# Influence of the Carer's Expressed Emotion on the Course and Twelve-month Outcome of Patients with Alzheimer's disease

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by

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I confirm that the work presented in this thesis is my own. The assistance and contributions that I have received is summarised in the acknowledgement section. Where known and possible, I have indicated and given reference for the information that I have derived from other sources.

Mangesh Marudkar

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# Abstract

**Influence of the Carer's Expressed Emotion on the Course and Twelve-month Outcome of Patients with Alzheimer's disease.**

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*Background:*

The evidence that patients living with high Expressed Emotion (EE) carers have a more adverse course and outcome compared to those with low EE carers is well documented in conditions such as schizophrenia, depression and some other disorders, but such evidence is lacking in patients suffering from Alzheimer's disease (AD).

*Aim:*

To investigate whether the baseline levels of EE in the informal carers of AD sufferers influences the course or the outcome of the illness over a twelve-month follow-up period.

*Methods:*

Seventy-five patients living in non-institutional settings and their informal carers were assessed at baseline. The assessments included: patients' cognitive, functional, and physical health status, and non-cognitive psychological and behavioural symptoms; carers' EE status (using the modified Camberwell Family Interview Schedule (CFI)); carers' general health and their distress levels; and any formal help received in the preceding six months.

At six and twelve-month follow-up, 51 and 49 respectively of those patients who were alive, and had not changed their domicile were reassessed. All baseline assessments except CFI were repeated.

*Results:*

Thirty-one carers (41%) had high EE at baseline. High and low EE groups were comparable at baseline. Four subjects (5%) either died or were permanently institutionalised over the twelve-month follow-up. No significant differences were noted in the course or the outcome between the two groups. The baseline levels of the carer strain, and general health; patients' cognitive and functional impairments; non-cognitive symptoms and physical health status did not influence the course or the outcome.

*Conclusion:*

In this sample, the informal carers' level of EE did not influence the course of the illness or the probability of death and institutionalisation over a twelve-month follow-up.

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# Abbreviations Used

AD – Alzheimer's disease

ADL – Activities of daily living

APA – American Psychiatric Association

AUC – Area Under Curve

BADL – Bristol Activities of Daily Living

BMD – Behaviour and Mood disturbance scale

BRS – Behaviour Rating Scale

CAPE – Clifton Assessment Procedure for the Elderly

CC (or CR) – Critical Comments (or Critical Remarks)

CCF – Congestive Cardiac Failure

CDR – Clinical Dementia Rating scale

CERAD – Consortium to Establish a Registry for Alzheimer's Disease

CFI – Camberwell Family Interview Schedule

ChEI – Choline-esterase Inhibitors

CI – Confidence Interval

CPNs – Community Psychiatric Nurses

CSDD – Cornell Scale for Depression in Dementia

CT – Computerised Tomogram / Computerised Tomography

CUSPAD – Columbia University Scale for Psychopathology in Alzheimer's Disease

DC – Day centre

df – Degree of Freedom

DH – Day Hospital

DSM III R / DSM IV – Diagnostic and Statistical Manual for Mental Disorders version three – revised / version four.

EE – Expressed Emotion

EOI – Emotional over involvement

FIQ – Family Interaction Questionnaire

GHQ-12 – General Health Questionnaire – 12 item version

GHQ-28 – General Health Questionnaire – 28 item version

GHQ-30 – General Health Questionnaire – 30 item version

GSS – Gilleard Strain Scale

H – Hostility

IQR – Inter Quartile Range

LACS – Leeds Attributional Coding System

LPT – Leicestershire Partnership NHS Trust

MHSOP – Mental health Services for Older Persons

MMSE – Mini Mental State Examination

MOUSEPAD – Manchester and Oxford University Scale for Psychopathological Assessment in Dementia

MRI – Magnetic Resonance Imaging

NPI – Neuro Psychiatric Inventory

NPI-DS – Neuro Psychiatric Inventory – Distress scale

OARS – Older American Resource and Services

OMFAQ – OARS Multifunctional Assessment Questionnaire

P or p – probability

PR – Positive Remarks

PRS – Patient Rejection Scale

RSS – Relative Stress Scale

UK – United Kingdom

US / USA – United States of America

$X^2$ – Chi squared test

W – Warmth

WHO – World Health Organisation

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# Chapter One

# 1. Introduction

## 1.1 The carers

*"He is not the man I married.....He was a kind and caring person who always was full of life and very active. Now he is so selfish.... All he is interested in is that his dinner is ready on the table; that his clothes are all clean and his bed is warm. He is not interested in anyone else.... This is not him.... This is just a shell of the man I married."* – *One of the participants in this research study.*

*"You know there's no light at the end of the tunnel. That's the only way you can go. But you really don't know anything about it. And you don't know what to expect."....* *"The golden years are when you can sit back, hopefully, and exchange memories. And that's the worst part about this disease. There's nobody to exchange memories with."* *Nancy Reagan on Alzheimer's (CBS news 2003)*

Experience of caring for someone suffering from dementia is varied and complex. Although sometimes it is described as a positive experience (Roff *et al.* 2004), more often it has negative connotations such as burden, stress, guilt, loneliness, and frustration. For the family and friends, this often involves either a change in the role or acquiring additional roles. Often neither the patient nor the relative is prepared for, or even aware of, this new role.

The experience of this change has been highlighted by the family members of a number of high profile dementia sufferers such as Ronald Reagan and Iris Murdoch.

Typically, the experience of caring involves having to deal with a progressive loss of cognitive and functional independence in the dementia sufferer, who often has very limited awareness of this loss. There is often very little appreciation of the help offered by the carer and the loss of appropriate emotional reciprocation by the dementia sufferer, which carers find emotionally hard to deal with. Sometimes the process of providing care to the dementia suffer takes such a prime importance that it becomes their primary identity and they are often addressed as 'carers' or 'care givers'.

In this thesis, I will use the term 'carers' to refer to those family or friends who provide care to the dementia suffers not as a part of their gainful employment.

## 1.2 Alzheimer's Disease

Alzheimer's disease (AD) is the commonest form of dementia affecting approximately 50% or more of all Dementia sufferers (Bachman DL *et al.* 1992, Evans *et al.* 1989). It is a primary degenerative cerebral disease of unknown aetiology with characteristic neuropathological and neurochemical features. The disorder is usually insidious in onset and develops slowly but steadily over a period of several years (ICD-10, WHO 2003). Although cognitive impairments form the key features of AD, the non-cognitive symptoms are extremely common and can be present at any stage of the

disease. They are a cause of distress to the carers (Coen *et al.* 1997), and risks to the patients (Yaffe *et al.* 2002).

It is estimated that in England and Wales there are over 700,000 people suffering from AD (Web reference 1 - Alzheimer's society website). Although AD has a relatively well-established course and progression, there are various sub-types with noticeably different course and progression of the symptoms (ICD-10, WHO 2003).

The diagnosis of AD is mainly based upon the clinical presentation, but can be supported by radiological investigation of the brain. A number of diagnostic criteria for AD exist, such as ICD-10 (World Health Organisation, 2003), DSM-IV (American Psychiatric Association, 1994), and NINCDS-ARDRA (McKhann *et al.* 1984). Haematological and biochemical investigations are mostly carried out to rule out other, possibly co-existing, causes of the cognitive and non-cognitive symptoms. A definite diagnosis of AD is made by brain biopsy, at autopsy.

Depending upon the severity of the cognitive and functional impairments, the severity of the AD is categorised as mild, moderate or severe. There are different ways to classify the severity of AD. A common method is to categorise the severity on the basis of the patient's scores on a clinical cognitive assessment scales such as Mini Mental State Examination (MMSE, Folstein *et al.* 1975).

There are no curative treatments for AD, and the management is mostly psychosocial. Various medications are used to control non-cognitive symptoms of AD. Since 1997, drugs to slow down the rate of cognitive decline (cholineesterase inhibitors (ChEI)), have been available for patients with mild to moderately severe AD in the UK (Eisai Ltd. Website – web reference 2).

Psychosocial interventions are aimed at modifying some of the individual psychosocial factors, which may play a role in the manifestation of the behavioural and psychological difficulties often seen in these patients, and at improving the carers' mental health (Hinchliffe *et al.* 1995). It therefore follows that in order to target the psychosocial interventions most effectively, a clear and systematic understanding of the relevant psychosocial factors and their influence on the AD patients is crucial.

## 1.3 Significance of Expressed Emotion

A large number of psychosocial factors have been investigated for their effect on the course and outcome of a range of mental and physical disorders. The construct of expressed emotion (EE) is one such factor. Although it has been studied extensively in conditions such as schizophrenia, the literature on EE in the context of dementia is limited.

One of the most consistent findings (Kavanagh 1992, Hooley and Richters 1995) from the EE research in schizophrenia, depression and some other conditions is that those patients who are exposed to a high EE environment

have significantly higher rates of relapse of their conditions and have a poorer outcome compared to those patients who live with relatives with low EE.

## 1.4 Why study role of EE on the course and outcome of AD?

Studying EE in AD patients is important because there are established psycho-social interventions in conditions such as schizophrenia that have been shown to reduce the levels of EE and also reduce the relapse by minimising the exposure of the patient to the high EE environment (Kuipers 2006)

Although AD has many major differences compared to schizophrenia in terms of its course and outcome, and the concept of 'relapse' is somewhat problematic in the context of a progressive neurodegenerative condition such as AD, there are also many similarities. Both are chronic conditions; both involve a significant change in personality; both conditions make the sufferer susceptible to a relative loss of insight into their condition; and the patients in both these conditions are generally significantly disabled and dependent upon help from others.

Logically, it is possible that similar interventions may also be effective in controlling some of the unpleasant psychological and behavioural symptoms of dementia. These symptoms are known to add to the carer burden (Matsumoto *et al.* 2007), to increase the use of psychotropic drugs (Omelan 2006), and to hasten the institutionalisation (Yaffe *et al.* 2002) of patients with dementia. Identification of the role of EE in the influencing the symptoms, course and outcome of AD is the first step towards developing such interventions.

In summary, EE is a psychosocial construct that has been extensively studied in schizophrenia and other conditions, but not in AD. In the management of schizophrenia, a number of interventions exist that are aimed at reducing either the extent of EE or the effect of EE on the patients. These interventions have been shown to reduce the nature and extent of relapse (Kuipers 2006). As psychosocial interventions are the mainstay of AD management, any such specific interventions of proven benefit will be a welcome addition. Before attempting such interventions in the AD population however, the role of EE in influencing the symptom profile, course and outcome of AD needs to be established. This study is one such attempt.

# Chapter Two

# 2 Expressed Emotion

In this chapter, I will summarise the concept of EE, and critically analyse its components, its assessment, and its relationship with some of the other psychosocial factors. I will then summarise the literature pertaining to EE in schizophrenia, depression, and other psychiatric and physical conditions. I will review the EE literature in dementia in some detail in the next chapter.

## 2.1 What is Expressed Emotion?

*'The attitude and behaviours shown toward the patient and the illness by a key relative.'* (Vaughn *et al.* 1999)

*'Expressed Emotion is a measure of the family environment that is based on how the relatives spontaneously talk about the patient.'* (Butzlaff & Hooley 1998)

*High expressed emotion* is *'the term used to describe families having persistently critical or hostile attitudes towards their schizophrenic kin.'* (Turner 2004)

The above are three of the many different descriptions of the concept of EE given in the literature. Unlike many other concepts in the mental health field, EE evolved primarily as an 'atheoretical' concept, *i.e.* to begin with there were no major psychosocial theories that underpinned it. The concept of EE in its

present form originated from the work of Brown and his colleagues in the 1950s (Brown *et al.* 1958). In an attempt to understand the role of families in the relapse of male schizophrenic patients who were hospitalised, a wide variety of factors were considered. Over a period of more than ten years, hundreds of patients with mental illness and their families were interviewed, both individually and jointly. The interviews were largely exploratory, and covered a wide range of aspects of family functioning and relationship. Over the years, those components of the interviews that were thought to be easily and reliably measurable were preferentially retained in the subsequent modifications of their instrument. Similarly, those aspects of the interview, which appeared to be important in relation to the relapse of schizophrenia, were retained in the subsequent modified forms of the interviews (Leff and Vaughn 1985). These modifications were eventually formalised in a semi-structured instrument called Camberwell Family Interview Schedule (CFI).

A number of interesting and often contradictory explanatory frameworks for EE have been offered over the years. First, it has been described as a measure of the emotional temperature of the relationship. Also, it has been considered as an indicator of stress between the patient and the carer (Schreiber *et al.* 1995). Various components that constitute the measure of high EE could be construed as paradoxical, such as Hostility and Emotional over-involvement. Attempts have been made to reduce EE to simpler components (Van Humbeeck *et al.* 2002), but to date the concept of EE has withstood the various tests of its validity, usefulness and reproducibility well.

## 2.2 What are the components of the EE?

The different components of the interview have been progressively reduced and five main components of the EE are retained in the CFI. These components are summarised from Leff and Vaughn (1985) as follows:

### 2.2.1 Criticism

This is defined as a 'statement, which by the manner in which it is expressed, constitutes an unfavourable comment upon the behaviour or personality of the person to whom it refers.' Criticism may be evident in the content of the comment alone, but it is principally evident in the pitch, speed and inflection imparted to the statement by the person making it.

### 2.2.2 Hostility

Hostility is considered to be present when the person (patient) is attacked for what she / he is rather than for what she / he does. For the purpose of the CFI rating, hostility is considered to be present when a statement and the vocal aspects of the speech indicates either a generalisation, where specific criticisms are extended into general pejorative comments about the person as a whole, or a rejecting remark that expresses a generalised negative feeling, which may involve a frank statement of dislike.

### 2.2.3 Emotional over-involvement

This component reflects an exaggerated or extreme form of concern expressed towards the sufferer of a serious illness. This component can be detected by both the reported behaviour of the respondent, and the behaviour of the respondent at the interview.

### 2.2.4 Warmth

This refers only to the warmth expressed in the interview itself about a particular person; the warmth of the respondent's personality is not a consideration. The warmth is assessed on the basis of the tone of the voice, spontaneity of the comments, the expression of sympathy, concern and empathy shown by the relative of the patient.

### 2.2.5 Positive remarks

These are specific statements, which express praise, approval or appreciation of the behaviour or personality of the person to whom they refer. A positive remark, unlike warmth, is defined primarily by its content. The tone of voice is taken into account in determining whether a remark is intended to be positive or not.

## 2.3 How is EE measured?

The original Camberwell Family Interview was an extremely lengthy process. The key relatives were interviewed alone, and the duration of the interview was

generally four to five hours (Leff & Vaughn 1985). Subsequently, it was demonstrated that a much shorter interview of around 60 to 90 minutes could reliably elicit from the relative the information necessary to make an assessment of their EE status. This led to the development of an abbreviated and modified Camberwell Family Interview Schedule, which has been used in majority of the studies assessing EE from 1972 onwards (Brown *et al.* 1972.)

The modified Camberwell Family Interview (CFI), a semi-structured interview, typically consists of one-to-one interview with the key relative of the patient. Ideally, the interview is done without the presence of the patient. The interview is audio-recorded for later evaluation.

The interview typically starts with a 'chat' about background information, including composition of the household and employment details of its members. It then covers certain questions about psychiatric history, family time budget, etc. before exploring the presence of and details regarding nagging, irritability and quarrelling. The interview then covers details of the clinical symptoms in the current episode, household tasks, and money matters. It then goes on to explore the relationship between the informant and the patient, parents' marital relationship, medication and attitude towards illness.

A formal training is required for both conducting the CFI interview as well as the rating of the recorded interviews, in order to achieve a high degree of consistency and inter-rater reliability.

## 2.4 Are there different methods of assessing EE?

The modified CFI was an attempt to reduce the length of the interview without compromising the quality of the measure, and it has become popular since its publication in 1972 (Brown *et al.* 1972.) Since then, CFI has been widely considered as the 'gold standard' (Bentsen *et al.* 1996) and 'standard measure' (Gerlsma and Hale 1997) for the assessment of EE.

There appear to be two fundamental limitations of the CFI given as reasons for attempting to develop alternative measures of EE. These are: a) the length of time it takes for application and rating of the EE; and b) the complexity of the construct of EE as defined by CFI.

In response to these limitations, attempts have been made to condense and simplify the assessment of EE without compromising on quality, reliability and validity. One such attempt is the assessment of EE on the basis of the Five Minute Sample of Speech (FMSS) (Magana *et al.* 1986). The FMSS is a very brief and a highly structured and recorded interview with the carer of the patient. It assesses the EE on the same components as those used in the modified CFI. FMSS-EE and CFI-EE have been shown to be highly correlated (Magana *et al.* 1986, Leeb *et al.* 1991, Malla *et al.* 1991)

Although no other reliable and validated assessment method has been reported for the rating of EE, a number of related concepts and their methods of assessment have been described. The Level of Expressed Emotion (LEE) (Cole

and Kazarian 1988) is one example. This measure assesses the patient's perceived levels of Expressed Emotion. The scale has been factorially derived and has 33 items, each rated on a 4-point Likert scale. There are three components (perceived lack of support, perceived irritability and perceived intrusiveness), with the total score being labelled as Perceived EE (Gerlsma *et al.* 1992). This scale has been shown to have good comparability with the measures of EE, especially criticism, as measured by the CFI, and is also shown to be able to predict relapses.

A number of other related concepts and scales have been developed. The more widely reported include Perceived Criticism (Hooley and Teasdale 1989), Patient Rejection Scale (Kreisman *et al.* 1979) and the patient's perception of their family member's attitude using Family Interpersonal Perception Test (Scott & Alwyn 1978, Scott *et al.* 1993). Other measures seem to primarily show a correlation with the measure of EE rather than attempting to substitute for EE; but some, such as attributional style of the carers, have been stated to predict schizophrenic relapse even better than measures of EE (Barrowclough et al 1994). (See chapter 2.7:'How is EE related to other psychosocial constructs?')

## 2.5 How are individual components of EE rated?

According to the CFI training manuals, the EE Scale concerns emotions expressed while talking about a particular person. Criteria such as tone of the

voice, content of speech and gestures are used to assess the degree to which emotion is shown. The measures are of two kinds:

*Frequency counts* - Two sub-scales involve recognition of particular comments ('critical' and 'positive') and consist of a count of all such comments occurring at any point in the interview. 'Critical comments' and 'Positive remarks' are the two components of EE that are measured on the basis of the frequency counts.

*Global scales* - Three sub-scales of EE involve recognition of particular kinds of comments. Their rating involves more than a simple summation; the rater must make an overall judgement about the degree to which the emotion was shown, taking into account the interview as a whole. 'Hostility', 'Emotional over-involvement' and 'Warmth' are the three measures of EE that are assessed using such global measures.

### 2.5.1 Criticism

Criticism is judged to be present by a) the content of the comment alone, or jointly with b) the vocal aspects of speech, such as the pitch, speed and inflection. In the original schizophrenia studies and in many others subsequently, a frequency count of six or more critical comments is taken to indicate presence of 'high' EE. If the total number of critical comments is less than six, then provided that there is not a high rating on 'Hostility' and 'Emotional over-involvement', the rating is considered as 'low' EE.

### 2.5.2 Hostility

In presence of hostility, negative feelings are generalised in such a way that it is expressed against the person himself / herself, rather than against particular behaviours or attributes. This differentiates a hostile comment from a critical comment. Hostility is measured on a four-point scale depending on whether the interviewee is expressing generalisation of the criticism alone, making rejecting remarks alone, or expressing both generalisation and rejecting comments towards the patient. Presence of any hostility indicates 'high' EE.

### 2.5.3 Emotional over-involvement

'Emotional over-involvement' (EOI) is measured on a six-point scale, ranging from 'none' (scored zero) to 'marked' (scored five). It is a global measure, and the degree of EOI is determined by both the reported behaviour of the respondent and also the behaviour of the respondent at the interview. Examples of the first type of behaviour include exaggerated emotional response in the past, unusually self-sacrificing and devoted behaviour, or extremely overprotective behaviour. The examples of the latter include statements of attitudes, and emotional displays such as dramatisation. A rating of three or more on this scale is considered to indicate 'high' EE.

### 2.5.4 Warmth

'Warmth' is another measure of the EE that is assessed using global measures. It is also rated on a six-point scale ranging from 'No warmth' (scored zero) through to 'high warmth' (scored five). The warmth is assessed only in relation to the warmth expressed in the interview itself about a particular person. The warmth of the respondent's personality is not a consideration. Warmth scores do not contribute to the EE status of the person, but are thought to influence the effect of EE in certain conditions.

### 2.5.5 Positive remarks

Like critical comments, positive remarks are counted on the basis of the frequency counts. Positive remarks do not contribute to the EE status of the person but may have a modifying role in certain conditions.

## 2.6 What is meant by 'high' and 'low' EE?

The three components that determine the 'EE-index' or the overall EE level as defined by the CFI are - Critical comments (CC), Emotional Over-involvement (EOI), and Hostility (H). The other two components, namely warmth (W) and positive remarks (PR) are thought to influence the overall effect of the other three components but are not considered in the ranking of EE status.

High EE status is judged on the basis of the presence of any one of the following. The three together constitute an index of expressed emotion and are

thought to give a measure of the 'emotional temperature' of the relationship of the patient and the interviewed carer:

- Critical comments – six or more (frequency count)
- Hostility – any (generalisation, rejection or both) (global rating)
- Emotional over-involvement – 3 or more (global rating)

If the threshold described above is not achieved / met by the interviewee, then they are judged to have low EE. The EE-index as originally described in the CFI manual is a dichotomous construct.

