important factor to consider when assessing the risk of hypothermia in elderly women, particularly if they are exposed to low environmental temperatures in the home.

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Effects of living with and looking after survivors of a stroke

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Abstract

Information from a two year, longitudinal study on a community sample of patients with acute stroke was analysed to determine the effects of the stroke on the mood of the chief carer (the person living with the patient). Increased anxiety was the most commonly reported change six months after stroke. Significant depression was seen in 11-13% of carers over the first two years after stroke. The patient's functional disability was associated with depression in the carer over the first year but not at two years. A perceived poor recovery by the patient, a low level of general activities by the patient, and depression in the patient were also associated with depression in the carer within the first year. At two years after stroke none of the measured factors were related to a carer's level of depression.

Carers of patients who have suffered stroke showed anxiety and emotional distress unrelated to the patient's physical disability after two years. More help from stroke support groups for carers is perhaps needed.

Introduction

"Stroke is a family matter."[1] Many survivors, left disabled after stroke, remain at home for months or years, cared for by their family. Caring is a labour of love intimately related to the woman's role,[2] though it is also recognised as a service warranting encouragement.[3] But at what cost to that family? About half of these families may suffer financial stress, perhaps because someone has to stop work,[1 4] and loss of social life may affect three quarters of carers.[1] Medical and psychiatric disturbance may be found in up to 60% of carers,[4-6] and disruption of sleep, the least tolerated aspect of caring for someone,[7] is also often a problem.[4]

Most of the studies mentioned above were based on patients selected by age,[6] the presence of aphasia,[5] or referral for rehabilitation.[14] This report is based on a community sample that incorporated routine standardised assessments of carers. Its main emphasis is on the prevalence of emotional stress and its associated factors.

Subjects and methods

In this study the main carer was defined as the person who lived in the same house as the patient and who was most closely associated with the patient. They were not necessarily giving obvious, active support to the patient; they may have been companions rather than carers. Neither wardens nor landladies were included, nor were people living nearby, even if they gave much help. The patients were the survivors from a longitudinal study on all acute strokes (defined clinically[8]) arising in a specified health district population of 215 000 people.[9] Each patient and carer was assessed at three weeks, six months, one year, and two years.

Psychiatric morbidity in carers was assessed using the Wakefield self assessment depression inventory[10]—the 28 question version of the general health questionnaire[11]—and by asking them directly about various mood changes in relation to their state before the stroke (see table II). The Wakefield inventory has 12 questions giving a score between 0 and 36. As with the patients,[12] a score on the Wakefield inventory of 15-18 has been classified as probable depression, with higher scores being classified as definite depression (the mood, not necessarily the clinical illness). Each patient and his or her carer were also asked independently to rate the patient's recovery of independence on a line scale 150 mm long, the end points being "the worst he was after the stroke" and "as he was before the stroke." Aspects of each patient's state were assessed using the Barthel index of activities of daily living,[13] the Wakefield inventory, the Frenchay activities index,[14] and the Hodkinson mental scale for confusion.[15]

Results

One year after their stroke 372 patients were at home but 70 lived alone, leaving 302 (81%) with a carer; 81 had more than one person in the house. The main carer was a spouse for 257 (85%) (86 (28%) were husbands), a son or daughter for 25 (8%), a brother or sister for 13 (4%), and a more distant relative or friend for 7 (2%). The effect of the stroke on a carer's work was recorded six months after the stroke, when 393 surviving patients were at home with a carer. Ninety four carers (24%) had worked before the stroke: 72 (77%) of these were working at six months, 15 (16%) had stopped, 4 (4%) had increased their work, and 2 (2%) had reduced their work. One person had started work. One hundred carers (33%) could drive.

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Table I shows the number of carers with depression as measured on the Wakefield inventory and the relation to the patient's disability. Analysis of variance and χ^2 testing showed that depression in the carer was significantly related to a patient's disability up to one year after stroke but not at two years. At three weeks after stroke 25 (11%) of 226 carers were depressed and 27 (12%) probably depressed. The numbers with abnormal general health questionnaire scores were 54 out of 259 (21%) at three weeks, 32 out of 270 (12%) at six months, 28 out of 246 (11%) at one year, and 20 out of 154 (13%) at two years. Table II shows the perception of the carers about their change of mood compared with before the stroke. The commonest changes were an increase in anxiety (43%) and irritability (28%) and a decrease in relaxation (32%).

