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Stroke. 1999;30:1517-1523

doi: 10.1161/01.STR.30.8.1517

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Print ISSN: 0039-2499. Online ISSN: 1524-4628

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Stroke Patients' Informal Caregivers

Patient, Caregiver, and Service Factors That Affect Caregiver Strain

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Background and Purpose—Research has revealed that caring for a stroke patient can result in caregiver strain and a myriad of other difficulties for caregivers. This study aims to identify the level of strain experienced by caregivers in the early months after stroke and to assess the relationship between caregiver strain and caregiver characteristics, patient characteristics, and service inputs.

Methods—Stroke patients were identified through a random stratified sample of general practices. Patients were asked to identify their principal informal caregiver. Strain was measured with the Caregiver Strain Index, and all data were collected from caregivers at 1, 3, and 6 months after the patient's stroke. Multiple regression analysis was used to examine the factors associated with caregiver strain.

Results—Six months after stroke, 37% of caregivers were experiencing considerable strain. The amount of time a caregiver spent helping a stroke patient, the amount of time the caregiver spent with the patient, and the caregiver's health were all significantly associated with the level of strain experienced. Although none of the services or patient factors tested in this study were consistently associated with strain, an indicator of stroke severity was significant at each time point.

Conclusions—Caregivers are experiencing strain, which has implications for research and service provision. Service providers need to identify caregivers at risk of greater strain and to help caregivers work through situations that services cannot alter. Research is needed to identify services that are effective in strain alleviation. Future research should also aim to identify the interface between patient characteristics and strain, burden, and depression and particularly to assess the caregiver's perception of these relationships. (*Stroke*. 1999;30:1517-1523.)

Key Words: caregivers ■ Scotland ■ stress ■ stroke management

It has been argued that informal caregivers are the backbone of the service provided to surviving stroke patients,^{1,2} but this situation is not without adverse effects on the caregivers.³⁻⁶ Greveson et al⁷ indicated that 30% of caregivers were under considerable strain 3 years after stroke, and Wilkinson et al³ found 21% under strain 5 years after stroke. However, the causes and patterns of strain in the early poststroke period have not been described.

There is also little evidence regarding the effect of existing services on caregiver problems. Research has attempted to find strategies to alleviate caregiver problems^{8,9} but without substantial success. It has been hypothesized that the research programs failed because they were not aimed at the aspects causing caregivers most difficulty,⁵ but the evidence is unclear.

Furthermore, it has been hypothesized that patient factors will have an effect on caregivers' health and well-being.^{5,6,10-13} However, a conflicting picture emerges, with some researchers reporting defined aspects of patient characteristics that affect caregivers^{5,10,12,13} and others finding no specific relationship.^{6,11,14} The converse relationship has also

been suggested, in that family problems may have an effect on the stroke patient's recovery.^{15,16}

Therefore, it is possible that caregivers may affect stroke patients' recovery and, conversely, stroke patients may affect caregivers' strain, but again the evidence is unclear. This study aims to provide among the first empirical data from a community-based sample of caregiver strain in the early poststroke phase and, as such, it will expand on previous published findings. Consequently, this report aims to address the following research questions: (1) What is the level of strain experienced by stroke patients' caregivers in the early poststroke phase? (2) What patient, caregiver, and service factors account for variation in the level of strain experienced by these caregivers?

Subjects and Methods

The study was conducted in 1 Health Board locality in Scotland that has both urban and rural areas and a population of 376 500. Ethical approval was sought and granted from the local ethics committee, and informed consent was obtained before study involvement. Access to subjects and sites was sought and granted from senior management.

Received November 24, 1998; final revision received May 6, 1999; accepted May 6, 1999.

