

The stress experienced by caregivers of stroke survivors: is it all in the mind, or is it also in the body?

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With a growing awareness that caring for an individual disabled by stroke may lead to stress-related health problems, fifteen major studies of the health status of carers of stroke survivors have been conducted since 1979. Although general stress theory indicates that stress-related health problems may be physical or psychological, in most of the studies reviewed psychological health is emphasized. Possible explanations for this bias are outlined in the present paper including: (a) how the backgrounds of the investigators involved may have influenced the nature of their research; (b) the effect of differences in the availability of standardized physical and psychological health measures; and (c) the possibility that the stress experienced by carers of stroke victims is primarily psychological. The commentary concludes with suggestions for future research to redress the imbalance and discusses some of the methodological difficulties potentially involved.

Research in disability has traditionally concentrated on the disabled and their potential for rehabilitation. In recent years the field of inquiry has expanded to include those who care for them. Much of this work has investigated the role of informal or unpaid carers because Government policy, which encourages disabled people to be maintained in the community, means that the burden of care is largely shouldered by nonprofessionals.¹ Carers, therefore, are extremely important in rehabilitation,

not only because they do most of the work, but because they are a limited resource.²

Considering the high prevalence of stroke induced disability (900 per 250 000), the carers of stroke survivors are an important subgroup.³ Since 1979, 15 major studies of such carers have been carried out. These studies have found stroke carers to be suffering from various general and psychological health problems including fatigue, anxiety and depression.^{4–18} The explanation for these observations has generally been that caring is stressful and that stress leads to illness.

However, the specific mechanism by which health problems are associated with caring for stroke survivors was not stated explicitly by the researchers above. If this omission is taken to

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mean that they assumed shared knowledge of this mechanism they were probably implicating 'general' stress theory. The theory proposes that perceived stress elicits a response which is characterized by arousal of various bodily systems (e.g. the adrenal glands), and suppression of others (e.g. the digestive system) in order to maximize the coping ability of the individual.¹⁹ As a result of exposure to stress, particularly of the long-term nature associated with the caring role, health can be compromised both physically and psychologically. The person under stress may be more prone to various kinds of illness including:

headaches, infectious illness, hypertension, heart, liver and intestinal disease, and cancer; and various expressions of negative affect including negative emotional tone, anxiety and depression.^{19,20}

One would, therefore, expect a comprehensive assessment of the effects of the caring role on carers to include studies of physical *and* psychological health. However, as can be clearly seen in Table 1, which outlines the methodologies of the papers examined, researchers have tended to focus on psychological health. All of the studies have included a concept of psychological health in their investigations. Dimensions have included

Table 1 Outline methodologies of 15 studies of stroke caregivers

Paper	Study type	Psychological aspects	Measures	Physical aspects	Measures	*
4	L	Enjoyment of life Life satisfaction	Informal ratings D-T Faces Scale	Nil	Nil	NM
5	CS	Morale	Philadelphia Geriatric Morale Scale	General health	Informal ratings No. GP visits	M
6	L	Anxiety Depression	Medication use Psychiatric treatment	General health	Medical treatment	M
7	CS	Psychiatric morbidity	Psychiatric Assessment Schedule Hamilton Rating Scale	Physical symptoms	PILL rating scale Medical history Medication use	M
8	CS	Enjoyment of life Tension/depression	Informal ratings	Nil	Nil	M
9	CS	Burden	Burden Scale	Nil	Nil	NM
10	L	Depression	CES-D	General health	Informal ratings	M
11	CS	Strain	Caregiver Strain Index	Subjective health	NHP	M
12	CS	Minor psychiatric disorder	GHQ Wakefield Medication use	Nil	Nil	NM
13	L	Emotional consequences	Informal ratings Medication use	Nil	Nil	M
14	CS	Positive/negative affect	Bradburn Affect Balance Scale	Nil	Nil	M
15	QE	Depression	Geriatric Depression Scale	Nil	Nil	NM
16	CS	Emotional health	GHQ	Subjective health	Informal ratings	M
17	L	Psychological well- being	CES-D Level of optimism scale	Subjective health Objective health problems	Informal ratings No. disabilities, medication use, chronic health conditions	NM
18	L	Psychiatric morbidity	Wakefield GHQ Informal ratings	Nil	Nil	M

* = Principal researcher's background; L = Longitudinal study; CS = Cross-sectional study; QE = Quasi-experimental study; NM = Nonmedical; M = Medical.

anxiety,^{6,8} depression,^{6,8,10,12} psychiatric morbidity,^{7,12,18} morale,⁵ life satisfaction^{4,8} and positive/negative affect,¹⁴ which seem to reasonably reflect the effects anticipated by theory. However, only seven studies have included physical health as an outcome; aspects including: general health,^{5,6,10,11,16,17} physical symptoms⁷ and health problems.¹⁷ These measures are fairly nonspecific but may include stress-related ill health. None of the studies have measured physical health only.

Not only does the comprehensiveness of measurement of the two axes of health differ in these studies, the quality of measurement diverges. Table 1 shows that psychological health tends to be measured with instruments such as the General Health Questionnaire (GHQ), the Centre for Epidemiologic Studies Depression Scale (CES-D) and the Wakefield Self Assessment Depression Inventory, which have been subjected to thorough reliability and validity testing, and are extensively cited in the literature. By contrast, physical health tends to be measured with less specific and less validated measures such as single-item health ratings, frequency of GP consultations, health problem counts and medication use.^{5,10,12,16} The two studies which did include standardized assessments of physical health^{7,11} used measures confounded with psychological symptoms: the Nottingham Health Profile (NHP)²¹ and the PILL Rating Scale (PILL).²² Thus, except for the study by Brocklehurst,⁶ which achieved a balance between psychological and physical health by using informal measures of both, none of the studies have comprehensively assessed the physical and psychological effects of the caring role, and their relative contributions.

