Subjective and objective appraisal of emotional stroke carers' capacity to absorb caregiving information.

BY

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Except where otherwise indicated this thesis is my own work.

Anne Therese McGown
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ABSTRACT

This research examines the relationship between carers' ability to absorb information and their level of emotionality. The literature pertaining to caregiving, stress and emotionality suggests that informational support may be important for the well-being of carers. Other research, however, suggests that carers do not always receive the information they desire or need. In particular, emotionality has been cited as a factor preventing carers from taking in information. This thesis therefore addressed two issues - (1) perceptions of the relationship between emotionality and information absorption and (2) the extent to which emotionality restricts information absorption. Emotionality and Information Absorption in hypothetical vignettes showed that both nurses and the general public perceived emotionality as an impediment to learning. The carers did not. A seminar run for nurses and carers showed that emotionality in carers did not interfere with their ability to take in information. Age of the carer was associated with a lower ability to take in information. Policy implications involving flexibly timed education programmes and greater attention to the needs of the carers are discussed.

(ii)
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Chapter 1

Introduction

It has been suggested that emotionality in family members of patients interferes with their ability to take in information. Some health professionals state that their judgements of emotionality influence the amount of information they give to family members about the patient's condition. Such information giving judgements have especially serious ramifications for family members who elect to care at home for a person with a long-term disability, such as a cardiovascular accident, which is more commonly known as a stroke.

One in seven Australians will suffer a stroke during their lifetime (National Stroke Association, 1985). A stroke occurs when the blood supply is blocked to a part of the brain, resulting in brain damage and loss of neurological function. It is the third cause of death and a major cause of disability in most industrial countries (Evans, 1979; Bonita & Beaglehole, 1982). There is no cure for stroke and the resultant disabilities are often permanent. Fifty percent of survivors have some residual disability.
Stroke survivors usually return to live at home. Sheikh, Meade, Brennan, Goldenberg, & Smith (1981) found 75% of 671 patients returned home and 7% moved to the home of a relative. An American study by Gibson (1974) found that out of 346 patients 56% returned home. A study by Granger, Greer, Liset, Coulombe, and O'Brien (1975) revealed 57% of patients admitted to an acute Boston stroke unit were discharged to their home, and after special rehabilitation, 10% more were able to live at home.

The trend is to encourage stroke survivors to return home much earlier, because of (a) the belief that their rehabilitation is better managed in the community and (b) the necessity to contain the spiralling cost of hospitalization by reducing the number of days patients spend in hospital. The majority of stroke survivors (80%) live at home with the help of a person (carer) who accepts responsibility for their care (Wade et al., 1985) — a commitment which permanently alters the lives
of both the stroke survivor and their carers. McDowell (1967) found that 30% of stroke survivors needed help from others to live at home. Increasingly, families are expected to care for the stroke affected person at home (Ballard, 1987; Wade & Langton Hewer, 1983; McDowell, 1967; Vetter, 1980; Wright & Robson, 1980; Bonita, Anderson & North, 1987; Mulley & Arie, 1978).

Supporting the stroke survivor at home is not short term. Bonita, Anderson and North (1987) found that stroke patients spend two thirds of their time in the first year after their stroke at home. Brocklehurst, Morris, Andrews, Richards, & Laycock (1981) found that 78% of stroke survivors, from a population of 500 000 people, lived at home one year after their stroke. Four years later, 29% of these people were totally dependent on their carers. It seems that in Australia and elsewhere an army of carers are providing long term home-based care (Gibson, 1984; Russell & Schofield, 1986; Hatano, 1976; Sheikh et.al., 1981; Adler, Hamatu, Brown & Potta, 1977; Gresham, Phillips, Wolf, McNamara, Kannell & Dawber, 1979; Mackay & Nais, 1979).
One alternative to home care is long term institutionalized care. A small percentage of survivors will need full-time long-term hospital care after their stroke. The proportion of stroke survivors cared for long-term in hospital varies across cultures depending on social and economic factors, such as families' willingness to care and the costs associated with that care (Wade, Hewer, Skilbeck & David, 1985). Aho, Harmsen, Hatano, Marquardsen, Smirnov & Strasser (1980) found that 16% of European stroke survivors were institutionalized one year after the stroke, whereas in Japan only 14% of stroke survivors spent their days in long term care. There were no survivors living in Indian or Sri Lankan long term care facilities in the 1980 study. In Mongolia, 4% of people required assistance in an institution and in Nigeria, the proportion of the stroke population requiring long term hospital care was 5%. Terent (1983) found that in Sweden, at any one time, 16-24% of stroke survivors were hospitalized and 7-17% resided in old people's homes. Of Christie's (1982) Australian sample, 26% were not living at home 6 months after their stroke.
The case against hospital care for stroke patients

Traditionally hospital care has offered 24 hour nursing care - an advantage which offers security to both the patient and their family. Such care is not without disadvantages. First, it is costly. Second, the patient can be unnecessarily exposed to infections. Third, the patient's dignity can be compromised, and fourth, they may not receive sufficient emotional support.

Caring for a person in hospital is a costly business, in both monetary and humanitarian terms (Russell, 1981), especially when the skills learnt by the patient do not equip them to cope with their disability at home (The Lancet, editorial, 1981). Patients frequently need to modify how they manage activities when discharged from hospital because home is not like the hospital. One advantage of hospitalization for the stroke person is the availability of 24 hour nursing care (Wade, Hewer, Skilbeck & David, 1985). However staffing shortages can limit the 24 hour nursing care which a hospital is expected to provide.

Hospital care exposes the survivors to additional
risks (Wade, Hewer, Skilbeck & David, 1985). Bed rest holds many dangers for these patients. There is a potential for them to develop bronchopneumonia, constipation and bed sores (Walker, Robin & Weinfeld, 1981). Deep vein thrombosis and pulmonary emboli have also complicated the convalescence of the stroke patient (McCarthy, Turner, Robertson & Hawkey, 1977; Warlow, Ogston & Douglas, 1976; Drake, Hamilton, Carlsson & Blumenkrantz, 1973; Wade et al., 1985). They are also exposed to, and more likely to succumb to iatrogenic infections because of contact with other patients and their compromised health status.

The survivor can experience a loss of dignity and status (Ford, 1979), as the focus of hospital care is acute illness and cure (Isaacs, 1985) and nurses have been found not to value the care they give to people who do not recover completely (Kratz, 1978). Hospitalized stroke persons are assisted by many nurses with activities such as eating, sitting, communicating, elimination and walking. The transience of nurses can leave the patient with an impression that such care is
impersonal, cold and mechanistic.

Although many attempts are made to make institutions homely, most stroke patients prefer to live at home with a carer's assistance, where they are surrounded by their own possessions and can enjoy life at their own pace (Russell & Schofield; 1986). At home their care can be more personalized providing greater freedom, protection, privacy and dignity for the individual.

Hospitalization has been viewed as detrimental to patient and family. Vetter (1980) noticed that the hospital environment encouraged the family members to overprotect the patient. This led the patients to relinquish some of their independence and lose some of their skills regained during their rehabilitation. Overprotectiveness of patients by family members has also been reported by Jarrett (1981) & Storker (1983).

Overprotection may reflect family members uncertainty about the best way to care for the patient as well as their reservations about their future prospects. The family may relieve the person
of responsibilities because they think the person's days are numbered. Overprotectiveness is associated with a poor medical outcome for patients (Davies, 1973; Derogatis, Abeloff & Melissaratos, 1979; Schmale & Iker, 1971; Simonton, 1980).

A further detrimental outcome for the patient and the family is that hospitalization has also been found to increase the patient's and family's expectations of a cure. Additional suffering is experienced by the patient and family when they realize that there is no cure for stroke. This realization often produces feelings of rejection and hopelessness (Wade, Hewer, Skilbeck & David, 1985) in both parties.

On the other hand short hospital stay may give the family time to adjust to the stroke (Wade, Hewer, Skilbeck & David, 1985). Often families are unwilling to accept that the recovery rate of the first few weeks will slow down (Wade, Hewer, Skilbeck & David, 1985;). While the patient is in hospital the family members are mostly exonerated from caring. This time may be used to work through their unrealistic expectations of cure and their
denial of the permanency of some aspects of stroke (Isaacs, 1985; Kinsella and Duffy, 1980;).

The case for home-based care

Many believe that the rehabilitation of stroke survivors is more successful at home (Wade et. al., 1985; Vetter, 1980; Wright & Robson, 1980; Jarrett & Storker, 1983; Brocklehurst, Andrews, Morris, Richards & Laycock, 1978a). Home rehabilitation has led to greater patient motivation to learn to manage their disability. When patients are cared for at home, families are more likely to become involved (Wade, Hewer, Skilbeck & David, 1985).

Wade and Hewer (1983) found that the most appropriate place to care for the stroke survivor was at home. They suggested that with support from a community health nurse, the family could learn to care for the person in an environment which was familiar and informal. It was believed that the home setting would facilitate open discussion of practical problems between family members and the visiting nurse.
Wright and Robson (1980) also recommended home care for the stroke patient. They believed the patient did not receive the equivalent quality or quantity of care from busy nurses that their family could give them. They suggested that stroke patients were often admitted to hospital because of the family members' fear of the stroke rather than the patients' needs, a finding supported by Brocklehurst et al. (1978a). Wright & Robson (1980) recommended that the family be gradually taught to care for the stroke person by caring for them at home for short spurts of time like overnight or on weekends.

Specialized units for stroke patients have been suggested as an alternate rehabilitative setting to the general ward situation. In a comparative study of patients from a specialized stroke unit and a general ward, Garraway, Akhtar, Hockey & Prescott, (1980a) found the stroke unit patients lost their advantage over patients from the non-specialized ward immediately after their discharge from hospital. The skills patients learnt in the special unit were not used when the patients returned to their home environment because they were not relevant to their home lifestyle (Wade,

A case controlled study by Bryant, Candland & Loewenstein (1974) compared the rehabilitation of stroke patients at home with 25 hospital rehabilitation patients. The home based patients were given the assistance of a domiciliary physiotherapist and the hospital group were not. It was found that the home-based rehabilitation group's care cost less money, resulted in a shorter hospital stay and increased the likelihood that members of this group would be living at home one year after their stroke. So, even when hospital care is compared with home-based care, patients do better at home.

In summary, the trend is to send stroke survivors home. Home-based care is preferable because it is claimed to be cheaper, the rehabilitative skills learnt are relevant, patients progress better, and their functional ability is maintained or restored more quickly. The majority of survivors need someone to assist them. Therefore, the whole idea of low-cost home-based care is reliant on the commitment of a person (carer) who is willing to be
responsible for the survivors' well-being. The existence of a home-based carer is the lynch-pin of the thrust for home-based care.

Is home care a preferable proposition?

In spite of widespread endorsement of home-based care among health professionals, the approach is not without its critics. It is suggested that home care costs have not been estimated properly and some question the claim of its cost effectiveness (Berk & Chalmers, 1981; Jorm, 1987). The costs of caring for a stroke affected person far exceed that covered by the carer's allowance provided by the Australian government. Often, the survivor commences a totally new lifestyle which requires modifications to their home and to many items such as clothing, heating, and furniture. Extra costs are also incurred when purchasing medicines, or providing transport and leisure activities for the patient (Brockelhurst et al., 1981).

This view was also supported by Opitt (1977) who, when taking into consideration the hidden suffering of patients and their families, judged the cost
similar to hospitalization. The functional impairment left by the stroke often prevents the person from performing activities without assistance. The strain of feeling that the family members needed to constantly entertain and/or organize activities for the survivor was constantly mentioned by carers in this research and has also been reported by Braithwaite (1990). Coupled with the financial restraints due to lost income, the social and psychological burden of caring becomes very great. The well-being of the carer has been found to deteriorate, adding to the cost of maintaining the survivor at home and many carers themselves become patients.

The option of home care has been viewed with caution by Waters and Perkin (1982) who suggested that home management of stroke was justified only when appropriate back-up care and support was available. They suggested that hospital or long-term institutional care must always be seen as a satisfactory alternative if the home care situation became impossible for either the patient or the carer.
The Need for Informed Carers

Good quality home care is essential if the stroke person is to remain at home. Health professionals are aware of the adverse consequences for patients if the carer does not understand about caring. Proponents of home-based caring (Wright & Robson, 1980; Vetter, 1980; Wade & Hewer, 1983; Jarret, 1981; Mulley & Arie, 1978) and carers themselves (Mathis, 1984; Rolland, 1987; Daley, 1984) have supported the importance of keeping the carer well informed about stroke and caring. In many respects carers of stroke patients are expected to be nurses even though they have no professional knowledge.

The importance of giving information to stroke families was recognized by Overs & Belknap (1967) who found the positive rehabilitation effects for the survivor were reduced by the well-meaning but ignorant practices of the family members after the survivor was discharged from hospital. Family members were found to be excluded from patient care by hospital staff and the exclusion resulted in inadvertent caring errors made by family members.
The consequences of lack of knowledge by family members are sometimes reflected in their behaviour towards the survivor. Kinsella and Duffy (1980) found an over-riding sense of anxiety, guilt, over-protection and lack of realism amongst 79 spouses of stroke patients. These relatives did not know what to do for the best, and claimed to have received little direction in their caring role. Many believed the patient's stroke and failure to recover reflected personal inadequacies of the patient. This attitude made the resumption of daily living difficult for both parties.

Interpretation of the effects of the stroke by family members may result in deteriorating family relationships. Mackay and Nias (1979) found that mutual incomprehension between stroke survivors and their relatives resulted in strain and distress. Similar findings have also been made by Christie & Lawrence (1978), Lawrence & Christie (1979), Labi, Phillips & Gresham (1980), and Brocklehurst, Morris, Andrews, Richards & Laycock (1981), and Stedeford, (1981).
Carers are aware of their need for more information and say they do not have enough knowledge. Bergman, Foster, Justice & Matthews (1978) found that the carer did not receive adequate support from health professionals in the general community. Instead the support was directed to patients living alone who were less likely to remain at home in the long run.

In a study of the perceived needs of brain-injured patients' families, Mathis (1984) found that during the hospital phase the family members had many information needs. Those mentioned by many family members were: to feel that hospital personnel cared about them; to be called at home if the patient's condition changed; to be told about the patient's exact treatment; to be given honest information about the patient's condition and progress, and to feel that there was hope.

