encouraged.

Safety. The absence or infrequent use of cotsides and chair trays can worry administrative nurses.

Hygiene. The patient's own best standards are, in most cases, adequate but are not necessarily even known, let alone permitted.

Nurses not wearing a uniform. Where there is little 'clinical' nursing but much social and rehabilitative nursing, a uniform may not be the most appropriate garb. This can offend the administrative nurse's sense of fitness.

Nurses working with remedial therapists. The idea of learning some simple practical skills from therapists can be perceived as an admission of incompetence and is often resisted.

'Involvement' with patients can be experienced as dangerous and difficult to control.

Informality in relationships between staff and patients, or amongst staff, can be perceived as lacking in respect for each other, although this is not necessarily so.

Some nurse managers have begun to understand that their own experience as nurses is almost irrelevant to the care needs of the non-acutely ill. They are posing questions about the quality of life for patients and are seeking ways in which nurses can undertake creative rather than custodial work.

When the nursing hierarchy gives leadership and encouragement in setting standards of nursing care appropriate for different groups of patients with differing needs, nurses, in conjunction with other professions, are able to adapt and develop not only their role but also the environment in which patients live. If the expectations of nurse managers are related to the total needs of patients and are not based on the conventional model of what a nurse should be and do, they will ensure further education and training for nurses of all grades in this kind of care.

When this happens, patterns of care for the chronically ill, physically and mentally disabled and the mentally handicapped improve, and nurses at all levels discover that this work is both rewarding and hopeful.

Indeed, it requires far more sophisticated interpersonal skills and a wider range of practical skills than acute nursing. In the latter, the nurse works in wards where many patients are admitted for relatively short periods and she has less opportunity to get to know them, which is essential in prolonged illness.

Work of the nurse

The nurse's work spans the whole of the patient's illness. If there was an acute phase in hospital she had the familiar nursing role, managing the drip, carrying bedpans, giving the medicines, charting the observations. But there are several further areas in which nurses can make important contributions.

Recognition, acceptance and adjustment to chronic illness or disability

When his acute phase is over and he has not gone home or recovered, there is for this patient the critical experience of coming to terms with his disability—the dreams he will not realise, the prospect of being a burden, the restrictions on his activities, all sorts of disadvantages. He and his family need great support from all the therapeutic team at this time.

It is upon the nurse that he will rely for most of the time, and her skill, knowledge and experience are tested. She needs to be able to listen, to encourage, to persuade, to foster recovery of as much independent function as possible. She must do this not only when the therapist, the social worker, the clergyman or the doctor is available to reinforce this programme, but at all times and often when the patient's mood changes and makes her task almost impossible.

The nurse who has no experience of the degree of independence achieved either in a hospital or at home by people with chronic illness or disability is hard pressed to convince such a patient that his prospects are probably much better than he imagines and that he can regain confidence and a measure of independence. She may also do too many things for this patient rather than letting him do them for himself.

Some patients with chronic illness manage to achieve their maximum possible levels of independence and self-determination because of the kind of people they are—resourceful, motivated, emotionally secure and psychologically dynamic. But far too many achieve much less than their potential best because they need more help than they get to reach the stage of needing less help. It is for these people that thoughtful, need-related nursing care is essential.

Rehabilitation

The programme of care for the patient who is expected to leave hospital should be one of preparation for the circumstances to which he will be discharged. We should never hear nurses admitting that the patient will, in the future, have to dress and wash himself, make his own bed and manage transfer to his wheelchair, while they are carrying a bowl of water to his bed, handing him his clothes or—worse—dressing him! Nurses, night and day, should work in close collaboration with the remedial therapists for these kinds of activities.

Intermittent admission to hospital

Another group of chronically ill patients is comprised of those who are admitted to hospital for short-term care. It is essential that they can continue their own well tried arrangements; for example, bowel and bladder management. Some may have found unusual ways of achieving a good night's sleep. I know of one person who sleeps in a chair at home and does the same when he is admitted for a short 'relief' period.

Long-term inpatient care

Those patients who are not expected to leave hospital should be enabled to do as much for themselves as possible. Indeed, until they are as independent as their disabilities allow, their programmes should be similar to those of patients who will be able to leave hospital. The patterns of the day should allow for as much variation for individual patients as possible. This implies that routines will not be geared to patterns appropriate for the acutely ill, but will take account of the abilities, preferences and needs of patients who are resident in the hospital which has become their home.

Diversional, recreational, occupational and social activities

These should rate as high in the priorities of nurses as basic nursing for the chronically ill. There are some grounds for expecting the need for basic nursing to decrease when the patients are taking a more active part in their own care, are stimulated to take an interest and become involved in what is going on around them.

Conclusion

If nurses of the future have the opportunity to learn their proper role in the care of the chronically ill during their basic training, the lot of this large group of patients, wherever they live, will be better than we have managed so far. Our task is to reach them with the kind of care which meets their needs with sensitivity and realism, and of which we should no longer feel ashamed.

Discussion note

The importance of the teacher's values to the trainee was stressed. During the formative professional years there is too little help in self-understanding, although much of the professional life thereafter is spent trying to help other people. There is little opportunity for further personal growth and development of staff in the general hospital environment. Menzies' study[54] of nurse trainees in a London teaching hospital showed how immature ways of coping with stress may be inadvertently reinforced rather than altered.

Some nurses equate the acquisition of more complex technical work with being more 'professional'. Whilst nurses may well need a broader range of skills than at present—sometimes because they are agents for other professions in their absence—it was felt that they should not move in the direction of attempting to become mini-doctors.

The idea that staff in local authority residential homes should be nurses was raised. However, these are meant to be homes first and institutions second, so that the community nursing service should provide care on request only, in the same way as it does in people's private homes.

4

The community nursing services

VIOLET KRETZER and ZURELL MORGAN

The health visiting and district nursing services came from the same roots in 1859 in Liverpool. Now they provide separate but complementary trained nursing services to people in their own homes. The health visitor's function remains largely 'prevention' and health education for the entire family whilst the district nursing sister provides the more practical aspects of nursing care in the home.

The role of the district nursing officer

Some district nurses still work in a defined geographical catchment area, but attachment to general practice teams is increasing. The primary health care team based in a health centre consists of general practitioners, health visitors, state registered and state enrolled nurses, social workers and ancillary staff.

The district nurse has had specific training after state registration and holds either a Queen's Institute of District Nursing Certificate or a National District Nursing Certificate. She (or he) may be assisted in her work by state enrolled nurses or nursing assistants.

District nurses are responsible for the nursing care of patients at home. To carry out this task it is essential that a planned programme of care is established bearing in mind the nature and prognosis of the illness. The programme must be flexible for each patient and be tailored according to the family resource and community services available.

Increasingly, the district nurse has to play an active role in coordinating rehabilitation; occasionally, this is with the assistance of community occupational therapists and physiotherapists. In any one day the district nurse's duties may range from technical nursing to basic bedside nursing. Tasks requiring less specialised knowledge, training and expertise may be undertaken by auxiliary workers.