Some of the studies have used different cut-offs to divide their sample into high and low EE groups (Bledin *et al.* 1990). This has involved either excluding some of the components of EE such as EOI or Hostility, or using a different threshold, such as the median count of CC, to categorise high and low EE groups. This has occurred more frequently in studies involving carers of patients with non-schizophrenic conditions and among elderly patients.

Various reasons have been offered for using different cut-offs. Exclusion of EOI centres on the belief that it is considered to be a 'softer' measure of EE, and that even in schizophrenia research it is not that strongly associated with adverse course and outcome. Hostility is excluded in some studies (Vitaliano *et al.* 1993) due to it being either relatively uncommon, or because of the overlap between Hostility and Critical comments. Varying the threshold of CC to determine EE status is quite common, and makes interpretations and comparison between studies difficult. Sometimes no rationale has been given for using a non-standard cut-off of CC in determining EE status. A different

cut-off could also have been used if only a small percentage of the subjects expressed six or more CC. In relation to depression, patients' sensitivity to CC has been given as one of the reasons for reducing the cut-off point for categorising EE status. In the next chapter, when I shall discuss the EE research in dementia, I will revisit these variations to the standard criteria in relation to studies in dementia subjects, the reasons offered for, and a critical analysis of these variations and their impact of the robustness and generalisability of the study findings.

## 2.7 How is EE related to other psychosocial constructs?

The EE is a complex construct. Over the last five decades, studies have attempted to identify relationship between EE & various psychosocial factors in order to:

- Understand the origins of EE;
- Understand the mechanism by which EE status may be related to the course and outcome of various health conditions;
- Describe the theoretical framework that can best explain EE in a complex psychosocial milieu;
- Identify a substitute for EE that is assessable and equally useful.

As EE is primarily based upon the interview with the carers, the carers' characteristics have been a major focus of these association studies. Carers' mental health and personality (King *et al.* 2003); their perception of the patient's illness (Spruytte N *et al.* 2002); their coping skills (Raune D *et al.*

2004) and problem solving strategies (Wendel JS *et al.* 2000); other life stressors such as unemployment; their attributional style (Brewin *et al.* 1991, Barrowclough *et al.* 1994), affective distress, affective attitude, and affective style; carer age; their differentiation of self and integration of the personality traits; locus of control - these are some of the characteristics that have been associated with EE status.

Some of the main themes that have evolved from the literature on EE and carer characteristics are as follows:

- EE as a personality 'trait' versus a 'state': There is supportive evidence on both sides of this debate. Earlier literature (Leff & Vaughn 1985) suggested that EE may have trait-like characteristics, but the observations that some carers, particularly professional carers, may express high EE towards one care recipient, but low EE towards another (Moore *et al.* 1992) suggests EE to be a characteristic only manifesting in certain situations, therefore a 'state'.
- A 'stress–vulnerability' hypothesis: This has been proposed (Zubin and Spring 1977) to incorporate the above diverse findings. This hypothesis has been further developed by Nuechterlein (1987) and Nuechterlein and Dawson (1984) (as summarised by Weardon *et al.*, 2000). In simple terms, high EE carers are considered as environmental stressors, and their presence causes physiological arousal in the patients. When this arousal goes beyond a certain point, relapse occurs. The 'latent trait' of EE also manifests itself

when the patient shows certain symptoms or behaves in a certain manner, so a relapse of symptoms may then trigger the manifestation of (high) EE.

- Cognitive models: These models of EE, proposed by Barrowclough *et al.* (1994), are based on the attributional styles of the carers. Carers who believe that the cause of the patient's symptoms are internal to and controllable by the patient tend to be critical of the patients, and those who believe that the cause of the symptoms of the patient are external to and uncontrollable by the patients tend to be emotionally over-involved. The attributional style of the latter group is quite similar to those who are low EE carers.

As EE is considered to be a measure of the emotional temperature, and a measure of the relationship between the carer and the patient, a number of interpersonal factors have been compared with EE, such as the quality of the pre-illness relationship (Yan *et al.* 2004); intimacy between the patient and the carer (both current and past) (Fearon *et al.* 1998); communication deviance; and empathy (Giron and Gomez-Beneyto 1998).

Some of the patient's characteristics have also been found to be associated with the levels of EE, such as their age, their behaviour (Vitaliano *et al.* 1988), and their perceived criticism and perceived EE (Tompson *et al.* 1995).

To date, no consistent picture has emerged, and many of the above associations need replication. However, it is generally believed that patient factors are less critical than carer factors in determining levels of EE. Indeed, the literature

suggests that, rather than the patients' symptoms or disabilities, it is the carers' understanding of these and their controllability by the patient that determine EE.

## 2.8 The association between EE and relapse of psychiatric disorders

### 2.8.1 Schizophrenia

The concept of EE evolved from studies into the determinants of relapse in schizophrenia, and it is the most studied relationship in EE research. In a meta-analysis of EE and psychiatric relapse, Butzlaff *et al.* (1998) concluded that EE predicts relapse in schizophrenia quite well. They calculated the mean effect size of EE predicting relapse as r =0.30, which, in practical terms means that in a hypothetical sample of 200 patients (high EE = 100, low EE = 100), it translates in to relapse rates of 65% and 35% respectively. Thus EE is associated with approximately one-third of the relapses that do occur and two-thirds of the relapses that do not occur.

### 2.8.2 Mood disorders

A number of studies, albeit fewer than in schizophrenia, have also shown a positive relationship between high EE and increased risk of relapse of mood disorders (Vaughn & Leff 1976, Hooley *et al.* 1986, Miklowitz *et al.* 1988, Priebe *et al.* 1989, Okasha *et al.* 1994). The consistency with which all the studies have found a positive relationship is quite remarkable. The relationship

between high EE and increased risk of relapse in mood disorders is even stronger than that in schizophrenia. Butzlaff (1998) has calculated an effect size of r = 0.39 which means that in a sample of 200 patients with 100 each having a high and a low EE carer, the relapse rate would be 69.5% for patients with high-EE relatives and 30.5% for patients with low-EE relatives.

### 2.8.3 Eating disorders

The definition of relapse and the cut-offs for determining high and low EE varies in these studies, compared to those is schizophrenia and mood disorders. Studies are even fewer, but are mostly consistent in finding a positive association between high-EE and increased risk of relapse. Butzlaff *et al.* (1998) have calculated the effect size as r = 0.51, larger than that for schizophrenia and mood disorders. However, due to smaller sample sizes and fewer studies, these results should be interpreted with caution.

### 2.8.4 Other psychiatric disorders

A number of other psychiatric and behavioural disorders have been studied in relation to the relapse in the sufferer and the levels of EE in the carers. These include: post-traumatic stress disorders (Tarrier *et al.* 1999); alcohol abuse (Fichter *et al.* 1997, O'Farrell *et al.* 1998); personality disorders (Hooley & Hoffman 1996); agoraphobia (Peter and Hand 1988); and children suffering from depression (Asarnow *et al.* 1993) or various other psychiatric disorders (Stubbe *et al.* 1993, Vostanis *et al.* 1994, Vostanis and Nicholls 1995).

Not all aspects of high EE lead to negative outcomes. There are occasional reports that some aspects of EE may be protective. High EOI were associated with better outcome and absence of hospitalisation, while criticism and hostility failed to predict outcome during a one-year follow-up of borderline personality disorder patients (Hooley & Hoffman 1996). Similarly, patients with agoraphobia who were in a high EE 'dyad' had a better outcome at one to two-year follow-up (Peter & Hand 1988). EOI and Warmth have also been associated with a better outcome at 18 and six-months respectively in patients with alcohol abuse (Fichter *et al.* 1997).

Overall, there is generally supportive evidence towards a relationship between high EE and poorer outcome or relapse in mental disorder. The strength of this relationship varies with the diagnosis, the duration of follow-up, the instrument used for assessing EE and the cut-off used for categorising EE status. As Weardon *et al.* (2000) have stated in their review of EE research in healthcare, this variability raises the problems of interpretation of the findings and also raises the possibility of Type-I errors, that is, accepting a chance finding as statistically reliable.

## 2.9 The association between EE and relapse in physical disorders

In a range of physical conditions such as epilepsy, diabetes, asthma, obesity, and rheumatoid arthritis, the potential association between EE and symptom

severity, course, and outcomes of the conditions have been investigated. These studies have been succinctly reviewed by Weardon *et al.* (2000).

Many of these studies are cross sectional. Even among those with some follow-up, the results are somewhat mixed. The studies suffer from the same limitations as those investigating psychiatric disorders.

While the research in this field suggests that there are some significant associations of EE with course, or outcomes of various physical illnesses and medical conditions, the amount and quality of this research does not yet allow any firm conclusions.

The research into chronic conditions suggests that it is possible, or even helpful to investigate the outcomes in ways other than to just to focus on the symptoms. This can include assessing the patient's (or the carer's) burden, or coping strategies or behaviour, such as additional help seeking, as well as utilisation of various services.

## 2.10 How is dementia related to other psychosocial factors?

The psychosocial correlates of the variability in the course and outcome of dementia have been studied (Lucca *et al.* 1993; Han *et al.* 2000), but are still poorly understood. A range of patient variables, illness variables, and environmental variables have been reported to influence the course and outcome of the patients with AD.

Patient and illness variables that can influence the course and outcome of dementia include; age (Knopman *et al.*, 1988, Smith *et al.*, 2000), age at onset of dementia (Heyman *et al.*, 1987); gender (Heyman *et al.*, 1987); pre-morbid personality, living situation (Smith *et al.* 2000, Yaffe *et al.* 2002); ethnicity, level of cognitive impairment and behavioural difficulties (Yaffe *et al.*, 2002); and co-morbid illnesses. The immediate environment, in particular the degree and nature of human contact with the family and friends of AD sufferers, can also have an important bearing on the course and outcome of the dementia. Studies have investigated the effect of the quality of relationship or the interaction between the carers and the AD patients on the course and outcome of AD patients. Not having a living-in carer is a risk factor for institutionalisation (Yaffe *et al.* 2002, Smith *et al.* 2000). Carer's age and stress levels (Yaffe *et al.* 2002) are also known risk factors for nursing home placement.

The impact of being a carer must not be forgotten. It has been reported that the role of care-giving (not specifically in dementia subjects) may put the carers at a higher risk of mortality (Schulz and Beach 1999).

# Chapter Three

# Expressed Emotion in Dementia

## 3: Literature review

### 3.1: Search Strategy

I searched the following electronic databases (listed alphabetically): Australian Education Index, AUEI (from 1979 onwards); British Education Index, BREI (1975 onwards); EMBASE (1980 onwards); Health and Psychosocial Instruments (1985 onwards); International Bibliography of the Social Sciences (1951 onwards); MEDLINE (1950 onwards); PsycARTICLES (1894 onwards); and PsycINFO (1887 onwards). I used the key words 'dementia', or 'Alzheimer', combined with 'expressed emotion' or 'EE'. I included all possible search fields such as citation, abstract, MeSH heading, or All Text, where available. I included studies published till July 2007.

I printed all the abstracts, and a full text article was obtained of those that focused on expressed emotions in dementia or Alzheimer's disease, either solely or partly. Reference lists of all the full text articles were scrutinised for any other relevant articles.

I contacted three researchers who had published on this subject previously, and requested them to inform me of any studies in this subject that they were aware of.

## 3.2 Results

The search identified seven cross-sectional studies and two longitudinal studies in the literature that focused on EE in the context of dementia. Some of the studies focused exclusively on dementia subjects (Fearon *et al.* 1998, Tarrier *et al.* 2002) while in others (Orford *et al.* 1987, Nomura *et al.* 2005) dementia subjects were a part of wider group of patients. Some (Wagner *et al.* 1997) focused psychiatric co-morbidity such as depression; others (Fearon *et al.* 1998) did not mention psychiatric co-morbidity, while still others (Vitaliano *et al.*1993) used depression rating scales and included depression rating scores in the analysis. Two articles (Vitaliano *et al.* 1988 – 89, and Vitaliano *et al.* 1993) were part of a series of publications from one large study, and as they focused on cross-sectional and longitudinal aspects of the same sample, they were considered together.

There were two other publications (Spruytte *et al.* 2002, Cooney *et al.* 2006) that used non-standard instruments to assess EE in their dementia carers.

These studies were extremely diverse in nature with very differing aims, objectives, materials and methods, the sample and its source, and the instruments used. It was therefore difficult to compare them against each other or even compare against EE studies in other groups of patients.

The following two tables summarise the two key aspects common to all these studies, namely the sample characteristics, and the assessment of EE. The

studies that used non-standard methods of assessment of EE are not included in the tables, although they are summarised in the text.

Table 3.1 summarises the sample size, the sample source and the criteria used for dementia diagnosis.

**Table 3.1: Sample characteristics of the studies**

| Studies ↓ | N= (Patient / carer) | Sample source | Dementia type / Criteria |
|---|---|---|---|
| Orford et al 1987 | 12 / 12 | Day hospital / centre | Senile dementia |
| Gilhooly and Whittick 1989 | 48 / 48 | Day hospitals | Senile dementia |
| Bledin et al 1990 | 20/25 (20 carer at f/u) | Day centres / CPN etc. | Alzheimer's type or multi infarct dementia |
| Vitaliano et al 1993 | 79 / 79 | Outpatient sources | AD (DSM-III-R) |
| Wagner et al 1997 | 57 / 57 | Outpatient sources | AD (NINCDS-ADRDA) |
| Fearon et al 1998 | 99 / 99 | Psychiatric services | AD (DSM-III-R) |
| Tarrier et al 2002 | 100 / 100 | Psychiatric services | AD (DSM-III-R) |
| Nomura et al 2005 | 20 + 20 / 20 + 20 | Psychiatric services / outpatients | Dementia (DSM-IV) / AD (DSM-III-R) |

Table 3.2 summarises the instrument used, criteria and cut-offs used to categorise the patients into low and high EE groups.

**Table 3.2: Assessment of Expressed Emotion**

| Studies ↓ | Instrument used | Method of assessment | High EE criteria | Inter rater reliability | Cut-off | | | | | High EE % (No / total) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | CC | Hostility (H) | EOI | War mth | PR | |
| Orford et al 1987 | CFI | Closely based on CFI interview | CC & EOI | No | 6+ & 2+ | | 3+ | | | 8 (1 /12) or 17 (2 / 12) |
| Gilhooly et al 1989 | ? CFI | Semi structured interview | CC | No | Continuous variable | | | | | ? |
| Bledin et al 1990 | CFI | CFI interview | Median CC & H | No | 4+ | 1+ | | | | 56 (14 / 25) |
| Vitaliano et al 1993 | FMSS | FMSS interview | FMSS – CC or EOI | ? | | | | | | 22 (17 / 79) |
| Wagner et al 1997 | FMSS | FMSS interview | FMSS – CC or EOI | No | | | | | | 40 (23 / 57) |
| Fearon et al 1998 | CFI | Modified CFI interview | CC, H or EOI | Yes | 6+ | 1+ | 4+ | | | 34.3 (34 / 99) |
| Tarrier et al 2002 | CFI | Modified CFI interview | CC, H or EOI | Yes | 6+ | 1+ | 3+ | | | 41 (41 / 100) |
| Nomura et al 2005 | CFI | CFI interview | CC, H or EOI | Yes | 6+ | 1+ | 3+ | | | 40 (8 / 20) in English sample & 5 (1 / 20) in Japanese sample |

The next two sections give the summary of the above studies in some details and the subsequent section summarises a critical analysis of these studies considered together.

### 3.2.1 Cross-sectional studies

#### 3.2.1.1 Orford *et al.* (1987)

The first published study was that by Orford *et al.* (1987). They sought 'to contribute to an understanding ...of the burden placed upon family members having to cope with dementia at home'. In particular, the study examined 'the relevance of two methods of assessments, for an understanding of dementia and the family.' These were: a) measures of EE, and b) the Family Interaction questionnaire (FIQ), based on the Leary's (1957) and Benjamin's (1974) schemes for coding interpersonal behaviour.

Focusing on '...the key relatives of elderly patients with dementia', the authors investigated four groups of families. The first group included 25 families containing a psychiatric patient aged between 18 and 46, and the other three groups included 12 families each, all containing a patient over 60. The patients in these three groups suffered from dementia, a functional psychiatric disorder, or a chronic physical disorder respectively.

In this study, the subgroup of patients with dementia (n = 12) ranged from 60 to 85 years in age; they had been attending a day hospital or day centre for between 1 to 3 months before inclusion into the study, and had a confirmed

diagnosis of senile dementia. They had no previous psychiatric hospitalisation for dementia and no psychiatric hospitalisation for any other reason in the last ten years. The 'key relatives' of these 12 patients consisted of 4 wives, 3 husbands, 3 daughters and 2 sisters.

The measurement of EE was based 'closely upon the previous work of the MRC Social Psychiatry Research Group...where one of us spent some time learning the procedure for administration and scoring...' The interviews were audio taped and covered '... such areas as the emergence of the problems, family relationships, time budget, impact of symptoms and the process of hospitalisation.' The authors only presented the results of the CR (critical remarks) and EOI, 'as these are the two measures that have contributed most to the overall rating of EE in previous research' (no reference given).

Using the standard cut-offs to rate high and low EE (6 or more CC and 3 or over on EOI), only one of the 12 carers of dementia was rated as high EE. The authors report that even 'if the CR criterion is relaxed to include those who expressed two or more critical remarks -....the elderly dementia and physically ill relatives group had the lowest rates of (high) EE (each 17%)'. They summarised their findings by stating that '... EE was not found to be so sensitive to interactions occurring in families with a member with dementia...'

Debating the reasons for the above findings, the authors highlighted some difficulties in rating relatives of dementia sufferers on CR (CC) and EOI. They state that although relatives of patients with dementia made frequent references

to behaviour, which they found frustrating or irritating (such as repeatedly asking questions), these were usually described in a compassionate and caring way. The authors conclude by stating that 'their comments about the patient during an interview mostly fell short of the criteria necessary for counting a critical remark.'

The authors also highlighted the difficulties they encountered in using the EOI component of the EE, 'particularly with relatives of patients with dementia.' 'The scale of EOI was originally designed for use when interviewing parents of young adult children with psychiatric disorders and may be of less relevance in the case of conditions such as dementia and in the context of relationship between older adults or between elderly parents and their adult offspring.' The authors conclude their paper by stating that 'Despite the high level of protective and controlling behaviours indicated by relatives of dementia patients on the FIQ, on interview, the exaggerated concern, unusually self-sacrificing behaviour or dramatisation necessary for rating of moderate or high EOI were rarely felt to be present. A large element of self-sacrificing behaviour was almost universal among relatives of dementia patients, and it is therefore difficult to judge whether this should be rated as emotional *over*-involvement' (italics of the authors).

Interestingly, on the FIQ in this study, the group of dementia relatives was quite distinct from the other three groups, and reported the most dominant and protective behaviours and the highest levels of hostile-dominance and the lowest levels of affection.

### 3.2.1.2 Gilhooly and Whittick (1989)

This was one of the earliest studies to investigate the link between the EE status in relatives of dementia sufferers and any adverse consequences to either the patient or the carer. Their aim was to further investigate the relationship between EE and outcome in dementia. Specifically, they expected that those caregivers expressing the greatest hostility to their dementing relative would be most likely to express a strong preference for institutional, rather than continued community care.

They recruited their sample from two Scottish day-hospitals. There were two groups of patients: a group of 24 dementia patients who each had a 'co-resident supporter', and another group of 24 dementia sufferers who each had a 'non-resident supporter'.

They interviewed the 'principal supporter' of the dementia patients using a non-standardised semi-structured interview that 'took about three to 12 hours to complete'. This interview specifically covered some areas that are not a part of the CFI. These include the supporter's physical and psychological resources and limitations.

In this study, the EE status was assessed only on the basis of the CC count. Even the description given of the criteria for rating CC did not mention 'critical tone', which is a vital aspect of the scoring of the CC. In contrast to the usual CFI criteria for differentiating between a critical comment and a hostile comment, in this study 'to be classified as critical, a comment had to show

considerable hostility directed at the dementing relative personally rather than the caregiving situation.'

The independent variables in this study were both the patient and supporter characteristics. The patient characteristics included age, sex, and three measures of the level of impairment, namely, a) a mental status questionnaire, b) ratings made by the author of the level of impairment, and c) day hospital staff ratings of the patients' functioning.

The supporter characteristics included age, sex, frequency of contact with the non-resident relatives and friends, a rating on a scale of 'social resources', satisfaction with the help from relatives, presence of a dependent child in the home, responsibility for another dependent relative, employment, and psychological well-being. The last was measured using the Kutner Morale scale and the 'mental health scale' of the OARS Multidimensional Functional Assessment Questionnaire (Duke University Centre for the Study of Ageing and Human Development 1978)

The mean numbers of CC for the whole of the interview were 12.67 (SD = 17.48), with a range from zero to 78 CC. The mean number of the CC in the first hour was 4.38 (SD = 6.02) with a range from zero to 25 CC.

The authors reported that there were significant correlations between EE and the sex of the caregiver, with the female carers being more critical of their demented relative. The levels of EE (CC) were inversely related to: a) the caregivers' psychological wellbeing, as measured by their 'morale' and 'mental

health'; b) caregivers' contacts with their friends; and c) quality of past relationship between the patient and the carer.

None of the patient characteristics, such as age, sex, levels of cognitive and physical impairment, was significantly correlated with the measures of EE.

It was also found that professional help in the form of Day hospital care, home help service, visits from a community nurse or meals-on-wheels were not significantly correlated to the measures of EE. Interestingly, and counter to their expectations, they found that those carers who were most critical of their dementing relatives were not the ones most likely to express a preference for institutional care.