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TABLE 1. Services Entered into the Regression Equation

Variables (NHS)	Variables (Non-NHS)
Physiotherapy	Day care
Occupational therapy	Lunch club
Speech therapy	Volunteer Stroke Services
Dietetics	Stroke club (not Volunteer Stroke Services)
Podiatry	Social worker
Community nursing	Home help
	Meals on Wheels
	Provision of aids and adaptations
	Crossroads
	Other caregiver support
	Other patient support

Subjects

Caregivers were identified through the stroke patients participating in the main study. Patients were identified through general practices to ensure representation of those cared for at home and in hospital. A total of 64 practices were stratified by geographic region (north, south, or east) and total patient caseload carried by the practice (<6000 or ≥6000 patients) and then randomly selected. A total of 24 practices agreed to participate (78% of those approached; 180 252 people, covering 48% of the population). Each practice was asked to prospectively identify all stroke patients (transient ischemic attacks were excluded) at stroke onset from May 1996 to April 1997. Stroke patients who were alive at 1 month and agreed to participate were asked to nominate their principal informal caregiver. This person was defined as "the person who helps you the most but who is not paid to do so."

Data Collected

General practitioners were asked to provide background medical and social history (premorbid illness, social circumstances, prestroke level of disability as determined by Barthel Index¹⁷) and a measure of onset severity (Glasgow Coma Scale¹⁸). Thereafter, outcome measures were recorded at 1, 3, and 6 months after stroke with the use of a structured interview and conducted either in the patient's home or in the hospital. Measures used were the Barthel Index,¹⁷ the Canadian Neurological Scale,¹⁹ the Mini-Mental State Examination,²⁰ and the Short Form 36 (SF-36).²¹

Agreement was reached with the departments of physiotherapy, occupational therapy, dietetics, podiatry, speech therapy, and community nursing to supply details of contacts with participating patients at the 1-, 3-, and 6-month time frames. Patients were asked about contact with other support services including volunteer groups (lunch, day care, support groups), social service inputs, and caregiver support (Table 1).

During the first interview (1 month after stroke), caregivers were asked to provide data regarding their demographic characteristics. At all 3 time points, caregivers were asked to identify the type of help they gave (physical, emotional, and/or being with the patient to maintain his/her safety) and whether the help they were giving now was more than before the patient had the stroke. They were also asked to self-report on the amount of time they spent with the patient in an average day (hours per day) and of the amount of this time spent with the patient, the amount of time that they spent helping the patient (hours per day). These were crude measures developed for the purposes of the study. They were intended to be questions that could be easily incorporated into professional assessment. For example, a sample question might be as follows: "Since your friend/relative had a stroke, would you say that your support or helping involves giving physical help?"

On the basis of a comprehensive literature review,²² 2 outcome measures were selected: the Caregiver Strain Index (CSI)²³ and the SF-36.²¹ The CSI had been used to measure strain 3 and 5 years after

TABLE 2. Patient Variables Entered into the Regression Equation

Variables
Age
Sex
Deprivation score*
Living alone before stroke
Geographic location (north, south, east)
Previous medical history (including heart disease, previous stroke, diabetes)
Glasgow Coma Scale ¹⁸ at stroke onset
Incontinent within 7 days of stroke onset
Premorbid disability (Barthel Index ¹⁷)
Hemorrhagic stroke (identified by CT scan)
Disability after stroke (1, 3, 6 mo) (Barthel Index ¹⁷)
Impairment after stroke (1, 3, 6 mo) (Canadian Neurological Scale ¹⁹)
Cognitive ability (1, 3, 6 mo) (MMSE ²⁰)

*Deprivation was assessed using the 7 categories defined by Carstairs and Morris.²⁷ Categorization by postal code is determined on the basis of employment, car ownership, social class, and overcrowding.

stroke^{3,7}; its use in this study in the early poststroke phase would thus allow comparison with later stages after stroke. In addition, the literature review identified that the CSI was useful both for the identification of individual items that caused most difficulty and for a global score. The SF-36 has been tested for validity and reliability^{24,25} and enabled assessment across a range of health dimensions. Using the CSI, previous researchers have used a measure of >6 to identify considerable/marked strain.^{3,7} To assess for a floor effect in this study, those scoring zero were also categorized separately. When possible, caregivers were asked to self-complete questionnaires while the research nurse was interviewing the patient. When this was not possible, questionnaires were left for caregivers to complete and return.

