

Chronic disease or physical disability? The role of the general practitioner

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SUMMARY. *There has been a lack of discussion and consensus as to what the role of the general practitioner should be in the care of patients with chronic diseases. Should general practitioners concentrate on the disease or should their remit include the resultant disability and handicap? General practitioners have tended to concentrate on the disease, but this may be inappropriate. For many disabled people, their general practitioner is their only source of health care and is the gatekeeper to other services. Greater knowledge among doctors of the functional and social aspects of disease would therefore improve the quality of care for patients, and should be assessed through clinical audit. Ways are described in which general practitioners, working together with their patients with chronic diseases and with other health professionals, can improve aspects of the care of these patients.*

Keywords: *chronic disease; physically handicapped; long-term care; attitude to health; social factors; health care models.*

Introduction

THE terms chronic disease and physical disability conjure up very different images to doctors. Chronic disease suggests the medical control of long-term diseases, such as asthma or diabetes, whereas physical disability suggests severe mobility problems. Yet the two terms are different ways of describing the problems experienced by one patient. When general practitioners are consulted by patients with asthma, for example, to what extent should they be concentrating on ensuring the patients are receiving the best medication and that their peak flow rates are satisfactory, and to what extent should they be thinking about how the patients' lives are affected, and how they are functioning?

The management of chronic incurable diseases has always been an important part of the work of the general practitioner, but three separate pieces of government legislation in the last six years have highlighted this. First, the government introduced and then revised health promotion bandings, so that for the first time general practitioners were financially rewarded for providing structured, organized care for patients with chronic diseases such as asthma and diabetes. Secondly, the division between purchasers and providers in the health service, and the development of general practitioner fundholding has led to discussion of the relative roles of general practitioners and hospital specialists in the care of patients with chronic diseases. Thirdly, with the National Health Service and community care act 1990, the government has emphasized the need for structured assessment of the needs of disabled people requiring care. This requires co-

operation between general practitioners and social workers, who represent different medical and social views of disability.

Despite all these changes, there appears to be little debate or consensus about the fundamental role of the general practitioner in caring for people with long-term health problems. Psychological factors are of great importance in this area, and it is known that people with chronic illness have high levels of depression and that general practitioners are poor at recognizing this.¹ However, this discussion paper concentrates on social and functional effects in relation to people with physical problems, although the issues also apply to people with chronic psychiatric illnesses and learning disability.

Definition of disease

A systematic approach to thinking about definitions of disease and the consequences of disease was first developed by Wood in 1980,² and this has subsequently been adopted by the World Health Organization. A disease and its consequences can be represented as a sequence:

Disease or disorder → impairment → disability → handicap

Impairment is defined as 'any loss or abnormality of psychological, physiological, or anatomical structure or function'. Disability is 'any restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being', and handicap is 'the disadvantage for a given individual, arising out of impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual'. Thus, disability means reduced function, whereas handicap is the consequent social disadvantage.

The benefit of such a taxonomy is that it enables one to look at a person's problem at different levels, and to view patients both in terms of their disease and their environment. However, there is not a linear relationship between impairment, disability and handicap. As Johnston points out, it is impossible to make simple predictions of the degree of disability or handicap from knowledge of the impairment alone.³ The patient's coping strategy, skills, occupation, and social and physical environment all play a part. For example, facial scarring may lead to no changes in the behaviour of one individual while another may become housebound for fear of other people's reactions. The lack of correlation between impairment, disability and handicap has been demonstrated systematically in several studies, including those of patients with multiple sclerosis⁴ and chronic respiratory disease.⁵

Size of the problem

The Royal College of Physicians summarized several prevalence studies and found that in a typical group practice of 10 000 patients, there would be between 600 and 1100 physically disabled adults, of whom a quarter would be severely disabled.⁶ A total of 72 patients would be regularly using wheelchairs, 1000 would have impaired hearing, and 52 would have severely impaired vision despite glasses. There would be between 1280 and 2900 people with osteoarthritis, between 100 and 250 with rheumatoid arthritis, 700 with coronary heart disease, 55 who had had a stroke, eight with multiple sclerosis, 50 with epilepsy,

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200 with diabetes and 500 with current asthma. Clearly this represents a major management task in terms of medical treatment of the diseases, without considering consequent disabilities.

