Survey of carers of elderly patients discharged from hospital

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SUMMARY. As part of a study to determine reasons for early unplanned readmission of elderly patients to hospital, the problems experienced by the carers of two groups of patients aged 65 years and over were analysed. Carers of 100 patients who had been readmitted in an emergency and 93 control patients were interviewed. The majority of carers were aged 60 year or over and two thirds were women. Forty one per cent of the carers were the patient's spouse. Forty per cent of the carers did not live with the patient. Many of the carers had been attending to the personal and domestic needs of their dependants for a considerable time. Carers complained about the effect the task had on their own health and the high levels of frustration experienced. Carer problems were important principal and contributory reasons for readmission. Carers of readmitted patients experienced more problems, frustrations and concerns than the carers of control patients. It is suggested that communication between professionals and carers should be improved, and, in particular, that the needs of carers should be assessed before discharge of patients from hospital.

Introduction

THE stated policy of the Department of Health is that elderly people should be cared for at home in the community if at all possible and it is apparent that the family is seen to be the main source of such care.[1] An investigation of carers in the community found that they supported elderly dependants at great cost to themselves and without adequate support from community services.[2]

During a study to determine reasons for early unplanned readmission of elderly patients to hospital, we examined the contribution made by the main carers to the successful resettlement of patients back into the community.[3] This paper presents the findings in relation to these carers and highlights those factors which may have an adverse effect on a carer's ability to cope.

Method

A total of 266 patients aged 65 year and over who had recently been discharged from hospital formed the total group. This consisted of 133 randomly selected patients from all specialties who were readmitted in emergency within 28 days of discharge and a matching control group of 133 patients who were not readmitted. Each patient was interviewed and also the principal carer if one was available. Eight patients (two study and six control) were living in homes for elderly people. As the aim was to study the problems of carers looking after old people in their own homes these people were classified as having no principal community carer. The reasons for the difference in outcome in the two groups and a full description of the methodology is given elsewhere.[3] The group was representative of the local population of elderly patients admitted to hospital in the main demographic indices.

Carers were present for 114 (86%) patients who were subsequently readmitted to hospital (study group) and 103 (77%) patients who were not readmitted; although this difference is not statistically significant it is noteworthy. A total of 193 interviews with carers took place: 100 involved readmitted patients and 93 control (non-readmitted) patients. The reasons for failure to obtain interviews were carer refusal (seven), patient refusal to allow carer to be interviewed (11) and inability to make contact (six).

Results

Characteristics of carers

Forty three per cent of the 100 carers of readmitted patients did not live with the person they looked after, compared with 38% of the 93 carers of control patients.

Over half the carers (54%) were aged 60 years or over, and 29% were between the ages of 70 and 79 years (Table 1); there were no significant differences in age distribution between control and readmitted group carers. The proportions of carers who were men rose in relation to increasing age (Table 1). Eighty carers were married to their dependant: 37% of the readmitted patients' carers and 46% of the control patients' carers.

Nearly a third (32%) of all carers had either a full- or part-time job. The carer's occupation or carer's spouse's occupation showed that the greatest proportion of carers were of social class 3M (43%), with fewer of the carers of readmitted patients in this group than control carers (38% versus 47%).

Almost half the carers (48%) reported having a long standing illness or disability; more of the readmitted group than control group carers (54% versus 42%). The majority of carers (57%) assessed their health as 'good' and 9% said that they were in 'poor health'. There was little difference between the two groups in this respect.

Frequency of visits by carers

Of 78 carers who did not live with the person they looked after, 37 (47%) visited the patient at least once a day and 19 (24%) visited more than once each day. Only three control carers called infrequently. Sometimes the carers lived in another locality and for 10 people the journey to the patient's home took over 30 minutes. Of the 43 carers of readmitted patients who did not

Table 1. Age–sex distribution of carers.

