Contemporary Themes

Domiciliary care for the elderly sick—economy or neglect?

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Summary

This paper reports an investigation of the costs of domiciliary care for 139 elderly sick patients under the care of the home nursing service. The data suggest that there may be little economic advantage in home care for seriously disabled elderly people. The revenue cost of domiciliary care was equal to or greater than the average associated with residential or hospital custodial care in such patients. Even so, the cost of services received at home did not disclose the real need for domiciliary care, since at present this is obscured by compulsory rationing and the separation of responsibility between health and social services. It is suggested that the supposed economic advantage of domiciliary care will depend increasingly on restricting such services, thus increasing the degree of neglect to some patients.

Introduction

Studies of the cost of domiciliary care[1-3] have mainly used population groups and standard statistical costing returns. Hence these rely on average costs over a large range of disability and illness and may be misleading if the object is to appraise the cost of alternative strategies of care for similarly disabled elderly people. But what proportion of severely handicapped patients require less expenditure or help to manage at home or indeed prefer staying there? Here I report an attempt to measure the use of resources by a sample of the elderly sick living at home.

Methods and comments

District nurses attached to 36 general practice panels in the Central Birmingham Health District were asked to provide data about a representative sample of six to 12 elderly patients whom they were attending from 1 August to 31 October 1974. Of the 581 patients aged 65 and over then receiving attention from the nursing service, 139 were chosen for study. They were not a random sample, but since the study was determining the level of service (and its cost) to individual patients, I felt that the sample should be representative of a wide range of social and medical problems.

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DATA COLLECTION

The nurses were given a structured inquiry form for each patient asking for data relating to housing, social contacts, disability, and medical condition. They were also given a detailed list and asked to score those activities provided for each patient and to estimate the time per visit that these needed during a week. They recorded distance of each patient's home from base; the number of visits by nursing staff members; the degree of family, neighbour, and volunteer help; and the use of social services, laundry, and equipment or aids. These data were checked at the social service agencies as well as the community services division of the area health authority.

Much of these data were converted into average visiting time per patient per week and assigned a monetary value.

CATEGORISATION

Each patient was categorised into an illness group, as follows:

Stroke—when the notes recorded stroke or evidence of hemiplegia or aphasia.

Dementia—patients with appreciable intellectual or behavioural disturbance without evidence of stroke.

Incontinence—patients who had no evidence of stroke or dementia but who had frequent incontinence of bladder or bowel without apparent cause.

Terminal—patients dying of malignancy.

Multiple pathology—the remaining patients, many of whom had varied conditions such as arthritis, obesity, leg ulcers, or heart failure, were divided into two groups according to the presence or absence of recorded moderate to severe blindness or deafness.

All patients were further classified by activity ability. The nature and source of the data prevented the use of a refined classification of disability such as that used by Harris *et al.*[4] Instead, three groups were identified: those bed-ridden or chairfast (bedfast); those ambulant and largely able to care for themselves (self-care); and the remainder partial self-care groups.

TIME STUDY

During the study three nurses kept a detailed time study of actual nurse-patient contact for 20 days.

THE SAMPLE—CHARACTERISTICS AND COMMENT

Demographic characteristics

One patient (a male tetraplegic) was under 60 while 26 were 60-69, 49 70-79, 56 80-89, and seven 90 or older. The overall proportion of women to men was 6·7 to 1. Forty-four patients lived alone, and of these 13 had unsuitable or unsatisfactory housing. Fifty-three patients lived with other old people, mostly a spouse. Two patients lived with mentally defective children. The housing conditions were unsatisfactory on nine occasions. The remainder of the patients were living within family groups, although a few stayed with friends or in trust houses; in eight cases this accommodation was "unsatisfactory." "Unsatisfactory" ranged from accommodation with only an outside lavatory to filthy and neglected conditions, and no source of hot water other than a kettle.

Disease and disability characteristics

Some 28 patients had had strokes (table I), and half of these were bedfast or totally dependent on other people. About the same number had disturbances of behaviour with confusion. A further 10 patients had intermittent behavioural disturbances and, of the total, 21 had intermittent or persistent incontinence. Sixteen patients had deafness and blindness without stroke or dementia; these often had additional recorded handicaps, such as severe arthritis or obesity. In all, 23 patients had some visual defect, 30 deafness, and 10 both. Among the blind were four patients who had diagnosed cataracts, two of whom had been on hospital waiting lists for some time.