Furthermore, not surprisingly, disabled people see more of their general practitioners than do the population in general. Thus, a survey carried out by the Office of Population Censuses and Surveys in 1988 found that 82% of disabled adults and 90% of severely disabled adults had seen their general practitioners in the last year compared with 72% of the general population.⁷ Whereas for the general population the mean number of contacts with their general practitioners was 2.9 in the last year,⁸ for mildly disabled adults it was 5.2 and for severely disabled adults it was 10.1.⁷ The fact that everybody has a general practitioner, and that he or she is usually the gatekeeper to other services, is also of importance. Several studies have shown that for most disabled people the general practitioner is their main, and often only, source of care.^{7,9} The 1988 survey showed that the proportion of disabled adults who had seen different health and social services professionals in the last year were: general practitioner 82%, hospital doctor 46%, district nurse 16%, health visitor 7%, physiotherapist 10%, occupational therapist 3%, and social worker 7%.⁷

Models of chronic disease

We have seen that the same person with the same illness can be considered in different ways and I find it useful to describe these as different models.

Medical model

The medical model is the traditional model that doctors are taught at medical school. In this the disease is seen as paramount, and it is assumed that the similarities between people with the same disease are far greater than the differences between them as individuals. Thus, people may be described as 'diabetics' or 'epileptics'. A standard protocol can be produced for caring for people with the same disease, and the outcome of care can be measured.

There are many problems with this model. The patient is not seen as an individual, and the disease is concentrated on rather than the disability or handicap. It is often inappropriate in general practice, where many consultations do not involve a specific disease and no diagnosis is made.¹⁰ In this model the patient is seen as dependent on the doctor and patient autonomy is discouraged.¹¹

The more severely the person's quality of life is affected by the disease, the more need there is to concentrate on issues other than the disease. Thus, for the person with diabetes and no complications, it may be appropriate to concentrate on good blood sugar control and the prevention of complications, but for the person with diabetes who has become blind and has gangrenous toes, there are other important considerations.

Clearly, an important issue is the effectiveness of therapy. If, as in asthma, there are effective therapies, then an important part of good medical care involves good therapeutics, in order to eliminate or minimize any disability. However, there are people with asthma who are severely disabled, despite use of all the latest medications. For many other conditions, such as osteoarthritis or multiple sclerosis, medical interventions can do little to prevent the course of the disease and the resultant disability and handicap. Moreover, many people with severe disabilities, such as blindness or paraplegia, do not suffer from any continuing disease process, and hence a medical model is particularly inappropriate in their care.

Functional model

In the functional model the emphasis is not on the disease but on

how someone copes with their activities of daily living. For example, somebody who has had a stroke will be assessed for their ability to walk, dress and feed themselves and so on. This will often be carried out by a team of occupational and speech therapists, physiotherapists and social workers, rather than by a doctor. Therapy will be aimed at improving these functional abilities, by exercises, providing aids and altering the home environment. This model is essentially looking at disability, and is person rather than disease oriented. However, as with the medical model, there is a tendency for it to encourage patient dependency rather than autonomy as the patient's view is rarely sought.¹¹

Although the functional approach has been most widely used for people with locomotor disorders, it can be useful in all chronic conditions, and can be applied by general practitioners in their normal consultations and incorporated into standard protocols. For example, Jones and colleagues have developed a morbidity index for patients with asthma, based on a patient's answers to three simple questions: 'Are you in a wheezy or asthmatic condition at least once a week?' 'Have you had time off work or school in the past year because of your asthma?' 'Do you suffer from attacks of wheezing during the night?'¹² The index can then be used to target care to those with the highest morbidity.¹³

Social model

In the social model the role of society is seen as of paramount importance, as described in the county of Avon's disability equality policy (1992): 'Disability is the disadvantage or restriction of activity caused by a contemporary social organization, which takes little or no account of people who have impairments, and thus excludes them from participation in the mainstream of social activity. Thus disability is not caused by the individual disabled person's impairments, but the way in which society fails to meet their needs.' The advantage of the social model is that it addresses the social consequences of disability. Townsend refers to the 'double burden of disability' where as well as suffering from the disability itself, disabled people and their families suffer financially and in other social ways.¹⁴ The other major advantage of the social model is that the views of the disabled person and carer are considered. Thus, in social work care planning, there is now a great emphasis on including the 'service user' in assessment and planning.