Data Analysis

Data were initially analyzed at a descriptive level with the use of SPSS.²⁶ Correlational analysis preceded multiple regression²⁶ to identify factors predictive of strain in a staged process. All caregiver independent variables (age, sex, spouse or not, time helping patient, time with patient, type of help, number of others helping) were entered into models with CSI score as the dependent variable. Variables that achieved significance at the 5% level were included in the model. Next, the patient variables (Table 2) were entered, and the significant variables were subsequently used to adjust the analysis by case mix. The relationship of health on strain was tested by the addition of the 8 individual SF-36 health dimensions as independent variables. Finally, all the National Health Service (NHS) provisions and non-NHS provisions were tested for their effect on caregiver strain (Table 1) with input between each time frame (up to 1 month, between 1 and 3 months, and between 3 and 6 months).

Results

A total of 232 stroke patients were identified who survived to 1 month after stroke. Of these, 66% (n=153) agreed to participate. Nineteen percent (n=45) of patients refused to participate. The remaining nonparticipants (n=34) were excluded on the advice of their general practitioner or consultant or could not be recruited for other reasons. Of the 153 patients who were recruited, 110 (72%) had caregivers who agreed to participate. Ten percent (n=15) did not have a caregiver who could be approached, 3% (n=4) preferred that their caregiver was not asked, and 16% (n=24) of caregivers

TABLE 3. Mean Patient Outcome Scores 1, 3, and 6 Months After Stroke

	1 Month	3 Months	6 Months
Disability (BI)	14.4 (13.3–15.4) (n=110)	16.1 (15.2–17.0) (n=103)	16.2 (15.4–17.0) (n=99)
Cognition (MMSE)	24.0 (22.6–25.3) (n=107)	25.2 (24.0–26.4) (n=102)	25.9 (24.8–27.0) (n=98)
Neurological impairment (CNS)	8.1 (7.7–8.5) (n=110)	8.5 (8.2–8.9) (n=103)	8.8 (8.4–9.1) (n=99)

Values in parentheses are 95% CIs. The higher the score, the smaller is the level of disability, cognitive difficulty, and impairment. Maximum possible scores were 20 for Barthel Index (BI), 30 for Mini-Mental State Examination (MMSE), and 10 for Canadian Neurological Scale (CNS).

refused or did not return questionnaires. This report concentrates on the data for the 110 patient/caregiver pairs. Not all caregivers were able to provide all the required information, and consequently the data represent proportions of respondents to the particular items.

Stroke Patients' Profile

On average, those stroke patients with caregivers who participated were aged 70.5 years (95% CI, 68.5 to 72.4; range, 35 to 93 years), and 54.5% (n=60) were male. Most patients were admitted to the hospital (77.3%), and the mean level of reported disability before the stroke, as measured by the Barthel Index, was 19.0 (95% CI, 18.5 to 19.6; range, 4 to 20). There was a range of premorbid medical history, eg, 41.8% (n=46) of these stroke patients were hypertensive before stroke; 33.6% (n=37) had heart disease; and 22.7% (n=25) had had at least 1 previous stroke. Mean Glasgow Coma Scale measurement at stroke onset was 13.8 (95% CI, 13.4 to 14.3; range, 3 to 15, with 15 indicative of fully conscious level), and 44.5% (n=49) were incontinent within the first 7 days after stroke onset.

Table 3 shows the mean disability, cognitive impairment, and neurological impairment scores for stroke patients. The mean scores for all outcomes measured improved from 1 to 6 months, yet even at 6 months after stroke the mean scores were well below the maximum possible scores. Thus, average patient function remained compromised 6 months after their stroke (on average at a mild level of disability).

Description of Stroke Patients' Caregivers

The average age of the caregivers was 60 years (95% CI, 57.5 to 62.2), and 43% were aged 65 years or older. Most caregivers were women (73%). A χ^2 comparison of caregiver against patient sex revealed that it was significantly more common that women were caregivers and men were patients ($\chi^2=38.1$; $df=1$; $P<0.0001$; n=110). The vast majority of principal caregivers were members of the patient's family (97%), with 62% (n=68) their husband/wife and 24.5% (n=27) their children. Caregivers reported that, on average, 1 or 2 other people helped them to care for the stroke patient.

