The Epidemiology of Disability

V. WRIGHT, MD, FRCP
Professor of Rheumatology, University of Leeds

Complex disability is common. Amelia Harris[1] estimated that in developed countries 3-6 per cent of the population was disabled, giving a figure of three million disabled persons in the UK, of whom 386,000 needed considerable support, and 157,000 were severely handicapped. The estimates of Wood and Badley[2] are shown in Table 1. Understandably, these figures are age-related (Table 2). The frequency of the causes of physical disability are shown in Table 3. In a survey in Leeds we found that causes of very severe or severe handicap were arthritis 27 per cent, strokes 17 per cent, mental subnormality 11 per cent, bronchitis 11 per cent, and cerebral palsy, poliomyelitis and paraplegia 10 per cent.

In the Third World, disability is common, but the distribution is obviously different. It might be noted that in the Third World 80 per cent of health budgets are spent on the richest 20 per cent of the population. With far greater problems of ill-health in the underdeveloped than the developed world, the health care system caters for the needs of far fewer. The health policies of most Third World nations have been to pursue Western-style solutions to ill-health, albeit with far less resources to spend on major hospitals or highly trained staff. Where most of the diseases can be prevented by better housing, sanitation and nutrition or treated by paramedics and health care workers, the expensive Western approach devotes the nation’s health budget to the lucky few.

Impact

Chronic disability has a profound effect on the sufferer, the relatives, and the spouse. In a survey of 738 impaired housewives in Leeds we found little or no shopping was done by 56 per cent, little or no cooking by 26 per cent, and little or no housework by 55 per cent. Harris[1] commented on the difficulty that such housewives have in preparing food (Table 4) and concluded that there is a lack of information about what is available for the disabled in the kitchen. We found that 60 per cent of handicapped patients were not able to climb stairs unaided; of these, three-quarters used an aid or another person, and one-quarter could not go up stairs at all. In a rural community, Buchanan[3] found that, among 220 disabled people, there was a lack of mobility in 46 per cent,

Table 1. Impairment and severe disability in Great Britain (after Wood and Badley [2].) Frequency per 1,000 adults.

| Impairment (All Degrees) | Severe Disability |
|--------------------------|------------------|
| Mental                   | 100.7            | 11.6 |
| Sensory                  | 159.8            | 5.4  |
| Physical                 | 82.6             | 18.4 |
| All classes              | 343.1            | 35.0 (3.5%) |

Table 2. Proportion per 1,000 of men and women, in different age groups, in private households, with some impairment.

| Age Group | Men | Women |
|-----------|-----|-------|
| 16-29     | 10.0| 7.9   |
| 30-49     | 30.2| 25.6  |
| 50-64     | 85.6| 84.6  |
| 65-74     | 211.4| 227.1 |
| 75 and over | 316.2| 409.0 |
| All ages  | 66.7| 88.2  |

Table 3. Frequency of causes of severe disability. (After Wood and Badley [2].)

| Estimated Rate of Occurrence per Quarter Million Population |
|-------------------------------------------------------------|
| Arthritis other than rheumatoid                              | 751 |
| Stroke and Parkinsonism                                      | 499 |
| Cardiorespiratory                                            | 453 |
| Rheumatoid arthritis (RA)                                   | 323 |
| Trauma and amputations                                       | 249 |
| Other rheumatic disorders                                    | 134 |
| Infancy and youth                                            | 102 |
| Multiple sclerosis                                           | 96  |
| Paraplegia                                                  | 45  |
| Other                                                        | 801 |
| All causes                                                   | 3,452 |

Table 4. Difficulties in preparing food in 5,572 patients.

| % |
|---|
| Reaching to shelves | 44 |
| Bending to oven     | 37 |
| Standing at cooker  | 35 |
| Lifting pans        | 34 |
| Opening screw top bottles | 34 |
| Opening tins or cans | 29 |
| Beating eggs, stirring or mixing                            | 19 |
| Cutting             | 17 |
| Peeling, scraping, vegetable preparation                     | 10 |
whereas pain was a problem in only 4 per cent. Eleven per cent missed activities outside the home, and a similar number missed activities within the home; 20 per cent missed their independence, and 8 per cent felt restricted.