Research by Daley (1984) found the prioritized needs of head injured patients' family members to be those of anxiety relief and information. Anxiety inducing factors identified by this group were: lack of knowledge about the patient's condition, prognosis, nursing care, treatments, transfer plans
and equipment used in their treatment. Anxiety levels were reduced when the hospital staff shared with them their opinion of the patient's future. Family members also mentioned the importance of knowing the patient was cared for by qualified staff. Twenty-four hour telephone access to patient's status was also important for these people.

In sum, the perspectives of both health professionals and family carers converge on the importance of providing information to the families of stroke victims. Families want such information and it seems to be an important part of allaying their anxieties. Furthermore, families need such information to provide good quality care.

Information and carer well-being

The burden literature:

Burden is a term which has been used in relationship to the stress of caregiving and is defined here as the carer's perception of how well they are managing both the caring role and their own life. While caring, carers face hassles, frustrations and threats to their
well-being on a daily basis. The burden of home care usually lies with one person (Brocklehurst, Morris, Richards & Laycock, 1981; Braithwaite, 1990) who may become overwhelmed by the constancy of the caring role - due to little forewarning, and insufficient guidelines for pacing themselves. Carers have been found to suffer not only from increased physical health problems but also manifest high levels of minor psychiatric symptoms, specifically depression and anxiety (Braithwaite, 1990).

Braithwaite (1990) found that perceived burden by carers was significantly related to their poor mental health. Carers whose lives were greatly disrupted because of their caring responsibilities by such things as being constantly on call, unable to finish anything and having to change plans at extremely short notice, reported experiencing more of the symptoms of depression and anxiety. Likewise, carers who reported feelings of inadequacy, such as being unable to get on top of things, and losing patience with the carereceiver reported more anxiety and depression.

Major factors identified by Brocklehurst, Morris,
Andrews, Richards & Laycock (1981) as contributing to carers' burden six weeks after the stroke were: irritable and demanding behaviour of the survivor, the physical tasks of lifting, assisting with bathing and incontinence, loss of sleep and feeling that they needed to constantly supervise the person. A twelve month follow-up of this group found the stroke person's behaviour still accounted for one third of the carer's perceived burden. Other factors contributing to carer burden were those of supervision and sleep loss. During this study carer reports of poor health trebled.

Unsatisfactory communication has been found to increase the family's burden. Bereaved women reported that the mental and physical health problems they experienced were exacerbated by having their expression of negative feelings blocked (Maddison & Walker, 1967). More importantly for this study is the finding that high burden is linked with inadequate knowledge of what is required in the caring role.
The stress literature:

While information for carers is seen as important in the nursing literature, the psychological literature on stress and carer burden also supports its usefulness. The psychological concepts of appraisal and coping are said to influence the type of reaction a person makes to a situation. Appraisal refers to how an individual evaluates a stressful situation, that is, is the problem regarded as a threat, loss or challenge (Lazarus & Launier, 1978; Folkman & Lazarus, 1985; Folkman & Lazarus, 1980; Folkman, Lazarus, Dunkel-Schetter, De Longis & Gruen, 1986a; Folkman, Lazarus, Gruen & De Longis, 1986b; McCrae, 1984). Appraisal influences the type of coping strategies people use. Coping refers to the actions employed by people to reduce the stress they experience (Fleming, Baum & Singer, 1984). Information is an important element in both coping and appraisal because it affects how we appraise and how effectively we cope. Coping strategies have been typed as either "problem-focused" or "emotion-focused" (Folkman & Lazarus, 1980; Billings & Moos, 1981). Problem-focused coping strategies are those which aim to manage a problem.
Information seeking is an example of this type of coping (Lazarus, 1966). Emotion-focused strategies, on the other hand, are those which avoid the problem and concentrate on dealing with the emotional suffering experienced over a situation.

The literature emphasizes the need to tailor particular coping strategies to particular situations (McCrae, 1984; Coyne, Aldwin & Lazarus, 1981; Felton, Revenson & Hinrichsen, 1984). Nevertheless, there is support for the effectiveness of a problem-focused coping strategy, such as information seeking, across a variety of situations.

The work of Felton, Revenson and Hinrichsen (1984) into the coping strategies of people suffering from either hypertension, diabetes mellitus, cancer or rheumatoid arthritis found that information seeking was related to positive mood. They defined information seeking as an active instrumental orientation to the illness, wanting to find out about the treatment, possibility of cure, or the expected progress of their condition.
In a study of self-reports on coping in stressful situations from 15 depressed and 72 nondepressed middle-aged people, Coyne, Aldwin & Lazarus, (1981) found that depressed people appraised the situation more frequently as requiring more information before they could make a decision.

McCrae (1984) found seeking information was one of the most commonly used coping strategies by a sample of 151 subjects enrolled in the Baltimore Longitudinal Study of aging, when they appraised that they were faced by a threat to their health or well-being.

Seeking information was observed by Folkman et al., (1986b) as a coping strategy used by people who appraised situations as changeable and who reported satisfactory outcomes. In contrast, emotion-focused coping strategies were used when the position was perceived to be unchangeable and outcomes unsatisfactory (Folkman et al. 1986b).

Lack of knowledge causes problems for carers, and may lead them to appraise the outcome of their situation as unsatisfactory or unchangeable. This
may lead to poor coping patterns in the carer. Without adequate knowledge family members cannot identify causes of their burden, frustration tolerance is low, and they develop a tendency to project blame (McCubbin & Figley, 1982).

Finally, it is of note that information seeking was found to be independent of other active coping behaviours by Fleishman (1984) in his study of personality characteristics and coping patterns. He suggested that this type of coping has an explicitly social orientation. As such, its use can be modified by the social environment.

In summary, in stressful situations, problem-focused coping behaviours such as information seeking have been used by people who believed satisfactory outcomes were possible, while the emotion-focused coping was used when people believed the unsatisfactory situation was permanent. In caring for stroke victims, lack of knowledge may lead to a negative appraisal and to negative coping that is not optimal for patient or carer. Carers of stroke victims should see the situation as a challenge rather than assume a loss. Inadequate knowledge may not only affect the
appraisal but result in emotion-focused coping strategies to the neglect of problem-focused strategies. An information seeking coping strategy is proposed as an effective one for carers of stroke victims to use. As the nurses are the most available health professional to the carer, stroke and caring information given by them may be important in influencing the type of appraisal made and therefore the coping responses chosen.

**The emotion literature:**

Two attributes which are characteristic of carers - having too little information and feeling highly emotional - may be related in such a way that has negative consequences for carers and their patients. Siminov's (1970) theory of emotion focuses on the effects of absence or availability of information. Emotion is seen as the interaction of need and the probability of goal achievement. When a person is unable to prepare themselves appropriately because of insufficient information, negative emotions are experienced. He suggests that too little information results in an experience of negative emotion.
The chapter documents the increasing popularity of home care but points out that the success of the program is contingent on the expertise/competence of an informed family caregiver. Inadequate knowledge on the part of the person has two negative consequences. First, care to the patient may be inadequate. Second, the wellbeing of the carer may be greatly jeopardized by insufficient knowledge. The burden literature, the stress literature and the emotion literature all suggest that inadequate information threatens mental well-being.
Chapter 2

Why don't carers have information

Having documented carer's needs for information, this chapter examines why some carers do not have sufficient information. A number of explanations exist for why carers are not as well informed as they should be or as they would like to be. Since nurses and doctors are the most likely source of information for carers, the first question is - do nurses and doctors pass on information to the carer? Second, is it difficult to get information across to the carer? Do they have difficulty taking in information given to them? Third, do carers want more information than they can be given in the situation? Is it possible to turn ambiguity into certainty. Fourth, do nurses and doctors use selective practices when giving information to carers? Evidence relating to these questions will be reviewed in this chapter.
Are carers given information?

Kratz (1978) found that the community nurse was the person most able and available to keep family members informed of current caring and stroke rehabilitation news. In a study of South Manchester stroke survivors and carers (Brocklehurst, Morris, Richards & Laycock, 1981), carers identified the nurses as their most available source of support and information. It is reasonable to conclude that carers look to nurses as an important source of information.

There is much literature to suggest that nurses have played an important role in informing carers. Gaynor (1989) found that for the first two years, women caring for husbands with neurological impairment reported receiving help from nurses. The nurses taught them nursing tasks and kept them up to date on the medicines with which the survivor was being treated.

Dring (1989) also identified the nurses as those who gave information to the carer. It was found that nurses assisted the carer with information about resources, scheduling of daily care and
activities, factual information about the physiological and cognitive effects of stroke and strategies for the management of these deficits in the home. They also organized a list of additional resources and monitored the progress of caregiver and carereceiver.

In cases where carers have not been given satisfactory information, two possible explanations are worthy of mention. First, nurses may model themselves on other health professionals they admire, but who do not tell carers much. Second, they may see the family as irrelevant to their care.

Nurses modelling their information-giving practices on those of others is consistent with Bandura's (1977) thesis that people learn by watching and imitating others who are perceived to be credible. If this is so, the information given to carers may be based on modelling learnt behaviours rather than on any assessment of the carer's ability to take in new information. Due to demands on their time, the doctors are often not as informative as they could be and often the task of assisting the carer to deal with the factual and emotional information
about stroke is delegated to health professionals with more time. While no data were found that directly addresses the modelling explanation for poor information giving practices, data are available to show carer perceptions of inadequate information giving, observations of poor information giving, and nurse perceptions of low priority of information giving to families.

Pueschel and Murphy (1976) found that 10% of their sample of parents of Down's syndrome children believed that they received inadequate information about the condition from their physicians. Information was given in an abrupt and unsympathetic manner to 15% of the parents by their attending physicians. Parents reported that no information was given to them in 6% of the cases.

A study by McDonald, Carson, Palmer & Slay (1982) found that few physicians gave all possible information to the parents of handicapped children. The decisions to give information were related to the child's prognosis, and the race, social class and perceived emotional stability of the parents.
The nurses may not give enough information to the carer. Providing the major support for another person is very stressful (Klein, Dean & Bogdonoff, 1967; Stern & Pascale, 1979). In a study by Hampe (1975) 75% of spouses felt they had not received sufficient support from the health professionals. Breu and Dracup (1978) found that cardiac patients' spouses received little assistance because they did not ask. Family members have also tended to put their informational needs on hold because they believed that the staff were needed by their patients (Molter, 1979; Leavitt, 1975; Freihofer & Felton, 1976).

Ballard (1987) found that nurses tried to reduce the fears of family members by involving them in the physical care of the survivor. This involvement often occurred without the nurses' guidance and support, family members being left to assist the person without tutoring. The results showed ambivalent feelings in the family members (Mathis, 1984).

The practice of restricting family members' information may be an artifact of past professional
prejudices when the family's importance was not recognized as a major factor in the well-being of the patient. The effect illness has on the family and their role in rehabilitation has been publically endorsed only recently (Northhouse, 1984). Historically, nurses have not attended to the family members' information needs or they have left it up to the members to obtain their own information. Bond (1982) found that in all but one instance it was the family members who started interaction with the staff. Family members needs may be ranked lower than those of the patient due to limited resources (Northhouse, 1984).

Northhouse (1984) suggests that information may be viewed as privileged and therefore not available for the carers, and that when this happens information giving becomes filtered. This practice prevents people from clarifying, correcting misinformation, or developing an effective relationship with the staff as filtered communication is usually one-way.

Litz (1957) noted that historically family
members have been perceived as a nuisance and worthy of little information. Families of psychiatric patients in the past have been regarded at times as the source of the patient's problem (Leavitt, 1975).

Family members of sick patients may be perceived as having less status (Northhouse, 1984). Family members were asked to leave the ward area if they impeded staff routine or became emotional (Sosnowitz, 1984).

Can carers take in the information they are given and is that information appropriate? Widespread dissatisfaction among carers with the information they receive from hospital staff (Rasie, 1980; Sosnowitz, 1984; Maus-Clum & Ryan, 1981; Molter, 1979; Stroker, 1983; Thompsen, 1974) may reflect an inability to remember what they are told under stress. It may also reflect an assumption on the information giver's part that facts and direction in activities are all that the carer needs.

Anxiety has been found to interfere with information acquisition. Harris (1961) found that the emotional factors which affected learning
in his schoolboy sample were family disorganization and the subsequent feelings of anxiety and uncertainty. Anxiety and family disorganization interfered with both the subjects' actual thinking processes as well as their motivation to learn.

Overs and Belknap (1967) have suggested that emotional information about stroke was not quickly absorbed by carers. They suggested that the doctor does not have time to wait for family members to absorb information at an emotional level and so they should give only medical information to the family. The coping and ongoing acceptance of the debility by the family is better managed by professionals who have more time available to spend with them, such as social workers.

Hawker (1964) recommended a family conference to keep family members informed of the patient's progress and treatment. These conferences consisted of open meetings with the rehabilitation team and the family. In this setting, specific problems met by the family members were discussed and help was found for them quickly. This forum helped the family members gain insight and prevented the readmission of some patients by smoothing the
transition from hospital to home, and leaving the hospital staff with a better understanding of the family situation.

The rehabilitation team's responsibility to the family in conference was to assist them to reduce their anxiety and to work through their emotional feelings about the stroke. Understanding the stroke was fundamental to alleviating some of the anxiety of the stroke victim's family. Emotionally laden information about the stroke was found to be more easily absorbed by family members when presented through group and individual discussion when the carer's anxiety was relatively low.

Brocklehurst et al. (1981) found that an effective counselling service was needed for carers. His sample particularly required assistance in understanding survivors with speech disorders. They also needed support to cope with the residual behaviour problems of the survivor, caused by the stroke. It was suggested that being told once was not enough.

Stone (1987) found that family members of survivors often required intensive counselling from social
workers. He described the necessity of a three
stage family support service. The first stage,
"explanation", included a preliminary discussion of
the nature and prognosis of the stroke as well as
information about the treatment plan for the
survivor. Co-therapy was the second stage - the
family members were invited to work alongside the
professional, helping the survivor relearn basic
tasks. The third stage where help was needed was in
the post-discharge stage. Here family members were
assisted to cope with their 24 hour-a-day care for
the survivor.