Age (years)	Number (%) of carers		Total number of carers
	Men	Women	
<40	2 *(15)*	11 *(85)*	13
40–49	7 *(19)*	30 *(81)*	37
50–59	10 *(26)*	28 *(74)*	38
60–69	12 *(34)*	23 *(66)*	35
70–79	26 *(46)*	31 *(54)*	57
⩾80	6 *(46)*	7 *(54)*	13
Total	63 *(33)*	130 *(67)*	193

$\chi^2 = 11.1$, df = 5, $P<0.05$.

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live with the patient, 24 (56%) visited at least once a day; 17 (40%) said that looking after the elderly person caused problems in their own home and six said that their own family life had been destroyed at the expense of meeting the patient's needs. Of the 35 control carers who did not live with the patient 13 (37%) visited at least once a day and seven said it caused problems for them at home.

Tasks performed by carers

Seventy one per cent of the carers of the readmitted group were involved in at least one intimate task (dressing, bathing, washing, coping with faecal or urinary incontinence and changing colostomy bags) compared with 47% of the control carers. Of the 15 carers who were involved in extensive care, that is helping with five or all of the above tasks, 12 cared for readmitted patients and only three cared for controls. Carers of readmitted patients had been seeing to these needs sometimes for a considerable length of time, up to a maximum of 19 years.

Carers of readmitted patients were far more likely than control carers to be involved in dressing the elderly patients and in getting them up in the morning and putting them to bed (54% versus 31%) (χ^2 = 9.3, df = 1, $P<0.01$). They were also more likely than control carers to include washing the patient as part of their regular care (49% versus 33%) (χ^2 = 4.3, df = 1, $P<0.05$). Twenty one per cent of the carers of readmitted patients and 11% of the control carers were coping with the frequent changes of laundry required because of the elderly person's incontinence of urine. More carers of readmitted patients were managing faecal incontinence (26% versus 11%) (χ^2 = 6.4, df = 1, $P<0.05$). This was the most distressing problem of all for carers.

Fifty eight per cent of carers of readmitted patients looked after practical household tasks (cooking, shopping and housework) as did 56% of the control carers. There was little difference between the two groups in the time they had been responsible for these tasks, the means being between three years and three years six months. There was also no difference in the range. Eleven out of the 12 carers of readmitted patients who cared extensively for the patient's more intimate tasks also attended to these household tasks, as did one of the three control carers. Eight of the carers of readmitted patients and 10 control carers had been looking after the elderly patient for between eight and 19 years. One control carer had attended to all the patient's needs for almost nine years and one carer of a readmitted patient had done so for more than 19 years.

Effects on health of carers

Fifty four per cent of all the carers of readmitted patients when asked directly said their own health had been affected by the task compared with 37% of the control group ($P<0.05$). For both groups of carers the most frequent comments were about the general strain of caring for the patient, resulting in problems with anxiety, fatigue and depression (48% and 32% respectively said they were fatigued) (Table 2). The next most frequent factor which affected health was the continuous tie and unremitting pressure of the patient's needs. Six carers of readmitted patients said their health had been affected to such an extent that they were unable to continue looking after the patient and in one of these cases this fact was a principal reason for readmission of the patient. Seven carers of readmitted patients felt their health had been adversely affected by having to cope with patients' incontinence.

Frustrations of carers

There was a highly significant difference between the two groups of carers in reported frustrations; 67% of all carers of readmitted patients said they felt frustrated compared with 37% of the control carers (χ^2 = 16.7, df = 1, $P<0.001$). Comments most often made by both groups were about being tied by the unremitting demands of the patient at the expense of their own needs for personal space (44% versus 27%) (Table 3). Dissatisfaction about the hospital's management of the patient's medical condition and follow-up support, followed by the exhaustion of caring for the patient were the next most common causes of frustration. Nineteen per cent of the carers of readmitted patients were frustrated about the difference between their perception of the severity of the patient's condition and the hospital staff's assessment; this applied to only 4% of the control carers. Although these cases were few, carers who perceived such inconsistency had a very heightened sense of frustration. They felt the hospital staff were underestimating the severity of the patient's condition and that both the patient and the carer were deprived of much needed care and support. Carers also felt helpless when they perceived that the patient's placement was inappropriate, for instance in a ward with patients suffering from senile dementia or when they thought the hospital staff were insensitive.