Why has such an apparent omission occurred?

Three explanations seem possible:

1) *The clinical background of the researchers may have influenced the nature of the research*

Most of the studies (10) have been conducted by medical practitioners e.g. consultants in neurology or geriatric medicine. In clinical practice the consultant's primary interest is, of necessity, the patient. Although an interest in carers develops from an interest in patients, carers remain somewhat peripheral. Unless they themselves show obvious signs of illness within the con-

sultant's specific area of expertise during the patient/carer consultation, it is unlikely that the consultant will have the time or indeed perceive the need to take a detailed medical history of the carer. This tendency to omit carer's physical health data in clinical practice would, in all probability, transfer to research, because hypotheses are often generated through clinical practice.

Data on psychological problems in carers are, however, likely to be collected by asking conventional questions such as 'How are you coping?' Carers are likely to respond in psychological terms and may not attribute any physical symptoms they might have – apart from those which are obviously related such as tiredness and back pain – to caring. Considering the above, the bias toward psychological measures of health is understandable.

2) *Comprehensive measurement is difficult*

It may be that it is simply easier to do a study which limits itself to the examination of the psychological concomitants of the caring role because it is easier to measure them. Several good measures of psychological health exist which are conceptually related to 'general' stress theory, i.e. they include symptoms of anxiety, depression and negative affect, and exclude major psychiatric disorder (e.g. the Mental Health Inventory,²³ the Wakefield,²⁴ and the Hamilton Rating Scale).²⁵ But, in several recent reviews of health measurement^{26–29} there are virtually no tests developed from a concept of stress-related physical ill health which could be readily applied to carers. The physically based measures which do exist (e.g. the Physical and Instrumental Activity of Daily Living (ADL) Scales³⁰) tend to be functionally oriented – springing from an attempt to measure health objectively by describing ADL limitations. A typical question is 'are you limited in doing housework because of illness or disability?'. It is inappropriate to apply such an item to carers. A carer with arthritis, for example, may have significant disability but be unable to limit their home duties.

3) *Stress-induced illness in carers is primarily psychological*

A third possibility is that the stress experienced by caregivers is primarily psychological. Much of the literature on the effects of stress on health has concerned itself with acute stress. Although the

assumptions that caring is associated with chronic stress and that chronic stress is more damaging than acute stress, have face validity the issue is probably much more complex.

One important factor which has been omitted from many dissertations on caring is the capacity of the individual's appraisal of the caring situation to alter their response to it. For stress to occur the individual must perceive a mismatch between the demands a situation presents and his/her ability to cope with those demands.³¹ Folkman *et al.*³² have suggested that fairly constant levels of negative appraisal are necessary for effects on physical health to be produced. Appraisal of the stresses of family life, at least as far as it has been possible to measure this construct, seems to be an inconstant.³² This may also apply to appraisals of the stressors of caregiving, another aspect of family life. Psychological outcomes, on the other hand, may be more closely related to relatively stable personality attributes, such as mastery (the extent to which one regards one's life chances as being under one's control) and interpersonal trust (the extent to which one trusts others). These variables may be more global or longer acting than the ones which lead to physical ill health, therefore producing measurable psychological effects.

It is possible, therefore, that pilot studies conducted in the developmental phases of the studies reviewed in this paper, found little evidence of physical symptoms and thus they were under emphasized in subsequent investigations.

Conclusion

This analysis of the current state of stroke caring research suggests at least three areas for future inquiry. First, there is a need for more sophisticated measures to be developed to determine the physical concomitants of stress in the carers of stroke victims. Broadly, these measures should at least attempt to include the kinds of illness predicted by theory to result from stress: headaches, infectious illness, hypertension, heart disease etc. In the development of these tests the important issues to consider will be how to strike a balance between 'objective' and 'subjective' methods of measurement. As previously observed, items which aim for objectivity through ADL limitations may have to be carefully worded to

accommodate carer's responsibilities. Subjective ratings, on the other hand, have been shown to correlate highly with hard data.³³

Secondly, when such measures become available the potential will exist to correct the 'bias' in stroke carer research. Initially, further cross-sectional descriptive studies using expanded protocols could be conducted.

Finally, longitudinal studies of physical and psychological health in stroke carers with appropriate controls are required. Issues to be considered here include (a) when to begin measurement; (b) when to repeat measurement; and (c) which moderating variables to include.

- a) It is unlikely to be feasible to start prospective measurement of stroke carers before caring begins. Because stroke itself is an unpredictable event, very large numbers would be required. A more practical approach may be to interview carers soon after the (caree's) stroke about their health pre-stroke. Although this data would be retrospective and thus vulnerable to recall bias, it would at least be relatively recent and could be cross-checked against health records.
- b) Most investigators who have attempted to follow-up carers over time have detected health effects at six months, one year, two years and some up to three years. This period seems to span early and late adjustment to stroke in carers as described by Holbrook.³⁴ In the author's opinion, measurement should be extended beyond this period because some of the presumed physical effects e.g. heart disease, have long latency periods.
- c) As Lazarus and Folkman have suggested, for stress to be experienced in the first place, it must be perceived as such. It is therefore imperative that appraisal be measured. Other important variables are likely to be: sex, age, marital status, employment status and social support.³⁵

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