MEDICAL PRACTICE

*Contemporary Themes***Formal and informal support received by carers of elderly dependants**

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Abstract

This study describes the activity of informal carers who look after elderly dependants and particularly investigates the role of formal services in supporting these carers in maintaining dependent, elderly people in the community. The results lend no support to the view that families neglect their elderly relatives or that community services displace the role of informal carers, but rather suggest that carers support elderly dependants at great cost to themselves and with inadequate support from community services.

Introduction

For many years the philosophy and consequent policy of government has been that the elderly should remain as far as possible in the community, living independently or with their families rather than in residential accommodation.¹ The emphasis has therefore been on community rather than institutional care: community services supporting families to care for their elderly dependants. This has implications not only for the frail elderly but also for those who are supporting them in the community. Interest has been shown recently in the problems of carers of elderly dependants. Most substantial studies, however, have been either concerned with carers of elderly and mentally infirm people^{2,4} or based on samples of elderly people who were already in contact with services, or both, thus giving a biased view of the role of services in supporting elderly dependants.^{2,3,5,6} There was therefore a need to investigate the problems of carers from a broad based sample of the community.

The term "network of care" has been coined and refers to the intermeshing of informal or family care with community services. This paper examines such networks and the degree to which the carers of elderly dependants are supported in the community by their family and community health and social services.

Subjects and method

A population of 1079 people aged over 70 was drawn from the age and sex registers of two general practices; a complete sample was taken from a four handed practice and a random sample from a six handed one. Of these, 1066 (98%) were successfully interviewed in their own homes with a semi-structured interview schedule to examine their general health and wellbeing. Areas covered in the interview included housing, family and social life, physical disability, and mental wellbeing. Each subject was asked if they needed any help with any of 15 tasks basic to daily living such as washing all over and cutting toenails. If they needed help the sources of help were identified: if they identified one main carer that person's name and address were noted. Of the 338 who needed help, 37 were in residential accommodation, 28 received support from statutory services only, and six could not name one main carer. Thus 267 eligible subjects remained, each of whom was then sought for interview alone in their own home, and 256 were successfully interviewed. Included in this interview schedule were questions concerning the type of help the carers gave; the consequences of caring on their own lives, in terms of social life, family life, health, and occupation; and the support they received from the community services.

We measured physical disability for both carers and their dependants as difficulty with, or the inability to perform, certain basic functions that are essential to the maintenance of independent living. This provided a grading of functional physical disability⁷ and included questions on the ability of the old person to manage nine basic functions when alone. These ranged from activities such as carrying heavy shopping or catching buses to climbing stairs and cooking a meal.

For each question such as "Are you able to wash all over?" the score 0 was given if the reply was "without difficulty"; 1 if the reply was "with difficulty"; and 2 if the reply was "unable to alone." The overall score had a range 0-18. Townsend regarded people with a score of 0 as having no disability, 1 or 2 slight, 3-6 some, 7-10 appreciable, 11-18 severe and very severe.⁷ Impairment of memory was measured with a standardised questionnaire,⁸ the results of which have been shown at necropsy to be associated with brain damage relating to Alzheimer's disease.⁹ It is a series of questions

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scoring 0 or 1 each and has a range 0-12. In the original work the scoring system was described as 0-3 normal; 4 or 5 mildly affected; and 6-12 severely affected.

Results

Most of the carers were either daughters or daughters in law (102 (40%)) or spouses (66); 61 were other relatives and 26 were totally unrelated to the elderly dependant.¹⁰ As most of the carers who were spouses were wives 202 (79%) of all carers were women; half (123) were middle aged (aged 45-64), 51 were aged over 75. A total of 164 lived in the same household as the elderly subjects—that is, they were resident carers; half (51) of the daughters were resident carers.

ASSISTANCE

The type of assistance given to elderly dependants falls into three main groups: house care, help with mobility, and personal care. Help with house care activities was common and mostly provided by the main carer unaided (table I). Cleaning and shopping were the tasks most often shared or taken over by others. Help moving about inside and outside the house was required by fewer people because it indicates a higher level of disability and incapacity. These tasks were mostly undertaken by the main carer alone, except that transport tended to be provided by sons or other relatives.