Table 2. Carers' comments about the aspects of caring which affected their health.

Aspects of caring which affect health	Percentage of respondents[a] Study (n = 100)	Control (n = 93)	Total (n = 193)
General strain of caring, resulting in:			
Fatigue	48	32	40
Disturbed sleep	12	5	9
Continuous pressure of patient's needs	16	13	15
Problems of physical work, eg lifting	10	8	9
Problems of patient's behaviour, eg aggression	9	3	6
Missing practical support of patient	7	4	6
Coping with patient's distress	7	2	5
Coping with patient's incontinence	7	0	4
Adverse effects on own family	4	1	3

[a] Respondents could make more than one comment. n = total number of respondents.

Concerns of carers

Twelve per cent of carers of readmitted patients and 4% of control carers said that the elderly people they looked after had neglected themselves to such an extent that their health was in danger. Eighteen per cent of the carers of readmitted patients and 11% of the control carers were very concerned about the high risk of a dangerous accident occurring or the elderly person over- or under-dosing themselves with prescribed drugs. A few of the carers had to contend with unpredictable behaviour. This applied to six readmitted patients and two control patients. Nearly one quarter of the total group of carers had communication difficulties with their patients and this applied more often with the readmitted patients (31% versus 14%) (χ^2 = 7.0, df = 1, $P<0.01$). Almost one third of the carers said that their sleep had been disturbed by getting up to see the patient.

Again this was true more often for the readmitted group (37% versus 24%) (χ^2 = 3.4, df = 1, $P<0.05$). Both groups of

Table 3. Carers' comments about the frustration of caring.

Reasons for frustration	Percentage of respondents[a] Study (n = 100)	Control (n = 93)	Total (n = 193)
Continuous pressure of patient's needs	44	27	36
Dissatisfaction with medical care in hospital	29	11	20
Own tension and nervous exhaustion	23	15	19
Inconsistency between professionals' and carer's perceptions of patient's condition	19	4	12
Dissatisfaction with hospital conditions, eg inappropriate ward	13	4	9
Uncertainty of patient's prognosis	13	4	9
Problems of patient's behaviour, eg aggression	10	6	8
Problems of physical work, eg lifting	11	3	7
Dissatisfaction with GP	11	2	7
Lack of support from family	5	4	5
General helplessness	7	1	4
Adverse effects on own family	6	2	4
Coping with patient's incontinence	6	1	4
Missing practical support of patient	6	0	3
Other[b]	5	2	4

[a] Respondents could make more than one comment. [b] Includes: problems at work, unable to find suitable accommodation for patient, positive aspects. n = total number of respondents.

carers were asked to make some general comments about their main concerns when looking after their elderly dependants (Table 4). The main concerns for both groups were lack of knowledge about the prognosis for the patient's condition and concern about the patient's vulnerability and distress.

Other comments included being taken for granted, patients' excessive expectations, the tension and responsibility of caring and the continuous pressure of caring, physical difficulties such as lifting the patient, other illness in the family and pressure from hospital staff to look after the patient.

Readmission owing to inability to cope

Carers' inability to cope was considered to be the principal reason for readmission in 19 (14%) of 133 cases. In general the period between discharge and readmission of these elderly patients was short — with a mean of only nine days. Fifteen of the patients were women and four were men; their average age was over 80 years and nine of them lived alone. The carer was a spouse in only five cases: the remainder were other relatives, a lodger and a neighbour. In 16 cases the problems experienced by the carer — ill health, intense distress and difficulties with relationships — were judged to be a result of caring for the patients. In three other cases there was no obvious connection: one carer lived in another locality, had a history of heart problems and was unable to give adequate support; in another case the carer had had a fall; in the third case the carer had a history of violence and depression and showed little interest in his wife's condition. These cases represent only the tip of the iceberg, however. Carer problems were considered by the authors to be contributory to

Table 4. Carers' main concerns.

