Stress in informal carers of hospitalised elderly patients

ABSTRACT—The aim of this study was to assess psychological well-being in carers of elderly hospitalised patients and to identify factors predicting those at risk. There are over six million informal carers in the UK. An objective measure of carers' mental health was obtained using the General Health Questionnaire and a subjective assessment (from the carer's point of view) of how caring affected their own everyday lives was also made. Of the 93 carers interviewed, 42 (45%) showed objective evidence of significant psychiatric disturbance. When questioned about their caring roles, 32% felt their health was affected by caring and 46% their social lives; 63% subjectively reported stress and 47% depression; 15% changed their employment patterns. Patients and carers received few statutory social services: 26% home care, 11% district nursing input, 8% meals on wheels and 5% either day centre or day hospital attendance. Cohabitation made it more likely that the carer's mental health would show some impairment. The informal carers' high stress levels and interference with their daily lives have implications for future care planning for the elderly.

There are currently more than six million informal unpaid carers in the United Kingdom; 50% of them have dependants over the age of 75 years [1]. Caring is usually performed at great personal cost and there is no evidence that the carers neglect their elderly relatives [2]. Although the needs of certain groups of carers are being increasingly recognised, particularly those who look after elderly demented patients [3,4] and stroke patients [5], the difficulties faced by carers of elderly patients admitted to acute medical wards have not been adequately investigated. In this study we assessed stress and depression levels in those who regularly look after this group of elderly patients and ascertained how caring affected their personal lives. We also tried to identify which factors might place those carers most at risk of psychological stress.

Subjects and methods

The study was conducted on two acute wards of a busy department of medicine for the elderly with a rapid turnover of patients and a mean duration of stay of six days. The protocol involved assessments both of the carer and the cared. For the purpose of this study an informal carer was defined as an unpaid person, usually a relative who either lived with or visited the patient on two or more occasions per week; this definition was somewhat arbitrarily chosen to aid standardisation and recruitment.

Randomly chosen carers were interviewed during the convalescent phase of the patients' illnesses. Carers of acutely ill, confused or dying patients were excluded. No other assumptions were made about the level of support given to the patients by the carers prior to entry into the study.

Carers were invited to answer a modified questionnaire on how their everyday lives were affected by their caring roles [2]. This formed a subjective assessment (from the carers' point of view) of the effects of caring. As part of this assessment the carers were directly asked how much stress or depression their caring role had caused them prior to the admission of the patient. They were also asked about the effect of caring on their social and family life, whether it affected their employment, their ability to take holidays or their health. Statutory social services received by the patients were also recorded during this interview with the carers.

The carers' mental state was objectively assessed using the 60 question General Health Questionnaire (GHQ) [6]. It was administered without specific reference to their caring role and concerned changes in the carer's mental state in the three to four weeks preceding the patient's admission to hospital.

The patients' functional status was measured during convalescence using a modified Winchester Disability Rating Scale (WDS) [7]. This scale concentrates mostly on the activities of daily living. It was administered by the primary nurse responsible for each patient. As part of the WDS, the nursing staff gave an assessment of how much stress they felt the carer was under and this was done in a blinded fashion, allowing us to quantify the nursing staff's ability to detect stress levels in the carers.

All interviews were conducted during ward visiting times by RL and LM. The carers were interviewed in a quiet room away from the patients. Statistical analysis was by \chi^2 tests (with Fisher exact or Yates corrections as appropriate), Student's t-tests (two sample assuming unequal variance) and Spearman's rank correlation tests. All analyses were two tailed and \p < 0.05 was taken as significant.

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Results

Ninety-three informal carers were interviewed. They cared for patients whose average age was 78.7 years. The mean age of the carers was 60.3 years (±12.6). Sixty-five carers were women, of whom 43 were non-spouse. Of the 28 male carers only 13 were non-spouse and most of these were sons (Table 1). Fifty-six of the carers were co-resident but less than one-third of them were men. Only 3 of the non-spouse men but 16 of the non-spouse women were co-resident. A heavy burden of caring was therefore carried by female carers.