One of the fundamental aspects of this approach is the emphasis on the common goals of all disabled people, which Finkelstein has called 'the commonality of disability'.¹⁵ However, this approach has been criticized by others,¹⁶ who feel that if impairment is seen as less important than society's reactions and the facilities provided, this can lead to an oversimplification, where the needs of somebody with chronic schizophrenia or severe learning disability are seen as the same as those of somebody with paraplegia.

Such an approach, which emphasizes handicap almost to the exclusion of disease and impairment, has been largely adopted by social service departments for community care assessments. This can cause problems when these departments liaise with health workers as the latter are more familiar with using medical and functional models for assessment. Moreover, in some cases knowledge of a specific disease is important. For example, in planning future care for a person with a chronic neurological problem, it is essential to know whether the person has a rapidly progressive condition such as motor neurone disease, or a static condition such as having had a stroke.

Sociological model

The sociological model uses qualitative methods to examine such themes as the meaning of chronic illness and the experience of

illness. It provides valuable insights into patients' perspectives and their true concerns, which are so often missing from other models.

As well as coping with the practical problems of living with a chronic disease, patients are continually trying to find a meaning for their illness, and its fluctuations, and to answer the question 'why me?'¹⁷ Patients are faced with uncertainty, both in terms of planning for the future and in the day-to-day variability of symptoms in diseases such as asthma and rheumatoid arthritis. The onset of a chronic illness constitutes a 'biographical disruption', and patients have to think again about their past and future.¹⁸ People with chronic diseases often feel stigmatized¹⁹ and this sense of feeling different and abnormal is also felt by people with hidden disabilities such as epilepsy.²⁰

The sociological model is also concerned with the doctor-patient relationship. Many patients complain of communication problems and report that doctors fail to provide adequate information.²¹ A study of patients with parkinsons disease and their general practitioners found that many general practitioners had problems coping with the uncertainty of the illness and with not being able to give definite answers.²² They often responded to patients with non-disclosure of information or with unfounded optimism, and with detachment rather than empathy. Most of all, the patients and their carers seemed to value the general practitioner 'just being there with time to listen'.

Biopsychosocial model

The biopsychosocial model was developed by Engel²³ and McWhinney¹⁰ to explain the different levels at which a doctor can relate to any patient's problem. It was developed from general system theory,²⁴ which recognizes that all nature is organized as a hierarchy of systems and that living systems go from organelle to cell, to tissue, to organ, to organism (person), to family, to community, to society. Each level in the hierarchy is both a whole in itself and part of a greater whole.

Such an approach can be applied to chronic illness and the levels of disease, impairment, disability and handicap. The disease is operating at the cell and tissue levels, impairment at organ system level, disability at the person level, and handicap at family and community levels. This holistic approach recognizes the fact that doctors often need to look at the disease process and the effects of the illness simultaneously. As Wade says, 'Disability cannot be managed in isolation from the disease, any more than the disease should be managed without reference to the disability. It is for this reason that the [general practitioner] is so well placed to manage chronic diseases, for only he has sufficient knowledge to span the whole range of his patient's problems from pathology to handicap.'²⁵

General practitioners' role

While there is a consensus that general practitioners have a major role to play in the care of patients with chronic illness,²⁶ there is little agreement as to what that role should be. Should their role be mainly confined to the medical model or should they extend into the functional and social models, that is should they be concentrating on the disease, the disability or the handicap?

The lack of consensus about the general practitioner's role is reflected in the general practice textbook on the subject *Continuing care: the management of chronic disease*.²⁶ While initial chapters by a psychologist and a sociologist emphasize the psychological and social aspects of chronic illness, the chapters on the management of different chronic diseases vary greatly in their emphasis. Arthritis and chronic neurological diseases produce similar locomotor disabilities, but while the chapter on arthritis (written by a general practitioner) concentrates on the

medical model with emphasis on drug management and investigations, the chapter on neurological diseases (written by a neurologist) concentrates largely on functional issues.

The last five years have seen a proliferation of clinical audit, facilitated by medical audit advisory groups which each publish a newsletter several times a year with examples of local audit. One of the aims of clinical audit is to define the parameters of high quality care, and it is interesting to see how this is defined by general practitioners for chronic diseases, and whether social and functional parameters are included. I examined the Avon Medical Audit Advisory Group database of all audits published in medical audit advisory group newsletters from 1991 to 1994 and found that despite arthritis and chronic neurological diseases being the most common causes of severe disability,⁷ there were no audits of the care of patients with arthritis, and only one on the care of patients with chronic neurological disease (excluding epilepsy). This one audit looked specifically at social factors and unmet need. Of the eight audits of epilepsy care, only three looked at any social aspects, despite the known social and psychological consequences of this disease.²⁷ There were 46 audits of asthma care, of which 20 included some functional and social parameters. However, in 18 of the 20, these parameters were the three criteria used in Jones and colleagues morbidity index¹³ (wheezy in last week, night wheezing, and time off work or school) and only two audits looked at any other social effects.