### 3.2.1.3 Wagner *et al.* (1997)

A subsequent cross-sectional study (Wagner *et al.* 1997) investigated the rates of EE in family caregivers of depressed AD patients. The authors hypothesised that: a) a significant percentage of patients would evidence high EE; b) caregiver EE status should be positively related to levels of caregiver burden and depression, and to the presence and severity of patient depression and other behavioural problems; and c) caregiver EE would be unrelated to caregiver demographics, or to patient demographics, cognitive or functional status.

They recruited 57 AD patients and their primary caregivers. The subjects were chosen from two outpatient sources and were already taking part in a controlled clinical trial of a behavioural intervention for depression in AD (Teri, 1994).

The patients were included in the study if they met the NINCDS-ADRDA (McKhann *et al.*, 1984) criteria for possible or probable Alzheimer's disease, as well as DSM-III-R Criteria (APA, 1987) and Research Diagnostic Criteria (Spitzer *et al.*, 1978) for major depressive disorder. Only those patients were included who were living in the community with their caregiver, not taking anti-depressants or other psychotropic medication, were not actively suicidal and were not hallucinating or delusional.

In this study EE was assessed using the FMSS and EE ratings were given according to the criteria documented by Magana *et al.* (1986). Carer assessment included a burden inventory (Zarit *et al.*, 1980) and the Centre for Epidemiological studies – Depression Scale (CES-D; Radloff, 1977). The patient measures included the Hamilton Depression Rating Scale scores extracted from the SADS (Endicott *et al.*, 1981), and Record of Independent Living (RIL; Vitaliano *et al.*, 1984).

In this study, 23 / 57 (40%) relatives had a high EE, of which only one had high EOI. This prevalence is higher than those reported by other studies (17% to 22%) in this population. The EE of the caregiver was unrelated to caregiver age, years of education, gender or relationship to the patient.

High EE caregivers were more likely to receive a diagnosis of depression (major or minor); they rated themselves to be more burdened and they endorsed fewer positive aspects of care-giving.

The caregiver EE status was not related to the patients' demographic variables (age, years of education or gender), or to level of patient depression, cognitive functioning, functional status or behavioural problems.

### 3.2.1.4 Fearon *et al.* (1998)

In this study the role of intimacy (both current and past) as a determinant of the levels of EE was investigated in 99 carers of people who met the criteria for the primary degenerative dementia of the Alzheimer's type (DSM-III-R; APA 1987). The authors hypothesised that current intimacy (and not past intimacy) would be strongly and inversely related to levels of EE.

The subjects in this study were known to the psychiatric services, and the carers were either co-resident or visited the patient at least four times a week. The EE was assessed using an audio-taped CFI. A relative was considered high EE if she / he made six or more CC, revealed any hostility, or was rated equal to or greater than 4 on the EOI. The authors reiterated the observations of Orford *et al.* (1987), in reasoning that the higher cut-off for the EOI was needed because the nature of dementia demands a level of involvement from carers that would be inappropriate with other disorders. The intimacy was assessed by a 22-item self-report questionnaire based on that developed by Morris *et al.* (1988)

In this study, the majority of the carers (N = 56) and the patients (n = 69) were females. Sixty five (65.7%) carers were classed as low EE. Of the 34 high EE relatives, nine were rated high due to 6 or more CCs, 21 made CC and

exhibited hostility, two exhibited hostility but made no CCs, and two were rated as being high EE solely on the basis of EOI.

The high EE carers were not different from the low EE carers with regard to the carer or patient age and sex, their relationship, duration of dementia, duration of care, face-to-face contact and cohabitation variables.

They reported that current intimacy was strongly related to EE, with low current intimacy being associated with high EE. Both the current and past intimacy levels were inversely related to CC and hostility, but not to warmth ratings. In the majority of carers (68/99) the level of intimacy had reduced since the onset of dementia.

They concluded that the association between intimacy and EE indicates that high EE may be a characteristic of 'low intimacy' relationships between the carer and the cared-for-person. Since the assessment of EE is time intensive, they suggested that a measure of intimacy may provide a shorthand screen for identifying critical and hostile caring environments.

### 3.2.1.5 Tarrier *et al.* (2002)

This is another publication from the same centre as that of Fearon *et al.* (1998), describing a cross-sectional study of 100 patient-carer dyads. The aim was to investigate the strain and distress in the carers of Alzheimer's disease patients by examination of the cross-sectional relationship between four aspects of these dyads, namely: a) the EE status of the carers; b) carer strain and distress;

c) the symptoms and behaviours exhibited by the patients with Alzheimer's disease; and d) the carers' beliefs about these symptoms and behaviour.

They assessed the EE using the modified CFI. They categorised the EE status on the basis of the traditional criteria; i.e. 6 or more CC or any hostility or a global rating of 3 or more on the EOI.

They assessed the attributions by extracting causal attributions made by the carer during the CFI and coding them using a version of Leeds Attributional Coding System (LACS: Stratton *et al.*, 1988). Carer well-being was assessed by measuring a) carer strain (Gilleard Strain Scale (GSS), Gilleard 1984) and b) the distress (the General Health Questionnaire – 28 items version (GHQ-28), Goldberg & Williams 1988). Global severity of dementia was assessed using the Clinical Dementia Rating (CDR; Hughes *et al.* 1982). Cognitive levels were assessed using the Mini Mental State Examination (Folstein, *et al.* 1975), and non-cognitive symptoms were assessed using the Manchester and Oxford University Scale for Psychopathological Assessment in Dementia (MOUSEPAD; Allen *et al.* 1996). They also measured the salivary cortisol of 95 / 100 carers over a 3-day period, and obtained average levels and changes over the time of the day (from morning at 9.00am to night at 11.00pm).

Forty-one of the 100 carers were rated as high EE. Of these, eight were rated high EE on CC alone; two on hostility alone; eight on EOI alone; 18 on CC and hostility; two on CC and EOI; and three on CC hostility and EOI. The mean number of CC was 3.7 (SD = 3.5), with 23% exhibiting hostility.

High EE status was not related to the global severity of dementia, cognitive impairment or ADL. High EE status was individually related to the behavioural disturbances, psychotic symptoms and depression.

High EE status was also associated with higher scores of carer distress and strain. It was not associated with high salivary cortisol levels in the carers.

There was no difference between high and low EE carers on the actual numbers of the attributions made by them. However, the high EE carers made more attributions personal to, and controllable by, the patient for negative events. Critical carers made more attributions of the patients' behaviour that was idiosyncratic. Warmth toward the patient was associated with the opposite of this pattern. Over-involved carers made attributions of the patient's behaviour to causes external to the patient and internal to themselves. Cortisol levels were associated with self-reports of strain and distress.

### 3.2.1.6 Nomura *et al.* (2005)

This is the most recent publication to focus on EE in dementia carers, and the first study of EE in dementia carers in Japan. In this cross-sectional study, they compared the EE of the carers of patients with dementia and schizophrenia in England and Japan. They had 20 in each of the four sets of the study sample, i.e. England Schizophrenia; England Dementia; Japan Schizophrenia; and Japan Dementia.

In this study they used the CFI and found that only the Japan Dementia sample had a significant correlation between the EE status and the level of burden. The authors describe the significant variation between the two sets of dementia samples (both the patients and the carers), differences in the instruments used and their standardisation and the language and cultural differences across the two sites as the possible confounders.

Commenting on the operational cut-off for classifying high and low EE on CFI, they stated, "In the study of dementia, there has been an ongoing process of acquiring a convincing and satisfactory CC cut-off." They added that if the CC cut-off in this study sample was reduced to 2 or more CC to classify high EE, the EE correlated significantly with cognitive impairment as well as clinical severity in the Japan Dementia sample.

### 3.2.1.7 Other studies

The literature search identified two other studies that have reported an association of EE in carers of dementia sufferers. Both of these studies used non-standard instruments to assess components of EE.

Cooney *et al.* (2006) interviewed 82 carers of dementia patients, recruited through a dementia register and through a Community Support Team (a specialist dementia service) in the Camberwell area of South London, with a view to 'examine the prevalence of elder abuse of dementia sufferers by their carers and to explore associations between abuse and patient factors, carer factors and aspects of the caring situation, in order to try and identify risk

factors...' They used the Patient Rejection Scale (PRS; Kreisman *et al.* 1979) as a measure of EE, because 'this measure overlaps with the hostility and critical comment aspects of the EE construct'.

They found that 43 (52%) carers admitted to having carried out some form of abuse. Carers who admitted to the abuse of the patients had significantly higher mean scores on PRS than those who did not, suggesting that high EE is correlated with all forms of abuse (physical, verbal and neglect).

Spruytte *et al.* (2002) interviewed 177 carers of patients with dementia recruited from 19 randomly selected teams of community nursing care services in Belgium. The aim of this study was 'to explore and compare the quality of the carer-patient relationship in... caregiving relatives of older adults with dementia and caregiving relatives of persons suffering from chronic mental illness'... and 'to identify the determinants of carer-patient relationship quality.'

They used the Perceived Criticism Scale (PCS; Hooley and Teasdale, 1989) to assess levels of criticism, and developed a quality of carer-patient relationship (QCPR) scale to assess 'warmth, conflict and critique'. They found that the disturbances in the patients' behaviour as well as the carers' perception of these behaviours were significantly related to the perceived criticism.

### 3.2.2 Follow-up studies

#### 3.2.2.1 Bledin *et al.* 1990

This is a study investigating the Expressed Emotion of the daughters of 25 people with dementia. The patients had 'Alzheimer's type or multi-infarct dementia' and the 'women (daughters) were known to the services and / or had been in contact with one or more self-help groups...' This was also the first follow-up study to report on the nine-month outcome of these patients.

The authors of this study based their arguments on the premise that 'to the extent that EE measures reflect usual patterns of family interactions, they may be a valuable source of information about the relationship between, the carer and the demented dependent, as well as about how families cope with the care of an elderly person.' They postulated that low-EE relatives may cope more effectively with the objective stress of caring, and as a result experience less subjective strain and distress. Thus, they may be able to maintain the elderly person in the community for longer.

Extending this argument further, they speculated that psychosocial interventions aimed at reducing EE in high-EE families of schizophrenia subjects (Leff *et al.* 1982, Tarrier *et al.* 1988) might then be helpfully employed in improving coping and / or reducing strain and distress, and possibly in promoting continuing community care in the patients with high EE carers.

The authors used a brief version of the CFI to assess the EE status of the daughters of these patients. An experienced and trained researcher rated the interviews to determine levels of EE. High EE was considered to be present in all those carers who had any hostility or who scored median numbers or more CC.

These two groups were then compared on a number of measures relating to the patients and the carers. Patient measures included Behaviour and Mood Disturbance scale (BMD; Greene *et al.* 1982), Behaviour Rating Scale (BRS) and the cognitive assessment scale of the Clifton Assessment Procedure for the Elderly (CAPE; Pattie and Gilleard 1979). Carer measures included a measure of the coping strategies (MacCarthy and Brown 1989), the Relatives' Stress Scale (RSS, Greene *et al.* 1982), the thirty-item General Health Questionnaire (GHQ; Goldberg 1978) and a BMD stress scale (Woods *et al.* personal communication to the authors, 1987)

These carers were followed-up *via* either telephone or postal questionnaire nine months after the baseline assessment. The main focus of the follow-up was to ascertain whether or not their status as the primary carer had changed.

The main findings of this study included the observation that the median CC score was 4, and on that basis, 14 of the 25 daughters were classed as having high EE. Nine of the daughters were rated more than zero on the 'hostility' scale. All of these nine had made four or more CC, and hence were already included in the high EE group.

They also found that EOI was either absent or low in this sample, with only nine daughters (36%) scoring greater than zero on the EOI scale. The EOI scale was therefore not included in further analysis. Interestingly, no subject was given the highest 'warmth' score and about half the sample made no 'positive remark'.

The high EE status was associated with higher levels of strain (RSS), distress (GHQ), and a higher score on the maladaptive coping strategies. High EE subjects more frequently had no siblings, and were more likely to have had a respite break from caring. Those who made fewer critical comments (low EE) and more positive remarks had more efficient coping strategies. In this study the EE status was not associated with the levels of their parents' cognitive impairment at the baseline.

Although the sample was small and the mortality in this sample was high (20% died at nine month; 3 / 11 from the low EE group, 2 / 14 from the high EE group), it was noted that the EE status was also not predictive of care recipients' cognitive or functional decline or continuing care in the community at a nine-month follow-up. However, high EE was predictive of increased negative behaviour over this period.

### 3.2.4 Vitaliano *et al.* (1988/89) and Vitaliano *et al.* (1993)

Vitaliano *et al.* (1993) have published the second follow-up study on this subject. They attempted to answer the question 'Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's

disease?' They hypothesised that initial ratings of caregiver EE would be predictive of the negative care recipient behaviours, whereas care recipient cognitive / ADL functioning would not.

The subjects were recruited from the general community in western Washington State. They included 79 patients who lived with a spousal caregiver and who met both the DSM-III-R (American Psychiatric Association 1987) and NINCDS-ADRDA (McKhann *et al.* 1984) criteria for a diagnosis of primary degenerative dementia. They were assessed at baseline and then after 15 to 18 months. All the baseline assessments were repeated at follow-up.

The EE was assessed using FMSS. Also assessed were: the carers' depressive symptoms (Beck Depressive Inventory – Beck & Beck 1972); anger (Spielberger Anger Expression Scale - Spielberger *et al.* 1985); and Life satisfaction (The Satisfaction With Life Scale – Diener *et al.* 1985).

Patients were assessed for their cognitive function (MMSE - Folstein *et al.* 1975); activities of daily living (The Record of Independent Living – Vitaliano *et al.* 1984); depressive symptoms (Hamilton Depressive rating Scale – Hamilton 1960); and 'negative behaviours' (Negative Care Recipient Behaviours – Vitaliano *et al.* 1991).

The mean age of the patients and the carers was 70.9 (SD = 6.9) and 67.2 (SD = 7.4) years respectively. Sixty-eight percent of patients were males.

Fifteen carers were classed as high-EE-critical and another two were rated high in Emotional over-involvement. As the EOI contributed very little to high EE in this study, they dropped these two cases from further analysis. The high EE status of the carers was reported to be mostly stable over the follow-up period, with only six carers' EE status changing between the two assessments. Only the baseline EE status was used as predictor.

The high EE care givers were more depressed, they scored higher on the measures of suppressed anger, and they were less satisfied with life. These differences were noted both at the baseline and follow-up. The patients living with high EE care givers displayed more negative behaviour both at the baseline and follow-up. The worsening of negative behaviour from baseline to follow-up assessment was more for patients with high EE caregivers.

Patients' cognitive functions, ADL skills and depression scores did not differ between the two groups, at baseline or follow-up.

## 3.3 Discussion

In this section, I will summarise the findings of the above studies and the critically discuss their implications before proposing the rationale for the present study.

### 3.3.1 Correlations of EE in families of dementia sufferers

The main findings from above studies can be summarised as follows:

- Caregiver (high) EE has been significantly related to:

- The negative behaviour and excess of non-cognitive symptoms in dementia patients, as reported by the carers;
- Caregivers' (female) gender, (poor) psychological well-being, inefficient coping strategies, fewer positive remarks for the patients, depression, burden, strain and distress, (less) contacts with friends, absence of a sibling for the carer or carer (and the patient) having had more respite breaks, carers making more personal, controllable and idiosyncratic attributions for the patients' (negative) behaviours;
- Quality of relationship between the patient and the carer, (inversely related to) current and past intimacy levels between the patient and the carer, low warmth and carer endorsing fewer positive aspects of the care giving.

- Caregiver (High) EE has been unrelated to:
  - Patient age, gender, education, ethnicity;
  - Patients' level of cognitive impairment, functional impairment, and severity of dementia, rates of decline of the behavioural or cognitive functions over nine-months, presence or severity of depression, memory & problem behaviours;
  - Carers' age, education, gender, ethnicity, relationship to the patient, severity of (but not the presence of) carer depression;
  - Carers' wish for the institutional care for the patient, or patients' continuing care in the community over a nine-month period.

EE has generally not been found to be correlated with the patients' demographic variables, severity of dementia, levels of cognitive and functional impairment or the rates of decline of the dementia.

The factors that most consistently seem to be associated with (high) EE are those related to the qualitative aspect of their relationship. Thus, the quality of the relationship, the (lack of) warmth, the intimacy and the expressed attributes of the patient behaviour are the better correlates of the EE status of the carers.

The caregiver's psychological status, presence of depression, strain, and distress are some of the other factors that are related to the caregiver EE.

The relationship of the formal services received by the patients and the carers, and the carers' EE status, has not been thoroughly studied. The limited evidence suggests that except for the more respite care and high EE, they are unrelated.

The two follow-up studies suggest that the high EE in the carers affect the stress levels of the carers and negative behaviour of the patients. Change in patients' domicile status in the first study was similar in both high and low EE groups. Vitaliano *et al.* (1993) do not state how many subjects continued to stay with their spouse at follow-up. Table 3.1 compares the two longitudinal studies on a number of study parameters.

**Table 3.3 – Comparison of the two longitudinal studies on the influence of carers' EE on the course and outcome of dementia subjects**

| **Studies →**<br>**Features ↓** | **Bledin *et al.* 1990** | **Vitaliano *et al.* 1993** |
|---|---|---|
| Sample size | 25 baseline; 24 at follow-up | 79 (77) baseline; follow-up numbers not stated |
| Sample source | Day centres and CPNs | General community |
| Patient diagnosis | "Alzheimer-type or Multi-infarct" dementia | Primary degenerative dementia |
| Diagnostic criteria | None specified | DSM-III-R |
| Duration of dementia | 4.7 (SD = 2.9) years | 4.3 (SD = 2.1) years |
| Patient Age in years | Mean 82.4 (SD 6.1) | Mean 70.9 (SD = 6.9) |
| Patient gender | 21 females, 4 males | 25 females, 54 males[1] |
| Cognition / MMSE | Not stated | MMSE 20.5 (SD = 5) |
| Living situation | 3 (of 25) did not live with their daughters | All lived with the spousal caregiver |
| Carer relations | Daughter | Spouse |
| Carer gender | All females | Not stated[2] |
| Carer age range | 35 to 62 years | 67.2 (SD = 7.4) years |
| Carer contact with the patient | 55.9 (SD 26.2) hours/week | Not stated but co-residents |
| EE instrument | Brief CFI | FMSS |
| High EE criterion | Median CC score of 4 or more | CC & Hostility |
| Percentage high EE | 56 (14 / 25) | 22 (15 / 77) |
| Length of follow-up | Nine months | 15 to 18 month |
| Nature of follow-up | Telephone interview or postal questionnaire | Face-to-face interview |
| High EE found to be related to - | Higher strain & stress, Less efficient coping, having no siblings, having had a respite break. | Caregiver depression, life satisfaction, suppressed anger.<br>Negative patient behaviour. |
| High EE found to be unrelated to - | Residential care at 9-months | Cognitive and ADL decline |

[1] Calculated from the percentage figures.
[2] Can be guessed from the gender of the patients.

### 3.3.2 Critical appraisal

It is evident from the above summaries that the literature does not yet allow any firm conclusions to be drawn regarding the relationship between EE in dementia caregivers and the course or outcome of the illness. The evidence so far supports a 'lack of association' between the carers EE and outcomes, and supports an association with behavioural disturbances in the patient.

#### 3.3.2.1 Cross-sectional studies

- *Number of studies and sample sizes*: There are very few cross-sectional studies published in the literature. Some of the earlier studies had very small numbers of subjects (Orford *et al.* 1987), and the methods for diagnosis of dementia were either not specified (Orford *et al.* 1987, Gilhooly *et al.* 1989) or loosely defined (Bledin *et al.* 1990). The more recent publications (Fearon *et al.* 1997, Tarrier *et al.* 2002) have used larger sample sizes and have more rigorously defined patient populations.

  Although it is difficult to be precise, the total number of subjects assessed in these nine publications (both cross-sectional and follow-up studies included) is 341. Two sets of publications (Vitaliano *et al.* 1988/89 and Vitaliano *et al.* 1993 Fearon *et al.* 1998 and Tarrier *et al.* 2002) seem to share their number of subjects and their authors, as well as the study centre. Hence, for the purpose of this review, these publications are considered together to avoid double-counting. The large number of independent variables compared with EE on a relatively small number of subjects

increases the probability of type-1 statistical errors, i.e. presuming an association is significant when it occurs only by chance.

As most of the studies were exploratory in nature, no power calculations were given for the determining the sample size.

- *Differences in the source and nature of the samples*: Perhaps unavoidably, all of the studies have used a sample of convenience. For most of them it is not known how many of the potential subjects had declined to participate and it is not known whether those who agreed to participate are representative of the much larger and more diverse population to which these findings are potentially generalisable. It can be inferred from Williams *et al.* (1988) that less than one in nine subjects who were approached took part in the study reported by Vitaliano *et al.* (1993). The sources of the sample have typically been psychiatric or geriatric day centres / hospitals (Orford *et al.* 1987, Gillhooly *et al.* 1989, Bledin *et al.* 1990), those known to CPNs (Community Psychiatric Nurses), or psychiatric services (Bledin *et al.* 1990, Fearon *et al.* 1998, Tarrier *et al.* 2002), outpatient sources (Wagner *et al.* 1997) or even non-clinical samples (Vitaliano *et al.* 1993).

- *Differences in the assessment methods for the EE and other variables*: In most of the studies, the assessment of EE has been based on the CFI (Orford *et al.* 1997, Bledin *et al.* 1990, Fearon *et al.* 1998, Tarrier *et al.* 2002, Nomura *et al.* 2005), FMSS (Vitaliano *et al.* 1993, Wagner *et al.*

1997), or a non-standardised semi-structured interview based on the CFI (Gilhooly & Whittick 1989). Some other instruments such as PRS (Cooney *et al.* 2006) and PCS (Spruytte et al 2002) have also been used, based on their conceptual overlap and association with EE. Where there are differences in the instrument used, any comparisons are very difficult.