TABLE I—Help given to elderly dependants. (Values are numbers (%) of dependants)

Type of help provided	No help	Carer only	Carer and other	Others
House care:				
Shopping	22 (9)	137 (54)	71 (28)	26 (10)
House cleaning	39 (15)	138 (54)	48 (19)	30 (12)
Preparing a meal	77 (30)	138 (54)	36 (14)	5 (2)
Washing clothes	40 (16)	159 (62)	28 (11)	29 (11)
Mobility:				
In and out of bed	208 (81)	41 (16)	5 (2)	2 (<1)
Moving about	222 (87)	29 (11)	4 (2)	1 (<1)
Going outside the house	161 (63)	48 (19)	37 (15)	10 (1)
Transport	148 (58)	42 (16)	24 (9)	42 (16)
Personal care:				
Washing face and hair	155 (61)	63 (25)	11 (4)	27 (11)
Dressing	194 (76)	54 (21)	6 (2)	2 (<1)
Help with toilet	227 (89)	25 (10)	4 (<1)	1 (<1)
Eating and drinking	235 (92)	20 (8)	1 (<1)	1 (<1)
Bathing	132 (52)	76 (30)	13 (5)	35 (14)
Giving drugs	209 (82)	41 (16)	2 (<1)	4 (2)
Medical help	234 (91)	16 (6)	2 (<1)	4 (2)

Personal care was much less commonly provided as it indicates a high degree of disability. Bathing and washing were the most usual forms of care. Again care was generally provided by the main carer, with little sharing; washing and bathing were the tasks most often taken over by others, such as community nurses.

Carers who were not spouses or daughters tended to share the tasks much more: they received more help and were more often part of a team or network. For all types of help more resident than non-resident carers gave help and were more likely to be unaided.

SERVICES

Table II shows the services that had visited the dependants' homes during the month before the interview. The services described are, of course, not mutually exclusive. The community nurse provided most support (50 (20%)), followed by the home help (44) and the day hospital (28). Day

TABLE II—Services received according to residency. (Values are numbers (%) of dependants)

Services	Residency of carer		
	Resident (n=163)	Non-resident (n=93)	Both (n=256)
Home help	20 (12)	24 (26)	44 (17)
Meals on wheels	7 (4)	12 (13)	19 (7)
Social worker	8 (5)	5 (5)	13 (5)
Nurse	40 (25)	10 (11)	50 (20)
Visit to day hospital	17 (10)	11 (12)	28 (11)
Occupational therapist	1 (<1)	—	1 (<1)
Physiotherapist	2 (1)	—	2 (<1)
Voluntary worker	4 (2)	—	4 (2)

centres were included in the category of day hospital. Few subjects had been visited by an occupational therapist or a physiotherapist and only four by a member of a voluntary or charitable organisation. One hundred and two subjects had seen their general practitioner within a month before the interview. Considerably more visits were made by home helps ($p<0.015$) and meals on wheels ($p<0.025$) to those with non-residential carers, whereas community nurses visited those with resident carers more often ($p<0.025$). There was a general and consistent pattern that dependants with close family received less support than did those with unrelated carers.

Most services increased with the degree of severity of disability of the elderly person (table III). Nevertheless, only 40 (34%) of the severely disabled were helped by a community nurse and 33 by a home help, and 23 visited a day hospital. Those who were housebound or bedfast were more likely to receive home helps and community nurses than those who were able to go out (table IV). Nevertheless, a third (2) of the bedfast dependants had not been visited by a community nurse and over half (4) had not been assisted by a home help. Services did not, however, vary noticeably with the degree of memory impairment of the elderly dependant (40 subjects were defined as

TABLE III—Services received according to disability of elderly dependant. (Values are numbers (%) of dependants)

Services	Disability of dependant			
	Mild (n=61)	Moderate (n=77)	Severe (n=117)	Not known (n=1)
Home help	4 (7)	6 (8)	33 (28)	1 (100)
Meals on wheels	4 (7)	7 (10)	8 (8)	—
Social worker	2 (3)	4 (5)	7 (6)	—
Nurse	3 (5)	7 (9)	40 (34)	—
Visit to day hospital	3 (5)	2 (3)	23 (20)	—
Occupational therapist	—	1 (6)	—	—
Physiotherapist	1 (2)	—	1 (1)	—
Voluntary worker	—	1 (1)	3 (3)	—

TABLE IV—Services received according to mobility. (Values are numbers (%) of dependants)

Services	Mobility of dependants			
	Bedfast (n=7)	Housebound (n=30)	Out with help (n=117)	Out without help (n=102)
Home help	3 (43)	9 (30)	21 (18)	11 (11)
Meals on wheels	1 (14)	2 (7)	9 (8)	7 (7)
Social worker	1 (14)	1 (3)	5 (4)	6 (6)
Nurse	5 (71)	14 (47)	25 (21)	6 (6)
Visit to day hospital	3 (43)	2 (7)	18 (15)	5 (5)
Occupational therapist	—	—	—	1 (1)
Physiotherapist	—	—	1 (<1)	1 (1)
Voluntary worker	—	1 (3)	2 (2)	1 (1)

severely impaired): in fact six severely impaired dependants were assisted by home helps and seven by community nurses, and two visited a day hospital. There was a significant association between memory impairment and physical disability ($p<0.001$): 22 of the elderly who were severely disabled also had severely impaired memories.