Table 2 shows how the carers were affected by caring. Forty-two (45%) carers scored positive on the GHQ (≥ 11/60), indicating a high probability that they had suffered some psychological disturbance in the three to four weeks prior to the administration of the questionnaire. When directly questioned about their caring roles, 59 (63%) said they were stressed and 21 of them said this was regular or constant; 44 (47%) felt depressed and 12 said it was regular or constant. There were good correlations between self-reported stress levels and positive GHQ scores ($r = 0.62$ and between self-reported depression and GHQ scores ($r = 0.54$).

Thirty carers said their own health was affected by caring. Typical complaints were of excessive tiredness (11), back strain (3), poor sleep (2), worsening angina (2), others (12). Of the 30 carers who had not had a holiday for more than two years, 17 had not had a holiday for over five years. Effects on social life, family life and employment are also shown in Table 2.

We also attempted to identify factors which might predict those most at risk of stress. Table 3 shows comparisons of carers with positive GHQ scores and those with negative scores: there were no statistically significant differences between the ages of the carers in these two groups nor between the ages of the patients or their disability scores; nor were there any differences in the level of social supports received by each group although the overall proportion of patients receiving social supports was low, with just 26% receiving weekly home care, 8% meals on wheels, 2% day hospital attendance, 3% day centre attendance and 11% district nursing input. Co-residency, however, was associated with higher GHQ scores although this did not quite reach statistical significance ($p = 0.056$). None of the patients received regular respite admissions.

| Table 1. Who is doing the caring? |
|----------------------------------|
| Relationship to patient | Number | Mean age (years) (SD) | Number co-resident (%) |
| Daughter | 32 | 51.1 (±5.8) | 16 (50) |
| Wife | 22 | 73 (±5.6) | 22 (100) |
| Husband | 15 | 72.8 (±6.2) | 15 (100) |
| Son | 10 | 48.1 (±5.2) | 2 (20) |
| Niece | 4 | 51.8 (±9.7) | 0 |
| Sister | 4 | 71 (±4.7) | 0 |
| Other relatives | 5 | 48.2 (±8.4) | 1 (20) |
| Friend | 1 | 64 | 0 |
| Total | 93 | 60.3 (12.6) | 56 (60) |

SD, standard deviation

| Table 2. How caring affects carers’ lives. |
|------------------------------------------|
| Effect of caring | Number | % |
| GHQ ≥ 11 (indicating objective stress/depression) | 42 | 45 |
| Carer felt ‘stressed’ by caring role | 59 | 63 |
| Carer felt ‘depressed’ by caring role | 44 | 47 |
| Carer felt caring was detrimental to health | 30 | 32 |
| Carer felt caring was detrimental to social life | 43 | 46 |
| Carer felt caring was detrimental to family life | 29 | 31 |
| Carer felt had to change employment patterns | 14 | 15 |
| Carer had no holiday for 2 years or more | 30 | 32 |

GHQ, General Health Questionnaire

| Table 3. Comparison of patients with high and low stress scores |
|---------------------------------------------------------------|
| Carers with GHQ < 11 (51 carers) | Carers with GHQ ≥ 11 (42 carers) | p value |
| Carer’s age* (years) | 59.3 (±12.2) | 61.5 (±13.2) | NS |
| Patient’s age* (years) | 79.3 (±7.4) | 77.8 (±7.6) | NS |
| Patient’s disability score* | 58.8 (±9.2) | 55.7 (±12.8) | NS |
| Co-resident with patient | 26 | 30 | 0.056 |
| Home care† | 10 | 14 | NS |
| Meals on wheels† | 2 | 5 | NS |
| Day hospital attendance† | 1 | 1 | NS |
| Day centre attendance† | 1 | 2 | NS |
| District nurse† | 4 | 6 | NS |

*Mean (± standard deviation) †Expressed as number of patients receiving service at least weekly
There was a poor correlation between the carers’ GHQ scores and the patients’ disability scores ($r = -0.25$). Only 11 of the 93 patients had significant problems with the activities of daily living: 2 were assessed as ‘needing much help’ and 9 as ‘manage with difficulty’; the remaining 82 patients were assessed as having ‘some difficulty with the activities of daily living’ (36 patients) or ‘minimal or no impairment’ (46 patients). There was also a poor correlation between GHQ score and the nurses’ assessment of stress levels in the carers ($r = -0.22$).