Hilt (1976) found that the comprehension ability of
parents of sick children was limited until they
began to cope with the situation. It was suggested
that an unplanned illness created a high level of
anxiety which interfered with communication between
nurse and parent. It was suggested that information
may need to be frequently repeated and expanded on
until the family members have understood it.

Finally, Daley (1984) suggested that nurses need to
be careful to use simple terms when explaining
conditions to family members and that even simple
information may need to be repeated several times.
Do carers have unrealistic information expectations?

Under stressful circumstances appropriately targeted information may not be perceived by the person as adequate. The carers' complaints may reflect the difficulty of meeting carers' emotional and information needs simultaneously. No matter how much information they are given, stressed people may always perceive their information to be inadequate. While this issue has not been addressed in the literature, it needs to be recognized in interpreting research findings. The question is one of causality. Does poor information provision lead to emotionality as theory would suggest? Or are those who are depressed and anxious more likely to be dissatisfied with everything, including the information which is supplied by the health professional.

Is information given to some carers but not others

Nurses may be selective in whom they inform and how much information they give. Their information giving decisions may be coloured by the status, emotionality, or perceived blameworthiness of the
family member.

The decision to give or restrict information has been influenced by the perceived status of those requiring information. In a study by Sherif, White & Harvey (1955) of a general public sample, people perceived as having high status tended to have their performance overestimated whilst the performance of perceived low status individuals tended to be underestimated. Status was also found to be an important factor by Rosenthal, Marshall, Macpherson & French (1980).

Perceptions of carer emotionality have been found to influence decisions to impart information. The amount and type of information provided to families of sick neonates has been found to depend significantly upon the hospital staff's judgement of the parent's emotional level (Lipton & Svarstad, 1977). Parents whose adjustment level was judged to be average were given more information from the medical and nursing staff than those whose adjustment was judged below average. The physicians admitted that the amount of information they imparted to parents of retarded babies, and the pace at which it was given, depended on their
judgement of emotional and cognitive factors in the child's parents. These physicians suggested that the degrees of emotion were important but they were unable to specify what level of emotion related to what proportion of information.

In one neonatal intensive care unit, if family members outwardly displayed emotion, the staff insisted that they were removed from the unit (Sosnowitz, 1984). If the emotional display continued the staff were observed to reward quieter family members of other patients with more detailed information (Hay & Okens, 1977; Tagliacozza & Mausch, 1972; Taylor, 1979).

In a study by McDonald, Carson, Palmer & Slay (1982), 44% of the physician sample (N=69) indicated that the amount and type of information they would give to parents would depend to some extent on their perception of the parent's emotional stability. Of the same sample, 13% identified parental emotional stability as the most important variable influencing the amount of diagnostic information they gave.
Selectivity may be influenced by the perceived blameworthiness of the family member. Ryan (1971) has identified a phenomenon called blaming the victim. Attention is focused on the alleged failure of the person and this failure becomes the explanation for the person's predicament. The family members may be perceived as causing or deserving their lack of information, being classified by nurses as good or bad.

Such classification has been noted by Brown & Forster (1982) and McGown (1986). A relative was likely to be perceived as "good" if they appeared to understand and conform to the nurses practices and schedules, asked appropriate questions, tolerated uncertainty, showed concern for the sick, visited regularly, responded in appropriate ways to good and bad news, showed potential ability to care for the patient, praised staff freely and were middle or upper class.

These nurses perceived "bad" relatives as those who: frustrated staff, appeared incapable of understanding the patient's condition, were uneducated or unintelligent, did not perceive the patient in the same manner as the staff, did not
telephone or visit regularly, made short visits, did not interact in a manner acceptable to the staff, did not have the skills, background, resources or facilities to care for the sick person, made what the staff considered to be unreasonable demands and always found faults Rosenthal, Marshall, Macpherson & French (1980).

Such carers may not receive adequate information about their sick family member because they are not perceived as deserving by the nurses.

Conclusion

This chapter supports the role that nurses can play in providing information for carers. At the same time, there is evidence to suggest that sometimes carers are not given the information they need, and are not considered important enough to be informed, sometimes the information is not presented clearly or is not appropriate. Carers often need emotional support before they can digest information, and some carers are perceived to be more worthy of information than others. One important factor influencing who is informed and who is not is emotionality, information is filtered for emotional carers. Yet as we saw in chapter 1, information is
likely to be a useful tool for helping carers adopt a more positive appraisal of their situation and more effective coping strategies to avoid mental ill health. This is the paradox which is the central concern of this thesis.

**Purposes of the study**

This study involving carers of stroke patients and nurses seeks to address four issues. First, the question is raised of whether nurses are selective in whom they give information to. In particular, do they believe that emotional carers are unable to absorb information.

Second, the question is raised of whether carers share this perception or whether their expectations are at odds with those who are major providers of information. If they are, this would explain some of the frustration which carers experience when dealing with health professionals.

Third, how is the relationship between emotionality and the capacity to absorb information viewed by the general population? Such an analysis should provide some insight into whether nurses'
perceptions are the result of professional socialization or are congruent with dominant beliefs in our society.

Having examined the prevalence of the belief that clients are less able to absorb information than others, the thesis proceeds to examine empirically the validity of such a proposition. The final study examines whether emotionality actually interferes with the amount of information carers can absorb in an educational intervention programme and at the same time, investigates other factors that may account for carer knowledge. These factors are gender, age, burden, workload, degeneration of stroke person, relationship to the care-receiver and length of time in the caring role. They have been included, not only because they may be linked with information acquisition in their own right, but because they may be confounded with the initial levels of emotionality reported by the carer prior to the intervention programme.
Chapter 3

Study One: Scale Development

The pilot study to be reported here was the first stage in testing the question of a relationship existing between judgements of emotionality and perceptions of information absorption. Data were collected via a set of hypothetical vignettes. For each vignette, participants judged how emotional the carer was and how much information could be absorbed. The first step was to analyze responses to these vignettes to derive a subset which could be used as items in a scale measuring perceptions of emotionality and perceptions of information absorption. A subset which were intercorrelated and which could be used as a scale provided the basis for the second study.

The questionnaire

Participants were presented with sixty vignettes each comprising one paragraph usually and each describing the behaviours of hypothetical carers.

Ten vignettes were written to represent each of five categories: no emotion, mild emotion, moderate emotion, severe emotion, and panic. An
additional ten vignettes described a carer with varying emotional states combined with high education qualifications. These sixty vignettes were collated in a random order and presented to the subjects for judgement.

The sixty vignettes are presented in Appendix 1.

The subjects were asked to judge and rate the carer in each vignette according to the questions presented in Table 3.1.
Table 3.1. Questions referring to Emotionality and Information Absorption by the carer perceiving each vignette.

Question 1: What level of emotion is Mary exhibiting? Please cross (x).

(1) (2) (3) (4) (5)
none a little moderate severe panic

Question 2: Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing?

(1) (2) (3) (4) (5)
none a little moderate almost all everything

It took the subjects approximately forty-five minutes to complete the questionnaire. These responses provided data for the development of the Emotionality and Information Absorption scales.

Subjects
The pilot sample consisted of four groups:
(1) Nurses who cared for stroke survivors;
(2) Nurses who taught nursing students;
There were no male volunteers in these groups. The subjects in the stroke carer group were elderly females who cared for the stroke survivor in the Brisbane community. The nurse clinician group worked in the medical wards of a Brisbane hospital. They routinely cared for stroke survivors and interacted frequently with stroke carers. The nurse teacher group worked in a nursing school at a Brisbane hospital. They taught nursing students in a basic general nursing certificate course. The subjects in this group had not cared directly for patients and their family members for some time.

The general public group came from a working class area of Brisbane. This group had not cared for a stroke survivor. They also had little experience of nurse information giving practices. There were ten subjects in each group of this study giving a total sample of 40. The carer and general public group completed the survey at home, the nurses completed
their questionnaires at work. There were no missing data as the interviews were conducted face-to-face.

**Debriefing**

Each subject was debriefed in full when the survey was returned. This was on a face-to-face level, and was very informative as most of the subjects felt the need to explain their judgements on some of the vignettes. Many mentioned that the vignettes did not give sufficient detail to make an informed judgement. The debriefing sessions averaged ninety minutes, with the carer group taking the most time.

**Scale Development**

In this chapter, the scales constructed to analyze relationships between Emotionality and Information Absorption are described. The goal was to reduce a large set of items to two multi-item scales, one representing emotionality and the other information absorption. For the purposes of this exercise, the response to an item refers to either the emotionality rating assigned to a particular vignette or the information absorption rating assigned to a vignette. Only items which contributed to variation in scores and which were
intercorrelated found their way into the final measures. Items were also selected to represent the different levels of emotionality which guided the construction of the vignettes. As a result of item analyses, the best six vignettes were selected for use in assessing both Emotionality and Information Absorption. These vignettes are presented in Appendix 2.

The Emotionality Scale

The alpha reliability coefficient (Cronbach, 1951) was satisfactory for the Emotionality scale (alpha = .71). Frequencies for all items and item intercorrelations appear in Appendix 3. Presented in Table 3.2 are the item means, standard deviations, and item-to-total correlations for the emotionality responses. The emotionality scale ranged from 6 to 30 with a mean of 19.4 and a standard deviation of 2.84.
Table 3.2. Means, standard deviations and item-total correlations from the Emotionality Scale items.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>N</th>
<th>MEAN</th>
<th>SD</th>
<th>ITEM TOTAL CORRELATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>40</td>
<td>3.20</td>
<td>.85</td>
<td>.54</td>
</tr>
<tr>
<td>16</td>
<td>40</td>
<td>4.12</td>
<td>.56</td>
<td>.58</td>
</tr>
<tr>
<td>18</td>
<td>40</td>
<td>3.20</td>
<td>.75</td>
<td>.42</td>
</tr>
<tr>
<td>25</td>
<td>40</td>
<td>2.02</td>
<td>.73</td>
<td>.34</td>
</tr>
<tr>
<td>28</td>
<td>40</td>
<td>3.80</td>
<td>.64</td>
<td>.47</td>
</tr>
<tr>
<td>56</td>
<td>40</td>
<td>3.05</td>
<td>.81</td>
<td>.40</td>
</tr>
</tbody>
</table>

The Information Absorption Scale

The Information Absorption scale was based on the same six vignettes used for the Emotionality scale. The alpha reliability for the scale was .79. Scale scores ranged from 6 to 30 with a mean of 19.4 and a standard deviation of 3.89. Presented in Table 2.3 are item means, standard deviations and item total correlations for responses to the question "how much information is Mary capable of absorbing?". The frequencies for the 6 items appear in appendix 4 as do the item intercorrelations.
Table 3.3. Item means, standard deviations and item-total correlations from the Information Absorption Scale.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>N</th>
<th>MEAN</th>
<th>SD</th>
<th>ITEM TOTAL CORRELATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>74</td>
<td>40</td>
<td>3.32</td>
<td>1.04</td>
<td>.69</td>
</tr>
<tr>
<td>76</td>
<td>40</td>
<td>2.50</td>
<td>1.06</td>
<td>.55</td>
</tr>
<tr>
<td>78</td>
<td>40</td>
<td>3.42</td>
<td>.84</td>
<td>.64</td>
</tr>
<tr>
<td>85</td>
<td>40</td>
<td>3.92</td>
<td>.79</td>
<td>.17</td>
</tr>
<tr>
<td>88</td>
<td>40</td>
<td>2.87</td>
<td>1.01</td>
<td>.61</td>
</tr>
<tr>
<td>116</td>
<td>40</td>
<td>3.42</td>
<td>.74</td>
<td>.61</td>
</tr>
</tbody>
</table>

The correlation between the emotionality and information absorption scales was .20, a relationship which was in the opposite direction to the stereotype of emotional people being less able to absorb information. The next study will explore further the link between emotionality and information absorption.
Chapter 4

Study 2 - Testing perceptions of the link between Emotionality and Information Absorption

The studies to be reported here examine the relationship between the two concepts, emotionality and information absorption in a new and larger sample (N=140). In this second research phase, the issue of whether or not the relationship is specific to certain disease types is partly addressed by comparing diabetic carers with stroke carers. The caring demands of the two groups differ in many respects. Of particular interest in this context is that carers of diabetics often need to provide swift treatment to prevent death, whereas there is nothing which can be done to reverse a stroke once it has occurred. This comparison is the purpose of the second study of this chapter. The first asks the question of whether or not nurses' perceptions of the amount of information that carers can take in is linked to their perceptions of the carer's emotionality. The further situation of whether or not this relationship extends into the general community is also examined.
Study A

The vignette format was identical to the pilot study, but much smaller, comprising the six vignettes chosen on the basis of the pilot study. The content of these vignettes described commonplace behaviours of carers such as giving chocolates for the nurses, asking them questions, being aggressive, complaining of physiological symptoms in themselves, hiding their anxiety from the patient and making themselves useful by assisting with patient care. The six vignettes were presented in a random order with a covering letter (see Appendix 5). Subjects were asked to read each vignette and answer the two questions which were presented below each one. These questions are presented with a response criteria from 1 to 5, as in Table 4. 1. The questionnaire took subjects approximately twenty minutes to complete.

The Subjects

In this study the Emotionality and Information Absorption scales were presented to a sample of 140 between September 1987 and April 1988. The sample was obtained from the Canberra and Newcastle areas. The all female sample
consisted of: 39 members of the general public, 47 nurses and 56 carers of stroke survivors.