During the first month after stroke, caregivers reported that they spent an average of 13.5 hours (95% CI, 11.6 to 15.3) a day with the stroke patient. At 3 months this had risen to 16.6 hours (95% CI, 14.7 to 18.5), and at 6 months it was 16.4 hours (95% CI, 14.5 to 18.3).

The amount of time caregivers spent helping the stroke patient was considerable, on average 6 hours per day (Table 4). Caregivers gave more help if the patient was at home or in an "other" location. However, caregivers of patients in the hospital reported giving considerable amounts of help, on average 2 to 3 hours per day.

Caregivers confirmed that they gave more help to the patient after the stroke than before it (77% reported this at 1 month, 85% at 3 months, and 80% at 6 months). At all 3 time points, caregivers said they most commonly gave emotional help (75% reported this at 1 month, 78% at 3 months, and 77% at 6 months). However, many caregivers reported providing physical help (49% reported this at 1 month, 54% at 3 months, and 47% at 6 months), and many felt they had to be with the stroke patient to ensure that he/she was safe (50% at 1 month, 48% at 3 months, and 51% at 6 months).

Caregiver Strain

On average, caregivers scored 4.5 (95% CI, 3.8 to 5.3; n=92) on the CSI 1 month after stroke, 4.3 (95% CI, 3.6 to 5.1; n=85) at 3 months, and 4.5 (95% CI, 3.7 to 5.3; n=81) at 6 months. At all measured time points after stroke, a small but considerable number of caregivers indicated that they were not under any strain (14% at 1 month, 17% at 3 months, and 19% at 6 months). In contrast, an increasing proportion of caregivers reported that they were under considerable strain from 1 to 6 months (25% at 1 month, 28% at 3 months, and 37% at 6 months).

TABLE 4. Mean Hours per Day Caregivers Spent Helping a Stroke Patient by Location

Location*	1 Month	3 Months	6 Months
At home	6.5 (4.4–8.6) (n=54)	5.5 (4.1–7.0) (n=64)	6.3 (4.5–8.1) (n=64)
In hospital	2.8 (0.9–4.7) (n=31)	3.4 (0.6–6.2) (n=9)	1.9 (–1.4–5.1) (n=4)
Other†	11.7 (5.0–18.4) (n=12)	8.7 (3.7–13.7) (n=15)	8.2 (3.3–13.2) (n=13)
Total	6.0 (4.4–7.5) (n=97)	5.5 (4.5–7.2) (n=88)	6.4 (4.8–8.0) (n=81)

Values in parentheses are 95% CIs.

*Location at time of visit.

†Other locations were living with a relative (not spouse), nursing home, or residential care.

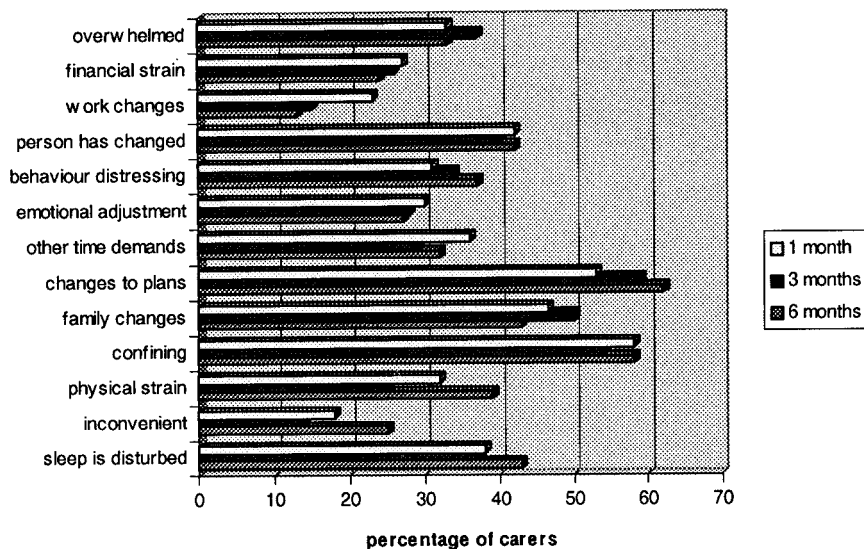


Figure 1. Percentages of caregivers reporting some strain to the 13 CSI²³ items. Caregivers were asked to respond positively or negatively to each of the 13 items, eg, it is a financial strain.

