Contemporary Themes

Geriatric medicine and disabled living

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Despite the established status of British geriatric medicine, questions are still asked concerning its *raison d'être* and real responsibilities. This was so at the outset: ideas expressed by Warren,¹ Howell,² and Sheldon³ differed, for example, in their emphasis on hospital care, the medicine of old age, and the sociology of the disabled elderly. Thomson⁴ and many others believed that problems of aging and chronic sickness were properly the domain of general physicians. Notwithstanding its commitment to understanding the aging process and the illnesses of very late life, the geriatric specialty has largely been grafted on to a State-run service of long-term institutional or hospital care dating from at least a century and a half ago. It is therefore scarcely surprising that colleagues in the NHS and the general public alike continue to see care of the irremediably sick as an important function of any geriatric department.

Committal to "continuing care"

Yet where is the emphasis in most current British geriatric publications? The many textbooks on the subject mainly adopt a traditional approach to describing diseases, their diagnosis, and their immediate management. Naturally enough much is made of the scope for treatment, remedial therapy, and rehabilitation, and to a varying degree different geriatric departments have taken a bite out of the "acute" hospital services (usually on an age-related basis) with a consequent and gratifying increase in turnover. Geriatrics has also moved into clinical science, emulating the practice of academic departments of medicine, and Anderson⁵ and others have argued the case for preventive medicine, urging that so many of the perplexing adversities of old age need not occur if appropriate action is taken in time. "Success" is often measured in terms of discharge from hospital even though it is known that the performances of different departments depend not only on their facilities and declared objectives but also on external resources and constraints—in psychiatry, general medicine, and the social services particularly, and in the private and voluntary sector.

The British Geriatrics Society defines the specialty as concerned with the clinical, social, preventive, and remedial aspects of disease in the elderly. Despite the comprehensive nature of this concept there is an evident risk that the role of medicine in helping to support irremediable disease may be overlooked. No matter how good medical practice may become, eventually many people will be inconveniently ill and disabled for a while before they die.⁶ Moreover, the better the medicine, the more probably these terminal events will take place in extreme old age with its attendant likelihood of sensory and intellectual as well as physical failure. There is no indication at present that Alzheimer's

disease can be arrested or strokes abolished, to name the two conditions that cause the most severe dependency among the old. The need to understand the problems of support and continuing care is therefore as great as ever.

It is often argued (see, for instance, Swales⁷) that such matters are beyond the responsibility of doctors and presumably belong to social work. Equally, other professions often see doctors as authoritarian and ill-informed, sometimes doing more harm than good in their approach to and management of the disabled at any age. Yet social work training is not concerned with the assessment of physical or mental capability, and such matters as incontinence, paralysis, or defects of communication are not, in the first place, social problems. Nurses and remedial therapists capably manage many if not most of the problems of disabled living but, if only by tradition, they are not granted the responsibility for the entire well-being of a patient or a community, which is the medical profession's prerogative. Indeed, no general practitioner can avoid considerable involvement with disabling disease, although it may be argued how far that involvement should go. For all these reasons doctors do need to understand and be committed to "continuing care"; the weight of British medical tradition is that they shall, and their failure to do so is often the cause of public rebuke.

Long-term care

A climate of opinion, however, all too often exists in which long-term care appears unpalatable. Persistent or progressive illness that cannot be cured or even ameliorated is depressing for everyone concerned, and there is no better description of this predicament in the institutional setting than that of Miller and Gwynne.⁸ Yet many aspects of medicine are equally discouraging in their outcome without sharing the opprobrium that seems to accompany medical support of the disabled and elderly. Other explanations therefore have to be sought, of which one of the most obvious is the hospital-orientated nature of medical education. Continuing care is perceived mainly as hospital or residential care, and it does not help that what is encountered is derived from (or all too often actually is) the nineteenth-century workhouse, inappropriate in size and location and parsimoniously staffed. Enlightened administration, structural upgrading, and medical emphasis on rehabilitation and turnover are rarely sufficient to eradicate the image, often only serving to confirm that successful treatment is "good" and continuing care is "bad."