The district nursing services will be involved in the management of all phases of life from birth to death occurring at home. In moving from house to house, district nurses have to adapt their skills and show a flexibility of attitude to enable the correct programme of care to be tailored to each patient.

There must be a close relationship between the nursing services and the general practitioners to ensure that both know about changes in the condition of the patient. The district nurse has an important part to play in the management of dying patients at home and can help to provide counselling for the bereaved.

Early discharge from hospital, not only of the elderly but also of postoperative patients of all ages, is throwing an increasing strain on the community nursing service. The alternative to institutional care is community care but this implies that more support must be given to the already hard-pressed district nursing services.

Health visitors

The role of the health visitor can be identified in five main aspects.

1 the prevention, or alleviation of the consequences, of mental, physical and emotional ill-health

2 the early detection of ill-health and the surveillance of high-risk groups

3 the recognition and identification of need for the mobilisation of resources

4 health education

5 advice on the practical aspects of care.

The health visitor, although a trained nurse, does not provide a basic nursing service. The health visitor has a post-registration training as the all-purpose family visitor and holds a Health Visitor's Certificate.

Her skills include observing and assessing people and situations, and taking part in the planning, organisation and coordination of programmes of care for groups and individuals. The fundamental skills are in communication, in establishing and maintaining personal relationships, listening and interpreting, counselling and, perhaps most important of all, teaching. She practises these skills, not only with an individual patient but with the whole family. She has the responsibility to refer to other agencies where and when necessary and should have full knowledge of all services in the community.

In short, she can advise on

disabilities (blindness, deafness, physical handicaps)

ill-health

social problems

money matters

accommodation

legal and other advice

transport and holidays.

Effects of chronic illness on the family

Chronic illness can be devastating to families, for the social implications to family life are tremendous. The frustrations, anxieties, uncertainties and eventual stress need to be considered in order to initiate successful management.

The patient, as well as his immediate family, needs reassurance and orientation to accept and adjust to his situation.

The members of the health care team, combining their individual expertise and specialised roles, can cater for entire family needs without worry about overlapping of roles.

The types of assistance required may be listed.

Family support, treatment of patients, adjustment of family following bereavement, ensuring that team members act in a coordinating and complementary role.

Support in maintaining independence and retaining self-respect.

Work towards a change of attitudes where applicable.

Liaison and support as necessary from other agencies, including hospitals.

Advising on future direction; for example, hospital care and more dependence on nursing and social services.

Health education, diet, nutrition and hygiene.

Ensuring home safety.

Persuasion to accept treatment and nursing care in order to maintain an acceptable quality of life.

Encouragement and reassurance. Help patients and families to accept their condition and to modify their lives accordingly.

Build up a relationship between patient, family and health care personnel, thereby providing awareness of nursing service facilities and encouraging communication.

We need more research into community nursing services. Meanwhile, we must use the present resources totally and efficiently for the good of family health and preventive medicine. After all, 'prevention and health is everybody's business'.[34]

Discussion note

The difference in training requirements of the state enrolled and state registered nurses was touched upon. Consideration was given to the conflict in using highly trained staff to do simple tasks such as washing patients and getting them in and out of bed. It was considered that support services are not readily available at home and a more highly trained person is necessary to cope with all emergencies. The need for close contact between the members of the health care team was discussed, as was the need for frequent case discussions.

The involvement of the health visitor with handicapped patients was stressed. The system in the North District of the Bedfordshire Area Health Authority was described. Health visitors are responsible for the handicapped up to the age of 16 years. One health visitor is based at the child development centre and works in liaison with health visitors in the group practice area. She is concerned entirely with the care of the handicapped.

With general practitioner attachment, all handicapped patients are visited by the health visitor. Medical aids, equipment loans, laundry service, night service, home adaptations, recuperative holidays, domiciliary visiting and chiropody—to name but a few of the available community services—are arranged by the health visitor in cooperation with the entire practice team and social services department.

5

Expectations and ethics in the care of the chronically sick

G R DUNSTAN

Expectations in ethics

A member of the seminar who is neither a doctor nor a scientist might have been expected to represent a 'consumer' interest. He might contribute as a potential chronic sick patient—one who requires medical attention over a long time, without prospect of cure or remission but only of medical support and relief from distress.

It is not my purpose, in fact, to contribute on that basis; but it is worth a moment's pause to consider what 'expectations' might have meant if I had.

Several present tendencies contribute to an answer. In good practice, patients are involved more in the process of their own treatment and recovery; it is considered important to gain not only consent, but also cooperation based as far as possible on understanding. There is much demystifying of the old practice of medicine and of nursing—perhaps more, sometimes, than is psychologically good for the role of the practitioner and the minimum of social 'distance' necessary to it. There is, on the contrary, much new mystifying with medical technology, with what can be easily and impressively portrayed on television. Some of this inevitably arouses a 'gut reaction' in lay viewers, making them an easy target for suggestion or criticism hostile to the practice of medicine. It is easy to mistake a queasy feeling for a moral judgment. There are more ways open for patients or the public to criticise medical or hospital practice, and more bodies, such as the Patients' Association, ready to articulate criticism. Practice and administration are open to scrutiny, and to organised hostile action, by unions such as the National Union of Public Employees and the Confederation of Health Service Employees, powerful enough to retard or halt hospital routine. Practitioners in the National Heath Service, in short, are left in no doubt as to what vociferous groups expect or do not expect of them. 'Expectations' are commonly expressed in the language of 'rights', even though, upon analysis, 'rights' sometimes turn out to be no more than aspirations—the articulation of expectations either unreal in themselves or unrealistic in given circumstances. This is not the burden of this chapter.

My discipline is moral theology. The assumptions I bring to my work are derived from the Judaeo-Christian religion which, with principles and rules drawn from the Greeks, have helped to form the Hippocratic tradition in medicine. My theology will not obtrude, but it is there to be drawn upon if required.

To a moralist working on social concerns the word 'expectation' is duty-laden and prescriptive, denoting what ought to be done, what people may properly look for, in commonly recognisable situations. The obligations involved are essentially mutual: what people may 'expect' of one another. So, within the profession, medical ethics consists of principles and rules of practice (including those of etiquette) which doctors expect one another to observe. Between the profession and the public, medical ethics extends to wider mutual obligations: what a patient may expect of a doctor, and a doctor's expectations concerning the patient's behaviour and what he may ask for. Such mutual expectations require the support of a common morality, a set of values, generally implicit in conventions and courtesies but also explicit in rules and in civil and criminal law. They embody duties as well as rights. Their basis is trust; they exist to maximise trust, a condition essential to any professional relationship and supreme in a medical relationship.

The moralist therefore has to work on two fronts: on the professional front, with the doctor; on the communal front, with the 'patient' public. His object is to promote trust (a due and proportionate mutual expectation) between the two. The test of the relationship is pragmatic—how well it serves the interest in the promotion of health; its ground is principle—what men, in the exercise of their capacity for moral reasoning, judge to be right.[17]

Expectations in professional practice

From such preliminary reading as I have been able to do, and from reflection on the medical care given in my own household, I conclude that there is no ethics special to the care of the chronically sick, as there is none special to intensive care in acute illness. The basis of all medical practice is the exercise of clinical judgment and the provision of a regimen or management consequent upon that judgment. The management must always relate to, and be conditioned by, the condition and circumstances of the patient, and the skills, apparatus, procedures, resources and human aids available. This is as true of chronic care as of all other. (The demands of chronic care on the emotional and moral resources of the practitioner and of others concerned in it may be special; but that is a personal matter, not one of general ethical distinction.)