Other patient and carer variables have also been assessed using a range of different instruments. These include:

a. Severity of dementia / cognitive impairment – Mental Status Questionnaire and Post's clinical sensorium (Gilhooly and Whittick 1989), Mini Mental State Examination (Wagner *et al.* 1998), Clinical Dementia Rating (Tarrier *et al.* 2002), Cognitive assessment scale of the Clifton Assessment Procedure for the Elderly (CAS-CAPE) (Bledin *et al.* 1990).
b. Activities of daily living - Instrumental Activities of Daily Living, Physical self-maintenance scale (Gilhooly and Whittick 1989), Record of Independent Living (Wagner *et al.* 1998).
c. Non-cognitive symptoms - Modified Crichton Royal Behaviour Rating Scales (Gilhooly and Whittick 1989), Behaviour and Mood Disturbance Scale, Behavioural Rating Scale – CAPE (Bledin *et al.* 1990), Revised Memory and Behaviour Problem Checklist, and centre for Epidemiology – depression scale (CES-D) (Wagner *et al.*1998), Manchester & Oxford University Scale for Evaluation of

Psychopathology in Alzheimer's disease (MOUSEPAD) (Tarrier *et al.* 2002), Neuro-psychiatric Inventory (NPI) (Nomura *et al.* 2005).

d. Strain / burden – Gilleard Strain Scale (Tarrier *et al.* 2002), Relative Stress Scale, and Behaviour and Mood Disturbance -Stress scale (Bledin *et al.* 1990), Zarit's Burden Inventory (Wagner *et al.* 1998).
e. Distress / general health - GHQ-28 (Tarrier *et al.* 2002), GHQ-30 (Bledin *et al.* 1990).

The differences in the tools used for these assessments may partly reflect the fact that there is no 'gold standard' instrument to measure some of these variables. The choice of instrument may also depend on the location and research interests of the groups conducting these studies. This may be justified on the basis that locally developed tools are likely to have been validated on the local population and so be more useful. However, the use of different instruments limits the comparisons that can be made between studies; it may be that this is a significant factor accounting for the differences in the findings.

- *Criteria used to classify EE status*: Even in those studies that have used a standardised assessment method for assessing EE (such as CFI or FMSS), there are variations both in the subscales of EE included in overall assessment of EE status, and the cut-off used to categorise the EE status into high and low.

Only three studies included all three components (CC, H, and EOI) of EE in judging the EE-index of the subjects (Fearon *et al.* 1998, Tarrier *et al.* 2002,

Nomura *et al.* 2005). The others used CC count alone (Gilhooley and Whittick 1989); CC count and H (Bledin *et al.* 1990); or else CC count and EOI (Orford *et al.* 1987) as the measure of the EE-index.

Critical comments have been the most consistently used measure of EE status across the studies. Hostility has been also used in a number of studies. In one (Gilhooly and Whittick 1989), it appears that the definition of CC was more akin to the presence of Hostility. Interestingly, very few of the cases in these studies have been rated as High EE solely on the basis of hostility. None of the high EE subjects of Bledin *et al.* (1990) were rated on hostility alone; only two of the 34 high EE subjects in the study by Fearon *et al.* (1998) had hostility ratings alone; and only two of the 41 high EE subjects of Tarrier *et al.* (2002) were so rated only on the basis of hostility. It can therefore be argued that inclusion of hostility in the EE rating may not be materially significant.

It appears that the concept and use of EOI as a marker of EE in the context of dementia care has not been adequately resolved. It has been stated that the 'EOI component of EE... is.... difficult to employ with relatives of elderly patients... with dementia' (Orford *et al.* 1987). On one hand, patients with high EOI carers have been excluded from analysis (Vitaliano *et al.* 1993); on the other, Fearon *et al.* (1998) have used the same argument to justify increasing the threshold cut-off of the EOI subscale from 3 to 4, due to 'the fact that the nature of dementia demands a level of involvement from carers that would be inappropriate with other disorders.'

There is a risk that EOI may get severely underestimated, due both to the higher levels of 'normal involvement' expected from these carers, and also the higher setting of the threshold that may doubly jeopardise the distinct recognition of the 'over' involvement from the 'normal' involvement.

Summarising EE research in dementia and commenting on the differences between the chosen outcome measurements for dementia EE research and that of schizophrenia EE research, Wearden *et al.* (2000) state that due to the differences in the nature and course of dementia, researchers have not focused on the course and outcome of AD. The focus is more on the association between EE and a variety of patient and caregiver variables such as strain and burden. 'The most reliable findings have been that the majority of caregivers are classified as low EE, that when they are high EE this is almost always on the basis of critical attitude rather than high EOI...'

### 3.3.2.2 Follow-up studies

Bledin *et al.* (1990) are credited with the first follow-up study on this subject. Their study is of interest due to its focus exclusively on the daughters of dementia sufferers. Small sample size however limits generalisability of the findings. By loosely grouping "Alzheimer's type or multi-infarct dementia", the natural variability of the course of the dementia becomes a significant confounding factor, and may mask any effects of EE.

The categorisation of EE based on the median CC count cut-off (as well as the decision to include three carers with 'median' scores in the high EE category)

is different from any other 'EE and dementia' study before or since. This is clearly not the standard approach, although it highlights the unease with use of the standard criteria which were developed from, and for, those suffering from schizophrenia. This unease may be due either to conceptual difficulty with the standard criteria, or more often the practical problem of very low prevalence of (high) EE if traditional criteria are used. This problem is encountered in a number of non-schizophrenic conditions.

There was a significant mortality over nine-months in this study due partly to the subjects being older.

Subjects for the Vitaliano *et al.* (1993) study were recruited initially as a part of another study investigating sleep disturbances and EEG changes in early AD (Williams *et al.* 1988). The sample was recruited from the general community, and recruitment involved advertisements in that community and referrals from other researchers. The sample size was larger than that of Bledin *et al.* (1990), and the inclusion criteria were clear and standardised. The study had clear aims and the methodology was appropriate for the aims. They used the FMSS interview and the standard criteria to allocate EE status. In contrast to the first study, the prevalence of (high) EE was much lower. They also excluded two cases that had high EE solely based on EOI. Other than the small number of carers who had high EE due to EOI only, no other reason for this exclusion was offered.

Given that the main outcome measures for this study were the changes in cognition, ADL skills and behavioural disturbance, the gap of 15 to 18 months between the initial assessment and the follow-up may have been too long. It is known that the non-cognitive symptoms in dementia fluctuate (Wobrock *et al.* 2003) and a shorter follow-up would have been desirable. The focus on problems with cognition, ADLs and negative behaviour are important, but translating statistical significance into clinical significance is a major challenge that this study was unable to deal with. Perhaps due to the nature of the sample (non–clinical), the service outcome measures could not be investigated.

Overall, this study was able to answer the questions that it set out to answer, but generalisability is limited due to the non-clinical nature of the sample and non inclusion of some of the clinically relevant course and outcome measures, such as use of services, including respite services and domicile changes.

#### 3.3.2.3 Overall appraisal

As the psychosocial construct of EE and its assessment in its original form (CFI) is complex and time intensive, researchers have attempted to identify and understand the factors that may underlie the development and maintenance of high EE. A number of other psychosocial constructs have been found to be related to EE and have been summarised in Chapter 2.7. It has been suggested that constructs such as intimacy levels, can be used as shorthand to identify hostile and critical environments in the families (Fearon *et al.* 1998). So far, however, attempts to find robust constructs with similar predictive power to EE

has eluded researchers, and CFI still is considered as the 'gold standard' method of assessing EE, and has a number of advantages over FMSS.

The clinical meaningfulness of the concept of EE partly comes from its predictive power regarding the course and outcome of schizophrenia and a number of other psychiatric and physical disorders. The popularity of the concept of EE comes partly from the fact that not only is it one of the robust psychosocial constructs with predictive power, but also that it provides therapeutic options which can be implemented in the majority of healthcare settings with a beneficial effect on outcomes.

Although AD is very different to schizophrenia, and concepts of remission and relapse may not apply in a similar fashion, there are at least two reasons why this issue needs to be investigated more systematically.

Firstly, there are no *a priori* reasons to conclude that the influence of EE is limited to only remitting and relapsing disorders. It is hard to conceptualise why such might be the case. Research in disorders like arthritis and Parkinson's disease suggest a potential role for EE in influencing their course and outcome.

Secondly, non-cognitive symptoms in AD are not necessarily progressive. They tend to fluctuate (Wobrock *et al.* 2003), and cause hospitalisation or institutionalization (Yaffe *et al.* 2002). Research suggests that non-cognitive symptoms and carer EE are correlated in AD, so it is possible that interventions to reduce carers' EE may reduce the risk of patient institutionalisation, hospitalisation or even survival.

## 3.4 Limitations of the literature review

This literature review, although extensive, can not be presumed to be exhaustive. The search strategy is summarised in the earlier section (Chapter 3.1). Regarding publication bias, it is possible (even likely) that there may be unpublished research in this field. Such work would be more likely to show an absence of significant relationship between EE and the course or outcome of dementia.

It was rather surprising that after the initial publications between 1987 and 1993, the research in this field has not been more extensive. The 1990s was the 'Decade of brain', and this may have contributed to the relative neglect of psychosocial research in an organic condition such as AD.

## 3.5 Conclusions of literature review, and rationale for the study

The main conclusion from this review is that the influence of EE on the course and outcome of AD has not been adequately studied.

The limitations of the literature are:

- Very few longitudinal studies;
- Significant heterogeneity of the sample;
- Different instruments used to assess EE;
- Differences in the rating of EE status;

- Small sample sizes;
- Varying nature of the follow-up assessment.

Limitations apart, the literature suggests that high carer EE is associated with non-cognitive symptoms of dementia, female carers, carers with poor support, coping and psychological well being, and (poor) quality of relationship between the patient and the carer. High EE is not related to the demographic characteristics of the patients or the carers.

High carer EE is associated with increase in patients' negative behaviour over 15 to 18 months, but not with the institutionalisation risk or survival over a nine-month follow-up.

The aim of the present study was to prospectively investigate the influence of the carers EE on the course and 12-month outcome of patients with a diagnosis of mild to moderate severity of Alzheimer's disease. The specific objectives were to prospectively investigate the influence of the carers' baseline EE on: a) the risk of survival and institutionalisation over a twelve-month period; and b) use of formal services from health and social services.

# Chapter Four

# Materials and Methods

## 4.1 Aims and Objectives

The principal aim of this study is to investigate the influence of the informal carer's Expressed Emotion (EE) on the course and twelve-month outcome of patients with Alzheimer's disease.

This overarching aim was divided into specific objectives. These were to investigate the influence of carers' baseline EE on:

- The likelihood of 'change in domicile', due to either death or permanent institutionalisation, of the patients over the twelve-month follow-up;
- The use of health and social service resources by the patient-carer dyad, over the twelve-month follow-up.

In selecting the measures of course and outcome, we chose those which were clinically relevant, had direct service implications, and those which were economic on the time of the researcher, i.e. those measures of course and outcome were preferred which could be accurately ascertained without a face-to-face follow-up, without compromising the meaningfulness of the measures.

## 4.2 Study design

This was a prospective one-year follow-up study of a selected cohort of patient-carer dyads. The follow-up assessments were done at six- and twelve-months after the baseline assessment.

### 4.2.1 Sample size

We estimated the number of subjects needed for inclusion in the study, to ensure acceptable power and confidence. The primary outcome of interest was the 'change in domicile' of the AD patients at the end of 12 months from baseline assessment. This was a dichotomous variable, i.e. at the end of 12 months, the patient was either continuing to stay in the community or she / he was not (either because she / he had gone into an institutional care or had died).

The target population for inclusion in the study were those suffering from mild to moderate AD who were receiving treatment from the local old age psychiatry services. The proportion of these patients, likely to experience a 'change in domicile' over the twelve months is not known, as the available literature on the risk of dying and risk of institutionalisation of the relatively newly diagnosed AD patients is limited.

It has been reported that the annual mortality rate in AD subjects is around 10% (Larson *et al.* 2004), and roughly 10% of the patients may go to live in an institutional setting (Courtney *et al.* 2004) *per annum*. If the above two figures are mutually exclusive, then we can expect that a total of 20% of the patients

will experience a 'change in domicile' over a 12-month follow-up. However, the two figures are unlikely to be mutually exclusive, as some of those who are institutionalised are also likely to die within the year. For the purpose of this study, we made the following assumptions.

- The annual rate of 'change of domicile' in the sample will be 15%;
- Roughly half the carers will have high EE;
- A difference of 20% in the rates of 'change in domicile', between high and low EE patients will be considered significant.

For a power of 80% (0.8) and a level of significance at 0.05, we used the following formula to calculate the sample size (Campbell & Machin 1990, p 169):

$$n = (Z_\alpha + Z_{2\beta})^2 \{\pi_1 (1 - \pi_1) + \pi_2 (1 - \pi_2)\} / \delta^2$$

$$n = 7.849 \times \{(0.05 \times 0.95) + (0.25 \times 0.75)\} / 0.02^2$$

**n = 46.11**

Therefore, a minimum of 47 subjects are required in each of the high and the low EE group to allow this study to identify a 20% difference (5% and 25% in low and high EE groups respectively) in the rates of outcome, with a significance level of 0.05 and a power of 80%.

### 4.2.2 Sample selection

We selected the sample from those patients referred to the specialist Mental Health Services for the Older People (MHSOP) of the Leicestershire Partnership NHS Trust (LPT). LPT serves the population of around one million in Leicester, Leicestershire and Rutland. Roughly 150,000 of these are currently estimated to be over the age of 64 years. The MHSOP provides comprehensive services to all new patients age 65 years or over, who present with a mental health problem. It also serves younger patients with a diagnosis of dementia.

Of those who were referred to, and were receiving input from the MHSOP, we considered for the recruitment into the study, those subjects who met the following criteria:

**For inclusion**

- A clinical diagnosis of dementia of Alzheimer's type of mild to moderate severity, made by an old age psychiatrist (consultant psychiatrist or a senior psychiatrist in the MHSOP), and receiving treatment with an acetylcholine esterase inhibitor drug (ChEI). We excluded those patients who had a diagnosis of mild to moderate AD, but were not receiving a ChEI, in order to control for the exposure to treatment which might alter the nature and the course of dementia over the follow-up period;

- Having a non-institutional domicile;

- Availability of an informal (unpaid) carer. The carer had to either live with the patient or have regular (at least once a week) contact with the patient;

- Carer being fluent in spoken English;

- Carer willing to give informed written consent and the patient able to either give an informed consent, or if lacking in mental capacity to give such consent, at least agree to participate in the study.

**For exclusion**

- Those patients who were eligible but not treated with a ChEI, due to their refusing the medication; experiencing side effects leading to early discontinuation of the medication; and the psychiatrist, the patient or / and the family unwilling to start the treatment due to potential risk / cautions related to these medications.

Of those patients with mixed dementia (Vascular and Alzheimer's type), we included those who were considered suitable for, and were judged to be benefiting from, ChEI treatment by their treating clinician. We did not systematically assess for co-existence of vascular dementia.

## 4.3 Assessment tools

The primary focus of interest in this study is how expressed emotion in (and of) the informal carers influences the course and 12-month outcome of the patients with Alzheimer's disease. The key variables to be measured were therefore:

- Carers' expressed emotion;
- Course of the illness (Alzheimer's disease); and
- Twelve-month outcome of the patients.

### 4.3.1 Expressed emotion

Although a large number of assessment scales / instruments have been published, that claim to assess EE or a variation of it, the two instruments that are most widely used for the assessment of EE are the Camberwell Family Instrument (CFI) and the Five minute sample of speech (FMSS). A recent review (Von Humbeeck *et al.* 2002) compares CFI and eleven other measures of EE, and concludes that 'CFI remains the best instrument for assessing the quality of the relationship.' CFI is also the most widely used instrument for measuring EE in carers of dementia subjects.

In this study, an adapted version of the CFI has been used. The questions and the interview in the original CFI cover the following areas:

- The background information: Composition of household and employment details.
- Psychiatric history.
- Family time budget.
- Nagging, irritability and quarrelling.
- Clinical symptoms: current episode.
- Household tasks / money matters.
- Relationship between the informant and the patient.
- Parents' marital relationship (if two-parent household).
- Medication.
- Attitude to illness.

The changes to the CFI for use in carers of dementia sufferers have been described by Tarrier *et al.* (2002) and include the following:

- Initial questions consisting of household composition and a section on the patient's medical history, rather than psychiatric history;
- Replacement of the CFI section on the current episode with a section on illness course, because dementia is a progressive and not an episodic illness;

- Exclusion of symptoms that were not relevant to dementia (e.g. the section on street drugs);

- Inclusion of symptoms specific to dementia (e.g. wandering);

- More emphasis on the key features of dementia (e.g. memory loss).

### 4.3.2 Course of the illness

Alzheimer's disease is a progressive condition. However, the symptoms and difficulties fluctuate over a period of time. These fluctuations can be both brief (hourly or daily fluctuations) and medium term (few days to few weeks). They can occur in both the cognitive and non-cognitive domains. A large number of factors influence their occurrence and severity.

In order to identify and measure these fluctuations, a much more intense monitoring and follow-up assessment would have been required, which would have been impractical.

Formal help received by the patients could in part be dependent on these fluctuations, and we used this as a proxy of fluctuations in the overall course of the illness. We recorded the following information on service use in the preceding six months, both at the baseline and at the follow-ups: Home care; Day care; Respite care; CPN visits; GP visits; and Hospital admissions (number and durations) (See Appendix 9.8)

We also assessed cognitive function, non-cognitive symptoms, functional ability, and physical health of the patient; and the carers' stress and general health, as indicators of the course of the illness and its impact on the carer.

### 4.3.3 Outcome

The primary outcome of interest in this study is the permanent institutionalisation or the death of the patient within twelve months of the baseline assessment. The secondary outcome of interest in this study is the use of formal services by the patients and their carers over the twelve-month follow-up.

*The primary outcomes*: The progression of AD means that the patient requires an increasingly supportive environment. With the improvements in the community care services and increasing use of technology for assisted living, it has been possible to care of more and more impaired patients in their own homes or in non-institutional settings. Even then, as many as 90% of patients may need placement in residential / nursing homes before their death (Smith *et al.* 2000).

A number of studies have attempted to identify risk factors for nursing home placement, or institutionalization in patients with cognitive impairment, dementia or AD (Andel *et al.* 2007, Brodaty *et al.* 2007, Coehlo *et al.* 2007, Becker *et al.* 2006, Rozzini *et al.* 2006, Chan *et al.* 2003, de Vugt *et al.* 2005, Dorenlot *et al.* 2005, Gaugler *et al.* 2005, Phillips and Diwan 2003, Wancata *et*

*al.* 2003, Yaffe *et al.* 2002, Pot 2000, Smith *et al.* 2000, Spruytte *et al.* 2001, Mittelman *et al.* 1996, Brodaty *et al.* 1993).

The majority of these studies are from the US, and are based on the data gathered from the Medicaid / Medicare / health insurance programmes. The follow–up period of these studies ranges from one to five years. The institutionalization rates were between 10 to 90 % of the subjects. As institutionalization is largely dependent on the availability and sources of funding for the placement, it is difficult to generalise the US findings to UK settings.

The above studies found a number of factors associated with the risk of institutionalisation and death in patients with dementia. These factors include patient variables, illness variables, carer variables or the interpersonal relationship variables, but the effect of the carers' EE on this risk of institutionalisation or risk of dying has not been studied.

For the purpose of the present study, the baseline sample consisted of patients residing in non-institutional settings, mostly their homes or their children's home. At baseline those patients who were waiting to change their domicile to a residential setting (i.e. those patients for whom such a decision had been made and they were waiting for an appropriate vacancy) were excluded.

The measurement of the outcome was dichotomised as institutional / non-institutional. We recorded whether the patient had continued to stay in a non-institutional setting at the six- and twelve-month follow-up. Change in domicile

could be due either to the fact that the patient had died or that they had moved to residential or nursing home with 24-hour care available to them. Any change in address to another non-institutional setting is not considered as an institutional outcome.

*The secondary outcomes*: The formal 'help' received by the subjects included a range of health and social care inputs, such as home care and mobile meals; attendance at the day centre, lunch clubs, coffee mornings; visits by the doctors, nurses, psychologists, occupational therapists, social workers, volunteers and hospital / respite admissions. The analyses of each of these items of 'help' separately was thought to be meaningless, due to the very diverse nature of the help the subjects were receiving, and due to the fact that only a very small number of subjects were receiving a given type of help at any given period. We therefore analysed the 'any formal help received' as a single, dichotomous variable.

A large number of variables in Alzheimer's disease sufferers and their carers have been known to influence the above three measures (EE, course, and outcome). In order to identify whether the influence (or the lack of it) of carers' EE on the course and outcome is an independent effect of EE, or due to presence of other such variables, they need to be measured.

These variables have been described as 'confounding', 'explanatory' 'mediator', or 'modulator' variables in the literature. Although there are conceptual differences between these four terms, in practice any given variable

can be either or more than one of these. It is impractical to measure all such variables and therefore some thoughts need to be given to those that are more persistently or more strongly related to the above three primary measures.

For the purpose of this study, the following variables were measured for the purpose of identifying their effect as the explanatory variables in this study. (See chapter nine (Appendix) for the assessment tools):

- Demographic information on the patient and the carer
- Baseline measures of -
    a. cognitive impairment of the patient
    b. non-cognitive symptoms of the patient
    c. functional status of the patient
    d. physical health of the patients
    e. general health of the carers
    f. carer strain.