To examine the nature of the distribution of services among the population total numbers of services were calculated (table V). For most people there was no extensive network of care. Those carers who were totally unrelated to the elderly person were the ones most likely to be part of a larger network or team of statutory or informal carers as were non-resident carers.

RELIEF CARE

Fewer than half of the carers reported having had a break of a few days away from their dependant within the past year—significantly more non-residents than residents ($p<0.0005$). The more disabled (mentally or

TABLE V—Total services received according to residency. (Values are numbers (%) of dependants)

Total services	Residency of carers		
	Resident	Non-resident	Both
None	95 (58)	48 (52)	143 (56)
1	37 (23)	27 (29)	64 (25)
2	18 (11)	11 (12)	29 (11)
3+	13 (8)	7 (8)	20 (8)
Total	163 (100)	93 (101)	256 (100)

physically) the dependants the less likely the carer was to have had any form of break or holiday: 16 (40%) of helpers whose dependant was classified as having a severely affected memory had not had a holiday of a week or more within the past five years and only 13 (33%) had had one in the past year. Again those who cared for more dependent or physically disabled subjects were less likely to have had a holiday recently, and again non-residential carers were considerably more likely to have had holidays than were residents ($p < 0.0005$).

A third (88) of all carers said that they would like a break more often, particularly those who were resident carers ($p < 0.025$). This desire was significantly associated with the degree of dependency ($p < 0.0005$), disability ($p < 0.0005$), and memory impairment ($p < 0.025$) of the elderly person. Many carers expressed a desire for a system of shared care when they would look after their dependant for a while and then he or she would spend some time in residential accommodation. None of these carers in fact had such an arrangement of planned respite care. The main problem expressed by these carers was the unremitting nature and "tie" of their support.

Carers were asked whether they had ever received respite or relief care organised by the health or social services while they had been acting as carer: only 17 said that they had. Proportions were similar for residents and non-residents. Only 11 of those with severely disabled dependants had been provided with respite care; four (10%) of those caring for elderly people with severely affected memories had received respite care. None of these carers received the services of night or day sitters to relieve them for a few hours at a time.

Discussion

These results reinforce previous evidence to contradict the long held myth that families neglect their frail elderly relatives.^{2,6,11,12} On the contrary some family members care for their dependants at great cost to themselves. This burden of care falls mainly on female relatives.^{2,3,12}

Help with household tasks was most commonly provided: most of these tasks were undertaken by the carer without support from either other members of the family or domiciliary services. Non-resident and non-familial carers were most likely to be part of a network or team of care—that is, they received practical help from others. Home helps, community nurses, and day hospitals were the most common sources of support from the domiciliary services. Occupational therapists, physiotherapists, and volunteers were rare visitors. The receipt of services was much higher in this sample than in that of a normal population of elderly people: in 1980 the General Household Survey showed that in the population of over 65s, 35% had seen a doctor, 6% a community nurse, and 10% a home help within the previous month.¹³ In this study also a considerable association existed between the receipt of services and the disability of the dependant, which implied a rational allocation of resources, but only a few of those who cared for severely disabled elderly received such help and not all of those who cared for bedfast dependants received help from community nurses. Most of those caring for bedfast or severely disabled people said that they would appreciate the help of community nurses for bathing, washing, and lifting. No such association was apparent between the receipt of services and memory impairment of dependants, which indicates that memory impairment is considered to be less of an indicator of need than a physical disability. Interestingly, there was an inverse association between memory impairment and visits to the day hospital—a service that was appreciated mostly by carers for its respite or relief benefits.