The CSI comprises 13 distinct factors (Figure 1), and 3 of these factors were consistently most problematic at all 3 time points: the confining nature of caregiving; changes to personal plans; and changes in family life. The χ^2 analysis comparing level of strain (none, some, considerable) by the patient's location (home, hospital, or other) did not reveal statistically robust differences that were consistently significant across time frames (ie, 1, 3, and 6 months after stroke).

Caregiver Health

On average, caregivers' health was found to be relatively poor (Figure 2). Descriptive comparison with mean figures for persons aged 55 to 64 years suggested that this population of caregivers was in worse health than published SF-36 norms for the general population.^{24,25} However, compared with age- and sex-matched norms,²⁸ there were few statistical differences (data not presented), and no single SF-36 dimension was statistically different from the norms at all 3 time points. Some caregivers reported that their health was worse than 1 year ago (23% to 24% at all 3 time points). However, it did not change substantially or consistently from 1 to 6 months after the stroke (Figure 2).

Services

Data were obtained about support services used by caregivers. Caregivers were specifically asked if they used Crossroads (a voluntary scheme that provides support workers for a few hours a week to allow caregivers to go out) or any other caregiver support services. The use of both these caregiver support services was low, at <5% in each time frame. Indeed, the use of all non-NHS services for patient support (Table 1) was low (all <33% use by stroke patients or their caregivers).

Predictors of Caregiver Strain

One month after stroke, 28% of the variation in caregiver strain was explained by decreased caregiver strain with increased time spent with stroke patient ($P<0.0001$); increased strain with increased time helping ($P<0.0001$); and decreased strain if the caregiver was male ($P=0.006$) (Table 5). Three months after stroke 19% of strain variation was explained by decreased caregiver strain with increased time with the stroke patient ($P=0.002$) and increased strain with increased time helping the patient ($P<0.0001$) (Table 5). At the final measurement, 30% of strain was explained by decreased strain as time with the patient increased

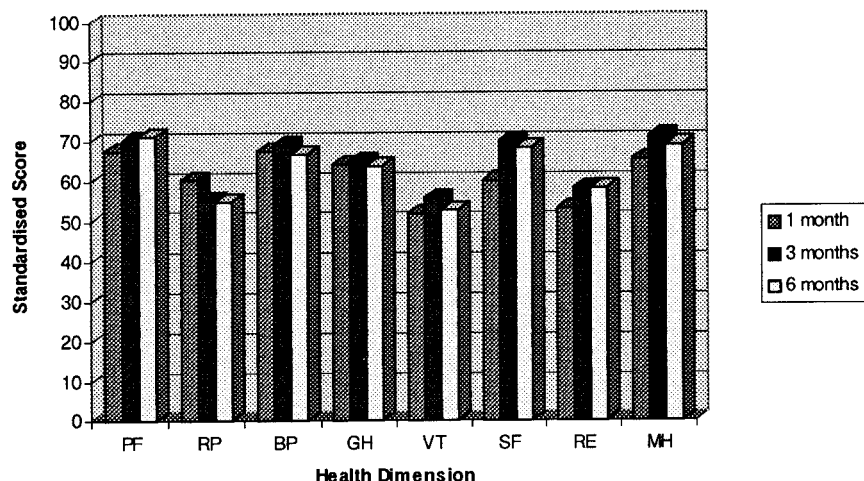


Figure 2. Mean SF-36 scores across the 8 health dimensions 1, 3, and 6 months after stroke. PF indicates physical functioning; RP, role physical; BP, bodily pain; GH, general health; VT, vitality; SF, social functioning; RE, role emotional; and MH, mental health.