Hasler, in his 1984 James Mackenzie lecture, describes the role of the general practitioner in caring for patients with chronic diseases as controlling the disease and providing well-planned care.²⁸ In contrast, the Royal College of Physicians views the general practitioner's role in much broader terms emphasizing the definition of the patients' problems in physical, psychological and social terms, the involvement of other members of the primary health care team, and the importance of being aware of facilities and sources of professional and voluntary help in the local area.⁶

If hospital doctors assume that general practitioners concentrate on functional, social and psychological assessments, whereas in reality general practitioners see their role as primarily disease management, this will cause major problems at the interface between primary and secondary care, particularly where a patient receives shared care. For example, if a patient with rheumatoid arthritis attends a hospital consultant, does the general practitioner assume all the patient's needs are being looked after by the hospital, or does the general practitioner feel he or she continues to have a role by concentrating on the psychosocial and functional aspects of the patient's care?

General practitioners' knowledge of disability and handicap

There are areas where it would appear essential, rather than merely desirable, that general practitioners should be aware of the functional and social aspects of their patients' conditions. This is particularly true in their role as adjudicator in the social security and welfare benefits system. For example, when assessing whether a patient is fit to work they must be aware of the disability that a person's illness is causing and match that to the patient's job.

There are many other occasions when general practitioners are called upon to make functional and social assessments of their patients with chronic disorders. For example, when completing an attendance allowance assessment form, general practitioners are asked to assess which of the following the patient can do by him or herself — rise from a chair, walk on the level indoors, get in and out of bed, dress and undress, attend to toilet needs, and where applicable transfer in and out of a wheelchair. It is as-

sumed that general practitioners know their patients sufficiently well to make all these assessments accurately without a specific home visit and examination, but is this true?

Despite the importance of this issue there is little research evidence as to general practitioners' knowledge of disability and handicap in their patients with chronic disorders, and in the few studies reported, the results have seldom been encouraging. An audit of patients with epilepsy in 30 general practices looked at doctors' and patients' perceptions of the disease and its management.²⁹ This revealed major differences, particularly in the effects epilepsy had on daily activities, such as work, social life, recreation and home life. For example, 98% of patients said that epilepsy interfered with home life whereas only 37% of general practitioners recognized this. Another study of patients with epilepsy also showed a low level of discussion of psychosocial issues, such as stigma and concealment, even though patients thought this important, and this situation was not significantly improved by personal continuity of general practitioner care.²⁷

In a questionnaire survey of disabled patients and their general practitioners, the general practitioners knew of only 50% of the patients' difficulties with daily living and 17% of the aids and appliances they were using.³⁰ This was despite the fact that they had seen 85% of these patients in the previous nine months and 25% in the previous fortnight. In contrast, Jones used an occupational therapist to carry out a functional survey of the 170 patients in his practice aged over 80 years, and found that the general practitioners were aware of the person's ability and agreed with the occupational therapist in 86% of functional measures of activities of daily living.³¹ He concluded that the general practitioners' knowledge of the functional ability of their patients was high, but it may be relevant that he worked in a small rural practice in Devon that had been making functional assessments for the previous decade.

Practical problems of assessments by general practitioners

Although it would appear necessary for general practitioners to assess their patients' needs in social and functional terms, there are major problems in the application of such a policy. Hospital consultants have access to a team of nurses, occupational therapists, physiotherapists and social workers who have all assessed the patient, but general practitioners usually see the patient alone, in their surgery for 10 minutes. However, the role of general practitioners is vital, first because they are the only health care professional that most people see, and secondly because they are the gatekeeper to other services from which their patients may benefit.

Much can be achieved in the normal general practice consultation, just by altering the emphasis and asking patients more functionally and socially oriented questions. This process can be helped by keeping a checklist in the patients' notes. In my practice a checklist has been used for people with epilepsy which includes occupation, driving status and fears for the future. The results have been audited and showed an improvement in discussion of these topics in consultations after the introduction of the checklist.³² Moreover, whereas time in a single consultation is short, general practitioners usually see patients with disabilities frequently and over several years. Home visits provide a useful opportunity to assess someone in his or her own environment and can sometimes give a very different perception of the patients' problems. Furthermore as general practitioners are family doctors, they may become aware of a patient's problems when seeing the patient's spouse and other relatives.

