

Caregivers' emotional well-being and their capacity to learn about stroke

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This study examines the effects of distress on the capacity of informal caregivers of stroke patients to absorb information about stroke and caregiving. Thirty-seven caregivers took part in a stroke seminar. Minor psychiatric symptoms were related to caregivers' knowledge prior to the seminar, with the more emotionally distressed being the least knowledgeable. The emotional state of the caregivers, however, did not affect how much they learnt. Knowledge after the seminar was best predicted from pre-seminar knowledge and age. Older caregivers were less well-informed afterwards, although they did not differ significantly from younger caregivers in their scores initially. These findings do not discount the possibility that emotional carers are too shocked to take in information from hospital staff at the time of admission. The data do demonstrate that, given time to accept the caregiving role, emotional carers are receptive to learning about stroke and the stroke patient's needs.

HOME-BASED CARE

Home-based care for stroke patients has long been recommended, and increasingly patients are being discharged from hospitals as soon as possible to continue their rehabilitation from home (Bonita *et al.* 1987, Brocklehurst *et al.* 1981, Mulley & Arie 1978, Wade & Hower 1983, Wright & Robson 1980). Arguments in favour of home care centre on cost containment and effective rehabilitation. Stroke survivors are unlikely to require medical treatment within the hospital so that their occupying a much needed bed is difficult to justify (Mulley & Arie 1978, Wade & Hower 1983). However, they do need rehabilitation to

assist them to resume independent living to the greatest degree possible.

Studies have shown that the skills acquired in a hospital setting do not always apply to the home; sometimes they are not relevant, and sometimes other skills are required (Andrews & Stewart 1979, Brocklehurst *et al.* 1981, Garraway *et al.* 1980, Labi *et al.* 1980). Home rehabilitation is the logical answer to solving these difficulties.

Home care for the stroke survivor, however, is not without problems. Responsibility for care is often transferred to a family member with no previous experience in caring for someone who has had a stroke. In addition, caregivers have their own adjustments to make. Not only must they learn to meet the needs of the stroke survivor, but they must cope with their own fears and anxieties as they are suddenly cut off from their old lifestyle

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and thrown into another (Bedsworth & Molen 1982, Braithwaite 1990, Brocklehurst *et al.* 1981, Croog & Fitzgerald 1978, O'Keefe & Gilliss 1988, Schulz *et al.* 1988).

Attitudes of family members

The attitudes of family members have a profound effect on patients' reactions to medical regimens, emotional adaptation and rehabilitation (Bedsworth & Molen 1982). Worry and anxiety can result in family members being overprotective, and inadvertently preventing stroke survivors from achieving their full potential after the stroke (Andrews & Stewart 1979, Brocklehurst *et al.* 1981, Kinsella & Duffy 1980, Labi *et al.* 1980).

In studying 18 families of convalescing myocardial infarction patients, Wishnie *et al.* (1971) observed a steady eroding conflict in the families and high anxiety about the patient and about caregiving responsibilities. The authors attributed the conflict to misunderstanding about the nature of the disease and misinterpretation of physician's orders. It is not surprising, therefore, that families have been encouraged to take part in supportive and educational programmes so that they are better prepared for caregiving (Dring 1989, Jarrett 1981, Mongiardi *et al.* 1987, Overs & Belknap 1967, Stone 1987, Stroker 1983, Wright & Robson 1980).

In spite of widespread support for educational and counselling programmes for patients and their families, clients continue to suffer from lack of information in a range of medical contexts (Boreham & Gibson 1978, Gardner & Stewart 1978, Kinsella & Duffy 1980, Mongiardi *et al.* 1987, Shapiro *et al.* 1983, Sosnowitz 1984, Todd & Still 1984, Waitzkin 1985). Client characteristics which have been most often studied in relation to information-giving have been medical (certainty of diagnosis, prognosis) and socio-demographic in nature (socio-economic status, education, age, sex), but some work has suggested that psychological demeanour affects how much clients are told by medical staff.