The doctor is the servant of the patient's interest. Generally, the patient's interest and wishes may be presumed to coincide; but this may not be so, and the doctor may have to decide which he is to serve. The chronically sick person may have a long-term interest in such things as general support, relief from distress, being enabled to live as full a life as his handicap or disability permits; certainly he has an interest, throughout it all, in being treated as a human being. He has an ultimate interest in dying, a process as natural to him as being born and living; and this interest also he may expect his doctor to serve. It is a matter of clinical judgment when the doctor should turn or incline—for it may be a matter of degree—

from serving the interest in living to serving the interest in dying, and to adjust his management accordingly.

Sometimes we speak not of the patient's interest, but of his 'good', and we say that the object of medical care is to serve that. This 'good' of the patient—the value we put on his life—is not to be measured only by its duration, any more than we can compute the value put upon human life by counting the crude number of lives being lived. Neither is it to be measured only by physical functioning—though a minimum of good physical function is necessary for its maintenance. We probably misdirect ourselves in discussing this good by isolating the individual from the common humanity, as though all that mattered was the effect of our acts or omissions on *him.* (This, the old Jewish theology would never do: the sense of the other being 'bone of my bone and flesh of my flesh', of our being 'members' of one 'body', was too strong; and it persisted in the earliest Christian thinking.) We may ask why civilised man has always abhorred an enemy who desecrates the dead. The dead cannot feel the hurt. The wound is to our common humanity, vulnerable in him.

Our common humanity, then, is embodied and reflected in the single patient, perhaps unconscious beyond recall but human still. And the quality of life we are discussing is not to be reduced to the physiological measurement of brain or cardiac activity. It stands rather in the relationship of others with him, and of him with them: in the quality of the respect and care which he, in his dependence, evokes from doctors, nurses, caring relatives and friends, and, by derivation, in the quality of their relationship one with another in respect of their common concern with him. He is the living centre of a wheel of human activity, linked by 'spokes' of discrete relationships with those caring for him, and so joining them in a circle. Humanity, then, is recognised as a relational quality embodied in and centred on a patient. This recognition of corporateness, or of common participation, in the notion of humanity does not lessen the protection due to each person.

Rather, it enhances it, giving it more significance because of what the patient, in his dependence, does for and to those on whom he depends.

The doctor in chronic care is therefore concerned first with the general physiological functioning of his patient and then with the context of concerted care which can enable the patient to live his humanity to the full, consistent with his handicap or disability. The demand on imagination, skill, determination and ingenuity may be no less than in any other discipline, such as intensive therapy or paediatrics. The temptations are no less though coming, perhaps, from different quarters.

A too-ready acceptance of things as they are could promote lethargy or stagnation, leaving patients with discomforts from which they could be relieved or in a state of deterioration which could be arrested; an acquiesence in administration or organisation inept for good patient care; a failure to advance the corporate knowledge and skill in the discipline. On the other hand, an excessive zeal for novel technology or for the pharmaceutical or administrative kaleidoscope could be adverse to the interest of the patient and make life worse. A mean between the two is the way to proper care for him, and to the advance of skills. And, as in all other medicine, good practice is specific to the patient, not to the disease, the technique or the drug.

Expectations in community attitudes

Attention is directed here, not to an individual patient but to the community of which he is a part and whose attitudes he must, to some extent, share.

Our community in Britain today—to look no wider—must, above all, come to terms first with dependency, which necessarily accompanies impairment or disability.[5,6] Anti-dependency remarks have been heard in this seminar, revealing a lurking assumption that dependency is a bad thing, though the context generally indicates that an undue dependency—not dependency itself—was the target for criticism. Proper child-rearing is directed towards promoting independence; not isolation, but a proper autonomy, or capacity to govern one's own life within normal social groupings. The cult of an exaggerated independence can become a theological blasphemy—a falsehood against man's created nature—and a crippling social and personal untruth. The extreme isolate is an object of pathological concern—social and psychological. The truth is that we are mutually dependent in all that matters in life.

In clinical care, therefore, the aim is to promote such a degree of independence as the patient is capable of within an essentially dependent relationship. This is as important in the care of the aged as of the young.[12, 42, 51] Some degrees of dependency tax personal capacities to the limit of endurance, some beyond. This was studied in families caring for children with gross myelomeningocele and spina bifida in the ten years of the celebrated Sheffield programme, in which every child taken to the hospital with this condition who could survive was actively helped to survive. The observations were one factor contributing to a general modification of the policy.[25, 35, 49, 72] Where such a strain exists, whether with a very young patient or with the very old—especially when the persistence of the strain is a consequence of our socially commended and skilled medical intervention at an earlier stage—there is a communal duty to provide social support by all appropriate means. It is on the quality of the care given in this group—medical, paramedical, social, familial—and on its humanity, as described above, that the well-being of the patient rests.[51]

As a nation we recognise our interdependence; it is the philosophy which underlies national insurance, a national health service, and all the provisions of the welfare state in all its complexity. It would, however, be wrong to ignore a mood, encouraged by the shallower discussions and portrayals in radio and television, which treats dependency as an unnatural or improper burden and induces self-pity in those who have to bear it. On the broad scale we have, it is true, an increasing dependency ratio in an aging population; but this is highlighted by a decreasing ratio in children because of the declining birth rate. It is at the personal level that suggestion is more insidious. From a growing ability (through genetic counselling, screening and abortion) to reduce handicap, consideration goes on to eliminating the handicapped on the ground that they are a burden to relatives or to society. Even in the pursuit of the reduction of genetic handicap there are degrees of propriety and proportion. A corporate prudence must be observed if we are to avoid the risks attendant upon an over-zealous pursuit: the risk of undue anxiety in parents or even potential parents; of social pressure on women to seek abortion on the suggestion of the slightest risk of handicap; of an imputed guilt for the mother who bears a handicapped child, even without warning; of a sense of being unwanted, 'a burden', in the dependent child himself.[3,40,66] Parallel to this is the courting of euthanasia—or professionally assisted suicide—as the escape route or way of deliverance from dependence either through incapacity or in old age. The suggestion of their being a useless burden on other people or on that anonymous abstraction, 'society', must be deeply troubling to sensitive minds; it is a form of social cruelty to put about speculative chatter in such terms. The high quality medical care of which we are now capable is useless unless those who can benefit from it feel wanted.

The antidote to this self-pitying mood—and one must be found—may lie in galvanising the community to accept dependency as a fact of life, part of the truth of our being, a condition of our developing our humanity. There is urgent need not only to provide the social, community and technical aids which the handicapped and the chronically sick require, but also to create the wealth to pay for it and to distribute our national wealth more caringly. Perhaps a better motive might be offered for higher productivity:

not higher wages and salaries for ourselves, but more wealth to achieve corporately what, when we realise it, we both ought and want to do.