The subjects were categorized into five groups, two groups of nurses, two groups of stroke survivor community carers, and a group from the general public. One group of nurses and stroke survivor carers were from Newcastle and the other group from Canberra. The nurse group subjects cared for stroke patients in the hospital and had the opportunity to interact with the carers regularly. They were contacted through hospitals in Newcastle and Canberra. The stroke survivor carer group were people who cared for a stroke person at home. The stroke carer subjects were volunteers contacted through the Canberra and Newcastle stroke clubs. The Canberra general public group consisted of people who had (a) not cared for a stroke person and (b) little exposure to the information-giving practices of nurses. They were contacted via public notices and a snowballing method, where the participants were asked whether they knew of anyone else who would be willing to participate in the study. The table 4.1 below presents a breakdown of participants from each region.
Table 4.1. Subject participation by region

<table>
<thead>
<tr>
<th>Participant Group</th>
<th>Canberra</th>
<th>Newcastle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>36</td>
<td>15</td>
</tr>
<tr>
<td>Stroke carers</td>
<td>35</td>
<td>21</td>
</tr>
<tr>
<td>General Public</td>
<td>39</td>
<td>0</td>
</tr>
</tbody>
</table>

The data were obtained by a combination of two methods - mail and whenever practicable, face-to-face interview. The data from the ACT stroke carer group was gathered by face-to-face interview in the carers' homes. The data from nurses, Newcastle stroke carers and the general population were collected by delivering questionnaires in person and using a mail back return or by collecting them personally after they were completed. Consequently the questionnaire was assembled so that it was suitable for either self-completion or face-to-face interviewing.

In order to collect data from the nurses the researcher arranged with the Nursing Research and Project Officer to leave the questionnaires in the wards for the nurses to complete. After a two week
period, the completed questionnaires were returned by mail in the stamped addressed envelopes provided.

Available nurses were debriefed in person, those not able to be present were sent a letter detailing the purposes of the study. Findings were also presented in person or by mail. A copy of the completed research was forwarded to the participating hospitals.

In order to obtain the stroke carer subjects, the chairperson of the stroke clubs was contacted by the researcher by telephone and arrangements were made for her to attend the club meeting to recruit volunteers for her study. The questionnaires were distributed to each person and returned to the researcher by post or she collected them in person. The Canberra subjects were interviewed face-to-face. After the data were collected, the subject was debriefed in person (Canberra) or by mail in the case of the Newcastle subjects. A public seminar was held to report the research findings and a formal letter reporting the findings was provided to the participating stroke clubs for their records.
The general public sample were volunteers from Canberra, who responded to some community advertisements. They had no experience in caring for stroke survivors or exposure to the information-giving practices of nurses. They were contacted by telephone, the survey was delivered or posted to them and they returned it by mail. They were debriefed either by telephone or by mail. They were also invited to the public seminar held to report the research findings.

RESULTS

The Emotionality scale, measuring perceived emotionality across six vignettes, had an alpha reliability coefficient (Cronbach, 1951) for this study of .49 (N=140). The Information Absorption scale, reflecting perceptions of the amount of information the hypothetical carers were able to absorb, had an alpha reliability coefficient (Cronbach, 1951) of .57 (N=140). Table 4.2 gives the means and standard deviations of the Emotionality and Information Absorption scales. Scale scores were calculated by summing the participant's responses to provide a score for each person on perceived emotionality and perceived
information absorption. The correlation coefficient between these scales was \(-.13, n = 140\).

Table 4.2. Alpha reliability co-efficients, means, and standard deviations for Emotionality and Information Absorption Scales.

<table>
<thead>
<tr>
<th>SCALE</th>
<th>NO. OF ITEMS</th>
<th>N</th>
<th>ALPHA</th>
<th>MEAN</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotionality</td>
<td>6</td>
<td>140</td>
<td>.49</td>
<td>19.05</td>
<td>6.38</td>
</tr>
<tr>
<td>Information</td>
<td>6</td>
<td>141</td>
<td>.57</td>
<td>19.76</td>
<td>12.38</td>
</tr>
</tbody>
</table>

A one-way analysis of variance performed on the responses of the general public, nurses and stroke carers produced no significant differences in group responses to either emotionality or information absorption questions. Presented in Tables 4.3 and 4.4 is the summary of these analyses.
Table 4.3. Group means for nurse, carer and general public responses to the Emotionality Scale.

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>F (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>20.45</td>
<td>2.77</td>
<td>1.82 (2,140)</td>
</tr>
<tr>
<td>Stroke carers</td>
<td>19.13</td>
<td>2.45</td>
<td></td>
</tr>
<tr>
<td>General population</td>
<td>18.88</td>
<td>2.63</td>
<td></td>
</tr>
</tbody>
</table>

The means and standard deviations of the Information Absorption scale are presented below.

Table 4.4. Means and standard deviations of nurse, carer and general public subject judgements to the Information Absorption Scale.

<table>
<thead>
<tr>
<th>The Information Absorption Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
</tr>
<tr>
<td>Nurse</td>
</tr>
<tr>
<td>Stroke carers</td>
</tr>
<tr>
<td>General population</td>
</tr>
</tbody>
</table>
Subjects' scores on the Emotionality scale were correlated with their scores on the Information Absorption scale separately for each group (see Table 4.5). Significant negative relationships emerged between the degree of emotionality and the ability to absorb information among nurses \( (r = - .48, p < .01, n = 56) \) and the general population \( (r = - .43, p < .01, n = 39) \). No significant relationship emerged between Emotionality and Information Absorption scale judgements among the stroke carers \( (r = .20, p > .05, n = 35) \).

Table 4.5. Nurse, General public and Carer Group correlations of Emotionality with Information Absorption Scales.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>56</td>
<td>-.48</td>
<td>.01</td>
</tr>
<tr>
<td>General Public</td>
<td>39</td>
<td>-.43</td>
<td>.01</td>
</tr>
<tr>
<td>Stroke Carers</td>
<td>35</td>
<td>.20</td>
<td></td>
</tr>
</tbody>
</table>

The differences between the correlations in Table 4.5 were tested for statistical significance. Significant differences were found between the
nurses and the stroke carers \( (z = -2.72, p < .005) \), and between the general public and stroke carers \( (z = -3.33, p < .001) \). There was no significant difference between the nurse and general public perceptions.

These analyses support the existence of a stereotype about emotional people not being able to absorb information among some groups. Nurses, like the general population, expect emotional people to have greater difficulty absorbing information about the condition and needs of a stroke victim than a person who is not showing emotional strain. Such a stereotype, however, was not characteristic of all groups. Carers of stroke victims themselves did not subscribe to this view. The correlation coefficient was in the opposite direction to that obtained for other groups. Although the correlation was not significant, the trend was for more emotional carers to be seen to be more able to absorb information. One might be tempted to interpret these finding as carers adhering to a policy of information giving regardless of the carers' emotional level. This interpretation was somewhat inconsistent with the means reported for
the different groups however. Carers of stroke victims did not consider the hypothetical carers as a group to be any more able to absorb information than did the nurse or general population samples. The other interpretation, that carers have a different view of emotionality than non-carers thus became more plausible.

A further issue arising from the data concerns the carer-non-carer dichotomy. Nurses are paid carers yet their judgements were more like those of the general population. Thus experience in caring does not seem to explain the findings nor could one argue that nurses' judgements are a product of their medical socialization. Turning to stroke carers, one notes that this is the group that is out of step with the stereotype. Indeed this is the group that the stereotype is about. If membership of the group is critical to rejecting the stereotype, these results should be replicated among other family caregiving groups.
Study B

A group of diabetic carers were recruited to determine if the perception of the amount of information that carers can take in was linked positively with perception of the carer's emotionality across disease type.

Diabetic Sample
The Diabetic carer group came from Canberra. These subjects were volunteers contacted through the Canberra Diabetic Association. The vignettes presented to these carers had the word "stroke" changed to read "diabetes". The remainder of the vignette content was unchanged. The sample consisted of 15 women who cared for a family member with diabetes. The researcher contacted the participants by telephone and arranged a mutually convenient time to deliver the questionnaire to them. After the questionnaire was completed, a debriefing period followed which took approximately one hour. During this time, the research purpose was explained and the subjects took the opportunity to reminisce about their experiences as a carer. On completion of the research, the participants were invited to a
seminar which presented the findings of the research. A formal letter containing the research results was posted to the Canberra Diabetic Association.

The correlation between the Emotionality and Information Absorption scales for the group was not significant ($r = .28, p > .05, n = 15$). The mean and standard deviation for this group's emotionality and information absorption judgements are presented below in Table 4.6.

Table 4.6. Means and standard deviations for the Emotionality and Information Absorption Scales among the diabetic carer group.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotionality</td>
<td>19.20</td>
<td>2.39</td>
</tr>
<tr>
<td>Information Absorption</td>
<td>17.40</td>
<td>3.09</td>
</tr>
</tbody>
</table>

**Conclusion**

Studies A and B provide two different perspectives on the impact of carer emotionality on capacity to
absorb information. Nurses and the general population endorse the viewpoint that the more emotional the carers, the less likely they are to absorb information. Carers of stroke victims and diabetics disagree and show a trend, though not a significant one, in the opposite direction. The next and final study to be reported is an attempt to investigate whether emotional carers do take in less information.
Chapter 5

The effect of Emotionality on carers' capacity to learn

The aim of study 3 was to discover if carers' emotionality interfered with their capacity to absorb information. Previously the focus has been on the attitudes and beliefs different groups held regarding the emotionality of hypothetical carers and their capacity to absorb information. In contrast, the present study was designed to investigate the validity of such beliefs - to ascertain the actual level of information absorbed as it relates to emotionality among carers rather than others' perceptions of this relationship. By so doing the validity of the stereotype about the lack of capacity of emotional carers to absorb information can be empirically examined.

The dependent variable of information absorption was defined in terms of the amount of new information carers acquired at a seminar on caregiving and stroke. To ensure that new information could be acquired, the seminar was trialled with a relatively knowledgeable group,
nurses. The nurse sample also provided a baseline for interpreting how knowledgeable carers were and how able they were to learn in this setting.

The independent variable, emotionality, was assessed in two ways. First, a general measure of neurotic symptoms was employed - the 4-NS (Henderson, Byrne, & Duncan-Jones, 1981). This measure has been used extensively in Canberra and has been found to correlate well with established measures of anxiety and depression.

In addition, a measure designed specifically to assess the stress of caring was employed. It could be argued that a more important factor than general emotionality was how threatened carers felt by the caring situation. Consequently a measure of caregiving burden was also included (Braithwaite, 1990). This has been previously found to correlate with symptoms of anxiety and depression.

One component of burden was personal inadequacy which was interesting from another perspective as well. It has been argued that we fluctuate between two states of self awareness - objective and subjective self-awareness (Wicklund & Frey, 1980). In a state of subjective self-awareness, the individual is receptive to what is happening in the
outside world. When objectively aware, however, the attention of the individual is directed inward toward evaluation of self. Carers who are feeling personally inadequate may be in a self-critical state and therefore may be unable to attend to the outside world. If this were the case, personal inadequacy should be the critical factor in explaining an inability to take in information rather than either feelings of disruption or more general feelings of upset.

The relationship between emotionality and information absorption could not be examined adequately without controlling for the intensity of care required by the stroke victim. Well informed carers could be the more emotional carers because of the demanding nature of the care required and because of their high motivation to meet these demands. In contrast, less emotional carers with fewer demands on them may be less interested in acquiring information and therefore may fail to take in what they have been told. The demands of caregiving were measured in two ways - in terms of a brief daily activities schedule and in terms of the degeneration carers perceived in the psychological and social makeup of the stroke victim.
The results of study 2 indicated a belief held by the general public and professional nurses that as the level of emotionality rises the capacity to absorb information diminishes. The carer groups' responses did not endorse the position that restricted information intake was necessarily characteristic of the emotional carer. The third study was designed to determine whether first, emotionality interferes with absorption of information, and second, whether carers' performance on the knowledge measure was different to that of a subset of nurses.

During April and May 1989, a series of seminars were run for two sample populations - nurses (N=26) and stroke survivor carers (N=37). The emotionality of the caring population was measured prior to the seminar. The seminar content comprised information from the caring, stroke association, and neuropsychological literature. The participants were invited to ask questions at any
time during the seminar. The seminars ran for approximately 2 hours. Measures of knowledge of caregiving were taken before and after the seminar.

Sample
The sample consisted of twenty-six professional nurses and thirty-seven stroke survivor carers from New South Wales and the Australian Capital Territory. Participation in these seminars was voluntary and the participants were assured that their contribution would be kept confidential.

MEASURES
Data were gathered by means of a self-completion questionnaire. This questionnaire for the nurse sample consisted of a pre and post seminar knowledge measure. The stroke carer sample completed an additional questionnaire containing five measures; knowledge, psychiatric symptoms, burden, caring activities and degeneration. They were also asked to provide demographic information on gender, age, relationship to care-receiver and length of time since the stroke. A copy of this questionnaire appears in Appendix 7.
Knowledge

The 19 item knowledge measure was developed from three sources: the general stroke literature which was easily accessed by both nurse and the caring population and the neuropsychological and caring literature which was not generally easily accessed by either population. The seven questions from the caring literature aimed to identify the carers' knowledge of practices which (a) protect the carer's well being, (b) situations which may threaten this well-being, (c) carer resources, and (d) hospitalization practices regarding stroke survivors. Four questions from the neuropsychological literature tapped the subject's knowledge of commonly affected functions when a stroke occurs in specific lobes of the brain. Eight items from the stroke association literature represented the carer's knowledge of statistics, treatments and effects of stroke.

Psychiatric Symptoms

Carers were asked to indicate, by circling those they had experienced on the Henderson, Byrne and Duncan-Jones' (1981) four neurotic symptoms (4-NS) scale. This is a 15 item inventory listing
physical and psychological symptoms the carer may have experienced in the past four weeks. Four of these symptoms indicate the presence of minor psychiatric symptoms. Recent research by Braithwaite (1990) has indicated that family carers report higher prevalence of minor psychiatric symptoms than the general population. Symptoms of anxiety, depression, irritability and nervousness were used to reflect the state of emotionality in this study.

**Burden**

This measure taken from Braithwaite (1990) combined an eight (8) item Disruption scale which explored deprivation of physiological and safety needs in the carer, with a nine (9) item Inadequacy scale which tapped carer feelings of frustration and dissatisfaction associated with personal loss and caregiving. Subjects were asked to identify by a tick which of the items they had experienced as a caregiver.

**Caring Activity (Workload)**

The extent to which the carer assisted the stroke person with 10 daily activities
(Braithwaite, 1990) was identified by the subjects on a three point scale (1 = not at all; 2 = a little; 3 = all the time).