Some 10 patients of the 23 with visual disturbance were diabetics. Six patients had terminal malignancy, five of them seriously ill. The largest group of patients, multiple pathology, included a wide spectrum of categories. Among the bedfast patients were three with Parkinson's disease, two with fractured lower legs, a tetraplegic, one with prostatism with indwelling catheter, and one with multiple sclerosis. Many of the less disabled were obese, suffering from osteoarthritis and congestive heart failure, while a few had no clear diagnostic label except old age.

TABLE I—*Direct costs of care*

Diagnostic category	Activity state		
	Bedfast	Partial self-care	Self-care
(a) Stroke	£23·10 (14)	£9·20 (12)	£16·60 (2)
(b) Dementia	£34·80 (4)	£10·40 (15)	£12·70 (6)
(c) Multiple pathology No recorded major visual or hearing defect.	£26·10 (12)	£9·00 (28)	£7·60 (19)
(d) Multiple pathology Recorded major visual or hearing defect.	£36·00 (2)	£9·50 (7)	£6·70 (7)
(e) Incontinence	£8·40 (2)	£8·20 (2)	
(f) Terminal	£26·50 (5)		£10·20 (1)
Activity average	£25·60 (39)	£9·40 (64)	£8·90 (35)

The cost figures are £ per week average and exclude costs associated with outpatient or inpatient attendance, social-worker time, blind welfare services, or day centre attendance.
One patient not classified.

Quality of care

The nurses' purely subjective classification of the quality of care showed 97 patients as receiving satisfactory care and 41 unsatisfactory care. Analysis of these assessments showed that the designation of unsatisfactory was associated particularly with increasing total average nursing work load per patient (table II).

TABLE II—*Estimated patient-nurse contact time a week*

	Cases classified as satisfactory	Cases classified as unsatisfactory	Total
$<\frac{1}{2}$ hour	21	5	26
$>\frac{1}{2}$ hour and ≤ 1 hour	28	6	34
>1 hour and $\leq 2{\cdot}5$ hours	26	17	43
$>2{\cdot}5$ hours and ≤ 5 hours	15	7	22
>5 hours and ≤ 10 hours	7	4	11
>10 hours	1	2	3

DIRECT COSTS

Nursing costs

Nursing costs were estimated from the average nurse contact time for each patient. The usual method of assigning costs per visit, as used by the Institute of Municipal Treasurers and Accountants, was believed to be unreliable, since visits may range between three minutes and several hours. The cost of contact time was obtained from the nursing award rates available in November 1974 adjusted to allow for the cost of area nursing and geriatric supervision, area administration, superannuation, and the maintenance of plant and buildings. It included the cost of uniform allowance, drugs, stationery, and telephone.

In addition an increment for central administrative costs was made. No allowance for mileage was included since these data were available for each patient-nurse contact. The self-recorded work study carried out by three nurses showed that on average only $3\frac{1}{4}$ hours a day were spent on actual patient contact so that the cost per hour visiting was then doubled to include the assumption that one hour of patient contact required two hours of a nurse's time. This estimate can be confirmed from a detailed study of district nurse work by Hockey and Buttimore,[5] which gives an average of $3\frac{1}{2}$ hours a day for time spent on visiting (table III).

TABLE III—*Nursing cost distribution. Corrected cost distribution using (b) and including mileage at 7·5p a mile*

£ per week average	Total
$<$£5	61
$>$£5$\leq$£10	35
$>$£10$\leq$£15	21
$>$£15$\leq$£20	8
$>$£20$\leq$£30	7
$>$£30$\leq$£50	4
$>$£50	9

(a) Deduced costs an hour for employment. SRN grade £2·24, SEN grade £1·51, and nurse attendant grade £1·18.
(b) Deduced costs an hour for visiting corrected for proportion of time spent visiting. SRN grade £4·48, SEN grade £3·02, and nurse attendant grade £2·36.

Home help

Since most home helps are part-time and are paid only for the help provided, the hours of work for which pay is received is very close to the hours of home help provided, so that no allowance was made for the discrepancy in assessing nursing costs. The latter include allowance for pensions, national insurance, transport, supervision, and administration. No allowance for overtime or central administrative costs was readily available, and the costs as given in most social service costings were almost certainly too low.