### 4.3.4 Cognitive status

Although a large number of scales for assessing cognitive function in patients with dementia are available, the Mini Mental State Examination (MMSE; Folstein *et al.* 1975) is probably the most widely used instrument for assessment and monitoring for the cognitive status of patients with a diagnosis

of dementia (Burns *et al.* 2004). Its psychometric properties have been reported extensively (Tombaugh & McIntyre, 1992). We used the MMSE to ascertain the severity of the cognitive impairment in the patients at the baseline and at six- and twelve-month follow-up.

### 4.3.5 Non-cognitive symptoms

Non-cognitive symptoms in AD are diverse and include agitation, aggression, anxiety, apathy, wandering, resistive behaviour, delusions, hallucinations, irritability, purposeless activities, depression, and socially or sexually inappropriate behaviour. Over 30 neuro-psychiatric assessment scales are summarised in a recent compendium (Burns *et al.* 2004), but the majority of these scales assess only one, or a limited set of non-cognitive symptoms. More global scales for the assessment of non-cognitive symptoms are few, and include the Neuropsychiatric Inventory (NPI, Cummings *et al.* 1994; Kaufer *et al.* 1998); the Manchester and Oxford Universities scale for the psychopathological assessment (MOUSEPAD, Allen *et al.* 1996); the Columbia University scale for psychopathology in AD (CUSPAD, Devanand *et al.* 1992); the BEHAVE-AD (Reisberg *et al.* 1987) and the CERAD behaviour rating scale (CERAD, Tariot PN *et al.* 1995)

Although all of the above five scales have satisfactory psychometric properties and are used widely, the NPI was selected for the purpose of this study for the following reasons:

- It is relatively brief to administer in majority of cases;

- It provides both a non-cognitive symptom score and a caregiver distress score.

The ten items rated on the NPI are – delusions, hallucinations, agitation / aggression, depression / dysphoria, anxiety, elation / euphoria, apathy / indifference, disinhibition, irritability / lability, and aberrant motor behaviour. For each of the ten items, there is a screening question to ascertain the presence or absence of that symptom. If a particular symptom is present, further questions are asked to elicit details of that symptom. Each of the symptoms present is then rated on a four-point frequency scale (occasionally, often, frequently and very frequently), and a three-point severity scale (mild, moderate and severe). Each of the points on these scales has an operational definition. The score for an item is the product of its frequency and severity ratings. A total score is obtained by adding the individual scores.

For each of the ten NPI items, there is an additional distress question, enquired from the carer, regarding the degree of distress they experience from that particular behaviour or symptom. The distress level for each item is rated on a six-point scale (0 - 5). The total distress scale is the sum of the individual distress scores.

Thus the NPI score ranges from zero to 120, with higher scores indicating more symptoms. The NPI – distress scale score can range from zero to 50, with the higher score indicating more distress.

The NPI training pack and further information, including a video showing use of NPI in a clinical situation, were obtained from the original authors of the NPI, and were reviewed by the researchers before using the instrument in this study.

### 4.3.6 Activities of daily living

We selected the Bristol Activities of Daily Living Scale (BADL) for the assessment of the functional abilities of the patients in this study, due to its brevity, ease of use and acceptable psychometric properties. The BADL was developed specifically for patients with dementia (Bucks *et al.* 1996). Its validity, reliability and sensitivity to changes have been demonstrated (Bucks *et al.* 1996, Byrne *et al.* 2000). This is an informant-based instrument and lists 20 different activities, each of which is rated on a 'zero' (fully independent) to 'three' (fully dependent) scale. If an item is not applicable because the person has never done that activity (such as cooking), it is scored 'zero'. The maximum score is 60 and minimum score is 'zero'. Principal component analysis of the scale groups seven items related to instrumental activities of daily living (drink preparation, use of telephone, food preparation, housework, communication, shopping and eating); six items related to self care activities (dental care, hygiene, bathing, dressing, using the toilet, drinking); five items relating to orientation (orientation to space, games and hobbies, orientation to time, driving, using public transport, managing finances); and two items on mobility (transferring and mobility) (Bucks *et al.* 1996).

### 4.3.7 Physical health of the patients

Some of the scales for the assessment of physical health focus on only one set of physical problems, such as neurological functions, or extra-pyramidal symptoms (Chen *et al.* 1995, Webster 1988). Others focus more on the handicap or functional disability (Harwood *et al.* 1994). Almost all of the scales that measure the 'general physical health' of older adults (with or without dementia / mental illness) use Likert-type categories such as 3-point (mild moderate or severe; Burvill *et al.* 1990), or 4-point (excellent, good, fair, poor; Lyketsos *et al.* 1999) scales. The Centre for Ageing and Human Development at Duke University has an Older American Resource and Services (OARS) section that has developed the Multidimensional Functional Assessment questionnaire (OMFAQ) (Duke University Centre for the Study of Ageing and Human Development 1978). This is a comprehensive assessment questionnaire that includes psychiatric, functional, cognitive, and also physical dimensions. The physical assessment is based on a list of questions and has a six-point summary rating ranging from 'In excellent physical health' to 'totally physically handicapped'. Each of these categories has an operational definition. We used this scale for assessing the overall physical health of the patients in this study.

### 4.3.8 General health of the carers

The carers of the Alzheimer's disease sufferers are a diverse group. While the majority of them are spouses and elderly, a significant proportion are children

or children-in-law, siblings or close friends. The carers' health in general can have a significant effect on their ability to continue to provide care, and is likely to be a significant confounding variable in this study. A comprehensive assessment of the carers' health was however not feasible

The General Health Questionnaire (GHQ) is the most widely used self-rating instrument for the detection of psychiatric disorder and psychological morbidity (Burns *et al.* 2004). This instrument is primarily a screening tool used in community and non-psychiatric clinical settings. There are four versions of the GHQ, with 12, 28, 30 and 60 items (respectively called GHQ-12, GHQ-28, GHQ-30 and GHQ-60).

For the purpose of detecting 'caseness' in non-clinical populations, the GHQ-12 has reasonably good psychometric properties (Goldberg and Williams 1988), and has the advantage of brevity and economy of time. The GHQ-12 has twelve statements about general aspects of the person's ability to cope or their health. Each statement has four alternative responses, ranging from 'better than usual' to 'much worse than usual'. Some of the statements are positively worded; such as 'been feeling reasonably happy, all things considered', while others are negatively worded; such as 'been thinking of yourself as a worthless person.' The person is asked to choose one that applies to him in the preceding (specified number of) weeks. This scale is then scored as either a continuous scale, with each item being scored on a four point scale (0-1-2-3) or a dichotomous scale with (0-0-1-1) scoring. The dichotomous score is used to generate 'caseness'. For GHQ-12 the generally recommended cut-off to

identify 'cases' is 1 / 2, i.e. anyone scoring more than 'one' is considered to be a 'case'. A higher cut-off (such as 4 / 5) is sometimes used for people already suffering from physical health problems or in older people (Goldberg and Williams 1988, Web reference 4 - NFER-Nelsons.)

The caregivers 'caseness' on the General Health Questionnaire (GHQ) has been reported to be a significant predictor of the breakdown of community care in dementia patients over a 12-months period (Jerrom *et al.*, 1993). As the carers in this study were primarily a non-clinical population, we chose to use the GHQ-12 for the assessment of their general psychological morbidity.

### 4.3.9 Carer stress

Carer stress is one aspect of psychiatric research where a large number of assessment scales have been developed. The contents of these scales reflect the differences in the scale developers' perceptions of what exactly constitutes carer stress. Dementia carer research that has used measures to assess effect of providing the care on the carers have used terms such as, 'stress', 'strain', 'burden', 'difficulties', 'depression', 'difficulty coping', 'hassles', and 'problems'. Of course, there are differences in each of the above concepts but they are significantly related to each other.

As the sources of stress in carers are likely to be varied, we chose to use the Caregiver distress scale of the Neuropsychiatric Inventory (NPI-D, Kaufer *et al.*, 1998) (See Chapter 4.3.6: Assessment of non-cognitive symptoms) to measure the specific nature of the distress in relation to the range of the

patient's non-cognitive symptoms assessed by the NPI. This context-specific measure of stress (or distress, as it is called) can potentially be more informative in terms of its effects on the carers' ability to continue to provide that role.

### 4.3.10 Demographic Information

We also collected relevant demographic information for both the patients and carers: patients' age, gender, cohabitation status, relationship to the carer, and carer's gender. We initially tried to measure the extent of face-to-face contact between the patient and the carer but soon abandoned it for two reasons. First, the majority of the spousal carers were spending virtually all (except maybe one or two half-days a week) of their wakeful time with the patient. Second, the non-cohabitating carers found it very hard to estimate the amount of face-to-face contact with the patient and the degree of variability over week to week made any estimate meaningless. It was judged more meaningful to compare co-habitation status rather than face-to-face contact.

In summary, the following assessment tools were used in this study:

**Patient assessment tools**

- Cognitive symptoms assessment – Mini Mental State Examination (Folstein *et al.* 1975) (Appendix 9.4)
- Non-Cognitive symptoms – Neuropsychiatric Inventory (Cummings *et al.* 1994) (Appendix 9.5)

- Functional assessment – Bristol Activities of Daily Living (Bucks *et al.* 1996) (Appendix 9.6)

- Physical health – OMFAQ physical health summary assessment (Dukes University Centre for the Study of Ageing and Human Development 1978) (Appendix 9.7)

**Carer assessment tools**

- Expressed emotion – Modified Camberwell Family Interview Schedule (Brown *et al.* 1972, Tarrier *et al.* 2002) (Appendix 9.2)

- Neuropsychiatric Inventory – distress scale (Cummins *et al.* 1994) (Appendix 9.5)

- General health – General health Questionnaire 12 items version (Goldberg 1978) (Appendix 9.3)

**Assessment of the course and outcome**

- *Primary outcome*: 'change of domicile' due to:
    - Institutionalisation (Yes / No)
    - Death (Yes / No)
- *Secondary outcomes*:
    - Any formal help received (Yes / No)

## 4.4 Recruitment

### 4.4.1 Method of identifying the subjects

The MHSOP clinicians provide a comprehensive assessment and treatment service for the patients with suspected dementia. Since 1998, and following an agreement with the primary care, treatment of the patients with mild to moderate Alzheimer's disease with ChEI drugs is initiated and supervised by the senior clinicians from the MHSOP. The assessment process of these patients is robust and involves a detailed clinical history and examination. A number of investigations are routinely performed before a diagnosis is made. The investigations include full blood count, differential blood count, liver, kidney and thyroid function tests, blood sugar, bone biochemistry, lipid profile and nutritional profile (Vitamin B12 and folate levels). An electrocardiogram (ECG) is routinely performed. Almost all the patients are sent for a magnetic resonance imaging (MRI) or a computerised tomography (CT) brain scan.

Once a clinical diagnosis of Alzheimer's disease of mild to moderate severity is made, patients are considered for initiation of ChEI drug treatment. Under the local agreement, these drugs are prescribed by the clinicians of the MHSOP for the duration of the treatment, and they are dispensed by the LPT's hospital pharmacy. The hospital pharmacy therefore has a comprehensive list of patients who are receiving these drugs.

We started the recruitment process by initially writing to all the consultant-led mental health teams within the MHSOP describing the study, and our recruitment intentions. The consultants and senior clinicians were requested to identify potentially suitable patient-carer dyads from those patients who were under their follow-up and were receiving ongoing care from their service.

One of the conditions of the ethical approval by the ethics committee was the requirement that the clinician should be the person who initiates the recruitment process / consent process. Each consultant psychiatrist was therefore given a set of the approved 'patient information leaflets' and the 'carer information leaflets' (Appendix 9.10 and 9.11). They were requested to ask the patients and the carers if they would participate in the study and to offer them the leaflets. The patients and carers were also offered an opportunity to discuss and clarify any issues with the researchers before deciding about their participation. In the first two years of the recruitment, the consultants were regularly reminded about the need for recruiting the subjects into the study. However, it was up to the individual clinician to remember to invite the patients and the carers, and to offer them the information leaflets.

Unfortunately, even after repeated requests and attempts to enhance recruitment, only a limited number of patients-carer dyads were recruited by this means. It became evident that, while all the clinicians were in agreement in principle for their patients to be approached and be invited to participate in the study, in practice, not many of them could either remember to or afford to

spend time explaining the details of the study, and inviting the patients for their participation.

After a discussion with all the consultants involved, it was agreed that the research team would obtain a list of all those patients commenced on ChEIs by each of the consultants, and that these lists would be sent to them. They would then be asked to identify those patients who they deemed suitable to be approached by the research team on their behalf. The patients thus identified were then sent a 'patient information leaflet', a 'carer information leaflet', and a covering letter on behalf of the consultant (Appendix 9.9), inviting the patient and the carer to participate in the study. The cover-letter also stated that a researcher would be contacting them in the near future to discuss this study, and their potential participation. A contact number was given to the carer and the patient to notify the researchers if they did not want any further correspondence including any phone calls regarding the study.

Approximately two weeks after the letters were posted, the researchers contacted the carers by phone to discuss the study, and seek their willingness to participate. Any questions and clarification sought by the carer and the patient were dealt with, and if they were willing, an appointment was made for a visit for the baseline assessments at a time and place convenient to the patient and carer.

Before starting the baseline data collection, carers were asked to seek any further clarifications. Another copy of the patient and carer information leaflet

was offered and a written consent was obtained from the carers and, if appropriate, from the patient. The patient's willingness for the meeting to go ahead was ascertained in any case. Although all the interviews with the carers were conducted separate from the patient, there were occasions, particularly when the interviews were at the subject's home, when the patients came into the interview rooms for brief periods 'just to check', or possibly due to their confusion and anxiety at being on their own in a separate room. The patients were asked to choose if they wished to be interviewed with or without the carer being present.

### 4.4.2 Baseline assessments

A research file was set up for each patient-carer dyad, for use at the initial and subsequent interviews. It contained copies of the assessment tools, 'information leaflets', and the consent form. After obtaining the written consent, the research interview started with either the patient or the carer. Patients were assessed using the MMSE. After obtaining the demographic information, the first part of the carer interview was the audio-taped CFI. Other instruments were subsequently administered in no strict order. Depending on the carer's preference, some of the questionnaires were jointly read with the carer to facilitate appropriate completion. At the end of the interview, their willingness to participate in a follow-up interview was ascertained.

The following table summarises the nature of the information, the person to whom that information refers, and the source of the information collected, at the baseline interview.

**Table 4.1 – Baseline information and its sources.**

| **Information collected / Assessment tools (See chapter 4.3 & appendix)** | **The person the information refers to** | **Source of the information** |
|---|---|---|
| • Personal and demographic details of the patient and the carer | The patient and the carer | The carer, and the patient |
| • Modified Camberwell Family Interview schedule. | The patient and the carer | The carer |
| • Formal help received by the patient and the carer in the last six-months | The patient and the carer | The carer, and the patient |
| • Bristol Activities of Daily living | The patient | The carer |
| • The Neuropsychiatric Inventory (NPI) | The patient | The carer |
| • Mini Mental State Examination | The patient | The patient |
| • Medical and treatment history (summary physical health rating of the OMFAQ) | The patient | The carer, and the patient |
| • The General Health Questionnaire (12-item version) | The carer | The carer |
| • Carer stress / NPI distress scale | The carer | The carer |

### 4.4.3 Additional baseline data collection

We were also interested in gaining some experience of using the alternative method of assessing EE by using the FMSS (See Chapter 2.4). FMSS is a briefer method of assessing EE and the aim of using this method on the first twenty subjects was to judge whether in our hands, it provided as good a quality of EE assessment as CFI. FMSS-EE has been reported to be comparable to CFI-EE (Magana *et al.* 1986, Leeb *et al.* 1991). We used the FMSS interview on the first 20 patient-carer dyads, to evaluate its utility in the

context of our own study. The researchers were not formally trained in using the FMSS technique, but the administration of the FMSS interview is a highly standardised one. One of the researchers (MM) administered the FMSS interview. The instructions for the interview, as stated in Tompson *et al.* (1995), were read out to the carer and the interview was recorded. This was done before starting the CFI interview. The audio recording of the interview and a typed script of the interview were sent to a FMSS-trained researcher in USA (Mr Jason Foglar – see Acknowledgements) for rating. He was otherwise not involved in this study.

After the first twenty assessments, the FMSS interviews were abandoned for the following reasons:

- As the researchers were not trained in using FMSS, their confidence in using the FMSS rating was less than that in using the CFI;

- The quality and quantity of information obtained by this means was thought to be too limited to give a meaningful impression about the EE.

- Some of the carers were not very expressive, particularly at the beginning of the interview, and hence they were unable to talk for five minutes. Although the FMSS administration guidelines give clear directions about the ways to deal with silences and briefer interviews, the overall influence on the EE rating was unknown.

### 4.4.4 Follow-up data collection

#### Six-month follow-up

Carers were contacted six months after the initial assessment. If the patient had either died or had moved to live in an institutional setting, then a note was made to that effect. If the domicile of the patient had not changed, then a visit was arranged. The follow-up assessment included the same assessment tools as at baseline (MMSE, NPI, BADL, Summary OMFAQ physical health, NPI-DS, & GHQ-12), with the exception of CFI.

#### Twelve-month follow-up

The arrangements and the assessments at the twelve-month follow-up were identical to that at six-month follow-up.

We also retrospectively collected the information on the survival and domicile status of the patients at two years from their baseline assessment.

## 4.5 Data handling and statistical analysis

A biostatistician (NT) was consulted at the stage of writing the research protocol and subsequently during the data analysis stage in order to consider the study design, appropriate power calculations, as well appropriate analysis of the data.

After the baseline assessment visit, the researchers listened to the audio-taped CFI, and rated the interview on the five components. Both the researchers were formally trained, and had achieved acceptable inter-rater reliability in administrating CFI and rating EE based on it.

The information was entered into a database using the Statistical Package for the Social Sciences, SPSS 12.0®. The follow-up information was also entered. A range of primary variables were generated from the information obtained from the assessment tools. A range of secondary variables were derived from the primary variables including grouping the continuous / ordinal data into categories (such as 'caseness' on the GHQ-12).

Data was checked for any incorrect coding, entries, omissions, and skewing. Subjects with missing data relevant to an analysis were excluded from that analysis.

Descriptive statistics such as Frequency counts, Cross tables and Averages, were used to get an understanding of the distribution and patterns of the data. Mean, median, mode, inter-quartile range were noted for continuous variables and the frequency counts of the categorical data were noted.

For inferential results, two-tailed tests were used throughout. The significance level was kept at $p < 0.05$. We initially assessed the distribution of the data and where the skewness was judged to be unimportant, a normal distribution was assumed.

For comparing categorical data, we used Pearson's Chi-squared test. For comparing continuous data that was not significantly skewed, we used the independent samples t-test and confidence interval. We used the Area-Under-Curve (AUC) analysis for comparing the changes in the continuous dependent variables over twelve-months, between the high and low EE groups.

For comparing those who were lost to follow-up with those who were followed up, we used Pearson's Chi-squared test and the Mann Whitney U test for categorical and continuous data respectively.

We considered analyses using multivariate statistical analysis such as ANOVA / MANOVA, to explore the effects of time, explanatory variables and EE status together on the outcomes. However, after discussion with the statistician (NT), these were considered unsuitable because our main interest was in identifying the changes from the baseline to six- and twelve- months and changes from six to twelve month. ANOVA / MANOVA tests are appropriate when it is not clear exactly what aspects of change in a measurement might be different between the study groups. In that sense these tests are considered more as an 'umbrella' tests. Repeated-measures ANOVA was also considered to be less attractive in this situation, due to there being only three time-points, and the need to make additional statistical assumptions (e.g. multivariate-normal joint distributions, structure of the covariance matrix showing 'sphericity'). We therefore decided that the bi-variate analysis and the AUC analysis were sufficient to identify any significant differences in the changes over time, between the two groups.

## 4.6 Data quality

Both the investigators (MM and PW) who collected the data were formally trained in the use of modified CFI and had achieved satisfactory inter-rater reliability following their training. We were keen to maintain the inter rater reliability between the two investigators. In the earlier stages of the study, the two investigators jointly assessed some of the recorded CFI interviews and any discrepancies were resolved after discussions and after referring to the CFI rating manual. At the end of the data collection, both the investigators individually rated seven of the tapes independent of each other. Four of these were rated as low EE by both the raters, two were rated as high EE by both the raters. There was a disagreement of the EE status on one of the interview ratings. This disagreement was due to different rating given by the two raters on the EOI subscale of the CFI (given as 'moderately high' by one rater and 'some' by the other rater). The Cohen's kappa value is one of the good measures of reliability (Bartko 1991). For these seven sets of ratings, the kappa value was 0.72, which suggests a good level of agreement.

## 4.7 Ethical considerations

We were very mindful of the ethical considerations of undertaking research on patients who might not have the mental capacity to give informed consent. This issue is even more critical when the research is unlikely to be of direct benefit to the participants of that research study. Although this research proposal was submitted many years before the Mental Capacity Act (2005) became law, we have followed the principles of this Act in this study. We ensured that, where possible, patients were encouraged and helped in making an informed decision about their participation. We ensured that the treating clinicians of the patients were willing for the patients to be considered for inclusion in the study. The initial invitation to the patients and the carers was made by the treating psychiatrist or on behalf of the treating clinicians. The patients and the carers were sent appropriate information leaflets approved by the local ethics committee.

Investigators contacted the patients and the carers after approximately two weeks of the initial invitation, so that the patients and the carers had sufficient time to think about and discuss with others before deciding about their participation. At the beginning of the assessment, another copy of the information leaflet was offered and any questions were answered before seeking a written consent from the carers and the patients.

With incapacitated patients, we ensured that they were willing for the interview to go ahead. We sought approval and consent from the informal carers of the

patients before we approached the patients. The patient's consent or an assent was sought only when their carer was present with them.