Degeneration

Braithwaite's (1990) 12 item scale was used to elicit the carer's experiences of problem behaviours in the stroke survivor. Carers were asked to identify with a tick, statements which described the behaviour of the person for whom they cared.

PROCEDURE

Nurse sample

Permission was obtained from two New South Wales hospitals to conduct a seminar on the experiences of community carers of stroke survivors. The hospitals were not charged for the seminar. Seventeen nurses participated in the first seminar. The second hospital found nine nurses willing to participate. The seminar content was reinforced and summarized by using twenty five slides to present the major points during the talk.

Before beginning the seminar, the researcher
introduced herself and the topic and asked the nurses to complete the knowledge measure. This took approximately twenty (20) minutes to complete. They were asked to keep this questionnaire with them until after the seminar, when it would be collected. The seminar then proceeded taking two (2) hours on average to complete. The content was interspersed by participants' questions, comments and group discussion. When the seminar was completed, the nurses were asked to remain seated and complete a second knowledge measure which was designed to measure their increased knowledge of caring and stroke. They were asked not to look back over their responses to their questionnaire. They were instructed to staple the completed second questionnaire to the back of the first one and return it to the researcher. After the second knowledge measure was completed, and the data collected, a debriefing session commenced. The nurses were informed of the research purpose. This debriefing session lasted on average forty-five minutes. The nurses were thanked for their participation and assured they would be informed of the research results. A formal letter of thanks was sent to hospital administration and participating
The hospital was sent a copy of the research findings when the project was completed.

**The Stroke Carer sample**

Thirty-seven (37) community carers of stroke survivors volunteered to participate in the seminar presented by the researcher. These seminars were run for groups or on an individual basis in the carer's home at their convenience. Individual seminars were necessary because many carer's daily activities and responsibilities made it impossible for the researcher to organize a large group to gather at any one time.

Before the seminar began, each carer completed a questionnaire containing the measures of pre-test knowledge, burden, psychiatric symptoms, caring activities, and degeneration as well as some biographical data. This took the carer on average, forty-five minutes to complete as they tended to elaborate on the experiences identified as they progressed through the measures. After this questionnaire was completed, the seminar content was presented to the carer. This took 1-2 hours depending on the discussion generated. Following the seminar the post-test knowledge measure was
administered. This was stapled to the back of the first questionnaire and placed in an envelope marked with the subject's name and identification number. A debriefing session followed in which the research purpose was explained. The carer was invited to a public seminar, at a date to be advised, where the research results would be revealed to the participating carers.
RESULTS

The results of this study are presented in the following pages and a copy of the measures are presented in Appendix 7.

Dependent Variable

Knowledge:

A 19 item multiple choice test which tapped knowledge of risk factors for stroke, the nature of stroke, its treatment, effects and prognosis, as well as awareness of issues related to carer well-being was administered to both nurses and carers. After psychometric analysis, 13 of these items were selected to form a scale to represent knowledge of caring for a stroke victim. The item frequencies and intercorrelations are presented appendix 8. The 6 items not included in the analysis were either items which did not discriminate among or which were not well intercorrelated with other questions. Each item was scored as correct (1) or incorrect (0). Pre-seminar scores on the knowledge scale ranged from 0 to 13 with a mean of 6.32 and a standard deviation of 2.55. The alpha-reliability co-efficient (Cronbach, 1951 ) for the final 13 items was .71. This scale is presented below.
Table 5.1. Individual Knowledge Scale item means, standard deviations and item-total correlations.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Item Total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good Caring</td>
<td>37</td>
<td>.37</td>
<td>.49</td>
<td>.16</td>
</tr>
<tr>
<td>Time in hospital</td>
<td>37</td>
<td>.81</td>
<td>.39</td>
<td>.43</td>
</tr>
<tr>
<td>Temporal lobe</td>
<td>37</td>
<td>.05</td>
<td>.23</td>
<td>.32</td>
</tr>
<tr>
<td>Breaking point</td>
<td>37</td>
<td>.27</td>
<td>.45</td>
<td>.19</td>
</tr>
<tr>
<td>Risk factors</td>
<td>37</td>
<td>.27</td>
<td>.45</td>
<td>.40</td>
</tr>
<tr>
<td>Treatment</td>
<td>37</td>
<td>.35</td>
<td>.48</td>
<td>.22</td>
</tr>
<tr>
<td>Susceptable age</td>
<td>37</td>
<td>.78</td>
<td>.41</td>
<td>.40</td>
</tr>
<tr>
<td>Stroke</td>
<td>37</td>
<td>.91</td>
<td>.27</td>
<td>.30</td>
</tr>
<tr>
<td>Personality change</td>
<td>37</td>
<td>.05</td>
<td>.48</td>
<td>.44</td>
</tr>
<tr>
<td>Future</td>
<td>37</td>
<td>.81</td>
<td>.39</td>
<td>.40</td>
</tr>
<tr>
<td>Occipital lobe</td>
<td>37</td>
<td>.16</td>
<td>.37</td>
<td>.37</td>
</tr>
<tr>
<td>Motivation</td>
<td>37</td>
<td>.67</td>
<td>.47</td>
<td>.29</td>
</tr>
<tr>
<td>Frontal lobe</td>
<td>37</td>
<td>.19</td>
<td>.40</td>
<td>.48</td>
</tr>
</tbody>
</table>

Independent Variables

Emotionality

(a) Anxiety and Depression.

Participants completed the 15-item Henderson, Byrne & Duncan-Jones (1981) 4-NS scale. Embedded in these
items were the four indicators of minor psychiatric symptoms, anxiety, depression, irritability and nervousness.

In this research the measure had the advantage of camouflaging indicators of mental well-being among physical symptoms such as backache and colds. The alpha reliability co-efficient for the scale was .60. In this study scores ranged from 0 to 4 with a mean of 1.22 and a standard deviation of 1.24. Thirty-eight percent of the sample complained of two or more symptoms. Presented below are the means and standard deviations for these items, scored such that 1 indicated symptom presence and 0 symptom absence.

Table 5.2. Carer item means, standard deviations and item-total correlations for the 4-NS.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Item total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>36</td>
<td>.22</td>
<td>.42</td>
<td>.25</td>
</tr>
<tr>
<td>Depression</td>
<td>36</td>
<td>.33</td>
<td>.47</td>
<td>.54</td>
</tr>
<tr>
<td>Irritability</td>
<td>36</td>
<td>.38</td>
<td>.49</td>
<td>.24</td>
</tr>
<tr>
<td>Nervousness</td>
<td>36</td>
<td>.27</td>
<td>.45</td>
<td>.49</td>
</tr>
</tbody>
</table>
(b) Burden. One item from the 17 item burden scale (Braithwaite, 1990) was deleted because it produced little variance and was considered less suitable for carers of stroke victims than for carers of the demented. Practically all participants disagreed with this item which asked if the carer felt they did not understand the nature of the stroke person's illness. 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 .82. Presented on the following page are item means and standard deviations for the burden scale.
Table 5.3. Burden scale item means, standard deviations and item-total correlations.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Item total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>On Call</td>
<td>37</td>
<td>.56</td>
<td>.50</td>
<td>.15</td>
</tr>
<tr>
<td>Resentful</td>
<td>37</td>
<td>.18</td>
<td>.39</td>
<td>.49</td>
</tr>
<tr>
<td>Inadequate</td>
<td>37</td>
<td>.37</td>
<td>.49</td>
<td>.65</td>
</tr>
<tr>
<td>Guilty</td>
<td>37</td>
<td>.32</td>
<td>.47</td>
<td>.64</td>
</tr>
<tr>
<td>Chores undone</td>
<td>37</td>
<td>.29</td>
<td>.46</td>
<td>.25</td>
</tr>
<tr>
<td>Can't get on top</td>
<td>37</td>
<td>.51</td>
<td>.50</td>
<td>.51</td>
</tr>
<tr>
<td>No routine</td>
<td>37</td>
<td>.18</td>
<td>.39</td>
<td>.42</td>
</tr>
<tr>
<td>Losing control</td>
<td>37</td>
<td>.18</td>
<td>.39</td>
<td>.65</td>
</tr>
<tr>
<td>Insufficient sleep</td>
<td>37</td>
<td>.24</td>
<td>.43</td>
<td>.45</td>
</tr>
<tr>
<td>Losing patience</td>
<td>37</td>
<td>.48</td>
<td>.50</td>
<td>.34</td>
</tr>
<tr>
<td>Can't rest when ill</td>
<td>37</td>
<td>.32</td>
<td>.47</td>
<td>.39</td>
</tr>
<tr>
<td>Resenting stroke</td>
<td>37</td>
<td>.24</td>
<td>.43</td>
<td>.62</td>
</tr>
<tr>
<td>Nothing done well</td>
<td>37</td>
<td>.21</td>
<td>.41</td>
<td>.41</td>
</tr>
<tr>
<td>Last minute changes</td>
<td>37</td>
<td>.13</td>
<td>.34</td>
<td>.26</td>
</tr>
<tr>
<td>Divided loyalties</td>
<td>37</td>
<td>.27</td>
<td>.45</td>
<td>.46</td>
</tr>
<tr>
<td>Ill from care</td>
<td>37</td>
<td>.32</td>
<td>.47</td>
<td>.22</td>
</tr>
</tbody>
</table>
Other Variables

Caregiving demands.

Participants were asked to indicate how much assistance they had to provide for the stroke victim on 11 activities of daily living – eating, dressing, standing and sitting, transferring, walking, toileting, bathing, communication, organizing, dealing with finances and making social contacts. Responses were made on a 3 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 a standard deviation of 5.32. The alpha reliability coefficient was .86.

Presented on the following page are the individual item means and standard deviations from the Caring Activity scale items.
Table 5.4. Means, standard deviations and item-total correlations obtained from Caring Activity Scale items.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Item total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating</td>
<td>33</td>
<td>1.59</td>
<td>.64</td>
<td>.47</td>
</tr>
<tr>
<td>Dressing</td>
<td>33</td>
<td>1.94</td>
<td>.70</td>
<td>.67</td>
</tr>
<tr>
<td>Standing &amp; sitting</td>
<td>33</td>
<td>1.54</td>
<td>.64</td>
<td>.69</td>
</tr>
<tr>
<td>Transferring</td>
<td>33</td>
<td>1.62</td>
<td>1.44</td>
<td>.65</td>
</tr>
<tr>
<td>Communicating</td>
<td>33</td>
<td>1.89</td>
<td>1.41</td>
<td>.41</td>
</tr>
<tr>
<td>Walking</td>
<td>33</td>
<td>1.62</td>
<td>.63</td>
<td>.40</td>
</tr>
<tr>
<td>Toileting</td>
<td>33</td>
<td>1.45</td>
<td>.76</td>
<td>.59</td>
</tr>
<tr>
<td>Organizing</td>
<td>33</td>
<td>2.27</td>
<td>1.40</td>
<td>.66</td>
</tr>
<tr>
<td>Finances</td>
<td>33</td>
<td>2.43</td>
<td>.72</td>
<td>.48</td>
</tr>
<tr>
<td>Social contacts</td>
<td>33</td>
<td>2.32</td>
<td>1.39</td>
<td>.36</td>
</tr>
<tr>
<td>Bathing</td>
<td>33</td>
<td>1.89</td>
<td>1.46</td>
<td>.75</td>
</tr>
</tbody>
</table>

**Behaviour difficulties**

A 12 item questionnaire (Braithwaite, 1990) which tapped the extent to which the care-receiver was psychologically and socially disabled was assessed by a behaviour checklist which identified mood disturbance and difficulty in relating to others.
From these data, an 8-item scale was developed. Four items were deleted from the original scale as they were found by the researcher and the carers to be not relevant to the stroke condition. Behaviours were checked as present (1) or absent (0). The scale scores ranged from 0 to 7 with a mean of 2.70 and a standard deviation of 2.12. The alpha reliability coefficient was .70. Presented below are the individual item means and standard deviations from the Behaviour difficulty scale.

Table 5.5 Means, standard deviations and item-total correlations for individual items from the Behaviour Difficulty Scale.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Item total correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goes on</td>
<td>37</td>
<td>.48</td>
<td>.50</td>
<td>.38</td>
</tr>
<tr>
<td>Constant demands</td>
<td>37</td>
<td>.13</td>
<td>.34</td>
<td>.37</td>
</tr>
<tr>
<td>Gets upset</td>
<td>37</td>
<td>.32</td>
<td>.47</td>
<td>.31</td>
</tr>
<tr>
<td>Irritable</td>
<td>37</td>
<td>.45</td>
<td>.50</td>
<td>.54</td>
</tr>
<tr>
<td>Mood</td>
<td>37</td>
<td>.29</td>
<td>.46</td>
<td>.50</td>
</tr>
<tr>
<td>Depressed</td>
<td>37</td>
<td>.37</td>
<td>.49</td>
<td>.40</td>
</tr>
<tr>
<td>Critical</td>
<td>37</td>
<td>.40</td>
<td>.49</td>
<td>.54</td>
</tr>
<tr>
<td>No sensible response</td>
<td>37</td>
<td>.21</td>
<td>.41</td>
<td>.06</td>
</tr>
</tbody>
</table>
Demographic data

The stroke carer sample consisted of 28 females and 9 males with ages ranging from 25 to 78 years (mean = 61.11, standard deviation = 10.38), with the majority (62%) being over 60 years of age. All carers were related to their care-receivers: 31 were caring for a spouse, 5 for their parents and one for an in-law. Time caring ranged from less than 6 months to 9 years (mean = 3.78, standard deviation = 2.77). The majority (57%) had been caring for more than 2 years. Presented on the following page is a summary table of the stroke person's survival time and the number of years each carer had cared for the survivor.
Table 5.6. Time in the caring role for carers.