Three related topics concerning the profession and the community

The foregoing has been rather general; it may hit or miss the mark. Seminars should have particular issues to examine—moral as well as practical. Three such, evident in the literature, seem to invite attention.

1 *Keeping confidences*

A new ethics is needed for a new development of professional care—new in that the doctor no longer stands alone in relation to his patient, but with others in concerted activity. In hospital the group extends beyond doctors and nurses to include radiographers, pathologists, social workers, record keepers, and others. Care of the chronically sick at home may involve a similar group. Difficulties are said to arise when communication within these groups is incomplete. The identification and protection of children at risk from parental violence has been deficient when the rule of confidence (now called, alas, 'confidentiality') has been invoked in a way which prevented significant information being passed to other persons professionally concerned. Notable advances in child protection, on the other hand, have been made where groups—paediatrician, general practitioner, health visitor, social worker, police surgeon—have worked out conditions of trust and co-operation based on a corporate keeping of professional confidences.[24]

The Hippocratic oath, if we may begin there, reads

> All that may come to my knowledge in the exercise of my profession, or outside of my profession or in daily commerce with men, *which ought not to be spread abroad* [my italics], I will keep secret and will never reveal.

The italicised words indicate a class of knowledge which must be kept secret. It implies that there is another class of knowledge which may, for good reason, be shared. (It is to be observed also that the prohibition applies to knowledge gained outside the professional relationship as well: gossip, the unsavoury discussion of other men's affairs, does not become the doctor, or the priest; it impairs trust.)

The rule, though mandatory in form, is utilitarian in purpose. It is to serve to the utmost the interest of the patient in being able to reveal, without fear of disclosure, all that the doctor needs to know for the exercise of his art. Respect for the rule requires a presumption that such confidences will be strictly observed. But the rule is not absolute: the presumption may be rebutted, for example, by order of a judge if there is a conflict of interests of serious magnitude between the patient and society in the administration of justice. In the new group care of the chronically sick, then, the question is what discretion may be allowed to the doctor, and to others professionally involved, to share confidential knowledge when the interest of the patient would be better served by the sharing.

2 *Ethical conditions for the exacting of a promise*

Maintenance dialysis is undoubtedly a form of care for the chronically sick. In some areas the facilities are adequate for the number of patients judged suitable for it; in other areas they are apparently not. In some units a patient is accepted for dialysis only if he agrees to have a transplant when a cadaver kidney becomes available. If he changes his mind, and refuses the kidney which is offered him, 'the flow of patients through the unit is curtailed, so that other patients who need treatment will not be able to be treated and will inevitably die'.[15] It is not enough to say that the dilemma would not arise if facilities were adequate: given finite resources and limited budgets, facilities could be extended only at the expense of services elsewhere.

The ethical question is this. Is it right to exact from a patient who is in a low condition from kidney failure, a promise which he has every inducement to make but which will fall due for performance after his condition has been improved by dialysis, when he may prefer his present well-being to the risk of a transplant operation? Are there better means of reconciling conflicting interests in areas, or times, of limited supply of the facilities required?

3 *How to reconcile expectations with reality?*

We shall have to learn to live with increasing public discussion of the health service and of medical practice. Public expectations will be voiced through new channels, sometimes stridently in the language of 'rights' asserted or denied. Behind what is said there often lie questionable assumptions, such as unlimited resources; or that clinical judgments are infallible so that there can never be mistakes, only negligence; or of procedures, palliatives, antidotes or 'cures', all free of risk. Even the proper encouragement of independence in a frail or convalescent patient is not without risk—not only to the patient, who might fall, but also to the nurse or attendant, who is assumed to be negligent in permitting the possibility of a fall. The public avidity for drugs, dyes, cosmetics, food additives and colourings, all without risk, is insatiable. It costs us dear, in money and in animals sacrificed to more and more elaborate testing, in not producing drugs for rare diseases because the market is too small to assure an adequate return on the capital invested.[16] Granted an assumption that medical intervention can be free of risk, it requires only a legal system which encourages lawyers and aggrieved patient to collude in claims for damages on the slightest provocation to inflict on the whole health system a crippling litigious paralysis.

At the other extreme lies the uncomplaining acceptance of whatever befalls—of ills which might, with effort, be alleviated or cured; of services below standard which ought, by public pressure, to be improved. Between these two undesirable extremes there must lie a mean. It will require at its base a common morality, a consistent ethics, a set of assumptions, expectations, shared between the health professions and the community. It is, perhaps, one function of the moralist to help uncover these expectations. It will require a long, honest, intelligent, unsensational, educational debate, through the media of communication, to secure their widespread acceptance.

Discussion note

Education

Medical education is based primarily in biological and behavioural science; but it must contain more because this science has to be applied to human beings in human relationships. The grounding in the common morality has to come from the wider community—from home, school, literature of other areas in the common culture. The student learns 'ethics', some from the consultants and firms to which he is attached in his hospital-based clinical course, and this is often supplemented by interdisciplinary discussions such as those arranged by the London Medical Group and similar bodies. These means are likely to be more effective than specific courses in medical ethics from moral philosophers.

Responsibility for decisions

Is it possible for decisions to be made adequately by consensus groups, or should the doctor take responsibility for these decisions as leader of a team?

6

Rehabilitation and chronic illness

HUGH J GLANVILLE

The purposes of this paper are to discuss some of the problems about caring for those with chronic disability and to indicate how rehabilitation services can help. Disability and chronic illness are not the same thing but they often coexist, and the main causes of severe and very severe handicap in adults of working age are indicated by Wood[75] and Harris[39], though the latter did not take into account disabled people in institutions. The main problems presented to rehabilitation services do not, however, come from the largest group (patients with arthritis), but from the smaller numbers who suffer from neurological disorders.

Fair shares?

Ultimately, demand dictates the provision of services; and demand has led to a health service well adapted to deal with emergencies and episodes rather than to provide the continuity and support required by the chronically disabled. It has been argued that the demands of the chronically disabled are not heard because they are not a vocal group. They are usually unaware of their entitlements and need help to define their problems and difficulties; this puts pressure upon the relatives and friends. One wheelchair user told me that the fact of his being confined to a wheelchair directly affected 49 people, which included his own family circle and his intimate colleagues.* Since it has been estimated that two-thirds

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*Personal communication from Professor S O Brattgard at the DIG conference on housing, Southampton, 1977.

of the population may expect to spend some part of their lives, possibly only a few days, in a wheelchair, the implications are obvious.*

Need and demand are not the same thing, and the greatest needs are often incapable of resolution. From the foregoing, it seems likely that there is under-provision for the chronically disabled if we accept that demand from them is often unheard and is usually less urgent than that of the acutely ill patient.