One such characteristic examined in relation to caregivers is level of emotionality or neurosis: the degree to which a person is observed or self-reports as having low tolerance for stress, emotions which are easily aroused, and a tendency toward symptoms of anxiety and depression (Braithwaite 1987, Eysenck 1967). Those who are unable to control their emotions are perceived by medical staff as being difficult and interactions with them are limited. Explanations for such avoidance vary: the time constraints of medical staff, their feelings of inadequacy, emotional self-protection, a desire to punish inappropriate behaviour, and a belief that clients are not ready to be told or

are unable to hear (Bedsworth & Molen 1982, Cassem & Hackett 1972, Lipton & Svarstad 1977, Sosnowitz 1984).

The belief that emotional clients do not retain the information that they are given is particularly threatening to effective rehabilitation programmes. Clinical reports have referred to families as being too anxious to hear what is being said (O'Keefe & Gilliss 1988, Stone 1987). Medical staff who associate poor information retention with emotionality have little incentive to provide information to distressed clients. Yet these are the clients who are purported to be most likely to benefit from greater understanding and knowledge (Dzau & Boehme 1978, Kinsella & Duffy 1980). Emotional carers are likely to be doubly disadvantaged by their psychological state, missing vital information initially and suffering increased anxiety through lack of knowledge.

Stereotyped emotional caregivers

In a recent study, McGown & Braithwaite (1992) found that emotional caregivers were stereotyped as being less able to absorb information than carers showing outward signs of emotional control. Respondents were presented with a series of vignettes describing wives interacting with their husbands and with medical staff after their spouse's stroke. Groups of nurses, caregivers and members of the general public rated each of the vignette wives on five-point rating scales which represented how emotional they considered the wife to be and how capable they thought she was of absorbing information about her husband's condition. While nurses and the general public judged emotional behaviour as a sign that information could not be taken in properly, caregivers themselves made no such inference. Caregivers, furthermore, were more positive than the nurses in their assessment of the wives' capacity to absorb information. Biases against emotional caregivers in medical settings were clearly not shared by the caregivers themselves.

If this bias against emotional caregivers is to be dealt with fairly and sensitively, information is required on how able emotional carers are to absorb information. The adverse effects of anxiety on memory have been well documented experimentally (Kausler 1990), but it would be a mistake to assume that such research translates unproblematically into this setting. Motivations to help the patient and ensure that the best care is provided are high in the relatives of hospital patients. Distress over the well-being of another person may lead to the facilitating effects of anxiety outweighing the debilitating effects, with the family's motivation to know and understand particularly high.

THE STUDY

The purpose of this research was to explore the capacity of more emotional caregivers to learn about stroke in an applied setting. As a first step in challenging and questioning biases against emotional relatives, caregivers were recruited for a stroke education seminar. The dependent variable was knowledge gained through the seminar.

Emotionality was operationalized in two ways. First, emotionality was defined in terms of mental well-being, or more specifically by symptoms of anxiety and depression. The second definition focused on caregiving burden and the stress associated with providing care.

Emotionality was reflected in the extent to which caregivers felt inadequate in the caregiving role and were experiencing disruption. Feeling inadequate as a caregiver was considered particularly important because of a possible relationship with Wicklund & Frey's (1980) notion of objective self-awareness. When objectively aware, the individual directs attention inward, evaluating the self, and is not receptive to happenings in the outside world. Carers who express personal inadequacy may be in a state of objective self-awareness, and therefore be unable to take in the information that medical staff have given them about the stroke survivor's condition.

The association between emotionality and knowledge among experienced caregivers is likely to be affected by a third variable, the intensity of care required by the stroke survivor. Well-informed caregivers could be the more notional caregivers because of the demanding nature of their role and their motivation to meet these demands. In contrast, caregivers with fewer demands may be not only less interested in acquiring information but also less notional. The demands of caregiving were defined in terms of the functional health of the stroke survivor and in terms of deficits in his or her social and psychological functioning.