<table>
<thead>
<tr>
<th>Elapsed Time</th>
<th>Number of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 months</td>
<td>2</td>
</tr>
<tr>
<td>1 year</td>
<td>7</td>
</tr>
<tr>
<td>2 years</td>
<td>7</td>
</tr>
<tr>
<td>3 years</td>
<td>4</td>
</tr>
<tr>
<td>4 years</td>
<td>5</td>
</tr>
<tr>
<td>5 years</td>
<td>1</td>
</tr>
<tr>
<td>6 years</td>
<td>4</td>
</tr>
<tr>
<td>7 years</td>
<td>2</td>
</tr>
<tr>
<td>8 years</td>
<td>1</td>
</tr>
<tr>
<td>9 years</td>
<td>4</td>
</tr>
</tbody>
</table>

Relationship between measures

Overall, participants' post-seminar scores on the knowledge test \((M = 8.89, \ SD = 2.14)\) were significantly higher than the pre-seminar scores \((M = 6.32, \ SD = 2.55)\) \(t(36) = 10.28, p<.001\). Change scores for individuals varied from -1 to 7 (mean = 2.57, standard deviation = 1.52).

These scores were not related to the demographic variables, with the exception of age. Older carers did less well on the post-seminar test \((r = -.38,\)
N = 37, p < .01), showing them to be less well informed at this stage than younger carers. While the relationship between age and pre-seminar knowledge tended to be in the same direction, the correlation was not significant. Older carers seemed to be disadvantaged by the seminar. Gain in knowledge was also negatively related to age, though the correlation coefficient just fell short of statistical significance at the .05 level (r = -.27, N = 37, p = .06).

The knowledge scores, (pre-seminar, post-seminar, and the changes) were correlated with the emotionality measures - Henderson, Byrne and Duncan-Jones' (1981) 4-NS and Braithwaite's (1990) burden scale - and with the indices of caregiving demands of activity and behaviour difficulties. These findings are reported in Table 5.7
Table 5.7. Correlation of the Pre and post-seminar knowledge scores and the change score with the 4-NS, Burden, Behaviour difficulties and Activity difficulties scales.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Pre</th>
<th>Post</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-NS</td>
<td>-.40**</td>
<td>-.35**</td>
<td>.18</td>
</tr>
<tr>
<td>Burden</td>
<td>.00</td>
<td>.08</td>
<td>.11</td>
</tr>
<tr>
<td>Behaviour Difficulties</td>
<td>-.14</td>
<td>-.02</td>
<td>.19</td>
</tr>
<tr>
<td>Activity Difficulties</td>
<td>.20</td>
<td>.06</td>
<td>-.26</td>
</tr>
</tbody>
</table>

The two emotionality indices related very differently to the knowledge measures. Burden was not related to how well informed carers were initially, nor to how much they learnt in the seminar. Furthermore, the inadequacy subscale of the burden scale did not relate to the knowledge measures. The measure of anxiety and depression, on the other hand, was related to the initial amount of knowledge carers had. The presence of symptoms, however, did not impede carers' capacity to learn. Although anxious and depressed carers were still less knowledgeable at the end of the seminar, there
was no evidence that they acquired less information during the session than those without symptoms. Thus, the capacity of the emotional carers to learn was no different from the capacity of those who were less emotional.

Those caring for someone who needed a great deal of assistance with activities of daily living were somewhat less likely to gain anything from the seminar, though this relationship fell just short of significance at the .05 level. Possibly they had had to learn through their own experiences. High caregiving demands were not related to emotionality in this group. Selection effects should be recognized here in that those who remained as carers when demands were high may have been the copers. Others would be likely to be offered nursing home placement.

To examine the contribution of emotionality, burden, caregiving demands and behaviour difficulties collectively to knowledge acquisition, two multiple regression analyses were undertaken, one to predict initial knowledge and one to predict knowledge gain. The results are presented in Table 5.8.
Table 5.8. Beta coefficients and R squared values for regression models predicting carers’ initial knowledge and knowledge gain.

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Initial Knowledge</th>
<th>Knowledge Gain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Model 1</td>
<td>Model 2</td>
</tr>
<tr>
<td>Initial knowledge</td>
<td>-.55***</td>
<td>-.58**</td>
</tr>
<tr>
<td>Anxiety, Depression</td>
<td>-.53**</td>
<td>-.21</td>
</tr>
<tr>
<td>Burden</td>
<td>.46</td>
<td>.33</td>
</tr>
<tr>
<td>Activity difficulty</td>
<td>.08</td>
<td>-.24</td>
</tr>
<tr>
<td>Behaviour difficulty</td>
<td>-.31</td>
<td>-.04</td>
</tr>
<tr>
<td>R squared</td>
<td>.27*</td>
<td>.30***</td>
</tr>
</tbody>
</table>

* = .05; ** = .01; *** = .001

Levels of anxiety and depression emerged as the major predictor of who was knowledgeable prior to the seminar and who was not. The more emotional the carer was, the less knowledgeable they showed themselves as being when filling out the questionnaire.

When knowledge gain was predicted, knowledge initially was entered first as a control, followed
by the measures of emotionality, burden, demands and difficulties. Only initial knowledge affected knowledge gain. The more knowledge carers had initially, the less they had to learn from the seminar. The amount learnt was unrelated to levels of emotionality.

Comparison of nurses and carers

While we have established that carers' levels of emotionality does not interfere with learning in this context, the question should be asked of whether carers were well-informed. Defining well-informed is difficult but some progress can be made through comparing carers with a group who should be well-informed, nurses. Scores before and after the seminar were compared for the 37 carers and the 26 nurses involved in the test run. The t test revealed a significant difference ($t = -5.37, n = 63, p < .000$) between carer and nurse knowledge before the seminar. Nurses knew more than carers (see Table 5.9). A comparison of nurse and carer scores after the seminar produced no significant differences in their knowledge of stroke and caregiving ($t = .09, n = 63, p < .928$).
Table 5.9. Comparison of carer and nurse knowledge scores before and after the stroke seminar.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-seminar knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers</td>
<td>37</td>
<td>5.54</td>
<td>2.02</td>
<td>5.37***</td>
</tr>
<tr>
<td>Nurses</td>
<td>26</td>
<td>8.11</td>
<td>1.63</td>
<td></td>
</tr>
<tr>
<td>Post-seminar knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers</td>
<td>37</td>
<td>8.89</td>
<td>2.14</td>
<td>.09</td>
</tr>
<tr>
<td>Nurses</td>
<td>26</td>
<td>8.84</td>
<td>1.71</td>
<td></td>
</tr>
</tbody>
</table>

*** = p < .001

These carers are not only capable of learning when they are emotional, their level of knowledge can be improved to equal that of nurses.
Chapter 6 - Discussion

This research found that:

(1) Nurses and the general public perceived an inverse relationship between stroke carer emotionality and the ability to take in information.

(2) Carers of stroke and diabetic patients did not perceive a relationship between emotionality and information absorption.

(3) The pre-seminar knowledge of nurses and stroke carers differed with nurses knowing more about stroke and caring than the carers.

(4) No difference was observed in the knowledge of carers and nurses after the seminar. During the seminar the carers had learnt more than the nurses, even though the nurses did not get all the questions correct on the pre-seminar knowledge measure.

(5) The amount that carers learnt was not related to their level of emotionality as measured by the 4 - NS (Henderson, Byrne & Duncan-Jones, 1981).
(6) Emotionality was significantly related to carer's knowledge prior to the seminar.

(7) Age was significantly inversely related to the carers' capacity to absorb new knowledge, though both older carers and younger carers gained knowledge through the seminar.

These findings point to three major issues for discussion. First, there exists a widespread tendency to associate high emotionality in carers with the inability to absorb information. The relationship was confirmed in both nurse and general population samples. The reasons why carers themselves did not support this view is one of the major questions addressed in this chapter. The second is why prejudices about the amount of information emotional carers can absorb exist when the final study clearly showed that emotional carers were able to learn as much as the less emotional carers and carers were able to be as well-informed as the nurses on the knowledge test. The third issue is to examine the implications of these findings for health care. Before doing so, however, the limitations of these studies warrant discussion.
Limitations

First, gender bias (most of the subjects were women) limits the generalizability of findings to male carers. Caring is predominantly a female issue, and participants in these studies reflected this bias. Second, all the subjects were English speakers. Non-english speaking carers may have perceptions greatly influenced by their culture of origin. Third, there was no attempt to stratify the subjects by education level or assess income level. The data collected from the study does not explore the effect of income or education on knowledge, psychiatric symptoms, burden, caring activities or degeneration. Fourth, the number of years experience of the nurses was not controlled. Whilst the majority of nurses were recent graduates, a few had been nursing for many years. Nurses who had a greater amount of clinical experience may have been more knowledgeable about the carers' difficulties. Finally, the two groups, carers and nurses, were not randomly selected. Biases in selection may have created differences between these groups.
Section A: Why do nurses and the general population support the stereotype while carers do not?

Initially the stereotype of highly emotional people being unable to absorb information was considered to be linked to nurses' socialization. This explanation now appears unlikely given that the general population made similar judgements to the nurses. The data suggest a widely held community belief that a negative relationship exists between emotionality and information absorption. Possibly the nurse and the general public groups felt uncomfortable giving distressing news to an already emotional carer, justifying their reticence in terms of the carer's lowered capacity to absorb information.

The reason for carers seeing things differently from others may be related to their intimate knowledge of what caregiving is like. The carer groups' judgements of emotionality may be accompanied by a different understanding of what emotionality means. They may have judged the emotionality presented to be a sign of information deficit as suggested by Siminov (1977), and in tandem been inclined to judge the vignette carer
capable of taking in information. It will recalled that the correlation for carers between emotionality and information absorption, while non-significant, was in the opposite direction to that found in the nurse and general population samples.

The fact that carers' perceptions differed from others may also be understood in terms of Bowen's (1981) thesis that a person's current emotional state influences the way they interpret ambiguous situations and leads to them producing emotionally congruent material. Bowen found that snap judgements were influenced by current mood. For example, an angry subject tended to make an angry judgment. It follows that carers who themselves are emotional and in need of information may judge a vignette carer to also have that same need. The carer subjects may have been in need of stroke and caring information as they judged the vignettes and projected this need onto their judgements of emotional carers.

The work of Arnold (1960a) and Lazarus (1968, 1981) may also help explain the findings. Interpretation or appraisal has been identified as a precursor of emotion (Arnold, 1960a, Lazarus, 1968, 1981).
According to appraisal theory people judge events as threatening or non-threatening and this influences their ensuing behaviour. The vignette carer may have been judged to be threatened by the stroke situation. Information giving may have been seen as a way to allay fear and encourage a positive reappraisal of the situation. Carers may have identified with this need more than those who had not had the experience of being thrown into the caring role without any preparation for it. The nurse and general population response might have been to downplay the threat rather than to learn to live with it.

The notion that those without personal experience of providing care may perceive an emotional carer as too distressed to absorb information may be likened to placing the emotional carer in the sick role (Parsons, 1951) with its accompanying exemptions and obligations. Parsons (1951) has outlined the major privileges and responsibilities that accompany enactment of the sick role. The person is exempted from customary role obligations. Whilst in the sick role, the person is obligated to accept, cooperate and submit to treatment from the professional. However the
obligations of the person placed in the sick role may outweigh for them the advantages of the exemptions. Mothers of new-born babies, despite the rigors of childbirth, rightly resist attempts to place them in a sick role, as their responsibility for another precludes their participation in such a role. Likewise, the emotional carer, who is inadvertently placed in the sick role, may perceive the relinquished responsibilities which accompany the role as antagonistic to their role of caring. Thus, carers are motivated to gain more information in spite of their emotionality, while observers are reluctant to provide the information because of their emotionality.

Perceived lack of ability to control emotion may also be relevant to the judgements of the nurses and general public. The health care system is such that the sick person is the focus of care and attention (Northhouse, 1984) and distress by relatives may be judged unseemly and attention seeking. The judgement made may be that, if such relatives can't control their own emotions enough to safeguard the well-being of the patient, they will probably be unable to concentrate to take in information. Carers, on the other hand, may see their
emotionality exacerbated by their exclusion by the health professionals. Not knowing may be more anxiety provoking for the carer than bad news.

Another reason for the discrepancy in judgements between actors in the home care situation and observers involves the status of the carer. Sherrif, White & Harvey (1955) found that the perceived high status of an individual led to their performance being overestimated. Low status people tended to be underestimated. The majority of carers are women, particularly older women, and the vignette carer was a woman of 45 years. Women engaged in caring tasks are accorded low status (Brocklehurst et al, 1981). When they are seen to have the additional quality of emotionality, a quality associated more with female than male behaviour, their status may plummet further and they may be perceived as incapable of absorbing information. In contrast, carers see themselves as not having access to the information which they desperately want (Stroker, 1981).
Section B: Why prejudices exist when emotional carers can learn as much as less emotional carers.

Carers were less well informed prior to the seminar than nurses, particularly emotional carers. Yet in the seminar, information was acquired to the same extent by both emotional and unemotional carers. Why then is the stereotype perpetuated?

This thesis does not challenge the proposition that emotion and information absorption are incompatible in the broader context of human behaviour. Thus, these findings are not interpreted as being in direct conflict with studies of the kind reported by Harris (1961) in which school boys' emotionality caused by family problems interfered with their ability to learn. In general, the stereotype about high emotionality and low information may be empirically valid. The present study does, however, adopt the position that carers are different from other populations in two important ways and that these differences are not appreciated by health professionals and the general public. First, carers appear to experience two distinct kinds of heightened emotionality - one in response to crisis and one which is more persistent and stable during
the caring process. Receptivity to information may be different at these two phases.

Acute or panic emotionality, which occurs in a crisis situation, such as when a previously healthy family member is admitted to hospital with a stroke as in studies 1 and 2, may be more aligned with shock than with experiences of anxiety and depression. In this state, carers may not take in the things they are told.

In contrast, Study 3, which examined the amount of information that emotional carers could learn, took place at a time well into the caring role and outside a crisis setting. The emotionality of the carers had stabilized at this stage and was more of a grieving response. They were learning to live with their distress and were receptive to, indeed wanted, more information. (w)

Away from the hospital and sometime after the stroke, the carer group were able to learn as much as the nurses from the seminar. Perhaps the nurses were complacent about their knowledge or the carers may have been more motivated to learn. Certainly the fact that the carers learnt more from the seminar than the nurses was not the result of a

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(w) Panic may re-emerge from time to time even after the carer has moved into grieving emotionality.
ceiling effect in the knowledge test for the nurse group. When given information prior to assuming their caring role, the carers may have believed they understood what lay ahead. Experience and hindsight may have heightened their determination to get as much out of the seminar as possible. This distinction between emotionality at the time of hospitalization and the emotionality which is often endured throughout the period of the caring role has not been made previously, yet it is likely to have important implications for how carers are treated by health care professionals.