TABLE I—*Depression in carer and disability in patient*

Carer's depression (Wakefield scores)	Patient's disability on Barthel scores (No (%))		
	None (20)	Mild (15-19)	Moderate/severe (0-14)
At 6 months	(n=115)	(n=75)	(n=34)
Normal (0-14)	102 (89)	56 (75)	21 (62)
Probably depressed (15-18)	8 (7)	4 (5)	4 (12)
Depressed (19-36)	5 (4)	15 (20)	9 (26)
Average (SD)	6·2 (5·5)	10·2 (8·0)	10·9 (8·8)
Significance: $\chi^2=16\cdot8$, $F_{(2,223)}=10\cdot27$; both $p<0\cdot01$.			
At 1 year	(n=110)	(n=74)	(n=51)
Normal (0-14)	93 (85)	60 (81)	25 (49)
Probably depressed (15-18)	9 (8)	6 (8)	14 (27)
Depressed (19-36)	8 (7)	8 (11)	12 (24)
Average (SD)	7·1 (7·0)	8·3 (6·6)	13·2 (8·3)
Significance: $\chi^2=26\cdot1$, $F_{(2,234)}=12\cdot9$; both $p<0\cdot01$.			
At 2 years	(n=68)	(n=40)	(n=26)
Normal (0-14)	56 (82)	29 (73)	18 (69)
Probably depressed (15-18)	5 (7)	6 (15)	3 (12)
Depressed (19-36)	7 (11)	5 (12)	5 (19)
Average (SD)	8·6 (7·0)	9·3 (7·6)	9·9 (8·7)
Significance: $\chi^2=2\cdot37$, $F_{(2,133)}=0\cdot28$; both NS.			

The various measures of mood were highly correlated. Using the results obtained at six months, we calculated direct correlation coefficients between all the items included in tables I and II and the general health questionnaire. The Wakefield score and general health questionnaire total score had a coefficient (r) of 0·83 (n=218; p<0·01). The carer's Wakefield score and own assessment of depression had coefficients of 0·52 (feeling low and run down) and 0·51 (feeling depressed). The only item with a low coefficient (r= −0·16) was the carer's assessment of his or her loss of confidence. Factor analysis of the eight expressed mood changes shown in table II showed that one factor accounted for 41% of the variance. The communalities varied from 0·52 to 0·70. This suggests that these perceptions of mood change largely related to a general alteration of mood, although increased anxiety and loss of relaxation did form a separate factor.

Factors associated with depression in the carer were studied using direct correlation coefficients (table III). This analysis was restricted to results obtained with the Wakefield inventory as the earlier analysis showed high intercorrelations between all other measures of mood. Correlation coefficients were calculated between the carer's Wakefield score at six, 12, and 24 months and the patient's score on various measures. At six months the carer's level of depression was correlated with a patient's depression and low level of social activities but not with confusion as assessed using the Hodkinson scale. The strength of the associations between the presence of depression in the carer and various aspects of the patient's function decreased with time and by two years no significant correlations were found.

Lastly, carers with increased levels of depression were more likely to

TABLE II—*Mood change in carers at six months, expressed in relation to state before stroke (n=223). Results are numbers (and percentages) of carers*

Mood	Change				
	Much less	Less	Same	More	Much more
Confidence	2 (1)	22 (10)	183 (82)	11 (5)	5 (2)
Irritability	1 (<1)	1 (<1)	159 (71)	51 (23)	11 (5)
Depression	1 (<1)	1 (<1)	181 (81)	33 (15)	7 (3)
Calmness	7 (3)	32 (14)	177 (80)	4 (2)	3 (1)
Low/run down	1 (<1)	4 (2)	160 (72)	43 (19)	15 (7)
Relaxed	14 (6)	58 (26)	146 (66)	3 (1)	2 (1)
Happy	4 (2)	29 (13)	185 (83)	5 (2)	
Anxious	2 (1)	8 (4)	116 (52)	77 (34)	20 (9)

TABLE III—*Correlations with carer's Wakefield depression score over time*

Time	6 Months		1 Year		2 Years	
	No	r	No	r	No	r
Patient's depression:						
6 months	192	0·35*	177	0·23		
1 year			200	0·25*	133	0·11
2 years					137	0·22
Patient's confusion:						
6 months	199	−0·10	154	−0·08	107	−0·02
1 year			217	−0·16	140	−0·05
2 years					142	−0·01
Patient's social activities:						
6 months	225	−0·34*	215	−0·26*	143	−0·20
1 year			235	−0·27*	151	−0·17
2 years					153	−0·07
Carer's perception of recovery:						
6 months	191	−0·45*				
1 year			205	−0·34*	121	−0·23
2 years					122	−0·15
Patient's perception of recovery:						
6 months	162	−0·32*				
1 year			173	−0·21	113	−0·22
2 years					106	−0·13

*p<0·01.

perceive the patient as having made a poor recovery. These patients were also likely to rate their own recovery as less complete than were the patients living with less depressed carers. The nature of these relationships is uncertain: possibly the patients had made a less good recovery or possibly the carer's depression biased their perception and that of the patient.