Other social service functions costed included meals on wheels, chiropody, night watch, and attendance by social-work aides. Cost components included salary, administrative costs, and transport.

Health service functions costed were laundry services, Marie Curie Foundation nursing, and day-hospital attendance.

Equipment costs

The home-nursing service provided nursing aids and equipment while the social services department supplied some additional aids—such as fitted handrails, shower equipment, and telephones. Additional equipment was available from the blind welfare section of social services.

So far as possible the items provided for each person were costed and the administrative costs of stocking, providing, and maintaining this equipment was added pro rata to the capital cost of the equipment (table IV). For equipment such as a telephone it is easy to associate a

TABLE IV—*Use of domiciliary services*

Service	No of patients receiving service	Average cost per patient week of service
Laundry	29	£2·08
Equipment:		
Telephone	9	38p/week
Other aids and equipment	83	Total £6·02 33p/week
Home helps	63	£3·23
Meals at home	35	£1·14 (2 meals) gross £0·84 nett
Social worker contact	67	?
Social-work aide visiting	4	£0·20
Occupational therapist	3	?
Chiropody:	14	£0·16
Hospital service (4)		
Domiciliary service (10)		
Blind welfare services	4	?
Day centres	3	?
Night watch	3	£14·85
Marie Curie Foundation nursing	3	£11·15
Day hospital attendance	23	£5·93

weekly cost with the equipment but for most items, which may have been collected over several years, this can be done only by estimating the annual cost of the capital investment and by using some simple depreciation schedule.

Neither of these schemes is entirely realistic. The cost of capital was set at 14% and depreciation schedule was over five years. Services that were not costed included social worker services, occupational therapy, blind welfare services, and day centres.

INDIRECT COSTS

Volunteers, neighbours, and family

Family, neighbours, and volunteers in the care of the elderly sick were important for two categories of patients. The first were those living alone and, of these 44, 24 were receiving almost daily support from these groups. The second category were those living with an aged relative, spouse, or child and, of the 53, 24 were supported in this way.

I expected that no realistic costs could be assigned for this help, even though this support spared the nursing and social services. It seemed important, nevertheless, to provide some rough guide to these sources of help.

SOCIAL SECURITY

The final component of cost was that associated directly with payment of money. Almost all these patients were pensioners, some received supplementary payments to cover such items as fuel, while others were cared for by their family, who might receive attendance allowance payments. I identified five such cases.

It was difficult to obtain reliable estimates of this cost directly from patients, and information about individuals cannot be obtained from the Department of Health and Social Security. Nevertheless, these payments have a particular significance when comparing the cost of domiciliary care with that in an institution, because there is a loss of the attendance payments on admission and a graduated loss of pension with increasing length of stay.

Results

HOME HELPS

The major social service support was provided by the home-help organisation and of our sample of patients, 63 were recorded as receiving home-help, with an average of 3·8 hours per person a week (individual maximum 20 hours a week, modal three hours). By using data provided by the social services accountant the gross cost of this service was estimated as 85p an hour. Patients might be asked to contribute but for the whole city the average was only 3p for an hour's service.

The distribution of home help to patients was skew: 76 of the patients received no help, while five received eight or more hours a week. These five patients represented only 3·5% of the sample but they received almost a quarter of the home help provided. The home help was concentrated on those patients living alone, with 3·9 hours a week for those receiving help (66%). Patients receiving nursing support received less than average home-help support. Thus the bedfast or totally dependent group (27% of the sample) received 16% of all the available home help. Details of some individual cases suggested that in cases with heavy nursing loads the district nurses were providing domestic rather than technical services, and their use was inappropriate to their skills. If nursing help and home help are substituting for one another, then the use of nurses at £4 an hour to carry out home-help duties that can be purchased for less than £1 an hour suggests some obvious deficiency in the integration of the organisations that supply these resources.

SOCIAL WORKERS AND OCCUPATIONAL THERAPIST CONTACT

Files existed in the social work departments for 67 patients in the survey. Only 14 files were classified as open or active, and, of these, only six patients were receiving regular social work or welfare aid visits. One had several visits scattered over a month mostly at his own request in a successful bid for residential accommodation, and one case was attended by a social work trainee. Three people had occasional visits from the occupational therapist.