The second explanation supposes that the chronic type of emotionality of carers is not so much tied to their own well-being but to that of another. Carers, particularly spouse carers, usually report enormous motivation to care and feel they must do something for the care-receiver. Under such circumstances, they are highly motivated to understand what is going on. Their emotionality is not a self-protective mechanism, but an expression of frustration about what can be done.

Thus, under normal circumstances, emotionality may interfere with the ability to absorb new
information. In the long-term caring situation, however, where a person has made a moral decision to care, their motivation to do the job may override their feelings of anxiety and depression. Their recent experiences of caring may heighten their awareness of their need to attend to information they are given, especially if they are solely responsible for the patient.

Implications for health care

To have carers well informed is important for quality care and carer well-being. To this end three important implications have emerged from this research. First, the timing of information given to carers is critical to their learning. Second, information seeking behaviours by carers in the grieving state of emotionality need to be recognized and responded to by health professionals. Third, information directed at an older audience needs to be delivered at a slower pace than that given to young people.

Timing of education

If the distinction between panic and grieving emotionality is made, timing of the information giving session is critical. Information given, even
if repeated, at the time of crisis may not be retained by carers. In the present study, health care workers insisted that basic explanations had been given to all clients. If it had been given later however, the outcome may have been very different. It was the case that after the patient went home, the carers were given the opportunity to initiate telephone and face-to-face contact with many health professionals. On their return visits, carers said that they were reluctant to ask for information and information was seldom offered spontaneously. The more assertive carers did receive information, but reported that this was given quickly as the health workers were very busy. Thus, carers were reluctant to seek out information they needed because they did not want to be a bother.

When carers were interviewed by the researcher, their emotionality was categorized as the grieving kind. Tears were often close to the surface, yet carers were able to ask and comprehend information which was relevant and able to be put to immediate use. This grieving emotionality stage did not affect their learning and fits with earlier observations that carers can learn better some time
after the event (Brocklehurst et al, 1981; Stone, 1987; & Lubkin, 1986). When teaching carers, flexibility in timing is important: carers must have time for panic emotionality to translate into grieving emotionality.

An alternative way of construing these two stages of emotionality is that some carers may need time in the "sick role". To assume stability in this state, however, is not legitimate. Given time they may opt for a caring role. Initially, carers may have been aware of their emotionality, realized they were not coping and retreated into the sick role voluntarily, thereby excusing themselves from learning caring responsibilities when information was given. They may not have tried to learn. After a period of time, their emotionality has a stable quality which they can come to terms with and they are able to learn.

**Attending to information seeking behaviour**

Apart from the issue of timing, health professionals need to recognize information as a potentially useful coping strategy which emotional carers probably need more of than the less emotional. Lack of information may result in emotionality.
Information seeking may not be recognized by nurses as a strategy carers use to cope with situations they see as threatening. Blocking this coping effort through restricting information may result in carers developing less effective coping behaviours and experiencing psychiatric symptoms.

Lack of sufficient information has often been cited as a major concern of family members of the sick (Stedeford, 1981; Mauss-Clum, 1981; Maddison & Walker, 1967; Overs & Belknap, 1967; Daley, 1984; Mathis, 1984).

Qualitative data gathered in the course of the research provided evidence to support two propositions raised in chapter 1. First, after the initial briefing of families, doctor's do not tell carers much. Many held the view that to teach about caring and stroke was not their role. Nurses admitted that they did not know much about caring other than on a shift and team basis. Some believed that caring for someone at home was all commonsense and did not warrant their professional attention.

Second, carers wanted more information. Their questions suggested that many needed support in
their role. For instance, many were concerned about identifying the point at which they could no longer care for the person. Many carers intended to continue caring as long as they were physically and psychologically able. A similar finding was reported by Skodol-Wilson (1989) and suggests a need for a service directed at assisting carers in the decision to relinquish care.

**Ageing caregivers**

Older carers were no less knowledgeable before the seminar than younger carers, but they did get less out of the seminar presentation. The manner in which information is communicated to elderly people may be an important factor in determining how much they learn.

The slower rate of the older carer may have been partly the result of the modes used (visual and verbal) when presenting the seminar. Additional modes such as written material and a longer discussion and question time may have increased the amount of material taken in by these carers. Furthermore, the information may have been needed to be presented at a slower pace.
Summary

To conclude, carers can be assisted to take in new information by having it presented slowly in a supportive atmosphere some time after the stroke. When this is done, as in the seminar run for this research, they are able to learn regardless of symptoms and age.

Further understanding about emotional carers may be gained by implementing a carer education program specifically designed for carers in the grieving stage of emotionality who display minor psychiatric symptoms. An important question for the future is whether education reduces carers' levels of emotionality over time. This question was not addressed in the present research. The direction of causality between information absorption and emotionality remains unclear, except to say emotional carers can absorb information.

In the meantime it would still be useful to use these data to identify carers at risk. The 4-NS (Henderson, Byrne & Duncan-Jones, 1981) could be used as a screening test by hospital and community nurses for identifying carers with minor
psychiatric symptoms. These carers may be the ones most likely to need informational support. The well-being of the survivor would be promoted by this strategy because their quality of care would not be threatened by reliance on a caregiver whose capacities to care were compromised.

Underlying all these implications are some basic assumptions about the delivery of health care. The individualisation of illness in western society causes the sick person and not the family to be the focus of care. Many health professionals advocate family-focused care, but most still deliver individualized care. The health care system tends to exclude collective family participation (Northhouse, 1984). Health insurance is oriented to individual care. Medical rebates are paid for individual illnesses, individual not family records are kept.

Perhaps a policy change at the health insurance and medical record keeping level, which directs the health system towards adopting a family-oriented approach to health care may redirect attention to the needs of those making the moral decision to care for someone at home.


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APPENDIX File 1

Pilot Study Vignettes for establishment of emotion and information scales.
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, a vet, was making him comfortable in bed with the nurses' help. She was elegantly dressed in a tweed suit, and a fragrance of Chanel No.5 lingered around her. She asked the nurse if she could possibly speak to the registered nurse in charge. When a suitable time was arranged she smiled gratefully displaying a set of perfect white teeth.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, managed his business from his bedside - receiving flowers, answering mail and telephone queries, and bouncing unwanted visitors. Everyone marvelled at her ability to cope with multiple stimuli at such a worrying time. Her hand trembled only slightly as she replaced the receiver.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)  
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)  
None A little Moderate Almost all Everything
Mr Jones aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, who had been sitting at his bedside, rose and walked the length of the dormitory ward picking up bread rolls from each lunch tray and stuffed one after another into her mouth. When she reached the end of the dormitory she began her trip in reverse, this time picking up all the jugs and draining them of their water.

What level of emotion is Mary exhibiting? Please cross (X):

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital with a diagnosis of stroke. His wife Mary, aged 45 years, approached the nurses station, she had sweaty palms, dilated pupils and she took rapid breaths. She complained of butterflies in her stomach and a "touch" of diarrhoea. Her bottom lip trembled but she managed to "pull herself together". She was dressed in jeans, joggers and a sloppy joe. In her left hand she held a lighted cigarette.

What level of emotion is Mary exhibiting? Please cross (X)

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, who had remained at his bedside since admission was having difficulty making the decision to leave the hospital and catch a few hours of undisturbed sleep at home. Her face looked very tense and drawn.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, tried to understand the jumbled words he uttered. Unable to comprehend his words, she shakily pressed the nurse call button, and when the nurse arrived, she asked the nurse in a calm voice for assistance.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, bumped clumsily into his bed tray overturning his soup. As she mopped it up with jerky movements she almost upset his milk. As the nurse helped her clean the mess, she asked her if she could have some medicine to stop her belching.

What level of emotion is Mary exhibiting? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  A little  Moderate  Almost all  Everything

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Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, a university lecturer in social work, sat unruffled at his bedside. She had tuned in on the radio to some restful classical music. She had just finished helping the nurse change her husband's pyjama coat, as he had spilt some porridge on the lapel.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50 years, father of four (4) teenagers was admitted yesterday evening with a diagnosis of stroke. His wife, Mary, aged 45 years, asks the registered nurse: "Will my husband be out of hospital next week in time to partner me in the ballroom dancing finals?" When told that her husband would not be ready for ballroom dancing, Mrs Jones flew into a rage and criticised the nursing staff for the paucity of their care. She then sank to the ground in a heap.

What level of emotion in Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband’s condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary, aged 45, a high school teacher waited pleasantly and patiently by his side. Whilst he slept, she sipped the hot tea the nurse had made her and marked her class exam papers.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary, aged 45, who remained with him continually made statements of her inferiority in the hospital environment and she complained of feeling very unhappy.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, smiled sweetly at him as she folded and rearranged his clothes in the top drawer of the chipped cream enamelled bedside locker.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary, aged 45, remained at the bedside. She was irritable with the nursing staff but obviously cared very much for her husband. She moved with 'jerky' abrupt movements and her expensive make-up was streaked with the track of old tears.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary, refused to leave his side and busied herself puffing up his pillows, offering him drinks, arranging his flowers and chatting to the other relatives.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, chatted quietly to him as she knitted a thick fluffy jumper.

What level of emotion is Mary exhibiting? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  A little  Moderate  Almost all  Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, approached the nurses station. The pupils of her grey blood-shot eyes were dilated, and she breathed rapidly and shallowly. She apologized for her washed out appearance, and mentioned that she had suffered a bout of diarrhoea.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, a physiotherapist, arrived at his bedside. She bounced up to him and kissed him loudly on the cheek, smudging it with her orange lip gloss. She began to gently straighten out his affected arm, murmuring that "you're in good hands, and it will all be alright".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, reached the door of his room. The nurse on duty noticed her take three big deep breaths, screw-up and relax her facial muscles, and enter the sick room, presenting a smiling relaxed face to her husband.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything

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Mr Jones aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, was found brandishing a knife at her husband, threatening to cut off his nose if he didn't "Get better in a hurry". She had tethered his hands to the bedside.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital with a diagnosis of stroke. His wife Mary, aged 45 years, has arrived on the ward. She sat in the waiting room, her eyes were lifeless and she was slumped with her slack jaw supported by her right hand. Her shoulders were rounded and every so often her eyes filled with tears. She seemed to be unaware of her surroundings. The registered nurse had been asked to give her news of her husband's condition.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, wept silently at his bedside. When questioned she said that she felt inadequate and she clung to the nursing staff as she spoke.

What level of emotion is Mary exhibiting? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  A little  Moderate  Almost all  Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, her green eyes occasionally darting from her pastime to her husband's face, carefully mapped out her family tree on a piece of butcher's paper.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, waited at reception. She waited to discuss her husband's condition. She looked very pale. Without warning, she fainted, narrowly missing hitting her head on the water cooler as she fell.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, an architect, arrives with a large bunch of carnations for the staff. She asks pleasantly for some information about her husband's condition; on noticing that the nurses are busy she offers to wait until they have time to talk with her.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)  
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)  
None A little Moderate Almost all Everything
Mr Jones, aged 50, father of four (4) teenagers has been admitted yesterday evening. He has been diagnosed as having a stroke. His wife Mary, aged 45 years, a well groomed impeccably dressed woman, walks confidently up to the nurses station, deposits a box of chocolates on the bench, saying "these are for the nurses who are caring so well for my husband" (looking directly at the registered nurse and flashing a smile which displayed pearly white teeth). She then proceeded to enquire about her husband's condition.

What level of emotion is Mary exhibiting? Please cross (X).

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Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

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Mr Jones, aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary, aged 45, dressed in an elegant silk suit, sat reading the newspaper to her husband in a gentle voice. She herself had been a nurse and had only recently retired.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, herself a medical doctor remained at his bedside. She complained to the nursing staff of 'slight diarrhoea' and a 'touch of indigestion'. She was very co-operative with the staff and she bought them a huge box of chocolates for taking her phone messages.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, who remained with him, was openly hostile to the attending nursing staff and she questioned each staff member closely about the purpose of the care and treatment they gave her husband.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary’s emotional level, what amount of information about her husband’s condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, approached the nurses station and enquired about her husband's condition. She had a hospital blanket draped around her shoulders and was very pale around the mouth. She complained that her mouth was very dry.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, assisted with his care. She was at times tearful and others 'chirpy', and very anxious to please the nursing staff and her husband.

What level of emotion is Mary exhibiting? Please cross (X).

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Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

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Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, slid into the chair beside the nurses station, she wanted some information about her husband's condition. She confided to the nurse that she was suffering from constipation, and that that morning she had felt nauseous and giddy.

What level of emotion is Mary exhibiting? Please cross (X).

(1)  (2)  (3)  (4)  (5)  
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)  (2)  (3)  (4)  (5)  
None  A little  Moderate  Almost all  Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, snuggled into the comfortable arm chair, and tapped her fingers as she watched an old movie on the rented television.

What level of emotion is Mary exhibiting? Please cross (X).

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Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

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Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, sat beside her husband. Her chaffed red hands left sweat marks on the newsprint of the paper she held. Her mouth trembled as she addressed the nurse, and she complained of a lump in her throat.

What level of emotion is Mary exhibiting? Please cross (X).

(1)   (2)   (3)   (4)   (5)
None   Mild   Moderate   Severe   Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)   (2)   (3)   (4)   (5)
None   A little   Moderate   Almost all   Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, a Senator, arrived at his bedside. The nurse was helping Mr Jones with breakfast, and Mrs Jones said..."Here, let me take over nurse, I'm sure you have other patients to care for...How are you sunshine...Feeling better...The nurses are so lovely here".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, adjusted the fan on her sleepy husband, checked his temperature chart after the nurse left the room, and then returned to reading Gideon's bible.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, is discussing her husband's condition with a nurse. "...Yes, well my husband thinks that it is best not to consider the future but take one day at a time, just until he gets over this little spot of trouble".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, asked to speak to the nurse about her husband's condition. She spoke very slowly, and in addition she complained of stomach cramps and palpitations.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, sat limp and defeated at his bedside. She rocked slightly in her chair muttering:

"It's gonna be OK ... It's gonna be OK".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday evening suffering from a stroke. His wife, Mary aged 45, sat silently at his bedside playing solitaire by the light of his reading lamp as he slept fitfully.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything

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Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, waited at the reception window of the nurses station. She wanted to obtain up to date knowledge of her husband's condition. Her muscles looked very tense and she complained of alternatively feeling hot or developing goose bumps.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything

168
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, coaxed him gently to drink from a feeding mug. She requested a chat with the nurse-in-charge when it was convenient.