A pilot scheme in rehabilitation

In 1952 the Nuffield Provincial Hospitals Trust funded a pilot scheme in rehabilitation at Odstock Hospital, Salisbury. The intention was to provide a comprehensive and, if necessary, full-time rehabilitation programme for patients recovering from illness or injury, as well as to provide support for people with chronic, unstable or deteriorating illness. They entered the programme by medical referral as inpatients or outpatients; then followed assessment of the social, occupational and psychological status by a multidisciplinary team, including the disablement resettlement officer from the Department of Employment. He was responsible for the resettlement of the patients and was expected to travel, if necessary, outside the hospital's local area to secure employment for them.[8]

The assessment programme led to the identification of the authorities and agencies outside the hospital service who would need to be involved—for example, education, employment services, employers themselves and housing. It was possible to impart a sense of urgency by bringing them in early and by forecasting a time scale with the dates that they would need to meet. Once in the

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*Personal communication from Professor S O Brattgard at the DIG conference on housing, Southampton, 1977.

system, a patient who had chronic problems was followed up indefinitely and was encouraged to return with any new problems; though based on the hospital, the service reached outward and encouraged the participation of the general practitioners, welfare services and voluntary organisations. Nursing aids or aids to independence were supplied direct to the patient, debited to him or the welfare or nursing budgets, and simple adaptations to the home were done direct from the rehabilitation department by the rehabilitation staff. It was inherent that a doctor (not necessarily the director) would be responsible for the medical care and for overseeing the agreed programme for the patient. Apart from that, the director of the unit would be responsible for its policy and for its day-to-day workings and would also have a clinical commitment. Established as it was in a small hospital group, communications were easy and so responsibility for the care of patients could remain with one hospital-based doctor and with the patient's general practitioner. It was relatively simple to see that an agreed programme was adhered to and coordinated.[28, 29]

Since the reorganisation of the NHS in 1974, it has been more difficult to coordinate the services because three authorities are responsible for eleven departments providing 26 different types of service.[71] All have their own hierarchies, programmed rehabilitation is more difficult to achieve, and patients become confused and bewildered.[30]

No new service can be expected to work smoothly at once. For the most part, staff and resources are available to carry out good rehabilitation and after-care for the chronically disabled. The problem is to coordinate and focus the activities of many people into an effective team. This raises questions such as who should be in charge of the patient, who will be the leader of the team and how will resources be allocated?

The increasingly important roles of district therapists as advisers, the obvious need for domiciliary remedial services and the need to provide a focal point for rehabilitation activities in which different departments and individuals must be concerned, dictate the need to devise an acceptable structural model in every district, for which a health care planning team in rehabilitation can be the starting point.

Priorities

In order to improve and coordinate services for the chronically disabled, my priorities would be as follows.

1 To introduce compulsory training in rehabilitation into the undergraduate medical curriculum. Experience suggests that those who do not get the message in their formative years often fail to receive it at all.

2 To press every area health authority to develop rehabilitation services based at a main centre, designed to focus and integrate the rehabilitation activities of the hospital and community.

3 To allocate funds for post-registration higher education for advisers to districts in occupational therapy and physiotherapy. They carry heavy responsibility and often administer large budgets. Few remedial procedures have been evaluated scientifically; thus, there is urgent need to develop members of the remedial professions for their new role in administration, research and evaluation. If necessary, provision for this purpose should be made from the budget for remedial therapy.

4 To support disabled people in the community. This carries a high priority[52], hence the importance of financing such schemes as the Crossroads and Focus schemes.[59] Perhaps less should be spent on the provision of allowances (they are open to abuse in the wrong hands) and more upon schemes devised to provide care which dependent people need to remain at home.

5 To explore more fully the potential of voluntary workers and voluntary organisations.

7

The impact of chronic illness upon the family – with special reference to mental handicap

STEPHEN PLATT

A child with a chronic illness is one who has any disorder 'with a protracted course which can be progressive and fatal, or associated with a relatively normal life span despite impaired physical or mental functioning. Such a disease frequently shows periods of acute exacerbations requiring intensive medical attention'.[53] While the child is physically (and often psychologically) affected by the disabling or handicapping nature of the illness, the immediate family rarely escapes a degree of dislocation and change which ranges from the barely noticeable to the cataclysmic.

After a consideration of immediate parental reactions to the birth and diagnosis of the chronically ill child, I discuss the problems associated with the illness itself and the caring function exercised by the family. I conclude with a necessarily brief overview of some of the most common methodological pitfalls which can be found in studies of the burden of illness.

Immediate parental reactions

Beverly Lawson, in a recent article on chronic illness in the school-aged child, discusses how the mother and father prepare for the new baby by fantasising a perfect 'dream' child.[47] When the baby is born with disease or defect, the mother has to grieve for the loss of the anticipated child and at the same time adjust to the imperfect child before she can develop a relationship with the baby. Some experts believe that parents with a defective child suffer sorrow throughout their lives in response to the tragedy. A crucial factor in determining parents' acceptance of the situation is their ability to master resentful and self-accusatory feelings over having in some way 'caused' the child's disorder. Mattson cites three main patterns of behaviour in the child which arise out of the way in which parents cope with these feelings. The first pattern is characterised by the child's tearfulness, inactivity and dependency on his family and the mother's over-protectiveness toward the child. In the second pattern, the child is over-independent, taking excessive risks and defying parental prohibitions. The child uses strong denial of realistic dangers, while the mother is over-solicitous and guilt-ridden. Finally, there is the less common picture of the shy, lonely and resentful child who directs his hostility toward normal people. His family usually emphasises his disability and tends to hide and isolate him. The child develops a self-image of the defective outsider.[53]

Wolfensberger, reviewing the literature on parental reactions to an abnormal child, concludes that the parents must cope with three crises. The first is the initial shock; second is the process of change in values, expectations and hopes which the parents must undergo in relation to their child; and third is the 'reality crisis' in which parents have at long last to confront the practical problems of daily life.[74] Gath believes that, if parents become aware of disability before becoming attached to the baby, outright rejection can ensue.

> 'When the abnormality is unrecognisable at an early age, parents may become gradually aware of it later. The parents will have formed loving attachments to the child and rejection is unlikely. The slow realisation is distressing and the ending of the period

> of uncertainty, even by the breaking of bad news, may have a beneficial effect on parents, especially if accompanied by an opportunity to air their feelings.' [26]

Another common parental reaction is to reject the diagnosis of chronic disease in the child. According to Hughes, this is a normal, impulsive, flight from the truth. Rarely is the child totally rejected once the diagnosis has been accepted.

> 'Nevertheless, there are undoubtedly secret moments of rejection. But these transitory rejection thoughts, born of the burden of the disease and the dashed hopes of the parents, are usually quickly overcome by the much greater love for the child. However, when parents catch themselves thinking this way, they have deep guilt feelings.' [43]

The variability of parental reaction to the birth of a chronically disabled child has led many practitioners and researchers to devise mechanisms for identifying families at greatest risk of maladaption. Lawson, for instance, attempts to construct a scale for detecting families at risk for adapting poorly to chronic illness.[47] The typical high-risk parents are black, recently married, young, with a low income, of high school education only, without religious conviction, community involvement or support from the maternal grandmother. The marriage is weak and both parents have negative feelings about chronic illness. There are two major methodological problems associated with the use of this scale. First, it has only been applied retrospectively as yet and, in the case of the more judgmental, subjective variables, it is not difficult to envisage how a manifestly non-coping family will be labelled weak or negative. Second, Lawson does not appear to have considered sufficiently the problematic time sequence of cause and effect. It may well be that the weakness of the marriage and the lack of community involvement are consequent upon the disruption caused by the child's illness, rather than a sign of intrinsic maladaption. This point is taken further in the section below.