Main concerns	Percentage of respondents[a] Study (n = 100)	Control (n = 93)	Total (n = 193)
Uncertainty of patient's prognosis	37	37	37
Vulnerability of patient	38	30	34
Distress of patient	23	9	16
Tensions of caring	14	13	13
Continuous pressure of patient's needs	13	13	13
Responsibilities of being carer	14	10	12
Problems of physical work, eg lifting	12	10	11
Presence of other illness in family	11	4	8
Problems of patient's behaviour, eg taking carer for granted, excessive expectations	5	9	7
Rapid deterioration of patient when hospitalized	3	9	6
Pressure from hospital staff to look after patient	9	2	6
Other[b]	17	12	15

[a] Respondents could express more than one concern. [b] Includes: economic problems, patient's diet, effects on carer's family, dissatisfaction with hospital, carer's embarassment about attending to patient's personal hygiene, criticism of general practitioner. n = total number of respondents.

62% of the total of 133 readmitted cases. Again the reasons were variable but principally reflected the problems described earlier.

Discussion

The whole group of patients studied were representative of the population of elderly patients admitted to local hospitals in terms of age, sex and marital status, but not representative of the general population. The problems of the carers of this group are therefore worth considering as they may be typical of those carers of elderly patients admitted to hospital. There were an appreciable number of patients who had no identifiable principal carer and were therefore reliant on statutory services.[4] The advanced age of many of the carers of the elderly and the fact that almost half had long standing illnesses or disabilities differed from Jones and Vetter's findings[2] and is probably related to the older age group of patients admitted to hospital and the fact that most carers were spouses. More of Jones and Vetter's carers were women (79%). The fact that a third of the carers in the present study were men was also noteworthy. The readmitted patients in the present study were clearly frailer than those in the control group and this is reflected in the higher percentage of carers among the readmitted group. In the Jones and Vetter study two thirds of the carers were resident in the home of the patients. Fewer than half were resident in the present study; most of those who lived separately made regular visits.

From the carers' descriptions of their involvement with those they looked after it was clear that the costs of caring were often high in terms of the effects on their own and their families' lives. This was particularly true of the carers of readmitted patients. Of the six carers who said their family life had been destroyed by looking after the elderly person one had carried this responsibility for 11 years and two had done so for eight years. Both groups of carers said their health had been affected but this was reported far more often by carers of readmitted patients. Similarly, the carers of patients who were later readmitted experienced

more frustration than control group carers. The main frustrations were being tied by meeting the patient's needs, tension and exhaustion, dissatisfaction with hospital management of the patient and lack of follow-up support.

As in the study of Jones and Vetter, carers were involved in a high level of intimate and practical tasks for their patients, especially in the study group. Sanford[5] reported on tolerance levels of carers of patients admitted to hospital and found that certain tasks, especially those associated with incontinence, had a low level of tolerance among carers. It would appear that in the case of carers of readmitted patients, tolerance levels for intimate tasks were often very near to the limit and on some occasions the tasks became unendurable. This undoubtedly accounts for the higher levels of problems among carers of patients who were readmitted. The carers reported differences in perception between themselves and the professional staff and this was more common among carers of readmitted patients. Another problem with communication was that carers lacked adequate information about the patient's condition. Uncertainty as to prognosis ranked very highly among the main concerns of carers. Many commented that their feelings of helplessness and despair were exacerbated by not knowing how the patient's condition was likely to progress, what would happen and for how long they would have to maintain their role.

Jones and Vetter concluded that there is a great deal of distress among carers[2] and this is clearly confirmed in the present study. General recommendations have been made in an earlier paper[3] about the procedure for discharging elderly patients back into the community. The needs of the carers are important at this stage and this means that a careful assessment of the patient should be made before discharge. It is necessary to communicate information and give the carer an understanding of the patient's medical condition and prognosis. Early support by district nurses, social workers and general practitioners is also necessary. This cooperation and help is essential to enable families to cope with what is often a responsible and arduous contribution to the care of the elderly in the community.

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