The research proposal was approved by the Local Research Ethics Committee prior to beginning of the data collection (See Appendix 9.1).

Individual research case files were made for each of the participants. These files contained the paper records and the audiotape of the CFI. The data was kept in locked cabinets in the principal investigator's office with the same levels of security as the clinical case notes.

Data was anonymised before being entered on the SPSS® database. The electronic data contained no information about the names, addresses or hospital numbers of the patients. We gave alphanumeric (such as M1, M2... or P1, P2...) consecutive numbers to the participants as they entered the study. These numbers were also entered on the case files and the audiotapes to cross-refer the electronic record with the manual record. The information was stored in keeping with the Data Protection Act (1998).

# Chapter Five

# Results

## 5.1 Data completeness

The data collection period was between July 2000 and April 2006. Seventy-five patient-carer dyads were assessed at baseline. These 75 subject pairs were recruited from nearly 2000 patients who had received or were receiving ChEI treatment, and were being followed-up by the clinicians from the MHSOP over the study period.

At six months, only 51 subjects could be followed up by a face-to-face interview with the patients and the carer. Two of the patients had moved to an institutional setting and were considered to have achieved the primary outcome. The other 22 subjects could not be contacted for various reasons, such as carer's death, change of carer, and inability to trace and arrange the follow-up with the carer within the six or twelve months from baseline.

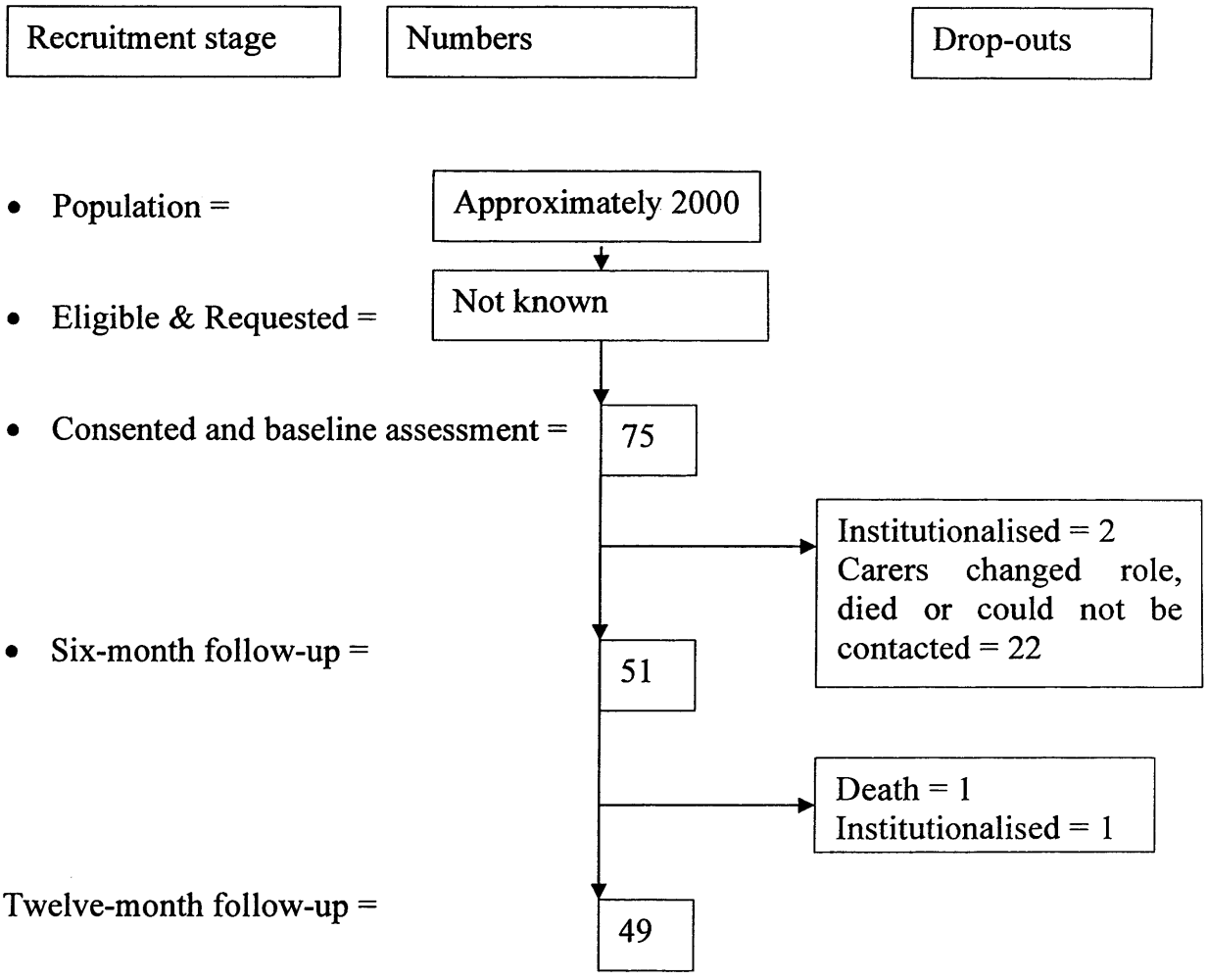
At twelve months, only 49 subjects could be followed-up by a face-to-face interview. This was due to one patient's death, and one patient moving in to an institutional setting between the six- and twelve-month follow-ups.

During the research interviews with the subjects, not all of the assessments could be completed in every case. There were a number of reasons for this, such as carer fatigue, other commitments of the carers such as a friend waiting

to take them for shopping, and distractions due to other visitors or patients getting more restless sitting in other room in the house and repeatedly coming in the interview room. Where information is missing, those subjects are excluded from the relevant analyses.

The stages of recruitment, the numbers at each stage and the drop-out numbers and reasons are summarised in Figure 5.1.

**Figure 5.1: Flowchart depicting the numbers at various stages of recruitment and drop-outs.**



## 5.2 Data Inclusion

The primary outcome (domicile status) for all the seventy-five patients was accurately ascertainable through the clinical case notes of these patients, and through the hospital's patient administration system. Therefore, the baseline analysis and primary outcome analysis includes all the 75 subjects.

In the analysis of the secondary outcome and explanatory follow-up variables, subjects with missing data were excluded on a case-by-case basis.

In view of the number of patients lost to follow-up, it was important to examine the extent to which those who completed the six-month follow-up were different from those who did not. The following tables (5.1a and 5.1b) compare the baseline measures of those subjects who were followed up with those who were not.

There were no significant differences between the two groups on any of the baseline measurements.

**Table 5.1a: Comparison of the categorical baseline variables between those subjects who had a follow-up and those who did not (Pearson's chi-square value - $X^2$, and two-tailed significance - p)**

| Variables | | No follow-up (N =24) | Follow up (N = 51) | Chi-square | p |
|---|---|---|---|---|---|
| Patient gender | Male | 12 | 28 | – 0.158 | 0.691 |
| | Female | 12 | 23 | | |
| Carer gender | Male | 8 | 20 | – 0.241 | 0.623 |
| | Female | 16 | 31 | | |
| Formal help | No | 11 | 33 | – 2.397 | 0.122 |
| | Yes | 13 | 18 | | |
| Levels of EE | High | 12 | 19 | – 1.093 | 0.296 |
| | Low | 12 | 32 | | |
| GHQ-12 case (4/5) | Case | 04 | 14 | – 1.041 | 0.308 |
| | Non-case | 20 | 37 | | |
| GHQ-12 case (1/2) | Case | 13 | 27 | – 0.01 | 0.921 |
| | Non-case | 11 | 24 | | |

**Table 5.1b: Comparison of the continuous baseline variables between those subjects who had a follow-up and those who did not (Mann-Whitney U Tests)**

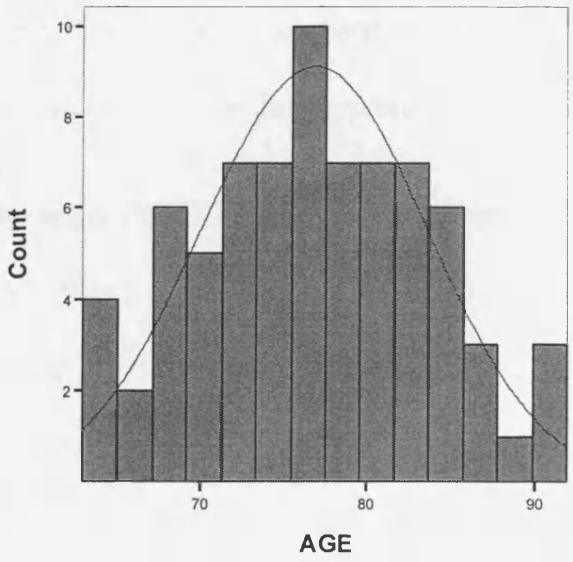
| Variables | No f/u (n = 24) | 6-month F/u (n = 51) | Mann-Whitney U | p-value |
|---|---|---|---|---|
| | Mean (± SD) | Mean (± SD) | | |
| Patient age in years | 75.46 (±6.63) | 77.47 (±6.86) | 494.5 | p=0.181 |
| MMSE scores | 21.86 (±3.94) | 21.40 (±5.29) | 521.5 | p=0.934 |
| NPI score | 11.83 (±11.22) | 11.04 (±10.28) | 596 | P=0.855 |
| BADL score | 19.17 (±12.83) | 15.08 (±10.16) | 506 | P=0.228 |
| OMFAQ summary score | 3.13 (±1.22) | 2.71 (±1.01) | 498 | P=0.176 |
| NPI distress score | 6.22 (±5.65) | 5.37 (±5.77) | 492 | P=0.385 |
| GHQ-12 score | 2.50 (±2.65) | 2.73 (±2.84) | 587 | P=0.772 |

## 5.3 Description of the sample

### 5.3.1 Demographic characteristics

*Age of the patients*: The mean age of the sample was 76.8 years (SD ± 6.8), with a range between 63 years to 92 years. The majority (n=48, 64%) of the patients were 75 years of age or older. Figure 5.2 shows the age distribution of the sample.

**Figure 5.2 Age distribution of the patients with superimposed normal distribution**




*Gender*: Forty-seven percent of patients (n= 35) and 63% (n = 47) of carers were female.

*Relationship of the carers to the patients*: Nearly half (n = 37, 49.3%) of the carers were wives and another 30% (n = 23) were husbands. There were four

partners, two sons, seven daughters, and two 'others' among the carers. Sixty-four (85%) patients were living with their carers at baseline.

### 5.3.2 Illness characteristics

The patients in this sample had a mean baseline MMSE of 21.54 (SD±4.88), indicating mild severity of dementia. Their physical health was also good to mildly impaired, with a mean summary OMFAQ physical health score of 2.84 (SD±1.09). On this scale a score of 'two' indicates good physical health, and 'three' mild physical impairment. The patients' mean NPI score was 11.29 (SD±10.52). The patients in this study had a mean BADL score of 16.39 (SD ±11.16). The BADL score range is from 0 to 60 with higher scores indicating more impairment. The patients in the study sample therefore had mild to moderate functional impairment.

The mean GHQ-12 score in the carers, using a '0-0-1-1' scoring method, was 2.65 (SD±2.76). The standard definition of 'case' as per GHQ-12 is anyone scoring 'two' or more. However, for people who are physically ill, a higher threshold is recommended for optimal discrimination between cases and non-cases (Goldberg & William 1988, Goldberg *et al.*. 1997). For the purpose of these results we have used the standard criteria as well as a higher threshold score of five or more.

Using a cut-off score of 'two' or more, 40 of the 75 carers were classed as 'cases' at baseline. With a cut-off of 'five' or more, 18 of the 75 carers were classed as 'cases'.

The mean NPI distress score in the whole of the sample was 5.64 (SD±5.71). This score ranges from 'zero' to 50, and a score of 5.64 would suggest a mild level of distress.

### 5.3.3 Baseline expressed emotion

Expressed emotion (EE) and its components (CC, H, EOI, PR and W) were rated using the Camberwell Family Interview Schedule (CFI). The results are as follows.

**Critical comments:** The carers expressed between 0 and 21 CC during the interview (Figure 5.2a). The mean number of CC was 4.35 (SD±3.74), the median was 3 (IQR 2-6), and the mode was 2.

If only CC numbers were used to rate EE and the standard cut-off of 6 or more CC was used to separate high and low EE relatives, 22 (29.3%) of the sample interviewed expressed High EE.

**Hostility:** The distribution of the hostility scores shows that 54 subjects (74%) expressed no hostility (Figure 5.2b). Nine subjects (12%) expressed hostility in the form of generalisation only. Another nine subjects expressed hostility as rejecting attitude only, and three (4%) expressed both generalisation as well as rejecting attitude.

Using Hostility alone as a criterion for rating EE, 21 (26%) of the subjects expressed high EE.

**Emotional over-involvement (EOI):** In this sample, seven out of 75 subjects showed a degree of EOI that was considered moderately high or greater (Figure 5.2c). Those seven subjects were considered to have high EE on this criterion alone.

**Warmth:** Warmth rating was moderately high or high for just 9 (12%) of the 75 people assessed (Figure 5.2d).

**Positive remarks:** In this sample, the range of PR was between 0 and 11 (Figure 5.2e), the mean was 2.61 (SD ± 2.20), the median was 2, the IQR was 1-3, and the mode was one.

**Overall levels of EE**

Table 5.2 summarises the levels of EE according to the individual components of the CFI, as well as when these criteria are combined (standard criteria - Six or more CC, OR EOI of moderately high or more OR any hostility). It shows that 31 of the 75 carers met the original criteria for high EE.

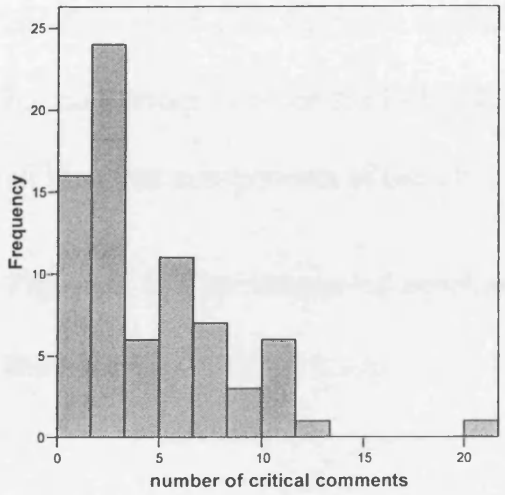
**Table 5.2: Distribution of high and low EE according to standard CFI criteria and its individual components.**

| Criteria used → | Critical comments Only | Hostility Only | EOI only | Standard Criteria |
|---|---|---|---|---|
| High EE | 22 | 21 | 7 | 31 |
| Low EE | 53 | 54 | 68 | 44 |

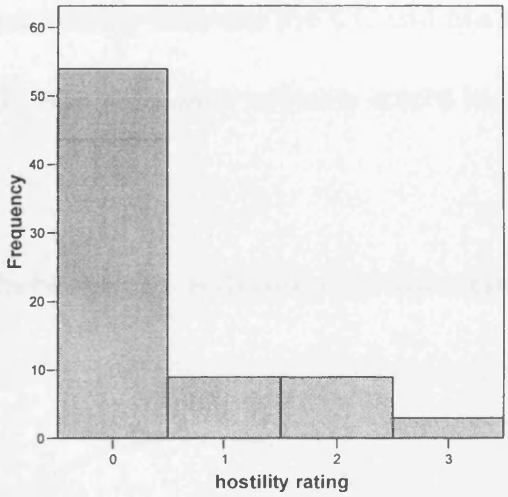
Figure 5.3 graphically shows the distribution of individual components of EE.

**Figure 5.3: Distribution of individual components of EE.**

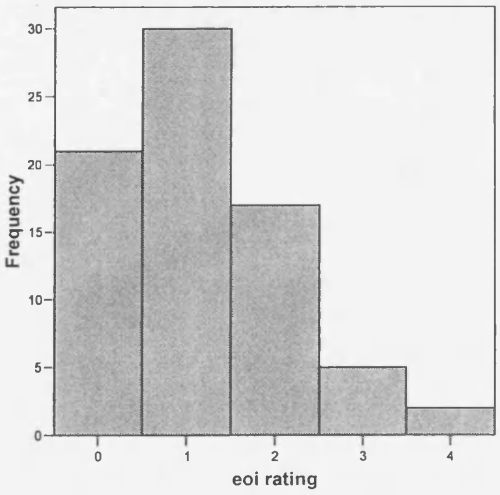
5.3a)



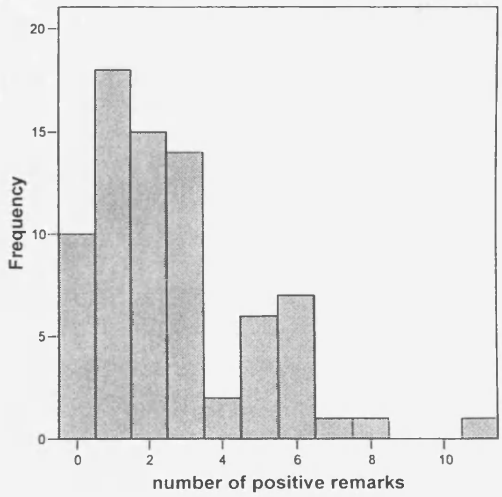

5.3b)




5.3c)




5.3d)




5.3e)

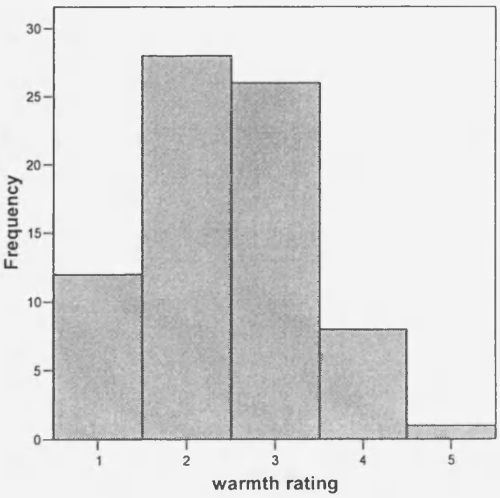
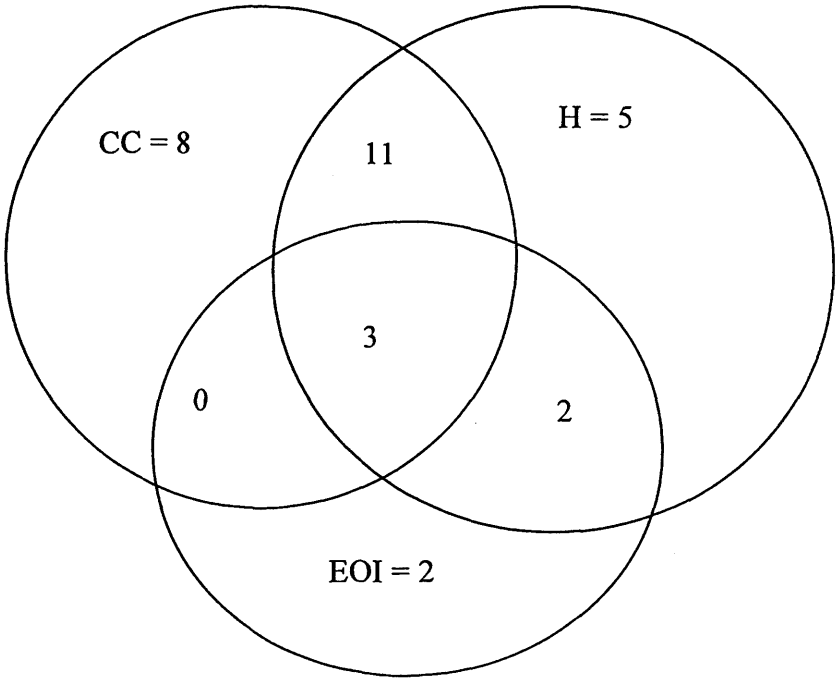


Figure 5.4 shows the degree of overlap between the individual components of EE. It is noted that there is a significant overlap between the CC and hostility, but no overlap between the CC and EOI, although three subjects scored high on all the three components of the EE.

**Figure 5.4: The degree of overlap between the individual components of the high EE.[3]**




### 5.3.4 FMSS-EE and CFI-EE

The FMSS interview was administered using the guidelines suggested by Tompson *et al.* (1995) on the first twenty carers. The reasons for this are summarised in Chapter 5.3.3. The researchers had not had any formal training in administering FMSS interview, but had had some discussions on this

[3] CC = Critical comments, H = Hostility, EOI = Emotional over involvement

interview technique with an FMSS trained rater (see Acknowledgements), prior to administering the interviews.

While the prevalence of low and high EE were very similar in both the FMSS-EE (9/20 having high EE) and the CFI-EE (11 / 20 having high EE), the high EE cases identified by each of the two methods were not the same and the correlation between the CFI-EE and FMSS-EE was not significant (Pearson's chi-square value, $X^2 = 0.002$; $P = 0.964$). Following some discussions with and feedback from the FMSS-trained rater, it was considered possible that the FMSS interview had not been administered strictly according to the guidelines. In view of this, the FMSS-EE interviews were discontinued.