The impact upon the sufferer is not merely physical but psychological. Corbett Woodall, the television producer, comments in his biography *A Disjointed Life*: 'One would have thought the obvious verbal bed-fellows of sickness would be words like pain and discomfort, self-pity and anger, but more and more it emerges that the predominant problem is one of frustration'. Christy Brown, in his biography *My Left Foot*, writes of his emotional problems. 'We who are handicapped need confidence and friendliness as well as, if not more than, medical treatment. It is not only our muscles and limbs which bother us—sometimes it is our minds as well. A child with a crooked mouth and twisted hands can very quickly and easily develop a set of very crooked and twisted attitudes both towards himself and life in general, unless he is helped to an understanding of them. Life becomes to him just a reflection of his own "crookedness", his own emotional pain.'

The unthinking reaction of the public often engenders feelings of inadequacy. Corbett Woodall describes the reaction of a lady into whom he had inadvertently bumped with his wheelchair. 'People like you shouldn't be allowed out; they should be put in homes; the public should be protected from you.' It was this attitude, of course, that caused the BBC to call its magazine programme for disabled listeners, 'Does he take sugar?'

The adaptation of close relatives to severe illness commonly occurs in three phases. Initially, there is a cheerful acceptance of the situation, and gladness that the patient is alive. This is followed by a depressive phase, and finally, a phase of either coping or maladaptation, in which the same questions are asked again and again. 'What is it?' 'How has it developed?' 'Why did he get it?'

The marriage relationship may be severely affected by chronic disability. In a study of young married women with rheumatoid arthritis of sufficient severity to require hospitalisation[4], we noted that the patients' physical concerns were tiredness, functional limitation, pain and restricted activities. Nevertheless, psychologically their concerns were anxiety, frustration, depression, fear of losing their independence, feeling of guilt, and a fear of being a burden. The patients were analysed according to the understanding of the husbands. Those whose husbands were the most understanding were the patients whose function was best, who had the fewest erosions of the joints, who had less than three children, who had the shortest marriage, or whose arthritis began before marriage. Those who had the most helpful husbands were those whose arthritis was either mild or severe, and in whom the arthritis began before marriage. We looked particularly at those patients whose rheumatoid disease began before they were married, and noted that there was less fear of losing their independence, greater understanding of the disease, fewer guilt feelings, better adjustment to the marriage, a greater understanding on the part of the husband, and less friction in the home. This is of importance when a young woman with rheumatoid arthritis comes to ask whether she should get married. It would seem that if the husband marries the arthritis as well as the woman, the marriage is more likely to succeed than if the rheumatoid disease began after marriage.

**Isolation**

Isolation of chronically disabled patients is bound up with their limited mobility on foot. In a study in Leeds of arthritic patients compared with matched controls[5], a third of the patients could not get beyond the garden gate, one half could not walk more than 100 yards, and only one-third could go beyond one-quarter of a mile. This meant that their access to local facilities on foot was severely limited; 30 per cent were unable to get to a shop, one-quarter unable to get to a bus stop, and 60 per cent unable to get to a park. The accessibility of shops was very dependent on the age of the housing. Pre-1914 housing had shops within 50 yards in 39 per cent, but for post-1945 housing it was 4 per cent, and for interwar housing 8 per cent. It is interesting, therefore, that in Stockport they are beginning to renovate housing of the Coronation Street type. In a rural community, Buchanan[3] found that the number who shopped was related to the size of the settlement. In a town 61 per cent shopped, in a large village 44 per cent, in a small village 35 per cent. She found that added difficulties of disabled people were related to uneven surfaces, steep kerbs, steep slopes, wide roads, and buildings with more than 10 steps. These restrictions are again related to age, and in the Leeds survey[5] half our patients over the age of 75 were unable to get beyond the garden gate. This limits the number of daily outings the patient can enjoy. Whereas 97 per cent of controls went out at least once a day, of our arthritic patients only 46 per cent under the age of 65, 33 per cent between 65 and 74, and none of those over 75 went out daily. This is bound up with public transport; 46 per cent of arthritics rarely, or never, used buses, and only one-third of these had a car available. Two-thirds of the severely handicapped used buses less than once a week, whereas only 7 per cent of the controls did not use a bus, and all these had access to a car. A similar number of arthritic and control subjects had a car. However, 83 per cent of the handicapped could not get a lift if needed, compared with 15 per cent of the controls.