METHOD

Participants

Forty-seven stroke carers volunteered to take part in the seminar: 28 females and nine males. Because they are patients, carers were difficult to contact through the national health system. This study used snowballing or work sampling to contact them; a strategy often used to locate subjects from less accessible groups (Burns & Grove 1987). Stroke clubs were the first point of contact. When interviewed, these volunteers were asked to help researchers find other stroke carers. While the representativeness of such samples is always open to question, the demographic profile was not dissimilar

from that reported in other caregiving studies (see Braithwaite 1990), with one exception. The present study had a disproportionately large number of spouse caregivers.

Participants ranged in age from 25 to 78 years ($M = 61.11$, $SD = 10.38$), with the majority (62%) being over 60 years of age. Thirty-one were caring for a spouse, five were caring for a parent and one for a parent-in-law. The sample comprised relatively experienced caregivers, all but two being in this role for more than 1 year. On average, the time that had elapsed since the stroke was 3.78 years ($SD = 2.77$). Participants were assured that any information they provided would be treated confidentially.

Design

The dependent variable, knowledge about stroke, was assessed by a multiple choice test taken by participants before the seminar and afterwards. The seminar lasted for 2 hours and covered: (a) the prevalence of stroke, (b) risk factors, (c) hospitalization practices, (d) the treatment of stroke and its effects, (e) the stresses of caregiving and (f) resources available to caregivers. A lecture format was adopted, interspersed with questions from participants and discussion of issues raised. Seminars were offered at a number of different times to accommodate as many interested caregivers as possible.

The seminar and the multiple choice test were pre-tested on a sample of 26 nurses to ensure that both gave adequate scope for caregivers to demonstrate and improve their knowledge. These data also provided a baseline for interpreting how knowledgeable the caregivers were and how able they were to learn in this setting. It is important to note, however, that the nurses were not representative of the nursing population. They were volunteers from two major hospitals.

Prior to the seminar, caregivers completed a short questionnaire which was appended to the multiple choice test. Symptoms of depression and anxiety in the caregiver, caregiving burden, functional disability of the stroke survivor, and psycho-social loss in the stroke survivor were assessed. Background information regarding the caregiver's age and sex, the relationship of caregiver to care recipient, and the elapsed time since the stroke was also collected via the questionnaire.

Measures

Knowledge

The knowledge scale comprised 13 items taken from a 19-question multiple choice test. The items tapped medical knowledge (e.g. risk factors for stroke, the nature of stroke,

its treatment, effects, and prognosis) and awareness of issues of carer well-being. The six items not included in the analysis were either ones which almost all carers were able to answer on the pre-test questionnaire or which were not well intercorrelated with other questions. Each item was scored as correct (1) or incorrect (0). Scores on the knowledge scale at the time of the pre-test were normally distributed and ranged from 0 to 13 with a mean of 6.32 and standard deviation of 2.55. The alpha reliability coefficient for the scale was 0.71.

Symptoms of anxiety and depression

A brief psychiatric screening instrument, the 4-NS (Henderson *et al.* 1981), was used. In this index, four mental health symptoms — anxiety, depression, irritability and nervousness — were embedded in a total list of 15 symptoms which included sore throats, backache, indigestion, palpitations, and so on. The instrument has been used successfully in community studies where an efficient and unobtrusive measure of mental well-being was required.

The reliability and validity of the measure has been investigated in community samples and in caregiving samples (Braithwaite 1990, Henderson *et al.* 1981). Henderson *et al.* reported correlations of 0.62 with the PSE (Present State Examination) and 0.52 and 0.58 with the GHQ (General Health Questionnaire), while Braithwaite found that the 4-NS correlated 0.63 with the DSSI/sAD (Delusions-Symptoms-States Inventory) and had an alpha reliability coefficient of 0.70. In this study, scores ranged from 0 to 4 with a mean of 1.22 and standard deviation of 1.24. Thirty-eight per cent of the sample complained of two or more symptoms. The alpha reliability coefficient for the scale was 0.60.