Discussion

This study confirms one of the main findings of a community based study by Jones and Peters that carers care for elderly relatives at great personal cost to themselves and that this burden is largely carried by women [2]. In this hospital based study we chose the GHQ to analyse carer stress because of its objective nature. We defined a carer as a person who either lived with or visited the patient on two or more occasions per week. This approach clearly will include some people who would not consider themselves as carers and exclude others who would. It did, however, aid recruitment and standardisation.

The GHQ is a well validated method concentrating on changing aspects of psychological functioning or breaks from normality. It has no role in assessing life-long traits such as personality disorders or neuroticism. Furthermore, it addresses a defined time period and is specifically aimed at changes in symptoms in the ‘few’ weeks prior to the administration of the questionnaire. A positive score of 11 or more out of 60 gives a probability estimate of the individual being mentally ill during this time period, the cut off of 11 indicating ‘just significant clinical disturbance’ [8]. Jackson et al previously used this tool to demonstrate high psychiatric morbidity in the carers of elderly demented patients in the community [4].

In this study we have found a high rate of probable psychiatric morbidity in the carers of elderly hospitalised patients, with 45% positive on the GHQ. This is akin to a recent general practice study (of fatigue) showing a 36.7% positivity on GHQ in a practice population of over 30,000, 50% of whom returned a questionnaire [9]. Their ages, however, were 18–45 years and it is unclear whether the subgroup who returned their questionnaires were representative of the population as a whole.

Many interpretations are possible for the high GHQ positivity in this group of carers. It may represent a reaction to the patient’s illness, it may represent guilt over perceived neglect, fatigue secondary to visiting or worry over the patient’s impending discharge from hospital. It is also possible that high stress levels in the carers helped to precipitate the patient’s admission in some fashion. An emergency admission could be expected to have an effect on the carer’s psychological well-being but it is noteworthy that there was a good correlation between self-reported stress secondary to a ‘caring role’ and positive GHQ scores. This indicates that positive GHQ scores were not solely a reaction to the patients’ illnesses. Acute medical admissions to general hospitals continue to increase and the reasons for this are unclear [10]. It is therefore essential to examine factors that might account for this. Pre-admission stress levels in carers may be one such factor. Carers unable to cope with their caring role may therefore directly affect general hospital services. A hospital based population is not appropriate to study such a phenomenon but we feel there is sufficient evidence in this study to support a larger community based study of the effects of carer stress on admission rates.

It is rather surprising that the degree of patient disability did not correlate with GHQ scores. This group of patients, however, was reasonably independent in the activities of daily living as they were convalescing, pre-discharge patients. The degree of patient disability may be less important than its duration. Co-residency was the only factor which did appear to be associated with higher GHQ scores in this study.

Along with the objective measures of psychiatric morbidity obtained from the GHQ, carers admitted to significant subjective stress and depression and significant disruption of their day-to-day lives by caring. The proportion receiving regular statutory social services was low. The nursing staff appeared to be unable to pick out carers with high GHQ scores. This may have been due to the traditional assumptions that the degree of patient disability is an indicator of stress in the carers rather than attempts to enquire directly into personal difficulties.

In summary, we have shown objective evidence of significant stress-related psychiatric morbidity in the carers of elderly hospitalised patients which may be related to their caring role. Disruption of carers’ day-to-day lives and co-residency may be important factors contributing to their high stress and depression levels. This may, in turn, affect hospital admission rates, with important implications for future health care planning.

Acknowledgement

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TRAVEL-ASSOCIATED DISEASE

Edited by Gordon C Cook FRCP

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