In reality, for every disabled person cared for in Britain in a hospital or other institution there are two or three with comparable disabilities in private households.⁹ Long-term or "extended" care¹⁰ is therefore a continuum to which institutions contribute only a part; it includes families, the informal sector (neighbours and friends), the organised voluntary sector, and the paid statutory services. Much has been written about all these aspects of community care, but relatively little in relation

to the actual disabilities from which people suffer: there is a potentially large and important body of knowledge to be accumulated and taught in order to answer very many practical questions. For example, is the home-help service adequate for a solitary widow with paralysis due to stroke? How may the informal sector best be concerned in managing middle-stage Alzheimer dementia? What are the family stresses to be expected when the household includes an elderly person who is severely deaf? The best title for such a discipline might be "disabled living"; in the past two decades the concept of disability has virtually replaced the unfortunate term "chronic sick" and, despite a popular view to the contrary,¹¹ two-thirds or more of all disabled people are past retirement age.

The discipline would include everything that is familiar in rehabilitation but would go further. Special attention would be paid to the psychological and social consequence of being disabled. These include altered prospects and life expectancy; ordinary wants that have become hard to obtain—freedom of decision and action, opportunities for privacy, social contact, occupation, recreation, and affection; the right to retain possessions; the need for help with mobility and transport. In respect of the elderly disabled there should be some concept of the aspirations, fears, and preoccupations characteristic of very late life. More knowledge is needed about the potentialities and limits of supporting the mentally impaired in private households: surveillance teams and systems, time switches and time displays, safe heating, fail-safe cooking appliances, audible and visible reminders—these are some possibilities from a rather thinly explored subject. Overall there is clearly much in this programme that is shared by the specialty of mental handicap, itself scarcely included in mainstream medical education. There are parallels too with the hospice movement, which has brought care of the dying from the realm of the unmentionable to the status of a respected discipline.

Impact of disabled living on families

Equally important is the impact of disabled living on families and informal supporters, and the relation of this impact to the demand for institutional care. All primary care workers know the great range in willingness and ability to support comparably disabled people that may be found in any community. As Goffman¹² observed in relation to mental illness in the United States, hospital bed occupancy is not determined by objective medical need so much as by contingencies, which include withdrawal of informal and family support for a whole variety of reasons. Since 1948 families in Britain have had no legal responsibility to their dependent adult relations. Nor are there guidelines for social workers, doctors, and others who are called in to help, who very often find themselves having to advise, persuade, cajole, or even oblige families to change their preferred plans of action if only because resources do not allow otherwise. Arie¹³ has described this as "micro-rationing," in contrast to the macro-rationing of politicians, administrators, and planners, and a large variety of difficult questions constantly has to be resolved. What should families and informal helpers reasonably be expected to cope with? What disabilities and circumstances should be considered too much for them? Are the judgments made in these matters consistent with available resources and overall priorities? The data collected by Sanford¹⁴ show how a collective view on these and similar matters could gradually be established. Other questions include the importance of first-degree and more remote kinship, and of personal relations before the onset of disability; the health or otherwise of available supporters; and the space and facilities offered by a household's accommodation. Experienced workers know that often it is supporters who are requesting or needing help, not the dependent people themselves. The dismissive, frequently used expression "can no longer live at home" covers an almost infinite variety of circumstances and judgments; the whole issue of family and informal support is central to the demand

and apparent need for services, both community based and institutional, yet there has been little assessment of how the various factors interact and how they differ in importance.

Understanding of institutional care

A fourth aspect of disabled living is an understanding of institutional care. By tradition consultants have become responsible for long-term residence in hospital yet they rarely have any formal instruction on the subject. True, in time they learn something from experience; doctors who refer for institutional care usually know nothing about it at all. What information is there about staffing requirements, timetabling, building location and layout, humane and satisfying groupings by age, sex, and nature and severity of disablement? Should long stay in hospital automatically mean segregation from the main stream of hospital activity? How effective is a regular short-term admission programme, and what problems may arise from it? Is disturbed behaviour necessarily intolerable in a well-run home or ward? Geriatricians can be criticised for ignoring their long-stay patients (H K Evers, unpublished observations) and the 1977 report of the Royal College of Physicians¹⁵ on the care of the elderly went so far as to describe long-stay patients as disruptive. At the very least a deeper realisation of the issues would help.