What level of emotion is Mary exhibiting? Please cross (X).

(1)   (2)   (3)   (4)   (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)   (2)   (3)   (4)   (5)
None  A little  Moderate  Almost all  Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted to hospital yesterday evening, with a diagnosis of stroke. His wife, Mary aged 45, struts up to the nurses station. She looks dishevelled, her hair is uncombed, clothes unironed and the colours clash. There is a marked tremor in her hands and voice, and when she opens her mouth to speak she begins to weep.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, had remained all night holding his hand tightly in hers. She appeared to be very angry at the situation she had found herself in and appeared to distrust the hospital staff. She said that she would remain at the bedside so that: "I'll know he's alright".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, who remained at the sick bed had a slight tremor in her hands. She admitted that she was frightened of what had befallen her husband and was unsure of what she could do to help.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)  
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)  
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening suffering from a stroke. His wife, Mary aged 45, asked the nurse the whereabouts of the toilet, she complained of urinary frequency and evening indigestion. She was also extremely restless.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, lacked the spontaneity in her speech which had been initially present when her husband had been admitted. Although she answered appropriately to requests her general mood was flat.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, thanked the nurse for the plate of sandwiches, but left them untouched. She had beads of sweat across her forehead, and she complained of pins and needles in her fingers.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, sat in an arm chair beside his bed. She was remarking to the relative of the patient in the next bed, how safe the hospital was.

What level of emotion is Mary exhibiting? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1)  (2)  (3)  (4)  (5)
None  A little  Moderate  Almost all  Everything
Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife, Mary aged 45, a dentist, sat placidly at his bedside. She was manicuring his nails. Placing his hand on the quilt, she rose to allow the cleaner to mop under his bed. She asked the passing nurse if she could speak to someone in authority about her husband's condition.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, arrived. She lost no time in explaining slowly where she had been and why she was five minutes late. She also remarked on how well-cared for Mr Jones appeared.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, sat at his bedside, knitting. Her hands went mechanically about their work, she smiled sweetly and rose to her feet as the registered nurse approached her.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, had persuaded him to try some hot tea (with her assistance). She put her arm round his back to support him and murmured "That's it darling! Just a sip at a time... You're doing fine!" as he endeavoured to drink.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, arrived. She gave Mr Jones a very loud kiss and proceeded to peel him a banana.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, pecked him on the left cheek and said:

"We was nearly washed out this morning; bin pouring cats and dogs; Ddja hear the rain? Youse lookin much betta taday; wull I readja the local rag? Look's like the tigers are set for a thrashin agin on Satiday".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted to hospital yesterday suffering from a stroke. His wife, Mary aged 45, shifted on her upright chair, which grated loudly on the floor.

"Hang in there, we'll beat this yet or make out the best we can. I'm going to have a talk to the nurse about what we can do".

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted to hospital yesterday suffering from a stroke. His wife, Mary aged 45, stood uncertainly for a moment looking at the nurse.

"May I talk with you? It's nurse isn't it?"

Her face was thin and intelligent. She had dark circles beneath her eyes.

What level of emotion is Mary exhibiting? Please cross (X).

1. None
2. Mild
3. Moderate
4. Severe
5. Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

1. None
2. A little
3. Moderate
4. Almost all
5. Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted to hospital yesterday suffering from a stroke. His wife, Mary aged 45, approached him cautiously. She saw him dropping his biscuit and trying to grasp it again while he looked at her like an aged bulldog. She watched the muscles of his face getting distorted with the effort of trying to control his hand. She steeled herself against the urge to cry and with inaudible steps she crept towards him.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Mr Jones aged 50, father of four (4) teenagers, has been admitted to hospital suffering from a stroke. His wife, Mary aged 45, sat at his bedside, her figure beneath her loose jumper shrunken and flat like a little girl's. Mary's initial expression of unbearable anguish had faded into resigned acceptance of her loss. Her greying hair hung lifeless on either side of her face and her green eyes were sunken in twin purple circles. Her face seemed drained of life's blood and there was a pinched look about her nose.

What level of emotion is Mary exhibiting? Please cross (X).

(1) None (2) Mild (3) Moderate (4) Severe (5) Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) None (2) A little (3) Moderate (4) Almost all (5) Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital. His diagnosis is stroke. His wife Mary, aged 45 years, has been constantly hovering round her husband. Her behaviour has been alternating between rudeness, making demands and inappropriate sugar coated politeness. She is excessively critical of nursing staff, her sense of humour is at the expense of others and she refuses to accept any responsibility for her husband's care.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None  Mild  Moderate  Severe  Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None  A little  Moderate  Almost all  Everything
Mr Jones, aged 50 years, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45 years, who has missed three (3) staff initiated appointments to discuss her husband's condition, arrives ten (10) minutes late, dressed in a pink taffeta skirt, dark green stockings and an orange pullover. She appears to be exaggerating her cheerfulness and her hands have a slight tremor.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
APPENDIX FILE 2

Vignettes used in Emotion and Information scales for 2nd study.
Please read the scenario presented below, and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening. He has been diagnosed as having a stroke. His wife, Mary aged 45 years, a well groomed impeccably dressed woman, walks confidently up to the nurses station, deposits a box of chocolates on the bench, saying "these are for the nurses who are caring so well for my husband". She looked directly at the registered nurse and flashed a smile which displayed pearly white teeth. She then proceeded to enquire about her husband's condition.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None     Mild     Moderate     Severe     Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None     A little     Moderate     Almost all     Everything
Please read the scenario presented below, and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted to hospital yesterday suffering from a stroke. His wife Mary, aged 45, stood uncertainly for a moment looking at the nurse.

"May I talk with you? It's nurse isn't it?"

Her face was thin and intelligent. She had dark circles beneath her eyes.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
VIGNETTE 3

Please read the scenario presented below and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45, who remained with him, was openly hostile to the attending nursing staff and she questioned each staff member closely about the purpose of the care and treatment they gave her husband.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Please read the scenario presented below, and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45, approaches the nurses station. The pupils of her grey blood-shot eyes were dilated, and she breathed rapidly and shallowly. She apologized for her washed out appearance, and mentioned that she had suffered a bout of diarrhoea.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
VIGNETTE 5

Please read the scenario presented below, and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, aged 45, reached the door of his room. The nurse on duty noticed her take three big deep breaths, screw-up and relax her facial muscles, and enter the sick room, presenting a smiling relaxed face to her husband.

What level of emotion is Mary exhibiting? Please cross (X).

(1) (2) (3) (4) (5)
None Mild Moderate Severe Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) (2) (3) (4) (5)
None A little Moderate Almost all Everything
Please read the scenario presented below, and answer the two questions based on your own beliefs.

Mr Jones aged 50, father of four (4) teenagers, was admitted yesterday evening to hospital suffering from a stroke. His wife Mary, refused to leave his side and busied herself puffing up his pillows, offering him drinks, arranging his flowers and chatting to the other relatives. Her eyes filled with tears occasionally and she blinked them away quickly.

What level of emotion is Mary exhibiting? Please cross (X).

(1) None (2) Mild (3) Moderate (4) Severe (5) Panic

Taking into consideration your judgement of Mary's emotional level, what amount of information about her husband's condition in your assessment is she capable of absorbing? Please cross (X).

(1) None (2) A little (3) Moderate (4) Almost all (5) Everything
Appendix 3. Study 1 - Scale development: Item intercorrelations for the Emotionality scale.

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Appendix 4: Frequencies for the Emotionality and Information Scales.

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Appendix 5

Cover letter for mailed questionnaires

Dear Participant,

Thankyou for your assistance with this research. Please find attached the questionnaire you have agreed to complete. When you have completed it, please return it to me in the stamped addressed envelope provided.

Yours faithfully

Anne McGown
Department of Psychology
Faculty of Science
Australian National University
Dear Participants,

Thank you for taking part in this research, the aim of which was to investigate perceptions of carer emotionality and its relationship to the amount of information this group of people are able to take in. Results showed a difference of opinion between community lay carers and the wider community. Carers perceived that emotionality did not interfere with their ability to learn. Nurses and members of the general public perceived emotional carers' learning capacity to be reduced. A follow-up study of nurses and carers found that although emotional carers knew less than nurses about stroke and caring before an information seminar, their knowledge after the seminar was equal to that of nurses. My research endeavours into the needs of community carers will continue next year. Thank you once again for all your help.

Sincerely

Anne McGown
Department of Psychology
Australian National University
APPENDIX 7

Please circle the answers you believe to be true in the following questions. There may be more than one correct answer.

A good carer is someone who:
(a) remains at the stroke person's side
(b) sacrifices their own needs for those of the stroke person
(c) does everything for the stroke person
(d) organizes a break for themselves from caring.

Which of the following are signs of emotional disturbance?
(a) spending money
(b) reading same page of newspaper all day
(c) worries unnecessarily
(d) constantly demanding attention.

How much hospitalization is desirable for stroke people?
(a) 12 months
(b) 6 weeks
(c) 2 weeks
(d) 12 weeks
(e) no hospitalization
(f) it depends on the person.
What makes caring so difficult?
(a) financial restrictions
(b) being constantly responsible
(c) social restrictions
(d) assisting the person with daily activities.

What would relieve the carer's burden?
(a) Money
(b) Forewarning
(c) Information
(d) Support programs
(e) None of these.

What functions may a temporal lobe stroke affect?
(a) bladder
(b) reading
(c) hearing
(d) swallowing
(e) none of these.

What situations could push a carer to breaking point?
(a) assisting with daily activities
(b) knowledge about the situation
(c) time-constraints
(d) unpredictability
(e) none of these.
How common is stroke?

(a) 1 in 7
(b) 1 in 1000
(c) 1 in 2000
(d) 1 in 20
(e) none of these.

What factors DO NOT increase the risk of stroke?

(a) obesity
(b) sexual intercourse
(c) cigarette smoking
(d) low blood pressure
(e) eye strain
(f) manual labour
(g) regular exercise
(h) none of these.

Which of the following DO NOT commonly follow a stroke?

(a) speech problems
(b) movement difficulties
(c) brain operations
(d) taking tablets to reverse the stroke's effect.
Strokes occur in ...
(a) any age group
(b) those over 60 years
(c) those over 40 years
(d) those over 30 years.

What is a stroke?
(a) a heart attack
(b) an epileptic fit
(c) a blockage in the brain
(d) a brain tumour.

What problems may a person suffering from a parietal stroke have?
(a) drawing
(b) swallowing
(c) taste
(d) bladder
(e) all of the above
(f) none of the above.

How does stroke affect the personality of the person?
(a) it has no effect
(b) the person is left with no personality
(c) they could attack at any time
(d) they cry easily
(e) none of the above.
What sort of future is there for stroke victims?
(a) most people will regain some functions
(b) they are just vegetables
(c) everyone will recover
(d) a good future in some cases
(e) there is no hope.

What functions may a stroke in the occipital lobe affect?
(a) speech
(b) sight
(c) personality
(d) co-ordination
(e) none of the above.

What is the best way to find out about caring for a stroke person?
(a) read books and pamphlets
(b) ask your friends and relatives
(c) ask other carers
(d) ask the physiotherapist
(e) ask the doctor
(f) ask the occupational therapist
(g) by trial and error
(h) none of these.
What must a stroke person do to improve their self-care abilities?
(a) Rest and not exert themselves
(b) Read about the condition
(c) Want to improve
(d) Follow the doctors orders.

What functions may be damaged in a person with a frontal lobe stroke?
(a) bladder and bowel control
(b) speech
(c) co-ordination
(d) personality
(e) none of these.
IN THE LAST FOUR WEEKS, HAVE YOU SUFFERED FROM .....

(PLEASE CIRCLE ONE NUMBER ON EACH LINE)

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Which of the following experiences have you had as a caregiver? Tick the ones that are relevant to you as a caregiver.

( ) Having to constantly be on call to assist the person you are caring for

( ) Feelings of resentment that this has happened to you

( ) Not being able to do your job as well as you'd like

( ) Feeling guilty about what you have or have not done for the person you are caring for

( ) Being unable to get your household chores done

( ) Feeling that you cannot get on top of all the things you have to do

( ) Not having a regular daily routine

( ) Feeling you have lost control over your life

( ) Being unable to get enough sleep

( ) Feeling that you don't understand the nature of the other person's illness

( ) Losing patience with the person you are caring for

( ) Being unable to rest when ill yourself

( ) Feelings of resentment at what has happened to the person you are caring for

( ) Feeling that you are not doing anything as well as you should

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( ) Having to change your plans at the last minute

( ) Feeling divided loyalties between the person you are caring for and other members of your family

( ) Having health problems as a result of caregiving
In how many of the following activities do you assist the person with stroke? Tick the category that best describes how much help you provide.

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<tr>
<td>Bathing</td>
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Which of the following stroke person behaviours have you had problems with? Tick the ones that are relevant to the person you are caring for.

(  ) Goes on and on about certain things
(  ) Constantly demands assistance
(  ) Gets very upset, may cry
(  ) Is irritable
(  ) Has sudden changes of mood
(  ) Gets deeply depressed
(  ) Is overly critical
(  ) Does not understand what is said
(  ) Does not respond sensibly when spoken to
(  ) Fails to recognize familiar people and places
(  ) Is not interested in news of friends and relatives
(  ) Does strange things

What is your gender? (  ) Female (  ) Male

How old are you? ______________________________________

What is the relationship between the care-giver and the care-receiver? ______________________________________

How long is it since the person had the stroke? ______________________________________

Thank you very much for your assistance.

Anne McGown

Australian National University
Appendix 8

Knowledge Scale - item frequencies

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### Knowledge scale - item intercorrelations

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