Effect on parents caring for chronically ill child

The results of investigations have been conflicting, probably for methodological reasons. There is evidence from two studies that the responsibility of caring for the subnormal child may be detrimental to the health and happiness of the mother.*[65] However, these results must be interpreted with caution, since neither study contained a control group. Tizard and Grad compared families with subnormal children living at home with families whose children were living in an institution. Their conclusion was that families with a subnormal child at home were dominated by the 'burden of care', while those with a child in an institution were able to lead nearly normal lives.[70] However, another study found no significant difference between the mothers of institutionalised and non-institutionalised children.[10] Erickson found that the parents of young retarded children resembled the parents of emotionally disturbed children, in the extent to which they manifested psychosomatic symptoms, anxiety and depression on the Minnesota Multiphasic Personality Inventory. She regarded her results as evidence of parental stress reaction in most of her subjects.[19] Cummings and colleagues compared mothers of mentally retarded children with those of chronically ill children (suffering, say, from diabetes mellitus), and concluded that the former group was subjected to greater psychological stress in day-to-day management.[13]

Apart from these studies of maternal reactions, there have been several attempts to study the effects of a subnormal child on the parents' marital relationship. Farber and colleagues used his Index of Marital Integration to measure how far husband and wife agreed on the rank ordering of domestic values. They found that subnormal boys, especially those over the age of nine years, were more disruptive than girls to the marital relationship, this difference

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* K S Holt, *The impact of mentally retarded children on their families,* MD Thesis, University of Manchester, 1957.

being more marked in the lower social classes.[21, 22] Fowle, using Farber's index, found no significant difference in marital integration between parents caring for a subnormal child at home and parents having a similar child in an institution.[23]

Sultz and colleagues reported that 9 per cent of the mothers in their study group felt that the ill child was a disruptive factor to their marriage. A total of 26 per cent reported it as a strengthening factor. Problems contributing to the weakening of the marriage included avoidance of sex for fear of having another sick child or of being unable to cope with another child in addition to the sick one, too little time left for each other after caring for the ill child and other children, and anxiety over finances. Disagreements about what to expect from the sick child also caused problems.[69] There are some indications that suicide and divorce rates are higher in families with chronically ill children than in the general population.[14] A divorce rate of nearly 50 per cent was seen in one group of parents with children with meningomyelocele.[46]

Finances are a major concern in many families. In one study, additional employment was necessary in 20 per cent of the families after chronic illness was diagnosed in the child.[69] In many cases, financial assistance is available, but, in the USA at any rate, it appears to be white upper-middle class families who know of its availability or how to seek it.

Social activities are substantially curtailed in many families with a chronically ill child. Citing difficulty in finding someone competent and willing to accept the responsibility of caring for the chronically ill child and lack of funds after meeting medical expenses, 25 per cent of the mothers in an American study reported this to be true.[69]

Effects upon siblings

Again, there is conflicting evidence. Farber and Jenné have indicated that the handicapped child often assumes the role of the youngest child, though there may be younger siblings. In this case, the older children can be expected to accept the problem.[21,22] Holt found this too, and with it the predictable corollary that the youngest children would seem to be more affected by their handicapped sibling. Over all, 15 per cent of the 430 siblings in his series were said to be adversely affected. Fear of physical attack was expressed by 24 siblings, and resentment of the parents' attention to the handicapped child by 18. The stigma of mental handicap caused 6 siblings to feel ashamed, and 9 others were over-burdened with domestic chores.* In another study, siblings of chronically ill children were reportedly unable to enjoy family outings and holidays.[65]

Fowle found significant differences in adjustment between siblings of retarded children cared for at home and siblings of similar children placed in an institution. It was found that older sisters were particularly likely to benefit from the handicapped child's absence.[23] However, if a subnormal child is placed in an institution early, so that he is never known to his brothers and sisters, the latter are not invariably spared from psychological disturbance.[64]

Other authors have not found any increased incidence of emotional disturbance among the siblings of subnormal children.[10,32] In these studies, the siblings from stable homes showed strong identification with parental attitudes and decisions regarding the handicapped child in the family. There was no support for the common fear that the presence of a handicapped child would lessen the siblings' chances of marriage. Gath concludes

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* K S Holt, *The impact of mentally retarded children on their families*, MD Thesis, University of Manchester, 1957.

> 'These studies suggest that the effects of a subnormal child on siblings may be mediated through the parents. If they have been able to adjust to the situation and cope with the practical realities, the other children are unlikely to suffer untoward effects.' [26]

Methodological problems

It will have become clear from the foregoing that the results of many studies should be interpreted with caution, because of the presence of one or more methodological defects. There are seven major problems to which I should like to draw attention.

1 A common deficiency is the lack of a control group, either from the 'normal' population or from the population containing other types of illnesses (chronic or acute). The absence of a control group often makes the interpretation of findings extremely difficult. One study, for instance, gives a frequency for parental quarrelling of 6 per cent.* As Gath points out, this is probably no different from that expected in a normal population[26]; certainly without such information the frequency is meaningless.

2 There is a failure to distinguish between two analytically distinct aspects of the impact or burden of the child's chronic illness–the 'objective' and the 'subjective'. Mizruchi puts the difference thus

> 'By *objective* we mean concrete behaviour clearly observable by both the member of the group and the outside observer. The objective sphere of action includes what people *do.* The *subjective* sphere, on the other hand, involves mental states and feelings.' [56]

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*K S Holt, *The impact of mentally retarded children on their families,* MD Thesis, University of Manchester, 1957.

For many families the objective impact of illness—for example, change in leisure patterns, fall in standard of living, tension in the household—and the subjective distress caused by these changes and, more directly, the patient's behaviour are not equally burdensome.[41] For the purposes of understanding family reactions and planning the types of social provisions which are most useful, the research instrument which puts into operation the concept of burden should consider separately the realm of facts and the realm of feelings.

3 No attempt is made to ensure that the respondent's report is valid and reliable. Reports about 'objective' data (see problem 2, above) are subject to considerable bias and distortion, and checks are necessary by using different research techniques and instruments, and by obtaining a number of corroborating reports from independent sources.* This point is especially important, since most data are generated from reports by respondents, rather than as a result of the investigator's direct observation.

4 The emphasis on securing reports from the child's mother, rather than his father, could be misplaced. There is some research evidence that the father may be the more reliable informant.[77]

5 It is often assumed by the investigator that visible family problems are caused by the child's chronic illness. However, it is possible that the problems predate the child's birth, hence the necessity to establish the time sequence of events very carefully. Or it may be that family problems are related to factors other than, or in addition to, the child's illness, hence the need to control for other serious concurrent events which might influence family burden (subjective or objective).