It was the consistent and unremitting nature of caring for elderly dependants that was particularly stressful to carers.^{2,14} Respite for carers further exemplified the inverse care law: the more disabled or mentally infirm the dependant the less likely the carer was to have breaks or holidays; resident carers were also less likely than non-residents to have breaks. Few carers had ever benefited from respite organised by statutory services, and none was enjoying a scheme of planned respite or shared care. Carers seem to be faced with the stark choice of looking after the dependant with minimal support from the community at great cost to themselves or putting them into residential accommodation permanently.

Future policies concerning the care of the elderly must be orientated towards the family not the individual; innovations are

required to support the family as a whole in order to maintain their integrity. Also the policy cannot be to maintain the elderly in the community at all costs, as this imposes too great a burden on some people and leads to a high level of guilt in those carers who feel that they cannot cope.

General practitioners are in an ideal position to monitor and assess the problems of elderly dependants and their carers. They have the only available register of people aged 65 and over who live in the community, and only members of the primary health care team are regularly in contact with elderly dependants and can assess needs and potential problems in the homes of dependants, thus being able to prevent crises before they arise. Health visitors who have been shown to be effective in increasing and coordinating services to the elderly might be the members of the primary health care team most suitable, owing to their multidisciplinary background and training, to provide training and information to carers, assess their needs, and coordinate available domiciliary services to reduce the burden and strain on carers and subsequent breakdown in care.^{15,16}

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References

- 1 Department of Health and Social Security. *Growing older*. London: HMSO, 1981. (Cmnd 8173.)
- 2 Levin E. *The supporters of confused elderly persons in the community*. London: National Institute of Social Work, 1984.
- 3 Equal Opportunities Commission. *The experience of caring for elderly and handicapped dependants: survey report*. Manchester: Equal Opportunities Commission, 1980.
- 4 Gilhooly ML. The impact of care-giving on care-givers: factors associated with the psychological well-being of people supporting a dementing relative in the community. *Br J Med Psychol* 1984;282:35-44.
- 5 Sanford JRA. Tolerance of debility in elderly dependents by supporters at home: its significance for hospital practice. *Br Med J* 1975;iii:471-3.
- 6 Koopman-Boyden PG. Problems arising from supporting the elderly at home. *NZ Med J* 1979;89:265-8.
- 7 Townsend P. *Poverty in the United Kingdom*. Harmondsworth: Penguin, 1979.
- 8 Wilson LA, Brass W. Brief assessment of the mental state in geriatric domiciliary practice. The usefulness of the mental status questionnaire. *Age Ageing* 1973;2:92-6.
- 9 Blessed G, Tomlinson BE, Roth M. Quantitative measures of dementia and senile change in cerebral grey matter of elderly subjects. *Br J Psychiatry* 1968;114:797-801.
- 10 Jones DA. A survey of those who care for the elderly at home: their problems, and their needs. *Soc Sci Med* 1984;19:511-4.
- 11 Green S, Creese A, Kaulert J. Social support and government policy on services for the elderly. *Social Policy and Administration* 1979;13:210-8.
- 12 Brody EM. Women in the middle and family help and older people. *Gerontologist* 1981;21:471-81.
- 13 Office of Population Censuses and Surveys. *General household survey*. London: HMSO, 1982.
- 14 Jones DA. Caring for elderly dependants: effects on the carers quality of life. (Paper in preparation.)
- 15 Vetter NJ, Jones DA, Victor CR. Effect of health visitors working with elderly patients in general practice: a randomised controlled trial. *Br Med J* 1984;288:369-72.
- 16 Hendriksen C, Lund E, Stromgard E. Consequences of assessment and intervention among elderly people: a three year randomised controlled trial. *Br Med J* 1984;289:1522-4.

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A 44 year old man has multiple lipomas that are increasing in number and size to the extent that his trunk and limbs are now covered with them. Some have been excised and their nature proved histologically. Is anything known of the aetiology of such large numbers of lipomas and is there any form of treatment other than excision?

The typical histology and the fact that pain has not been mentioned presumably combine to rule out Dercum's disease, multiple angioliipomas, and lipoblastomatosis. Ordinary lipomas may be single or multiple—as is the case here. Occasionally multiple lipomas are familial or are associated with neurofibromatosis or Gardner's syndrome, but in most patients multiple lipomas have no special significance, nor is their exact aetiology fully understood. The only non-surgical treatment I have heard of is to inject lesions with triamcinolone,¹ but this would not be suitable for multiple lesions.—J A SAVIN, consultant dermatologist, Edinburgh.

- 1 Domonkos AN, Arnold HL, Odum RB. In: *Andrew's diseases of the skin*. 7th ed. Philadelphia: WB Saunders, 1982:703.