However, general practitioners will only operate effectively in this field if they work well with other members of the primary

health care team. District nurses and health visitors usually have much better training in making social and functional assessments than general practitioners, and use these assessments routinely. In an audit, in my practice, of physically disabled people aged under 60 years who were unable to work, I found that the general practitioners knew what benefits their patients were receiving in only 39% of cases, whereas the district nurse or health visitor knew in 66% of cases (unpublished results). Clearly general practitioners do not have to carry out all the assessments themselves, provided that they have ready access to the results. Good liaison and sharing of information is vital, both within the primary health care team and with other people working in the community such as physiotherapists, occupational therapists and social workers.

Since the introduction of the 1990 contract for general practitioners, many practices have employed practice nurses to help with monitoring chronic diseases, such as asthma and diabetes, using established protocols. If such protocols include relevant questions, they can be an ideal way of assessing disability and handicap, and for auditing quality of care. Many practices have also employed nurses to carry out health checks on patients aged 75 years and over. These checks have been much more useful in detecting functional problems, such as poor vision and hearing, than in detecting new diseases.³³ Their scope could be expanded to include a social assessment and they could be administered to younger disabled people.

Nevertheless, there will continue to be a discrepancy between the large number of people that general practitioners see with chronic conditions and potential disabilities, and the numbers they can refer on to other health workers or social workers for detailed assessment and help. One solution would be for general practitioners to ask patients to define their own problems. Patients and carers could complete a questionnaire to establish the patient's level of disability and areas of difficulty. There are a variety of well-validated questionnaires, and Chesson and Sutherland have suggested the use of a standardized questionnaire for all patients with physical disability.⁹ Some of these, such as the health assessment questionnaire for arthritis,³⁴ are disease specific and look at functional ability, while others, such as the SF-36,³⁵ look at overall quality of life. It is therefore important to consider carefully the scale chosen and its limitations. Patients with high scores overall or in particular areas could be offered additional help, or a fuller assessment by a nurse, as has been reported by Jones and colleagues with their morbidity index to target asthma care.¹³

Conclusion

This paper has described different models for looking at people with chronic incurable conditions, and reasons why a broad-based approach including elements of all these models would appear to be appropriate for general practice. While not negating the importance of the medical model, reasons why greater recognition needs to be given to the functional and social aspects of disability and handicap have been identified and ways in which this can be achieved suggested. Clearly there is a need for greater research in this area.

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Support for widowers

This Canadian paper augments the growing evidence that bereavement is a neglected area for health promotion. The health care use patterns of a sample of 113 newly bereaved men were analysed retrospectively. Of these men, a group of 61 had been randomly selected and assigned immediately to a nine-week treatment intervention (weekly semi-structured peer group sessions). The other 52 men acted as a control group and they had been requested to wait eight months for the treatment intervention. Additionally 109 married men, matched for age, had been selected for comparison. Monthly rates of visits to family physicians, psychiatrists and all other specialists were examined for the three cohorts.

Rates of visiting by the married men remained stable over the study period. Rates of visiting family physicians declined after the intervention in the treatment group but continued to rise in the control group of widowers. These findings reiterate those in a study of widows published in 1964 by Murray Parkes that is quoted in this paper.

Although an increased number of visits to a doctor does not indicate that there is illness resulting from bereavement, it does lend weight to the theory that structured support programmes are required for those who become bereaved. The findings of this paper, together with Dewi Rees' evidence from 1967 of a seven-fold increase in mortality among bereaved people, further demonstrate that management of grief is a neglected area of primary care.

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Source: Tudiver F, Permaul-Woods JA, Hilditch J, *et al*. Do widowers use the health care system differently? *Can Fam Physician* 1995; **41**: 392-400.

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Food for thought...

'The views of patients and general practitioners about the best type of general practice evidently differ. General practitioners have been seeking to develop practices to provide comprehensive and effective clinical services from well-equipped premises staffed by multidisciplinary teams. In contrast, this study shows that patients prefer a personal service. Given the current approach to practice organization, patients are more likely to obtain a service that meets their requirements if they attend small, non-training practices that operate personal list systems.'

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