### 5.3.5 Explanatory variables

#### 5.3.5.1 Patients' explanatory variables

The MMSE, NPI, BADL and OMFAQ physical health rating were assessed at baseline and at six and twelve months.

a) *Mini Mental State Examination*: The baseline MMSE scores indicated that two patients (2.8%) were 'severely impaired' (MMSE $\leq$ 10); six (8.6%) were 'moderately impaired' (MMSE 11 to 14); eight (11.4%) were 'mildly impaired' (MMSE 15 to 17); twenty-eight (40%) scored in the 'borderline impairment' range (MMSE 18 to 23) and twenty-six (37.2%) scored 24 or above.

b) *The Neuropsychiatric Inventory*: The frequencies of non-cognitive symptoms (NPI items) at the baseline were as follows: delusions -19 (25%),

Hallucinations -18 (24%), Agitation – 23 (31%), Depression – 24 (32%), Anxiety – 35 (46%), Elation – 4 (5%), Apathy – 41 (55%), Disinhibition – 12 (16%), Irritability – 31 (41%), Abnormal motor behaviour – 23 (31%). Thus, apathy was the commonest non-cognitive symptom (present in 55%) and elation was least common (present in 5%).

c) *Bristol Activities of Daily Living*: Table 5.3 summarises the baseline scores on the BADL. Basic personal care activities such as eating, drinking, toileting, mobility, or and ability to getting in and out of the chair, showed milder levels of impairment. Activities such as pursuing hobbies, preparing food, using phone, transport and shopping were most severely impaired.

**Table 5.3: Baseline BADL scores of the patients.**

| Item No. | BADL items | No problems – N (%) | Some problem – N (%) | Moderate problem – N (%) | Severe problem – N (%) | Not applicable – N (%) |
|---|---|---|---|---|---|---|
| 1 | Preparing food | 26 (35) | 8 (11) | 13 (17) | 21 (28) | 7 (9) |
| 2 | Eating | 62 (83) | 13 (17) | 0 | 0 | 0 |
| 3 | Preparing drinks | 44 (59) | 8 (11) | 15 (20) | 6 (8) | 2 (3) |
| 4 | Drinking | 71 (95) | 4 (5) | 0 | 0 | 0 |
| 5 | Dressing | 51 (68) | 15 (20) | 6 (8) | 3 (4) | 0 |
| 6 | Hygiene | 57 (76) | 7 (9) | 7 (9) | 4 (5) | 0 |
| 7 | Teeth | 59 (79) | 5 (7) | 7 (9) | 4 (5) | 0 |
| 8 | Bath / Shower | 41 (55) | 15 (20) | 12 (16) | 7 (9) | 0 |
| 9 | Toilet | 64 (84) | 9 (12) | 1 (1) | 1 (1) | 0 |
| 10 | Getting In/Out of chair | 69 (92) | 4 (5) | 1 (1) | 1 (1) | 0 |
| 11 | Mobility | 60 (80) | 2 (3) | 13 (17) | 0 | 0 |
| 12 | Orientation to time | 18 (24) | 34 (45) | 21 (28) | 2 (3) | 0 |
| 13 | Orientation to place | 25 (33) | 38 (51) | 9 (12) | 3 (4) | 0 |
| 14 | Communication | 50 (67) | 10 (130 | 12 (16) | 3 (4) | 0 |
| 15 | Phone | 28 (37) | 9 (12) | 23 (31) | 14 (19) | 1 (1) |
| 16 | House work | 16 (21) | 28 (37) | 22 (29) | 9 (12) | 0 |
| 17 | Shopping | 15 (20) | 15 (20) | 27 (36) | 12 (17) | 5 (7) |
| 18 | Finance | 17 (23) | 29 (39) | 17 (23) | 10 (13) | 2 (3) |
| 19 | Hobbies | 10 (13) | 19 (25) | 19 (28) | 22 (29) | 3 (4) |
| 20 | Transport | 11 (15) | 9 (12) | 39 (52) | 13 (17) | 3 (4) |

d) *OMFAQ summary physical health score*: On this scale, five (7%) patients were judged to be in excellent physical health, 28 (37%) in good health, 23(31%) had mild impairment, 13 (17%) had moderate physical handicap, five (7%) had severe physical handicap and one (1%) was totally physically handicapped.

Table 5.4 gives a summary score of the patients' explanatory variables at baseline, at six- and twelve- month assessment.

**Table 5.4: Baseline and follow-up scores on the patients' explanatory variables**

| Tools | Time (N=) | Mean (± SD) | Median (IQR) | Mode |
|---|---|---|---|---|
| MMSE | Baseline (70) | 22 (4.88) | 23 (19 – 25) | 23 |
| | Six-month (48) | 20 (6.32) | 21.5 (15 – 26) | 26 |
| | Twelve-month (39) | 19 (6.88) | 21 (12 – 24) | 21 |
| NPI | Baseline (75) | 11 (10.52) | 9 (3 – 16) | 1 |
| | Six-month (51) | 13 (13.25) | 10 (4 – 17) | 9 |
| | Twelve-month (49) | 16 (16.42) | 9 (4 – 26) | 0 |
| BADL | Baseline (75) | 16 (11.16) | 14 (9 – 25) | 9 |
| | Six-month (51) | 17 (12.60) | 14 (8 – 24) | 14 |
| | Twelve-month (49) | 19 (13.77) | 18 (7.5 – 28.5) | 8 |
| OMFAQ - physical health | Baseline (75) | 2.84 (1.09) | 3 (2 – 4) | 2 |
| | Six-month (48) | 2.6 (0.92) | 2 (2 – 3) | 2 |
| | Twelve-month (49) | 2.41 (0.99) | 2 (2 – 3) | 2 |

### 5.3.5.2 Carer explanatory variables

a) *General health Questionnaire*: In this sample, 23 (31%) of the carers scored 'zero', twelve (16%) scored 'one', six (8%) scored 'two', nine (12%) scored 'three', seven (9%) scored 'four', and 18 (24%) scored 'five' or above on GHQ-12.

Thus, 40 (53%) carers were classed as 'cases' using the standard criteria. With a higher cut-off (4/5), only 18 (24%) carers were classed as 'cases'.

b) *Neuropsychiatric Inventory – Distress score*: The NPI-DS scores refer to the carers' level of distress to the items on the NPI. Overall, apathy was the most common distressing symptom, with 31 (42%) carers reporting some distress due to this. Anxiety was the second most distressing symptom with 29 (38%) reporting some distress. This was followed by irritability in 22 (31%), depression in 21(27%), agitation in 20 (27%), aberrant motor behaviour in 14 (19%), delusions in 14 (29%), hallucinations in 13 (17%), disinhibition in seven (9%) carers causing some distress. Interestingly, 'elation' did not cause any distress to the carers of four patients who had this symptom. The severity of the distress for each of the NPI items is summarised in Table 5.5.

**Table 5.5: Distribution of the carer distress on each item of the NPI.**

| NPI Item (N = number reporting distress) | None – N (%) | Minimal – N (%) | Mild – N (%) | Moderate – N (%) | Severe – N (%) | Very severe – N (%) | Not applicable – N (%) |
|---|---|---|---|---|---|---|---|
| Delusions (14) | 11 (15) | 0 | 5 (7) | 6 (8) | 2 (3) | 1 (1) | 50 (66) |
| Hallucinations (13) | 10 (13) | 4 (5) | 5 (7) | 2 (3) | 1 (1) | 1 (1) | 52 (69) |
| Agitation (20) | 12 (16) | 4 (5) | 5 (7) | 7 (9) | 2 (3) | 2 (3) | 43 (57) |
| Depression (21) | 10 (13) | 5 (7) | 3 (4) | 13 (17) | 0 | 0 | 44 (58) |
| Anxiety (29) | 13 (17) | 3 (4) | 10 (13) | 14 (19) | 1 (1) | 1 (1) | 33 (44) |
| Elation (0) | 15 (20) | 0 | 0 | 0 | 0 | 0 | 60 (80) |
| Apathy (31) | 15 (20) | 10 (13) | 5 (7) | 12 (16) | 2 (3) | 2 (3) | 29 (38) |
| Disinhibition (7) | 13 (17) | 0 | 4 (5) | 2 (3) | 1 (1) | 0 | 55 (73) |
| Irritability (22) | 17 (23) | 5 (7) | 5 (7) | 8 (11) | 2 (3) | 2 (3) | 36 (48) |
| Aberrant motor behaviour (14) | 14 (19) | 9 (12) | 2 (3) | 3 (4) | 0 | 0 | 47 (63) |

Although apathy was the most common distressing symptom, the two most common symptoms for which the carers reported 'severe' or 'most severe' distress were delusions (3/14, 23%) and agitation (4/20, 20%).

Table 5.6a summarises the baseline and follow-up scores on NPI-DS and GHQ-12 in this sample.

**Table 5.6a: Baseline and follow-up scores of the carers' explanatory variables**

| Tools | Time (N =) | Mean (± SD) | Median (IQR) | Mode |
|---|---|---|---|---|
| NPI-DS | Baseline (75) | 5.64 (5.71) | 3 (1 – 10) | 0 |
| | Six-month (51) | 6.22 (5.76) | 5 (2 – 10) | 0 |
| | Twelve-month (48) | 6.23 (5.86) | 5 (2 – 8) | 0 |
| GHQ-12 | Baseline (75) | 2.65 (2.76) | 2 (0 – 4) | 0 |
| | Six-month (51) | 2.61 (2.68) | 2 (0 – 4) | 0 |
| | Twelve-month (49) | 3.16 (2.96) | 3 (0 – 5) | 0 |

### 5.3.5.3 Changes in the explanatory variables

We analysed the changes in the MMSE, NPI, BADL, OMFAQ scores, as well as GHQ12 and NPI-DS scores between baseline and six-month follow-up, baseline and twelve-month follow-up, and six- and twelve- month follow-up, using the Wilcoxon Signed Ranks test. The results are shown in Table 5.6b. It shows that for MMSE, NPI, BADL and GHQ, the changes between six and twelve months were more significant than those between baseline and six months. This was not the case with OMFAQ scores and NPI distress scores.

**Table 5.6b: Comparison of changes in the explanatory variables over the follow-up period[4]**

| Measure | Comparison[5] | N | Z | P value |
|---|---|---|---|---|
| MMSE | Base / 6M | 45 | -1.734 | 0.083 |
| | 6M / 12M | 37 | -3.324 | 0.001 |
| | Base / 12M | 35 | -3.001 | 0.003 |
| NPI | Base / 6M | 51 | -0.672 | 0.502 |
| | 6M / 12M | 49 | -1.452 | 0.146 |
| | Base / 12M | 49 | -1.806 | 0.071 |
| BADL | Base / 6M | 51 | -1.910 | 0.056 |
| | 6M / 12M | 49 | -3.281 | 0.001 |
| | Base / 12M | 49 | -3.012 | 0.003 |
| OMFAQ | Base / 6M | 48 | -1.105 | 0.269 |
| | 6M / 12M | 46 | -0.812 | 0.417 |
| | Base / 12M | 49 | -2.005 | 0.40 |
| GHQ12 | Base / 6M | 51 | -0.326 | 0.744 |
| | 6M / 12M | 40 | -5.518 | <0.0001 |
| | Base / 12M | 40 | -5.447 | <0.0001 |
| NPI-DS | Base / 6M | 49 | -0.363 | 0.716 |
| | 6M / 12M | 48 | -0.110 | 0.912 |
| | Base / 12M | 46 | -0.249 | 0.803 |

### 5.3.6 Secondary outcome variables

All the patients were being followed-up by the MHSOP clinicians as a part of the monitoring of their ChEI treatment. As every one of the subjects received these visits, these were not counted as 'formal help'. Any additional visits, contacts, or help offered by the health and social services was considered as formal help. Thirty-one subjects (41%) had received some formal help in the

[4] Cases with missing data were excluded on a case-by-case basis.
[5] Base = Values at baseline assessment; 6M = Values at six-month follow-up; 12M = values at twelve-month follow-up

six months preceding the baseline assessment. Four patients had had hospital admissions in the preceding six-months, six had had respite admissions of varying duration, twelve patients were attending day care, eleven patients were receiving home care including mobile meals, and a smaller numbers of subjects were receiving other helps such as sitting-in service, or help from their local church or other charitable organisations. Some had formalised the help they were receiving from their relatives or friends, and were paying for the help they were getting. These payments were made either from the patient's own monies, or with the monies paid to them as part of the 'direct payment' (Community Care (Direct Payment) Act 1996) by the local authority social services departments.

## 5.4 Comparison of high and low EE groups at baseline

The standard CFI criteria and cut-off scores were used in grouping the cases in high and low EE categories.

### 5.4.1 Demographic characteristics

The low and high EE groups were compared with regard to their basic demographic characteristics (Table 5.7). There were no significant differences between the two groups in any of the assessed demographic measures.

**Table 5.7: A comparison of the demographic characteristics of high and low EE groups[6]**

| Characteristic | Categories | High EE | Low EE | Chi square | P value |
|---|---|---|---|---|---|
| Patient gender | Female | 12 | 23 | 1.344 | 0.246 |
| | Male | 19 | 21 | | |
| Carer gender | Female | 22 | 25 | 1.556 | 0.212 |
| | Male | 9 | 19 | | |
| Mean age | | 76 ± 6.7 | 77 ± 6.8 | | 0.593 |
| Patient age group | Below 75y | 13 | 14 | 0.808 | 0.369 |
| | 75y + | 18 | 30 | | |
| Carer living with the patient? | No | 7 | 4 | 2.644 | 0.104 |
| | Yes | 24 | 40 | | |

### 5.4.2 Explanatory variables

Table 5.8 compares the high and low EE groups on the patients' baseline explanatory variables. These included severity of dementia (MMSE total score), severity of non-cognitive symptoms (NPI total score), functional ability (BADL scores), and overall physical health (summary OMFAQ scale). We also included carers' general health (GHQ-12 total score as a continuous variable) and carer distress (NPI distress score) at baseline as explanatory variables. There was no difference between the two groups on any of these variables.

[6] Categorical data analysed using Pearsons $x^2$ test, and continuous data analysed using independent samples t-test.

**Table 5.8: Comparison of baseline explanatory variables between High and Low EE groups**

| Explanatory variables | EE status (n) | Mean (±SD) | P value | T (df)[7] | 95% confidence interval |
|---|---|---|---|---|---|
| MMSE | High (28) | 22 (±4.17) | 0.813 | 0.238 (68) | -2.110 – 2.681 |
| | Low (42) | 21 (±5.35) | | | |
| NPI | High (31) | 13 (±11.43) | 0.241 | 1.182 (73) | -1.995 – 7.814 |
| | Low (44) | 10 (±9.79) | | | |
| BADL | High (31) | 17 (±9.18) | 0.518 | 0.649 (73) | -3.533 – 6.943 |
| | Low (44) | 16 (±12.42) | | | |
| OMFAQ | High (31) | 2.97 (±0.98) | 0.398 | 0.850 (73) | -0.293 – 0.729 |
| | Low (44) | 2.75 (±1.16) | | | |
| GHQ-12 | High (31) | 2.65 (±2.87) | 0.983 | -0.021 (73) | -1.316 – 1.288 |
| | Low(44) | 2.66 (±2.72) | | | |
| NPI-DS | High (29) | 6.34 (±5.39) | 0.393 | 0.860 (70) | -1.559 – 3.923 |
| | Low (43) | 5.16 (±5.92) | | | |

[7] T = Independent t test value with equal variances assumed, df – degree of freedom.

Table 5.9 shows that there was no significant difference between the High and the Low EE group on whether they were receiving 'any formal help'. It also shows that there was no significant difference between the low and high EE groups in the proportion of carers classed as 'cases' on GHQ-12.

**Table 5.9: Comparison of High & Low EE groups on the measures of help received at baseline, and caseness of the carers.**

| Baseline | | High EE | Low EE | Chi square | P value |
|---|---|---|---|---|---|
| Formal help at baseline? | No | 15 | 29 | 2.303 | 0.129 |
| | Yes | 16 | 15 | | |
| GHQ-12 5+ cases? | No | 26 | 31 | 1.795 | 0.180 |
| | Yes | 5 | 13 | | |
| GHQ-12 2+ cases? | No | 14 | 21 | 0.048 | 0.826 |
| | Yes | 17 | 23 | | |

## 5.5 Comparison of high and low EE groups at six months

### 5.5.1 Primary outcome

Only two patients were permanently institutionalised within six months of the baseline assessment. None of the patients had died within the first six months, but two of the carers had died and one of the carers could not be contacted.

The carers of the two patients who were institutionalised were both rated as having low EE at the baseline.

### 5.5.2 Secondary outcomes

Thirty-seven of the 48 (77%) subjects for whom information was available, received some formal help in the six months between baseline and six-month follow-up. Fifteen of the 19 high EE and 22 of the 29 low EE subjects received formal help. There was no significant difference between the two EE groups (Pearson Chi-square 0.062, two-tailed p = 0.804).

There was also no significant difference in the percentage of subjects whose formal help receiving status changed between the two assessments. Nine of 19 high EE, and 14 of 29 low EE subjects' formal help receiving status changed between the two assessments (Pearson chi-square 0.004, two-tailed p = 0.951).

### 5.5.3 Changes in the explanatory variables

The four patient explanatory variables (MMSE, NPI, BADL, and OMFAQ) and the two carer explanatory variable (NPI-DS, and GHQ-12) were measured again at six months.

Table 5.10 summarises the comparison of these variables between the high and the low EE groups. It indicates that there was no significant difference between the high and the low EE groups on any of the explanatory variables measured at six-month follow-up.

**Table 5.10: Patients' and carers' explanatory variables at six-months between high and low EE group (Independent samples t-test)**

| Explanatory variables | EE status (n) | Mean (±SD) | P value | T (df)[8] | 95% confidence interval |
|---|---|---|---|---|---|
| MMSE (6m) | High (17) | 21 (6.11) | 0.802 | 0.252 (46) | -3.394 – 4.365 |
| | Low (31) | 20 (6.52) | | | |
| NPI (6m) | High (19) | 16 (16.20) | 0.294 | 1.060 (51) | -3.593 – 11.632 |
| | Low (34) | 11 (11.29) | | | |
| BADL (6m) | High (19) | 17 (9.91) | 0.935 | -0.082 (49) | -7.711 – 7.106 |
| | Low (32) | 17 (14.1) | | | |
| OMFAQ (6m) | High (19) | 2.74 (0.73) | 0.423 | 0.809 (46) | -0.327 – 0.766 |
| | Low (29) | 2.52 (1.02) | | | |
| GHQ-12 score (6m) | High (19) | 2.53 (1.92) | 0.854 | -0.185 (48.807)[9] | -1.538 – 1.278 |
| | Low (32) | 2.66 (3.07) | | | |
| NPI-DS (6m) | High (19) | 7.47 (6.23) | 0.233 | 1.207 (49) | -1.334 – 5.344 |
| | Low (32) | 5.47 (5.43) | | | |

[8] T = Independent t-test value with equal variances assumed except see below, df = Degree of freedom
[9] T = Independent t-test value with equal variances not assumed

## 5.6 Comparison of high and low EE groups at twelve months

### 5.6.1 Primary outcome

Between the six- and the twelve-month follow-up, one patient died and one patient's domicile changed to an institutional setting. Seventy-one of the patients assessed at baseline, therefore, continued to stay in a non-institutional setting.

The carer of the patient who died had been assessed as displaying low EE, and the carer of the patient whose domicile was changed to institutional setting had been assessed as displaying high EE at baseline.

### 5.6.2 Secondary outcome

Information on whether subjects were receiving any statutory help from either health or social services in the previous six months (between the six- and the twelve-month follow-up) was available on all the 49 subjects who were followed up. Overall, 33 of these (67%) were receiving some help. Thirteen of the 19 high EE and 20 of the 30 low EE subjects received some help. The difference between the groups was not significant (Pearson chi-square 0.016, two-tailed P = 0.898)

Similar to the results at six-month follow up, there was no significant difference in the percentage of subjects whose help receiving status changed from six- to twelve-month assessment. Six of 19 high EE and ten of 30 low EE

subjects had a change of their help receiving status. (Pearson chi-square 0.016, p = 0.898)

### 5.6.3 Changes in the explanatory variables

The following table (Table 5.11) shows the comparison of the six explanatory variables as assessed at the 12-month follow-up, between the high and low EE group.

**Table 5.11: Comparison of the high and low EE groups on the explanatory variables at twelve-month follow-up.**

| Explanatory variables | EE status (n) | Mean (± SD) | P value | T (df)[10] | 95% confidence interval |
|---|---|---|---|---|---|
| MMSE (12m) | High (14) | 20 (6.84) | 0.593 | 0.539 (37) | -3.448 – 5.946 |
| | Low (25) | 19 (6.99) | | | |
| NPI (12m) | High (19) | 21 (18.70) | 0.061 | 1.922 (47) | -0.420 – 18.432 |
| | Low (30) | 12 (14.02) | | | |
| BADL (12m) | High (19) | 22 (13.07) | 0.339 | 0.966 (47) | -4.226 – 12.033 |
| | Low (30) | 18 (14.20) | | | |
| OMFAQ (12m) | High (19) | 2.63 (0.95) | 0.216 | 1.254 (47) | -0.220 – 0.950 |
| | Low (30) | 2.27 (1.01) | | | |
| GHQ-12 score (12m) | High (19) | 3.89 (2.58) | 0.170 | 1.393 (47) | -0.530 – 2.920 |
| | Low (30) | 2.70 (3.12) | | | |
| NPI-DS (12m) | High (18) | 7.22 (6.27) | 0.369 | 0.906 (46) | -1.939 – 5.117 |
| | Low (30) | 5.63 (5.63) | | | |

This table indicates that apart from a trend towards higher NPI scores in the high EE group, there was no significant difference between the High and the Low EE groups on any of the explanatory variables measured at twelve-month follow-up.

[10] T = Independent t-test value with equal variances assumed except see below, df = Degree of freedom

To explore the trend of the higher NPI scores in high EE group further, we compared the overall NPI scores at the three data collection points (baseline, six- and twelve- month) together, between the low and the high EE group by calculating the Area Under Curve (AUC) for the NPI scores of each subject and then comparing the AUC between the low and the high EE groups using the independent samples t-test. The mean values of the AUC for high and low EE were 195.95, and 126.20 (NPI scores X time in months) respectively. The difference was not significant (independent samples t-test t = 1.863, df = 47, p = 0.069, CI = -5.569 – 145.064).