**Financial Provisions**

The disabled are financially disadvantaged. At the time of the Leeds survey[5] when the national average wage was £60 a week, only 12 per cent earned between £50 and £75, 34 per cent between £30 and £50 and 52 per cent earned less than £30 a week. Twice as many controls as arthritic subjects were employed. Because so many arthritic subjects have an income of less than £30 a week there are few with cars in this income bracket. Their housing facilities were poorer than those of their contemporaries. Only one-quarter had central heating compared with one-half of the controls. There was slightly less indoor sanitation, and rarely a downstairs lavatory or bath. Of those living alone 42 per cent had to go upstairs to a bathroom.
Again, while 63 per cent of the general population had washing machines, only 47 per cent of the disabled had.

Official Attitudes

One of the regrettable attitudes of officialdom is the tendency to clump all disabled patients together, rather than consider their problems individually. A letter referring to the Northampton Social Services Department typifies this.

Dear . . . .

We have received a letter from Northampton Social Services Department saying that you have recently had your legs tested at a Hospital in Leamington Spa. Following this examination it is possible that you could be placed on a special register for visually handicapped people.

This is the sort of attitude that occasioned one of the biting front covers of World Medicine, on which a sprightly octogenarian lady is shown in avid discussion on a telephone, and the caption asks: 'Another one for the geriatric dustbin'?

Alleviation

Simple measures may help the chronic disabled considerably. In our survey of married women with rheumatoid arthritis we found that they particularly wanted advice on the general effect of the disease, how to cope, and the level of activity in which they should engage.

In the home, provision should be made for mobility. General safety should be ensured with secured carpets and well-lit stairs. Heating should be adequate and easily maintained. Stairs and steps should be eliminated wherever possible, and the fitting of access rails can be a great help. In designing houses, entrances should be wide enough for wheelchairs, and internal planning such as to permit ease of movement. There should be a bathroom, WC, and at least one bedroom on the entrance level. In San Diego, California, it is required that all public authority housing meets these requirements. Our survey in Leeds revealed that half the patients required self-care aids. The provisions most valued were raised toilet seats, rails in the lavatory and bathroom, bath seats, and non-slip bath mats. In a further survey[6] we found that two-thirds of patients had difficulty in getting out of the bath. While the provision of a shower might be a simple remedy for this, disabled patients, particularly the elderly, do not like showers. Of those who were very severely, or severely, handicapped, 41 per cent preferred a shower; of those appreciably handicapped 38 per cent, and of the appreciably handicapped over 70 years old only 21 per cent.

When these aids are supplied it is important that they should be used. We have done a controlled study in which aids have been supplied to patients in hospital. Half the patients were taught by an occupational therapist in the home, while the others just relied on the teaching they had in hospital. Three months later an independent observer visited the homes to assess the use of the aids. Where the occupational therapist had been to teach in the home environment many more aids were used than in the control group.
Chiropody problems occurred in half of the handicapped patients in the community, and a study of our rheumatic patients in hospital showed that 49 per cent required chiropody (59 per cent of the women and 18 per cent of the men). The reasons were that some were unable to reach their feet because of hip or knee involvement, some had hands too weak to attend to their feet, and others had specific problems such as callosities under the metatarsal-phalangeal joints.