Superficially, therefore, one might be tempted to assume that the cost of this service for these patients was negligible even given that the cost of a half hour visit from a social-work aide is £1·80 and from an occupational therapist £2·00. The files themselves are, however, a testimony to time spent writing, travelling, telephoning, and talking even if little visiting is identified. Any field social workers cost a lot even if the care of the elderly has a relatively low priority in their work, so that the inability to cost satisfactorily the work of social workers is a serious deficiency in this study. To achieve such a costing needs a detailed work study of social work, and this is currently being examined by the Research, Planning, and Development Section of the Birmingham Social Service Department.

COSTS OF PATIENT CARE AT HOME

Direct costs

Direct cost data for individual patients, and relating this cost (and its implied measure of the use of resource) to patient disability, are inevitably inexact because of the method of costing and the complexity of much illness in the elderly (table I). The data suggest that the activity status indicator is more useful than the diagnostic class in classifying these costs. The latter for all bedfast groups was £25·60, close to the average for all diagnostic groups except incontinence. The range of cost values a week for bedfast patients was £2·95-£83·75; 20 patients in this category had costs of £20 a week or more, while eight had weekly costs of over £30 a week.

For those classified as partial self-care, the activity class average was again similar to the averages within diagnostic groups (range per week £1·14-£35·02). In over half (36) the cost was £8 a week or less, while in seven cases it was over £20.

The self-care patients had average weekly cost values that varied little among diagnostic classes except for stroke patients, when the sample numbers were very small. The values for self-care patients ranged from £0·56 to £26·02 a week; in just less than half of the sample (15) the cost was £4 or less, while for two-thirds (23) it was less than £8. Two cases had costs greater than £20.

INDIRECT COSTS

Cash costs associated with living at home must be taken into account, particularly if the costs of domiciliary care and institutional care are to be compared. These costs were not available for individuals but may be estimated in two ways. One method is to add to the direct costs the cash value of maintaining a house: it includes upkeep, heating, rent, rates, and food. This approach was adopted by Rickard[3] and would increase the direct costs in my analysis by £16 to £30 using data from pensioners' household expenditure.[6] An alternative approach is to regard pension, benefit, and attendance payments as part of the cost of domiciliary care, particularly since these payments are reduced or abolished on admission to an institution. This "saving" may be estimated for the social service institutions by looking at the difference between the nett and gross costs. In Birmingham this amounted to an average of £15 a patient week in 1974.

One other important indirect cost is the use of labour and goods obtained from neighbours, friends, and family. There is no credible way of assigning a money value to this activity but this study suggests that it could be considerable, and valuable (cases 1 and 2).

Case 1—An 83-year-old widow was living alone with no social contacts in a large neglected house. She had evidence of severe dementia with incontinence and was receiving 3½ hours of nursing and 15 hours of home help a week. The total cost assigned to this patient was £30·10 per week.

Case 2—A 78-year-old widow was living alone but receiving daily visits from her neighbours. She had severe blindness and had been on the waiting list for cataract extraction for two years. She was also deaf and frail, having difficulty in walking without help. She received only about 15 minutes of nursing visits a week and three hours of home help. The weekly total cost assigned for the care of this patient was £6·09.

Discussion

This study shows that domiciliary care of severely handicapped old people is not cheap, even given that the level of care provided was probably often inadequate. Often workers have claimed,

however, that this is not so.[3] Nevertheless, it is difficult to validate my results from other costing studies. Each depends on the nature of the data collected, the sample, and the assumptions made. These variables are determined at the outset by the objectives of the costing exercise.

My study was concerned with determining the costs of health and social services in caring for individuals and this differs from other studies.[2 3] A study reported by Wager[7] has some similarity. Although his sampling was different, he used a classification of disability and provided data that related disability to the use of some domiciliary services. Once again, data relating to nursing contact were limited and costed per visit. The social workers were asked to make recommendations about additional social service or nursing help required, and these were also costed. Wager concluded that the marginal cost difference between residential care and intensive domiciliary care was small or negative for some groups of people.

All studies have one serious limitation in their reliance on an estimate of cost at one point in time and failure to consider the dynamic nature of the patients' state. Equally important, the data in this and other studies relate to cost at the current level of provision, and the latter does not imply that the care provided is the best. Thus, the cost of domiciliary services has largely been depressed by rationing of scarce resources. The use of money to indicate the use of resources does not disclose the limited availability of staff time or equipment. Hence, some patients who are receiving large amounts of social service or nursing care at home are in competition with other patients who also need these resources.