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*Stephen D Platt in a paper presented to the British Sociological Association Medical Sociology Group Annual Conference, University of Warwick, September 1977.

6 Studies concentrate almost exclusively on the possible negative aspects of chronic disease. However, there is some evidence (as from the work of Stevens on the dependence of chronic schizophrenics on elderly relatives) that there are advantages as well as disadvantages to the relationship for both patient and relative.[67]

7 What is the 'meaning' of the illness for the family? Meaning can be considered in terms of the interpretation or definition of the illness given by the family (subjective meaning), and in terms of the context of situational and structural factors in which the disease is located–for example, whether outside support is available, financial status and housing conditions (objective meaning). The differential meaning of the child's illness (in subjective and objective terms) has to be considered in order to ensure that categories have a sociological as well as a medical basis. To take an example, while a group of children with a similar degree of physical impairment from polio are comparable in medical terms, they are to be considered a near-group or non-group if the objective and subjective meaning of the illness is unduly discrepant among the children's parents. The possibility of a differential meaning of a disease should be taken into account when looking at the alleged causal relationship between the child's disease (independent variable) and problems in the family (the dependent variable). It is quite possible that the objective extent of handicap as perceived by medical personnel may be relatively unimportant for an understanding of the parental reaction in comparison with the family's definition of the situation and the way in which the situation is objectively structured.

8

A view from the USA

GEORGE L MADDOX

I have been reflecting on the saying that the Americans and the British are two peoples separated by a common language. At this seminar I have felt that we have similar problems. The difference is in the ways we organise our lives, our communities and our medicine. For example, in the UK many of the problems I have heard presented seem to be potentially solvable by money; but I see few significant problems of health and welfare in the USA which could be solved by money because most of our problems are essentially organisational at heart. In the USA we like to talk about money when we should be talking about organisation.

Although the title of the seminar is 'Management of chronic illness', I prefer to talk about the management of chronically ill people. We have been saying for years, in the USA, that medical schools have a perverse tendency to refer not to people but to categories. So the title was a little unnerving to me. Indeed, much of our discussion in the seminar has been about the managers of the chronically ill, not so much about the people being managed.

Older people and chronic illness

When we talk about the chronically ill we very often mean older people. That is not a contradiction. Chronically ill people are not by definition old, but there is a high probability that many of them are. Yet there is a danger in generalising; when you have seen one older person or one chronically ill person, you have not seen them all. There is enormous variation, even in later life. We have heard that people over 75 do not have the same problems as those who are 65–70. In the USA we have included a third group, the 'young-old' 55–65s. If we do not take a close look at this group, we are probably missing a real opportunity to understand chronic illness and the potential of programmes stressing prevention and early intervention.

There is another point which needs further emphasis. Those of us at this seminar are medically or service-oriented and we deal with many older people; but they are a very small fraction of the older population. The great majority live at home, in health, and will spend the rest of their lives there. In the USA, we had this in mind when we were arguing about creating a National Institute on Aging as one of our National Institutes of Health. We tend to associate age with disease; age may be correlated with disease, but it is not a disease in itself. Aging is a normal process. So we decided that a National Institute on Aging might bring a breath of fresh air into our National Institutes of Health by introducing a normative concern and not just a pathological one, and an interest in behavioural sciences which had been neglected over the years.

We have a lot of evidence from longitudinal studies that disabled people often show improvement in functioning—sometimes spontaneously, sometimes in response to intervention. We now take the position at Duke University that no one in our clinics shall assume that age automatically accounts for disability. Our research has established a basis for therapeutic optimism, and this is important for later life.

Environment

People do not change their life styles just with the passing of the years. One of our students recently presented a dissertation trying to explain why some impaired people go to institutions while others, similarly impaired, are maintained in the community. He found it had to do with what he called 'family ideology'—

the perceptions of family responsibility compared with public responsibility. Those who went to institutions had been doing so all their lives in times of sickness, not simply as a matter of economic necessity but of preference. They had been 'trained' to turn to the public services rather than to their kin or friends.

The more limited a person's resources, the more his environment matters. We know that culture in the broad sense—the structure of our society and its institutions—is a social construction of reality. So we see many different health systems throughout the world, with many different ways of paying physicians, different doctor-patient ratios, different hospital bed-population ratios, and so on.

Nature seems to tolerate considerable variation in our environment or in the health services that we create. Keeping this in mind, how have we chosen to structure the environment in which we offer services to people? None of us seemed to want to make prescriptions about how to do it. Sometimes we structure our services in such a way that we assume that only those services which are publicly provided are really going to matter. But, as the Danes have discovered, there then arises a fear that bureaucratic interests will assume responsibilities historically assumed by families. Public policy, however well meaning, can have unforeseen consequences. In the USA, and indeed in many Western societies, we are increasingly concerned about this.

Evaluation

So, as we talk about various schemes for organising care, remembering that nature can tolerate great variation, we also have to ask how we are to evaluate the alternatives. I offer six basic considerations.

Capability

What is the system capable of handling? When we created our geriatric screening clinic at Duke University, our first questions concerned the number and kinds of personnel and what their training should be. We found we could not answer these without establishing what was likely to be presented. We knew that older people typically present with multiple problems. It is not common to see a single impairment, nor does it stay that way for long. For example, we almost never find a mental health problem in an older person without some relationship to a physical health problem. So we decided we would never have a psychiatrist in our clinic without having an internist there, too.

Access

We talk a lot about the 'consumers' who have access to the care system, and we forget about the barriers that keep people away. Both here in Britain and in the USA, once a service gets a client, it tends never to let him go! But what about the ones we do not see; are they more seriously handicapped than the ones we see?

Performance

Are we getting value for money or not? I find that, while in the USA we talk about this constantly, we never come up with particularly convincing answers. By contrast, the Briton almost never raises the question. There is no simple answer, but the prudent will keep asking the question, recognising that the chosen ways of organising services have alternatives—possibly better ones. The question is not a simple-minded attempt to reduce everything to dollars or pounds. Every time we commit a dollar to one service or a part of the service, we are choosing not to commit that dollar somewhere else. We work with impaired people of various kinds.

So we must ask, what is the outcome of our work, our intervention? Is it the outcome we intend and want?

Many of us in the seminar have asked if the medical model is the right way to work with the problems presented by older patients. If one has X amount of money, does it go to medically related services or should it go to some other kind of service? Should it be spent on supporting volunteer services or on some new equipment in the clinic? A few years ago it was pointed out in the USA that if one really wanted to reduce mortality, money should be put into preventing accidents not into teaching new medical students. These considerations remind us that there are 'opportunity costs' in our choices, and may help us to think through where our resources should be going.

Satisfaction

It is not only important to examine the satisfaction of the recipients of a service and of those who refer clients to it, but also that of the providers. If they are not enthusiastic about coming to work, what sort of a system do we have?