Burden

The stress of caregiving was assessed through a 16-item scale which asked carers the extent to which they felt inadequate, guilty, resentful, disrupted and disadvantaged by the caring experience (Braithwaite 1990). The original scale contained 17 items, but one was excluded because of insufficient variability among this sample of caregivers. The reliability and validity of the scale had been established in two previous studies of caregivers (Braithwaite 1990, Groube 1990). The items were scored in terms of whether they were true for the carer (1) or not (0). Scale scores ranged from 0 to 14 with a mean of 4.89 and a standard deviation of 3.78. The alpha reliability coefficient was 0.82.

The burden scale could be separated into two highly correlated components, inadequacy and disruption. Because of the relevance of feelings of personal inadequacy

to the hypothesis, the two subscales were also used separately. The alpha reliability coefficient for the inadequacy scale was 0.78 and for the disruption scale 0.68.

Functional disability

Carers were asked how much assistance they had to provide for the stroke survivor with 11 activities of daily living: eating, dressing, standing and sitting, transferring, walking, toileting, bathing, communicating, organizing, dealing with finances, and making social contacts. Responses were recorded on a three-point scale according to whether assistance was not provided (1), was provided a little (2), or was provided all the time (3). Scale scores ranged from 13 to 33 with a mean of 19.90 and standard deviation of 5.32. The alpha reliability coefficient was 0.86.

Psycho-social loss

The extent to which the care recipient was psychologically and socially disabled was assessed by an eight-item behaviour checklist which tapped mood disturbance and difficulty in relating to others (e.g. goes on and on about certain things, constantly demands assistance, does not understand what is said, gets deeply depressed). Behaviours were checked as present (1) or absent (0). The scale scores ranged from 0 to 7 with a mean of 2.70 and standard deviation of 2.12. The alpha reliability coefficient was 0.70.

RESULTS

Overall, participants' post-seminar scores on the knowledge test ($M = 8.89$, $SD = 2.14$) were higher than the pre-seminar scores ($M = 6.32$, $SD = 2.55$) ($t(36) = 10.28$, $P < 0.001$). Change scores for individuals varied from -1.00 to 7.00 ($M = 2.57$, $SD = 1.52$). From Table 1, knowledge scores before and after the seminar were not related to the caregiver's sex, the relationship to the stroke survivor, or the time that had elapsed since the stroke. The caregiver's age, however, was related to knowledge. Although older carers were not significantly less informed than younger carers prior to the seminar, they were less informed on the post-seminar test ($r = -0.39$, $n = 37$, $P < 0.01$).

The indices of emotionality, symptoms of poor mental health and caregiving burden, correlated with each other as expected ($r = 0.51$, $n = 37$, $P < 0.001$). The symptom measure also correlated with the inadequacy ($r = 0.45$, $n = 37$, $P < 0.01$) and disruption ($r = 0.48$, $n = 37$, $P < 0.001$) subscales. The emotionality indices were not significantly related to the caregiver's age, sex, relationship to the stroke survivor, or the time that had elapsed since the stroke.

Table 1 Correlations of emotionality and caregiving characteristics with pre-seminar and post-seminar knowledge and change scores

Variables	Knowledge		
	Pre	Post	Change
Background			
Sex	0.08	0.15	0.08
Age	-0.16	-0.39**	-0.27
Spouse	0.12	-0.02	-0.22
Time Caring	0.02	-0.11	-0.18
Emotional status			
Symptoms	-0.40**	-0.35*	0.18
Burden	0.00	0.08	0.11
Inadequacy	0.14	0.25	0.11
Disruption	-0.12	-0.08	0.09
Caregiving demands			
Functional disability	0.20	0.06	-0.26
Psycho-social loss	-0.14	-0.02	0.19

* $P < 0.05$; ** $P < 0.01$.

As the first stage in testing the hypothesis that emotional caregivers are disadvantaged in learning about stroke, Pearson product-moment correlation coefficients were calculated between the knowledge indices and the emotionality and caregiving demand measures (see Table 1). Symptoms of poor mental health were related significantly to both pre-seminar knowledge and post-seminar knowledge. Variables which were specific to caregiving, that is, stress, workload and disability resulting from stroke, did not correlate significantly with either knowledge measure. In particular, carers who felt inadequate were not less well-informed either before or after the seminar. Clearly, inadequacy does not reflect a state of objective self-awareness.