I found that there was a waiting list for laundry services and that far more were needed than were provided. Similarly, the number of blind or partially sighted patients known to the blind welfare services is only a fraction of those entitled to this aid.[8]

Clearly the demand for domiciliary services is already greater than can be provided with present resources and some assessment of benefit or quality of service is needed. Unfortunately, no objective assessment of the quality of care is available. In my study, however, I asked the domiciliary nursing staff to provide a subjective assessment. They identified almost 30% of their cases as receiving either inadequate or inappropriate care, and I found it difficult not to agree with their assessment in most instances. Many of this "unsatisfactory" group were severely disabled with serious irreversible conditions such as stroke or dementia and in spite of the considerable degree of support, I doubt whether a satisfactory environment could have been maintained for them at home. Since some of these cases could have been suitable for transfer to residential or custodial beds, it is interesting to compare the costs with the estimated revenue costs of this care. In the Birmingham region the cost per week for geriatric hospitals varies from £21 to £54 (1973-4). These costs include specialist staff and diagnostic and therapeutic facilities, and money can be subtracted to correspond to these. If this is done the probable average cost for 1974-5 would be about £45 a week, although this estimate is mainly guesswork. Similarly, the average gross cost per patient week in residential homes was £34 in Birmingham (1974-5). If these values are compared with the average cost for bedfast patients of £26 and allowance made for an average indirect cost of £15, some 20% of this study sample were more expensive to manage at home than in a geriatric hospital. No allowance is made for capital costs of these institutions.

If the work created by this sample of patients represents half of the total nursing work (although it is only for 25% of the patients) then for the whole nursing area 5% of all patients would actually cost more to support at home than in hospital. Moreover, about 10% would cost more than in residential care, even given the present inadequate level of domiciliary support. Of course, any decision to treat patients in home or hospital should not be made mainly on economic grounds. But it is equally unrealistic to ignore this factor completely, for compulsory rationing deprives some patients of adequate care when the limited resources are used heavily for some other persons.

It is quite possible to keep many seriously disabled old persons at home, but to do so without neglect will require a large investment in the support services. Even then, the quality of life for some of these patients or their families may be far from compatible with any civilised humanitarian standards. Whatever may be said about the quality of care for the elderly sick at home it is not cheap to provide, if the data in my study are representative of those elsewhere. Thus, services for a patient receiving four hours' visiting a week, four hours of home help, and two meals will cost as much as the cost of non-medical resources given to a person in a residential home and about two-thirds of that given to a patient in an established geriatric inpatient unit, if the assumptions about the graduated loss of pension and other allowances with hospital or residential home admission are valid.

During this study I found it difficult to avoid the conclusion that some of the cost incurred could have been reduced by appreciable changes in the organisation of the health and social services. If the present policy of passively transferring the elderly chronic sick from hospital to home continues by limiting the various types of accommodation available for them, a substantial additional financial allocation for domiciliary care will be needed. If this does not occur then domiciliary care for the elderly sick will be increasingly "economic" simply because the level of care provided becomes increasingly inadequate.

I thank the senior nursing officer, nursing officer (home nursing) and all area nursing staff who co-operated to provide the data on which this study is based. I also thank the many people in the Birmingham Social Services Department who provided information and access to files and data. Mr T Dowdell carried out much of the inquiry into the social service facilities available and his help is gratefully acknowledged.

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What is the inheritance of polycystic kidneys and what genetic advice should be given to both a brother and sister who are affected and whose mother and maternal uncle had the disease and died in their 30s?

The classical adult form of polycystic disease of the kidneys is a regular dominant. The family history in this family also suggests dominant inheritance. The risk of any individual child of either the brother or sister inheriting the condition is therefore 1 in 2.

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A patient attending an antenatal clinic, who has been using nystatin pessaries for vaginal thrush, complained that three pairs of her pants have inexplicably developed holes. Could nystatin have this effect?

This is unlikely. There may be a complicated series of chemical reactions going on in the pants, depending on the material, the detergents used in washing, and the composition of the vaginal fluid (which may be very acid in pregnancy at a pH ranging from about 3·5 to 4·5). There are also many enzymes and other chemicals to be considered. The solution to this problem is not simple.