Other services requested by the handicapped in our community survey were a visiting hairdresser, more home helps, a downstairs toilet, electric plugs higher than ground level, and an emergency buzzer.

A specific problem that Janette Munton has investigated in our Unit is the use of easy chairs by disabled people, since they spend much time in them. In a survey of 378 patients 42 per cent had difficulty in rising from a chair. Ease of rising was, in fact, the factor they ranked as most important in an easy chair, followed by comfort, a high seat, ease of getting into it, ease of moving the chair and fire-proofing. Expense was sixteenth on this list. This ranking order is of interest since manufacturers refuse to construct fire-proof chairs because they would be too costly for the purchaser. Certainly, as far as disabled people are concerned, this would not seem to be true. Amazingly, half the patients had not sat in their chairs before buying them.

In the community, life would be easier for the disabled if busy roads had a central reservation. The disabled person’s badge used as a car sticker is sometimes abused, but it has enabled many disabled to visit central shops, etc. Although one may have reservations about the symbolic wheelchair in that it takes no account of mental subnormality, and has even caused some people to think that only those who are wheelchair patients are allowed to have the sticker, it is an internationally recognised symbol, and it is not likely that we shall get it changed—or indeed that a better symbol could be thought of. The height of a bus step often prevents disabled people from using public transport. It is to the credit of some authorities that they have overcome these problems. In South Yorkshire, kneeling buses, in which the steps subside on a pneumatic principle to within four inches of the kerb, are in operation, and other buses have split steps. The new Tyne and Wear metro system has been made accessible to pushchairs, prams and wheelchairs, and the San Francisco underground is similarly totally accessible. In Seattle, buses on certain routes have been modified for wheelchair users. Some doubt has been expressed recently, however, about the cost-effectiveness of the hoists that are necessary for this. All these provisions require money, and the disparity of provision throughout the country is well illustrated by figures per 1,000 disabled people. In a recent survey we found that the City of London was spending £2,537, Tower Hamlets £2,403, Lewisham £1,557, Wandsworth £1,076 and Leeds £62!

Summary

Chronic disability is common, involving three million people in the UK. It has a profound effect upon the sufferer, both physically and psychologically. Many relatives have problems in coping with the disability, and marriage relationships are strained. Where the spouse marries the disabled before the illness, the marriage is more likely to survive than if the disease develops afterwards. The disabled are financially disadvantaged and this is reflected in their inability to buy a car, in their poorer housing, and in the purchase of important equipment such as washing machines. There is a regrettable tendency by officialdom to clump these patients together rather than consider their problems individually. Nevertheless, simple measures may help. It is important to discuss problems with the patient. Mobility in the home can be made easier by adequate planning of the housing and simple modifications within the home. The provision of self-care aids is required in half the patients, but the patients were more likely to use them if they were taught within their home. Chiropody is an often overlooked provision and is needed in half the patients. In the community, central reservations are required for busy roads to enable disabled people to cross them. The kneeling bus and the split level bus are helpful in making public transport available. Throughout the country there is a wide disparity of public funding by local authorities.

This article is based on a paper read at the Conference on Assessment and Management of Complex Disability held at the Royal College of Physicians in November 1981.

References

1. Harris, A. (1971) Handicapped and impaired in Great Britain, Part I. London: HMSO.
2. Wood, P. H. N. and Badley, E. M. (1978) International Rehabilitation Medicine, 1, 32.
3. Buchanan, J. M. (1981) Personal communication.
4. Wright, V. and Owen, S. (1976) Rheumatology and Rehabilitation, 15, 156.
5. Chamberlain, M. A., Buchanan, J. M. and Hanks, H. (1979) Annals of the Rheumatic Diseases, 38, 51.
6. Chamberlain, M. A., Thornley, G., Stowe, J. and Wright, V. (1981) Rheumatology and Rehabilitation, 20, 38.