Training

I was impressed to hear so much discussion about whether working with older people requires specialisation, and, if so, what kind? These issues are far from being resolved in the USA. A phrase I have heard at this seminar, and which I think would be congenial for the American setting, is 'a doctor in family medicine with a responsibility for geriatric care'. I do not expect to see any substantial increase in geriatric specialisation in the USA in the near future, though it is happening in social work and the behavioural sciences. We are seeing more interest in training for family medicine, which, in itself, is becoming a specialty. In Britain, as I see it, there are relatively few places where research, training and service are merging to explore alternatives, to seek the specific information required, and to be concerned with relating inputs to outputs. It is difficult to bring research into a setting that is primarily for service, but it is possible and very desirable.

Self-help

Someone remarked in the seminar that there are many vigorous people in their late 50s and 60s who may suffer later through ignorance about their health and how to maintain it. Self-help and self-education are important issues in the USA at the present time. We do not know the limits of self-help, but it seems clear that we need to introduce these ideas. My colleague, Marvin Sussman, is beginning to ask questions in his studies about those people who assume or are willing to assume responsibility for a dependent older person. Everyone suggests that alternatives to institutional care are necessary, but this implies more care by the family. Support systems for the elderly, and for those who care for them, will be needed, similar to the services already established for children.

Leadership

On a final note, I am convinced that there is nothing to replace good leadership. Good services deteriorate through the loss of the leader. Where in our training do we make provision for developing the quality of leadership? I know that in the UK at least, the King's Fund has placed special emphasis on the notion that leadership is not just happenstance! It is indeed essential, whether we are talking about medical services, health services generally, or social services.

These are my reactions to the proceedings of the seminar and I leave them with you in continuing discussion.

9

The challenge of chronic illness: retrospect

PETER H MILLARD and MARK McCARTHY

The individual and his social networks

Throughout the seminar, we continually came back to the needs of the individual, and the importance and difficulties of his participation in making the decisions about his treatment and welfare. He has to know what resources are available to be able to make rational judgments. Our failure to provide this knowledge is one of the factors which have led to the growth of patients' organisations—over 200 are known to the King's Fund.

Day-to-day support for the chronically sick individual is provided mainly within a family network, by untrained people, without the knowledge or assistance of the so-called 'caring agencies'. In times of crisis, when their assistance is asked for, what is provided is mainly institutionally based and often inappropriate.

Levels of dependency vary, but we are all interdependent. The question is, therefore, what degree of dependency can the family network tolerate? It is, so far, an unidentifiable quantity, different for each individual. For example, correct gadgets and adaptations can help relieve physical dependency, and the proper use and provision of these requires a professional team. Co-ordination of social, nursing and voluntary services required for the individual should be the responsibility of the primary care team.

Planning must ensure that full use is made of the willingness and capability of the family and the neighbours to provide support.

We should find out why these supporting networks work in some parts of the country and among some groups and not in others.

Legislation may lead us to think that dependency is not a problem for us all, but only for the state services. Too much interference with the network of voluntary, community and family support may lead to its collapse—and if that happens, the already hard-pressed institutions would probably collapse as well.

Teamwork and boundaries between professional groups

Specialisation has led to a multiplicity of different professional agencies, each with its own skills, jargon, hierarchy and professional jealousies. Yet it is from these separate agencies that we must develop teams in order to care for chronically ill people, for chronic illness has a multiple nature. In addition, the management structure of many of our services seems to hamper progress, yet the first purpose of management is to create the conditions for good people to do the job. Different countries try different approaches, and each system has its faults. The present structure in the UK is unduly complex, for example. Comparative studies of methods of delivering health care, both inter- and intranationally, might help each country to improve its own system.

A more balanced provision of resources is needed. We provide too little for the management of chronic illness. But no advantage would be gained from attempts to redistribute resources if that led to deterioration of services for diagnosis and treatment of acute illness. For that, in turn, could create even greater problems in coping with chronic illness in the future.

There is also the unresolved issue of separating acute diagnostic and treatment services from the longer term services. There are advocates for and against separation, and advantages and disadvantages. The development of services in isolation enables attention to be focused on a particular need. Study of service requirements can be coordinated and new techniques developed. But the isolated system comes to be considered as the 'correct' and therefore 'only' way, and further isolated systems may be created which do not have the success of the original innovator. To encourage isolation of any type of service may be to create further problems for future generations.

Education of health care workers is essential. But professionalism may lead to problems of status: what one professional group regards as not its duty is pushed on to a group lower down the hierarchy, and perhaps not done so well. There is also a danger of demarcation disputes between professions. If professional demarcation were less distinct, staff would be more ready to carry out all aspects of the job. This happens when a family looks after its sick member, but it is difficult in the present structure of our institutional services. The end result of over-specialisation is the development of groups of staff who cannot do the work they should be doing because they are not properly prepared for it. This leads to frustration and disappointment.

Each professional group develops its own jargon which enables its members to demonstrate that they have a body of knowledge which makes them different from all other professional groups. This makes it difficult for professional groups to communicate, either with each other or with the sick individual and the members of the family–neighbour support network.

Staff rewards, goals and education

We need to give more thought to methods of monitoring staff rewards and goals. How are staff motivated to work with the chronically disabled when they have been mainly educated to see their success and status measured in terms of the treatment and management of acute illness? The knowledge bases for the prevention, diagnosis, management and treatment of chronic disability must be better identified. The treatment base will undoubtedly fail without the others. There is widespread ignorance of the intellectual challenge of dealing with chronic illness. Failure to rotate staff between the acute and chronic services in hospitals has been identified as one of the causes of poor recruitment. Inferior facilities and isolation are, of course, other factors.

'Litigious paralysis' may inhibit change. Nurses are taught to be the guardians of the sick and to be responsible for what happens. They must not be blamed if accidents happen when they are following a policy of encouraging independence. Institutional fear of litigation may well be a cause of the over-protectiveness which inhibits the individual from achieving his full potential.

Fundamental to a balanced approach is a basic knowledge, available, disseminated and discussed by everyone involved. More attention must be given to the continuing education of members of health care teams, particularly in the exchange of their knowledge. Multidisciplinary teams require good leadership, perhaps more so than single discipline teams. And we believe that leadership qualities can be taught.

Priorities for the future

Many chronic illnesses are diseases of premature mortality and morbidity, much of which is preventable. Reduction in smoking would reduce the incidence of respiratory and vascular disease. Excessive alcohol consumption leads to medical and social disability. Early attempts to treat hypertension could affect the incidence of stroke. Better prevention of accidents would reduce the number of severe head injuries and fractures. Better support for families would help prevent rejection of the chronically ill and their eventual long-term institutionalisation. These are some pointers for the future.

Early, optimistic rehabilitation, with accurate medical and social diagnosis by enthusiastic teams, reduces long-term disability. No team, however good, can work without facilities. Better equipped departments for rehabilitation, and adequate numbers of beds allocated to departments of geriatric medicine in the acute hospitals, would help to reduce the need for long-term care. This, in turn, would enable some of the resources now required for long-term care to be diverted to short-term relief.

Whatever plans we make, or indeed carry out, medical care is going to be associated increasingly with the problems of managing large numbers of people with chronic disability. This is the challenge which we shall have to face.

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