Knowledge

The greater knowledge of caregivers with better mental health after the seminar appears to be more a function of their knowledge initially than of their greater capacity to learn. The low correlation between symptoms and change in knowledge scores is consistent with this interpretation. Another way of examining the effect of symptoms on a caregiver's capacity to learn was through a regression

Table 2 Beta coefficients and R^2 values for a hierarchical regression analysis predicting post-seminar knowledge

Predictors	Post-seminar knowledge	
	Model 1	Model 2
Age	-0.26*	-0.25*
Pre-knowledge	0.77***	0.73***
Symptoms		-0.12
R^2	0.73***	0.74***
Change R^2		0.01

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

model in which post-seminar knowledge was regressed on symptoms of poor mental health, once the pre-seminar knowledge of the caregivers was controlled. This strategy was considered preferable to using change in knowledge scores because it avoided the problem of increasing the error term in the dependent variable with a relatively small sample. Also included as a control variable in the regression model was the caregiver's age.

From Table 2, the major predictors of knowledge after the seminar were age and pre-seminar knowledge. Those who were younger and who were better informed initially were more likely to be more knowledgeable after the seminar. Of importance is the finding that minor psychiatric symptoms, the major correlate of pre-seminar knowledge, did not contribute to explaining the gains in knowledge made during the seminar.

These data suggest that emotionally unstable carers are as capable of learning about stroke as those who are emotionally stable. Such an inference needs to be made with caution because it involves accepting the null hypothesis in a situation where the statistical test has low power. An interesting question to ask in conjunction with this conclusion, therefore, is whether or not emotional caregivers improved on their pre-seminar score as much as unemotional caregivers. Two subgroups of carers were formed: those without any symptoms and those who reported two or more symptoms prior to the seminar. The mean knowledge scores of carers without symptoms changed from 7.47 to 9.87 over the course of the seminar, a 2.4 point difference ($t(14) = 6.87, P < 0.001$). The mean for carers with two or more symptoms changed from 5.50 to 8.14, a difference of 2.6 ($t(13) = 7.10, P < 0.001$). For this group of caregivers, knowledge acquisition was not sacrificed because of their feelings of anxiety and depression.

Table 3 Comparison of carer and nurse knowledge scores before and after stroke seminar

Knowledge	n	M	SD	t
Pre-seminar				
Carers	37	6.32	2.55	-3.40**
Nurses	26	8.11	1.63	
Post-seminar				
Carers	37	8.89	2.14	0.09
Nurses	26	8.84	1.71	

** $P < 0.01$.

Comparison group

Practical constraints militated against the use of a control group in this study, leaving unanswered the question of whether change in a caregiver's scores reflected a better understanding of stroke or a 'practice effect'. Some insight into this problem can be gleaned from a comparison of the pre- and post-test scores of the 26 nurses who had volunteered for the pilot study (see Table 3). No significant change was observed in this group, suggesting that the gain of the caregivers was more likely to represent information than methodological artefact.

A further question which can be answered from these data is how well informed carers were initially. The knowledge of a professional group such as nurses provides a useful benchmark for addressing the question. The scores of the 26 nurses who had completed the multiple choice knowledge test in the pilot study were compared with those of carers before and after the seminar (see Table 3). Nurses scored significantly higher than carers on the test before the seminar. A comparison of nurse and carer scores after the seminar produced no significant differences in their knowledge of stroke and caregiving.

DISCUSSION

This study examined the capacity of caregivers to learn about stroke and the extent to which those who were more emotionally distressed were handicapped in their acquisition and recall of knowledge. Previous research has suggested that families may be provided with less information than they would like because medical staff doubt their capacity to absorb information, particularly when they are emotionally unstable.