So, although the support and understanding of disabled living are certainly not for doctors alone, the medical profession has a contribution to make based on a knowledge of the disabling effects and prognosis of disease and the consequences for disabled people and their supporters, and on whatever medical responsibility there may be for residential care. Moreover, in keeping their disabled patients under review by whatever system seems most appropriate, physicians may monitor changes in condition or circumstances, ensure correct intervention when needed, and satisfy themselves that appropriate resources are being used. Many general practitioners visit their dependent patients regularly and specialist follow-up is a tradition of hospital outpatient clinics. No new concepts are therefore indicated except the recognition and definition of medical responsibility and, since disabled living means restricted mobility and a home-based life style, the frequent need for peripatetic follow-up by secondary-care teams in private households and residential homes (as suggested by Townsend¹⁶). A further aspect is the medical planning and advisory role, especially perhaps in relation to those diseases in which disability becomes progressively more severe.

Deficiencies of medical education

Skills of this kind may be, and no doubt usually are, practised by every clinician when necessary, but examples of neglect are all too frequent, and many of them can be attributed to the deficiencies of medical education. British academic departments of geriatric medicine are doing much to put matters right but the overt or implied reservation remains that geriatrics is mainly about something else. A further and much-argued problem is the bar between hospital medicine and psychiatry: the training in medicine and nursing for the two specialties is quite distinct, and doctors find it nearly impossible to obtain a double qualification. Yet among the disabled generally, and especially among the elderly, mental and physical disabilities are not at all distinct, and the mental impairment displayed is often justifiably considered to need neither hospital medical nor psychiatric management as orthodoxly conceived. Here is still another difficulty created not so much by the nature of the demand as by the rigidity of response imposed by medical training.

Conversely the link between a disabled living service and the emergency medical care of sick old people, now well established in geriatric departments, appropriately reflects the fact that so many old people are both disabled and acutely ill at the same time, besides allowing these departments to decide their own

priorities between emergency and longer-term care. All too often, however, if only because of weight of numbers, the link leads to disregard of the long-term patients and a blind eye to problems that may arise after discharge from hospital. If geriatrics is to be linked with general medicine the same risk will arise. The right reason for any link along these lines is not because continuing care is professionally unsatisfying, but because disabled living is of fundamental importance to clinical practice.

In summary, medical training has to take serious account of the problems of disabled living, and in the process new types of initiative may be needed. The profession should make a more realistic contribution than has been usual and may have to rethink the allocation of responsibility among different specialties. Geriatric medicine has greater responsibility than most but disabled living is not confined to old people, and geriatrics has other important and legitimate concerns. Since in different ways disability is encountered by nearly every practitioner, the time to learn about it is during undergraduate education.

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Couples facing death

II—Unsatisfactory communication

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Abstract

Forty-one couples facing the prospect of separation by death were interviewed about how the nature and prognosis of their illness had been discussed with them by their general practitioner hospital staff, and the staff of the continuing care unit to which they were admitted. Communication between husband and wife and how they coped with telling their parents and their children was also assessed. Treatment was given when they were anxious or dissatisfied about the quality of communication in any of these areas.

The couples found hospital doctors least successful at communication. Almost all who were dissatisfied wanted more information, not less. The wish to protect dependent relatives conflicted with the wish to be open, making decisions very difficult. Considerable suffering is caused by poor communication, and much of this is avoidable.

Introduction

When a patient visits a doctor with a complaint that could be the first symptom of serious illness both begin negotiations about what to ask and what to tell. Concurrently decisions are made, either actively or by default, about who else shall be informed. This issue of communication is so important to

patient and family that a detailed study was made of it with the 41 couples described in the previous paper.¹ The sample comprised all married patients under 40 and a random selection of other married patients admitted to a continuing care unit over a period of 18 months. All but one had cancer.

Method

Patient and spouse were interviewed separately and asked to give a detailed account from the onset of what was said to them about the illness and how they felt. They were questioned separately about their general practitioner (and others helping in home care), hospital staff before admission to the unit, and staff in the unit. Overall satisfaction or dissatisfaction was recorded only if the attitude expressed could be substantiated by at least one example or incident illustrating why the interviewee felt as he did. Those who could not do this, or whose impressions were mixed, were rated as "uncertain/mixed."

An assessment was made of how much each partner knew, how much they had shared, and whether they were content with the level of understanding they had reached together about the illness.

They were also asked about attitudes to telling parents, children, and other close relatives. In each instance where this issue was a source of anxiety or distress it was recorded as a problem and explored further in individual, conjoint, or family interviews as seemed appropriate.

Results

Tables I to IV show the views expressed about communication in the various areas by patients and their partners. Where husband and wife both held the same opinion this was noted in the third column headed "couple."

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