TABLE 5. Regression Parameters for Caregiver Strain Models at 1, 3, and 6 Months

Time After Stroke, mo	Regression Term	Regression Parameter (β)	SE	<i>t</i>	<i>P</i>
1	Constant	6.318	0.628	10.054	0.000
	Hours with patient	-0.189	0.040	-4.768	0.000
	Hours helping patient	0.225	0.049	4.570	0.000
	Male sex	-2.142	0.757	-2.828	0.006
3	Constant	5.308	0.744	7.136	0.000
	Hours with patient	-0.131	0.042	-3.135	0.002
	Hours helping patient	0.223	0.058	3.877	0.000
6	Constant	9.465	1.322	7.161	0.000
	Hours with patient	-0.149	0.044	-3.358	0.001
	Hours helping patient	0.166	0.061	2.732	0.008
	Support involves physical help	2.162	0.758	2.851	0.006

($P=0.001$); increased strain as time helping increased ($P=0.008$); and increased strain if the caregiver was giving physical help ($P=0.006$) (Table 5).

Overall, the amount of time caregivers spent helping the stroke patient and the amount of time that they spent with them were consistently significant predictors of strain at 1, 3, and 6 months after stroke. The significant variables were added into the case-mix model for subsequent analysis.

All patient independent variables and patient outcome measures were added to establish a case-mix-adjusted caregiver strain model. One month after stroke, male stroke patients ($P=0.008$) and patients with less neurological impairment ($P=0.037$) were associated with less strain in the caregiver and explained an additional 11% (total 39%) of variance in strain. At 3 months after stroke, lower levels of disability were associated with less caregiver strain ($P=0.033$) and explained an extra 5% of strain variation (total 24%). At 6 months after stroke, better motor function at stroke onset (as measured by the Glasgow Coma Scale; $P=0.036$) and continence within 7 days of stroke onset ($P=0.007$) were associated with less caregiver strain and together accounted for an additional 17% of strain variation (total 47%). Although there were no consistent individual patient variables that affected the level of caregiver strain over time, an indicator of stroke severity was significant at each time point.

The caregivers' general health was also considered by adding the 8 individual SF-36 profile scores separately into the models adjusted by case mix for caregiver and patient variables. Five variables were consistently individually significant at all 3 time points: mental health, emotional role limitations, physical role limitations, social functioning, and vitality, with general health also significant at 6 months. The regression parameters for each of the significant variables suggested that those in worse health were under greater strain. The correlations between the SF-36 dimension scores were highly significant and, as a result, adding combinations of these dimension scores into a model was not informative in assessing the relationship between strain and caregiver health.

To identify any services received by stroke patients that were also of value in relieving caregiver strain, the NHS and

non-NHS service inputs were added into the models containing caregiver and patient variables. One month after the stroke, input from the Volunteer Stroke Services ($P=0.008$) and Meals on Wheels ($P=0.002$) explained an additional 11% variance to the patient/caregiver model (total 50%). At 3 and 6 months after stroke, none of the service inputs significantly affected caregiver strain.

Discussion

We have described the strain experienced by stroke patients' caregivers. In interpreting the findings, certain issues must be considered. First, only 66% of surviving stroke patients provided data, with many of the nonrespondents being too ill to be approached or giving ill health as the reason why they did not want to participate. It is possible that the caregivers of these nonrespondents are providing the most care. Given that increased time spent helping patients was associated with higher levels of caregiver strain, it may be that caregivers generally are under greater strain than the levels reported. Second, 24 caregivers of participating stroke patients did not respond. It is speculated that this nonresponse may be a result of the caregiver being too busy with care of the patient or not perceiving himself or herself as a caregiver.

Caregiver strain is a complex and multilayered concept. In this study, the percentage of caregivers under considerable strain in the early poststroke phase was notable, and the proportion increased with time. During the first 6 months after the stroke, time helping the patient and time with the patient were significantly associated with caregiver strain. More time helping and less time spent with the patient increased the strain. This tends to suggest that the caregivers under the greatest strain are those who have to set aside specific time to provide care, that is, those who are not normally with the patient and have to fit caring into an already busy schedule felt under the greatest strain. Interestingly, the location of the patient (home, hospital, or other) was not a predictor of strain. Thus, regardless of where the patient is residing within the first 6 months after stroke, there will be caregivers under strain. Qualitative analysis by Periard and Ames²⁹ identified time and confinement as key issues for caregivers within the early poststroke phase. In this

study, time helping and time with the patient were crude measures provided by the caregiver. Given the ease of the collection of this data and its relationship with strain, these simple measures could be incorporated into routine audit of patients and their caregivers as a means of identifying caregivers potentially at risk of high strain.