Emotionality was defined in this study in terms of caregiver stress and symptoms. Both are considered appropriate indicators of emotional instability in experienced caregivers. These data provide no evidence of either psychological state hindering caregivers in their quest for knowledge. Before elaborating further on the findings, however, two limitations imposed by the sample need to be acknowledged. First, the carers who participated in this study had settled into the caring role. The sampling strategy did not provide the researchers with access to families of stroke survivors at the time of hospitalization or of a medical diagnosis. Second, the carers who took part were volunteers, and as such were probably keen to improve their knowledge and understanding of stroke.

The gains in knowledge accomplished by this group of caregivers were not inconsequential. By the end of the seminar, the mean knowledge score for caregivers equalled that of nurses who had been caring for stroke patients. These data suggest that the capacities of caregivers, particularly emotional caregivers, may be underestimated by medical staff.

Differences in information gain

At the same time, differences did exist in this group in how easily information was assimilated and in how knowledgeable caregivers were initially. Older caregivers had more difficulty with the seminar than others. Although their knowledge scores increased significantly as a group (from 5.33 to 7.60 for those aged 65 and over) ($t(14) = 5.72$, $P < 0.001$), older carers showed less of a gain than those who were younger. This result is a reminder that presentation style and pace should be modified to suit the age group, and that consultation with the group about preferred presentation styles is appropriate and efficient in the long term.

The second important finding was that, although carers with minor psychiatric symptoms were not disadvantaged in the course of the seminar, they were less knowledgeable initially. This result is consistent with the underlying rationale of the study, that medical staff underestimate the informational capacity of caregivers. Nevertheless, an alternative explanation must be seriously considered. Symptoms of poor mental health may not pre-date the medical staff's sharing of knowledge with families, but rather be a consequence of inadequate knowledge. For whatever reason, some families may not be provided with information at the time of the stroke and may fail to open channels of communication themselves. As a consequence of their ignorance, their emotional well-being may suffer.

The seriousness of this problem is well recognized in the medical literature. According to Stedeford (1981), 'Poor communication causes more suffering than any other problem except unrelieved pain'.

While this interpretation cannot be rejected, it is made less plausible by what we know of the association between symptoms of anxiety and depression and having an emotional temperament. Depression and anxiety have been linked not only to life events, but also to personality dispositions, in particular, neuroticism (Braithwaite 1987, Costa & McCrae 1980, Eysenck 1967, Eysenck & Eysenck 1969, Henderson *et al.* 1981). It is likely that depressed and anxious caregivers have temperaments of the kind that would lead them to be also highly emotional at the time of the stroke crisis. Their emotionality at this stage is likely to be linked with their missing out on important information.

Emotional caregivers

If emotional caregivers miss out on information at the time of the stroke crisis, is the problem one of not being told or not being able to comprehend what they are told? It is tempting to infer from these data that the problem is one of not being told. Such a conclusion assumes that the emotionality carers experience in the caregiving role is comparable to that which they experience in the crisis situation. This may not be the case. At the time of the stroke, emotionality may involve shock, passivity and self-protection; a shutting down response to avoid further threatening information. This is consistent with clinical descriptions of carers as shocked, numb, and unable to comprehend or make decisions in the early stages of the illness (Kinsella & Duffy 1980, O'Keefe & Gillis 1988).

When the responsibility for care is transferred to family carers, emotionality may be no longer an expression of shock, but rather of responsibility, dread and worry about what to do. In this state, carers may be aware of their need for information and be more receptive to those who are willing and able to provide it. Although this qualification of the data is speculative, it offers the advantage of accommodating disparate clinical observations and research findings.

CONCLUSION

Whether or not the emotionality of carers in the crisis situation can be shown to be functionally different from emotionality in the caregiving role is a question for future research. In the meantime, successful intervention with stroke survivors may be increased by the adoption of a more dynamic conception of caregivers' needs. The

challenge facing medical staff is to recognize the right time for providing information.

These data demonstrate that the stigmatizing of emotional carers as being unable to absorb information is unjustified. They may initially forget what they have been told. They may irritate staff by repeating the same question and making unrealistic demands. But after they have had time to adjust to their new role, emotional carers can become more knowledgeable about stroke. Heightened emotionality need not impair capacity to learn.

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