Discussion

It was surprising how little measurable psychological stress was detected in the companions of patients after stroke in this study. Only 11-13% of companions were definitely depressed, with 7-12% being probably depressed at any one time. Over the first year after stroke depression was associated with the patient's observed disability, the carer's perception of recovery, the patient's level of depression, and the level of their activities of daily living. By two years depression in the carers was unrelated to any of the measures used in this study.

This is the first study to include all carers of all patients derived from a defined population. Some carers were not seen—for example, those out at work—but these were rare and most were willing to miss work to see the interviewer. If a carer could not be seen the general health questionnaire was left to be filled in and sent back. The study included all patients, including some not admitted to hospital and some never referred for rehabilitation. We consider that the results are valid and unbiased by selection.

The measures of depression used are standardised and valid.[10 11] The results from this study lend support to their validity in that there was a good correlation between the carer's own assessments of their mood changes and their moods as assessed using the general health questionnaire and the Wakefield scale. One outstanding problem, however, remains: it is unknown how many of the general elderly population are depressed when assessed using the Wakefield index. Further, our results do not necessarily relate to clinical depression but simply to a depressed mood felt by the carer.

The most interesting finding was that a patient's observed disability seemed to become increasingly unimportant in relation to depression in the companion or carer. The other main items associated with a carer's level of depression were the patient's level of depression and general activities, themselves highly interrelated at one year after stroke.[12] These associations also decreased with time. Depression in the carer was not related to confusion, as measured using the Hodkinson mental scale, and it was no greater in the carers of patients treated at home[16] or of patients with aphasia.[17] This last observation contrasts with another study, also based on the Wakefield scale, which did find that the carers of patients with aphasia were more depressed.[5]

In addition, depression was not uncommon in the companions of independent patients: 13 (28%) of the 45 depressed carers at six months lived with patients who were completely independent (as

measured using the Barthel index). At that time depression in the carer was associated with the perception, by the carer, that the patient's recovery was poor. This may be simply a pessimistic view secondary to depression or it might indicate that the carer was doing more for the patient than was necessary. As activities of daily living indices have limited sensitivity, and there was also a notable correlation between a patient's perception of his recovery and depression in the carer, depression in the carers of apparently independent patients might have been associated with minor disability in the patient.

One hypothesis that could explain our findings is that depression in the carer was related to the occurrence of a major, life threatening illness and not due to the physical stress of caring. The fact that carers of more disabled patients were initially more upset could simply be because the obviously more severe stroke might engender more worry about the future. As time passed this might lessen. In support of this hypothesis we have shown that increased help for patients at home did not decrease stress on the carer[9] and that almost all disabled patients at home had help from community services (unpublished observations). Moreover, the most commonly expressed mood change was an increase in anxiety, which factor analysis suggested was part of a non-specific alteration in affect.

We must emphasise that this study has investigated only one aspect of the potential stress on carers. It has not directly measured the financial costs, the reduction in the carer's social life, the effects on family or marital relationships, or the effects on the physical health of the carer. These are also important.

We conclude that companions of the survivors of a stroke showed some emotional distress, most commonly anxiety. This was only partly related to the extent of the physical disability engendered by the stroke. Possibly adequate community support was given to patients with physical disability, or possibly many carers adapted well to the patient's disability. By two years depression in the carer was unrelated to any of the patient factors measured, suggesting that other factors influenced the prevalence of depression. For example, increased personal support, such as given by stroke support groups, may be more important than extra physical support in reducing depression in the carers.

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Sulphasalazine for rheumatoid arthritis: toxicity in 774 patients monitored for one to 11 years

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Abstract

Sulphasalazine is being used increasingly to treat rheumatoid arthritis, though its long term safety profile has not been established in this condition. The incidence and nature of adverse effects occurring in 774 patients with rheumatoid arthritis treated with sulphasalazine for periods ranging from one to 11 years were therefore noted. Altogether 205 of the patients stopped treatment permanently due to an adverse effect. One hundred and fifty six (76%) of these events occurred within three months and few beyond the first year. Most events were trivial and were self limiting after withdrawal of the drug; of the potentially more serious adverse effects, 33 (66%) occurred within three months of treatment. None of the patients died or suffered lasting ill effects.

It is concluded that adverse effects of treatment with sulphasalazine are generally seen within three months; though regular monitoring is desirable during that period, thereafter few worrying problems occur.

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Introduction

Several reports have suggested that sulphasalazine is a useful treatment for rheumatoid arthritis,[1-6] and the drug has been claimed to be safer than such alternatives as gold,[5 7] though this is disputed.[8] Any new treatment needs prolonged follow up of large numbers of patients so that its tolerability and serious toxicity can be estab-