Caregivers in poorer health were found to be under greater strain even when other patient and caregiver characteristics were taken into account. Hence, there is a need to identify those caregivers who are caring and perceive themselves to be in poor health. Others have reported that physical health is at least 1 part of poor caregiver outcome.¹⁴ This study found an increasing proportion of caregivers under considerable strain, while, in general, caregiver health did not change greatly over time. This raises 2 issues. First, the impact on caregiver health may only be seen after caregiving for periods longer than the 6 months considered in this study. Second, it is possible that caregivers' perceptions of their health are dependent on many other life factors, and as such we would not expect there to be a simple relationship between health and strain. An intervention study is needed to test for a causal effect between caregiver health and strain. However, in this study we have identified that individuals in poor health were under more strain (however the ill health was caused) and therefore need to be identified and supported. The SF-36²¹ takes only 5 to 10 minutes to complete and could be incorporated into routine assessment of caregivers to identify those who perceive themselves to be in poor health.

Although we did not find consistent patient factors that were associated with the level of strain experienced by caregivers, measures of severity were statistically significant at each time point. Others have reported that patient characteristics have an effect on burden^{5,10} and caregiver depression.¹³ In this study, the patient factors significantly associated with strain were found to differ with time. Similar findings were made by Wade et al¹² and Hodgson et al.¹⁴ Each of these studies^{5,10,12-14} has looked at different caregiver factors (strain, burden, depression, psychological well-being), and it may be that each of these aspects is associated with different variables. From this study there appears to be an association between strain and stroke severity, yet the aspects of the patient's condition causing the most difficulty are unclear. At this stage it might be useful to undertake some qualitative work to explore how the caregivers themselves see the interface between strain, burden, depression, and psychological well-being and how they rate the importance of the differing patient factors on these dimensions.

In accordance with previous findings,¹ support services for patients' caregivers were not frequently used, and no service was consistently associated with decreased caregiver strain. An intervention study would be required to test effectiveness, but the presence of high levels of caregiver strain suggests that current service provision and utilization is unsatisfactory. One possible solution to alleviate caregiver strain (a stroke family care worker) has been evaluated in a randomized controlled trial but did not produce major differences in caregiver outcome.^{8,9} Thus, alternative strategies are needed to identify the services that are effective in supporting caregivers. The strain index identified that caregivers re-

ported changes to family life, changes to personal plans, and the confining nature of caregiving as 3 common factors that increased strain. Two issues arise from this that would be helpful in shaping services. First, time helping and activity restriction could potentially be alleviated by increasing the provision and use of support services. Since utilization of services is low, there is a need to identify caregivers' thoughts about available services, in particular regarding barriers to their use, and subsequently to plan services that caregivers would use. Second, there are some aspects of caring for a stroke patient over which health and social services have no control, for example, changes to family life and to personal plans. Other than by prevention of stroke, services cannot alleviate all the associated problems, and therefore their goal should be to help families cope with their altered circumstances.

Conclusions

Key issues remain for service provision and research. For service providers, caregivers were under strain in the early poststroke period, and this strain seemed to increase with time. Strain was unrelated to where the patient was living or the services received. Consequently, providers need to identify those caregivers at risk of strain. In particular, caregivers who spend greater proportions of time helping the patients, those caring for patients with more severe strokes, and those in poor health should be identified. Support services may alleviate some of the physical aspects of strain but cannot affect changes to family life. Therefore, there is also a need for realistic support for caregivers to help them to adapt to situations that cannot be changed.

Different factors were associated with strain at different time points and that the factors identified in this study were not the same as factors predicting depression, burden and psychological well-being in previous studies.^{5,10,12-14} More work is required to explore the interface between measures of burden, depression, psychological well-being and strain and to identify how caregivers perceive these relationships.

Acknowledgments

The authors are grateful to Ayrshire and Arran Health Board, Scotland, for funding the study. The views expressed are those of the authors and do not necessarily represent the views of the funding body. We are grateful to Dr Drew Walker for his comments and support during the study.

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