We also compared the mean change in the NPI scores from baseline to twelve-month follow-up, between the high and low EE groups. The difference was not significant (independent samples t-test t = -1.245, df = 47, p = 0.219, CI = -13.17 to 3.19). Similarly, there was no significant difference in the mean change of MMSE, BADL, OMFAQ, GHQ-12, and NPI-DS, from baseline to twelve-month follow-up, between the high and low EE groups.

## 5.7 Comparison of high and low EE groups at two years

As the low rates of primary outcome in one-year follow-up did not allow a comparison of the low and high EE groups, we collected further data on the two-year primary outcomes on these subjects. These data were obtained from the hospital patient administration system.

Information was available on 71 of the 75 patients, with the records of four patients not clearly showing the two-year status.

At two years, 22 of the 71 patients (31%) had attained a primary outcome. Overall, ten of them had died. Eleven of the 28 patients (39%) from the high EE group had achieved a primary outcome, with four having died and seven having been institutionalised. Eleven of the 43 patients (26%) from low EE group had achieved a primary outcome, with six deaths and five institutionalisations. The difference between the two groups in the rates of these primary outcomes was not statistically significant (Pearson chi-squared 1.489, two-tailed P = 0.222).

## 5.8 Summary of results:

The results can be summarised as below.

- The sample consisted of 75 patients and their carers assessed at baseline.
- Sixty-four percent of the patients were over the age of 75 years. The majority of the patients (53%) were males and the majority of the carers (63%) were females. The majority of the carers (85%) were spouses.
- As a group, the patients were mildly cognitively impaired (MMSE mean 21.5; IQR 19 to 25), their physical health was generally good (OMFAQ summary score 2.84; IQR 2 – 4), and their level of functional impairment was mild (BADL mean 16.39; IQR, 9 – 25)
- The baseline levels of non-cognitive symptoms were of mild severity (NPI scores 11.29; IQR, 3 – 16)

- The rates of high EE in the sample using standard criteria were 41%.

- Nearly a quarter of the carers scored high enough on the GHQ-12 (5+) to be classed as cases. Using a lower threshold to define cases (2+), 53% carers were classed as 'cases'.

- The carers' distress levels to the non-cognitive symptoms in the patients were also mild (Mean NPI-DS score 5.64; IQR 1 – 10)
- The high and the low EE groups did not significantly differ on any of the measured parameters, either at the baseline, or at follow-ups at six and twelve months.

- Seventy-one of the 75 patients continued to stay in non-institutional settings at twelve-month follow-up. Three patients died and one changed his domicile to a residential setting. Levels of EE did not significantly influence the course or twelve-outcome of the patients with Alzheimer's disease in this sample.

- Two-year data on domicile status showed that 49 (69%) of the 71 patients continued to live outside an institution. Overall, ten patients had died and twelve were institutionalised. These primary outcome rates, although higher in high EE group (39% versus 26%), were not statistically different.

# Chapter Six

# Discussion

There are a number of aspects of this study that strengthen the confidence in its results. As with all studies, there are also limitations. Before discussing the study findings and the implications, a brief mention of these strengths and limitations is warranted.

## 6.1 Strengths of the study

Compared to the only other British longitudinal study (Bledin *et al.* 1990) on this subject, the present study has the advantage of a larger sample size. The only other longitudinal study (Vitaliano *et al.* 1993) had similar numbers of subjects at the baseline, but the follow-up numbers are not known. We calculated the sample size beforehand, and although we did not manage to recruit the numbers calculated, the final baseline sample size was close to the required number.

The sample in this study was also clinically more relevant than the other two studies. The sample in the Bledin *et al.* (1990) study consisted of a clinical sample of patients with 'Alzheimer's type or Multi-infarct dementia' (no operational criteria given), while the sample in Vitaliano *et al.* (1993) was a non-clinical sample and consisted of DSM-III-R Primary degenerative dementia sufferers. Our study sample was a clinical sample that had had a

comprehensive assessment and diagnosis as described in the methods section (Chapter 4.4.1). This would increase the generalisability of the results to the clinical population of AD sufferers on treatment with a ChEI drug.

The present study is the first of its kind to study the influence of EE on AD patients who were on treatment with a ChEI. With the increasing use of ChEIs and other drugs to treat AD, the subjects in this study are more likely to be representative of the clinical population of mild to moderately impaired AD patients and their carers than the patients from the earlier two studies. Similar to the findings in schizophrenia, the pharmacological treatment could have significantly modified the influence of EE on the course and outcome of AD patients. As in the future AD subjects are increasingly likely to be receiving such treatments, our sample is likely to be more representative of them.

Using a comprehensively but clinically diagnosed AD sample as opposed to one using more formalised criteria such as DSM-IV or ICD-10 also increases the generalisability of these results. In clinical practice, although AD is diagnosed on the basis of criteria very similar to ICD-10 or DSM-IV, these are not adhered to rigidly. Thus, patient with mixed Alzheimer's and vascular causes for their dementia may get excluded on the basis of formalised criteria but not clinically if the overall burden of vascular impairment is mild and the clinical history is more akin to that expected in AD. The sample in the present study is therefore not too diverse and heterogeneous on one hand, and not too restrictive and exclusive on the other.

The face-to-face follow-up at six monthly intervals is also an advantage over the earlier studies, where the follow-up was either by telephone or post (Bledin *et al.* 1990) or at a much longer interval of 15 to 18 months (Vitaliano *et al.* 1993). Symptoms and care needs of AD patients fluctuate over a much shorter period and a shorter follow-up is more likely to identify these changes. However, as discussed below, the impact of ChEIs may mean that long-term follow-up is also necessary.

## 6.2 Limitations of the study

When this study was planned in 1999, the aim was to investigate the influence of the informal carers' Expressed Emotion (EE) on the course and outcome of Alzheimer's disease sufferers. A number of assumptions were made in the planning of this study. Some of those assumptions were based on the available literature, and others were based on the clinical experience of the researchers.

During the data collection and analysis stage of the study, a number of limitations and difficulties were encountered. Some of those could not be overcome and hence they could have influenced the overall results.

### 6.2.1 The sample, the sampling, and the sample size

We were unable to achieve the required sample size of 47 subjects in each of the low and high EE groups. The sample size was based (see Chapter 5.2.1) on expected 15% annual rates of achieving the 'primary outcome' i.e. either death or institutionalisation. For 80% power, five percent level of significance, and

an expected 20% difference in the rates of primary outcome between low and high EE groups, a study with 31 subjects in high and 44 in Low EE group may not be sufficient.

In the study sample, the annual 'outcome' rates were much smaller (4 out of 75, or 5.3%). Clearly, with this 'outcome' rate, an even larger sample size would have been needed to have sufficient power in the study. This small sample size would lead to the higher risk of type two errors, and that should always be kept in mind when interpreting the results.

The population from which the sample was drawn for this study was of those patients who were diagnosed as suffering from mild to moderately severe AD by their treating psychiatrists, who were being treated with a ChEI drug, and were being monitored by the treating teams. This would have excluded a number of AD patients due to:

- severity of their illness;
- absence of a close relative to ensure compliance with the medications;
- co-existing medical conditions which preclude use of ChEI;
- those who were un-cooperative with either the medication or the monitoring;
- those who did not tolerate the medication;

- those who were deemed not to have benefited from ChEI treatment and in whom treatment was discontinued.

Thus, the sample could not be considered representative of the full range of AD patients that are generally assessed and managed by the old age psychiatric services in UK.

However, this relative homogeneity had its benefits too, as it allowed for controlling of the effects of other variables such as ChEI treatment, and certain co-existing cardiac conditions, which could otherwise have altered the course of the illness.

The recruitment process for this study was fraught with difficulties. Initially, we planned that all the senior psychiatrists would approach those of their patients who were potentially suitable for the inclusion. We sent sets of patient and carer information leaflets to the psychiatrists, with a request to give those leaflets to the patients and carers. It was soon clear that very few of the psychiatrists were remembering to ask and to give the leaflets to their patients and carers. This difficulty, combined with the fact that the principal researcher changed his job to a busy full-time NHS consultant, meant that the recruitment process virtually ground to a halt for a significant period of time. After some months, when additional assistance from a research associate became available, the recruitment process was reinvigorated and a more assertive approach was used. Even with this approach, however, patient recruitment was limited. The reasons for this are not known, but one possibility could be that the clinicians

may be reluctant to 'add' to the burden upon the carers already trying to come to terms with the diagnosis, learning about the treatments and various support services, and dealing with various appointments and visits by a variety of professionals.

It is therefore likely that a number of patients and carers could not be included because of failure in approaching all those who were potentially eligible.

### 6.2.2 The assessed, the assessor, and the assessment

In the data collection process, the majority of the interview was with the informal carer of the AD sufferer. The patient had to be interviewed only for the assessment of their cognitive function.

As the carers were mostly spouses who were themselves elderly, many had their own health problems and limitations. There were occasions when carer fatigue during the assessment was a distinct possibility, and although further meetings were sometimes rearranged, it is possible that for some of the questionnaires, their responses may not have accurately reflected their true intention or choice.

Another potential source of bias is recall bias by the carer. On questions about receipt of the formal help in the preceding six-months, there were occasions when the carer did not recall episodes that the patient was recorded as having received within that period. For example, some of them did not consider the patient attending a social day-centre, or visits by an occupational therapist, as anything to do with receiving formal help.

There were also a few carers who did not agree to participate in the study, and some of the reasons offered by them include:

*'I am too upset to talk about it.'*

*'I don't see myself as 'carer'.*

*'I don't want to 'express' my 'emotions'. I just want to get on with it.'*

It is therefore possible that those who agreed to take part in this study may not represent the true distribution of EE among the carers of AD sufferers.

Another potential for bias was introduced by the fact that the principal investigator was a senior clinician, and therefore the carers occasionally tended to digress from the research interview to a clinical problem-solving and information-gathering conversation. Although the principal investigator did not conduct research interviews with those patients and the carers with whom he and his team were clinically involved (they were interviewed by the research associate), it is always possible that this clinician – researcher role confusion by the carers and the patients may have introduced a bias in their responses.

There were at least two aspects of the assessments, which could have introduced bias. The first was the location of the interview and the presence of the patient, and the second was the length of the interview and the variety of the assessments, especially at baseline.

Most of the interviews were conducted in the patient's or the carer's house, and majority of the interviews with the carer were carried out when the patients had

either gone out somewhere or the patient was in different room from the interview room. Some patients though, tended to return into the interview room, or were nervous about 'being talked about them behind their back'. The potential presence of the patient may have limited some carers' willingness to express themselves freely.

The baseline interview lasted for around 90 minutes. The first 60 to 75 minutes were the audio-recorded Camberwell Family Interview Schedule (CFI). The last 15 to 30 minutes were the administration of the rating scales. Occasionally towards the end of the interview, the carers became rather tired, and may not have been concentrating on the assessment questions to the same extent that they had been at the beginning.

This research project was carried out by the principal researcher alongside his full-time NHS consultant old age psychiatrist's responsibilities. This study was not a part of another research programme. Although the principal researcher's 'consultant job plan' had one half-day a week of research time, in practice this was not always available and the research activity had to be woven into the clinical work or had to be done in private time. There was no dedicated support staff for this research project until 2003, when a University research associate assisted the principal researcher with recruitment and data collection.

### 6.2.3 The instruments and what they measured

The details of the instruments that were used in this research have been discussed in the chapter on methods (Chapter 4.3)

In relation to the use of the CFI with the carers of the dementia sufferers, it is worth noting that the interview schedule has been modified to make it more appropriate for dementia sufferers' families. Although this is acceptable, is done for research in a range of conditions, and the modifications were approved by one of the original author of the CFI (Dr Christine Vaughn), it raises the issue of whether the original CFI schedule and schedule with these modifications are equivalent in their ability to identify the high and low EE carers.

Although in this study we chose to use the standard criteria for the categorisation of the EE, the literature on EE and dementia has argued for the cut-off threshold to be different, due to inherent differences in the carers, the patients and the perceived nature of the illness. Some of the published studies have used different cut-off criteria, and their results may not be comparable with ours.

### 6.2.4 The Diagnostic accuracy

We accepted the diagnosis of AD given by a senior psychiatrist and did not systematically check its accuracy. In virtually all the cases, the diagnosis was based on a clinical assessment by a senior psychiatrist, along with either a CT or an MRI brain scan, as well as a wide range of screening blood tests to exclude other conditions which might contribute / cause symptoms akin to those of AD. One reason for the choice of patients receiving ChEI drugs was that a high and consistent level of accuracy of the diagnosis could be assumed.

However, as we did not independently check this using operationalised diagnostic criteria, it is possible that there may have been some patients with 'mixed' vascular and Alzheimer's disease, or indeed other co-existing psychiatric disorders. There were practical limitations in formally using research diagnostic criteria, as sometimes information on the longitudinal course and previous illnesses wasn't readily available from the informal carer, and therefore it was difficult to establish presence of necessary diagnostic criteria without looking at collateral sources of information.

However, the purity of the diagnosis of AD was not considered critical for the purpose of this study. The main reason for restricting inclusion of patients to those with AD was to minimise the potential for bias due to different course and outcomes of different types of dementia and their inclusion would have introduced another potential explanatory variable and rendered results more difficult to interpret. By only recruiting those patients who were receiving a ChEI, we reduced both the bias due to different subtypes of dementia and also bias due to the effects of treatment with ChEI.

## 6.3 What do the results mean?

Before discussing this issue, it is important to note that in this study sample, only a very small minority (5%) actually reached the primary outcome (survival or institutionalisation). In contrast, the secondary outcome (formal help received) was extremely common (77% and 67% at six and twelve months respectively), with the majority of patients in both groups achieving it. It is

therefore possible that these outcome event rates (very uncommon or very common) limit statistical differentiation of the two groups from such a small sample for a relatively short period of follow-up. Notwithstanding the prevalence of the outcomes in this study, the results can be summarised by the following two statements:

- The levels of baseline EE in the carers did not influence the primary outcome of interest, i.e. survival or the risk of institutionalisation of the AD patients over a twelve-month period.

- The levels of baseline EE in the carers did not influence the secondary outcome of interest, i.e. receipt of formal help by the AD patients and their carers over a twelve-month period.

### 6.3.1 Levels of EE and survival of patients

Only one of the 75 patients died over the 12-month follow-up, and that patient had a low EE carer. In the study by Bledin *et al.* (1990), although the mortality rates were high (five out of 25 had died at nine-month follow-up), the rates were no different between the high and the low EE group. Their patient group was older than this sample (mean age 82.4 years; our sample's mean age 76.8 years), had predominantly female patients (over 80% (21 / 25); our sample 47% (35/75) female patients), and they had a diagnosis of "Alzheimer's type or Multi-infarct dementia".

The mortality rates in patients with AD vary with the stage of the disease and with the coexistence of other factors such as cardiac problems and cerebro-vascular ischemia. As a group selected for ChEI treatment, this sample is expected to be relatively free of significant cerebrovascular disease and certain cardiac problems (e.g. supra-ventricular arrhythmias). In addition, the fact that these patients were in the milder stages of illness, were being treated with ChEIs, and the majority of them had a cohabitant spouse could mean that they were at a lower risk of dying (Yaffe *et al.* 2002).

Due to such low rates of 'outcome', it is not possible to meaningfully compare the high and low EE groups. There is very little published literature investigating the influence of EE on the survival in other chronic disorders in the elderly. In one study investigating the influence of EE in patients with chronic heart failure (Benazon *et al.* 2006), EE was not found to predict survival in 137 male and 47 women patients with this condition.

The two-year data on these patients' survival and domicile status showed that although numerically more patients from the high EE group had had the primary outcome (39% versus 26%) at two years from baseline, the difference did not reach statistical significance.

Further follow-up data may be valuable for a survival analysis, comparing the high and the low EE groups. Studying the survival rates in carers would also be of interest. These analyses require a longer-term data not available at the time of writing this thesis.

### 6.3.2 Levels of EE and risk of institutionalisation

Only three patients were placed in an institutional setting over the twelve-month follow-up. Two of them had a low EE carer and one had a high EE carer. Similar to the survival rates, such low rates do not allow for any meaningful comparisons to be made between the two groups.

There are several possible reasons for such low rates of institutionalization, including the fact that most of the patients were in the mild to moderate stages of dementia, functioning at a mild level of impairment with a slower rate of decline of their activities of daily living, were cooperative with the help they were getting, and were living with a spouse.

Additionally, the fact that local old age psychiatric services are fairly well developed, and carers of AD patients (specially those who are regularly monitored in the anti-dementia drug treatment clinics) are routinely and proactively offered a range of educational, supportive and practical help from health and social services, could also explain why in the first twelve months of the follow-up the institutionalization rates were much lower than what the literature would predict for AD patients generally. There are studies that show that providing educational, counselling and other support to the families reduces the risk of institutionalization (Mittelman *et al.* 1996, Brodaty *et al.* 1993) of patients with dementia.

The only other British longitudinal study (Bledin *et al.* 1990) also found that the EE status in the carers did not predict the risk of institutionalisation. Their

sample was different, however, as described in Chapter 3.2.2.1. In that study, only 17 out of the 25 carers remained as the primary carer at 9-month follow-up. Two patients moved in an institutional setting, five patients died and one patient had a change of carer from the daughter to son. However, despite these differences, the findings were similar.

Another possible reason why there were no differences in the primary outcome between the low and the high EE group may be the effect of ChEI medication. In the schizophrenia literature, it is well known that patients living in high EE environments are relatively protected from relapse if they are on regular neuroleptic medication (Leff *et al.* 1983). All the patients in this study were on regular ChEI therapy and were thought to be benefiting from it. It is possible that the medication may have had some protective effect on the risk of behavioural relapse. The results of this study show that the NPI scores of the patients with a high EE carer were slightly higher at the baseline and the difference between the two continues to increase at six and twelve months. At twelve months the difference approaches significance at the 0.05 level ($p = 0.061$). It is possible that had this group not been on treatment, the differences in the NPI scores (and therefore the behavioural / non-cognitive symptoms) would have been greater.

### 6.3.3 Levels of EE and survival of carers

Although death of the carer was not identified as an outcome variable at the outset of this study, two carers died within the first six months of the initial

assessment. Both the carers had been rated as expressing low EE at the baseline. Both the carers were spouses (a husband and a wife) of the patients, and neither the caregiver factors nor the patient factors in these two cases were significantly different from rest of the sample. It is not possible to comment further on the causes of death in these two carers, but generally, as most of the carers were spouses and were themselves elderly, a degree of age-related mortality in this sample can be expected. The caregiver role has been reported to be an independent risk factor for mortality (Schulz and Beach 1999).

### 6.3.4 Levels of EE and the 'formal help' received

Relationship between the levels of EE and formal help received by the patients and the carers is unclear. The association between high EE daughters of dementia sufferers and increased likelihood of utilising respite care (Bledin *et al.* 1990) could indicate that the respite care may have been a service response to the high EE situation. However, as those high EE carers were also likely to have had no living siblings, this means that the respite break could merely be a substitute for the breaks that such close relations (such as a sibling of the carer / child of the patient) would have offered.

In this study, over half of the high EE relatives were receiving some formal help at the baseline, but only one-third of the low EE relatives were receiving such help. The difference, though noteworthy, was not statistically significant.

It can be hypothesised that the high EE relatives are offered and receive formal help sooner than the low EE relative, but eventually virtually all of those who have some unmet needs get the appropriate services.

In schizophrenia research, there is evidence that reducing face-to-face contact between the high EE carer and the patient (to less than 35 hours a week) is one of the effective ways to reduce the probability of relapse (Vaughn and Leff 1976). A number of statutory services offered (such as day centre or day-hospital attendance, sitting-in services, activities group, luncheon clubs, respite care) may, directly or indirectly, help in reducing this face to face exposure by physically removing the patient from contact with the (high EE) carer and hence reduce the risk of relapse. In relation to dementia research, this possibility has not been systematically investigated. In contrast to dementia patients, those suffering from schizophrenia do not in general spend nearly whole of their time with one close (spousal) relative. In dementia subjects it is very difficult to reduce the exposure levels to below (or anywhere near) 35 hours per week, even with a fairly comprehensive care package, for obvious reasons. It is not even known whether such a reduction is of any benefit to these patients. Such drastic attempts may even have negative effects by unsettling the patients and making their confusion even worse.

In this study, the relationship between the duration of face-to-face exposure and the outcome was not systematically investigated, for two reasons. First, it was difficult to estimate accurately this period in spousal carers (who constituted 85% of the sample), due to their virtually spending all the time

(both day and night) with the patient, with only a very small and variable amount of time being spent away from each other. Second, there was a clear split between the spousal and non-spousal carers, with the later having much less face-to-face contact. We therefore compared the outcome, and EE status between the spousal and non-spousal carers rather than comparing the effect of the duration of face-to-face exposure. In this study, the proportion of cohabitating carers were not significantly different between the low and the high EE groups (24 / 31 in high EE group, and 40 / 44 in low EE group; Pearson chi-square 2.644, p = 0.104)

### 6.3.5 Levels of EE and the explanatory variables

The follow-up data strongly support the conclusion that this study sample not only consisted of mildly impaired subjects, but also that the changes over the twelve months were few compared to other studies, and to what is generally known about the rates of decline in patients with dementia.

The mean MMSE change was only about 2 points over the 12-month period (Mean MMSE score of 21.5 at baseline, and 19.13 at 12-month follow-up - Table 5.4). This remained the case even if only those patients who had both baseline and 12-month MMSE records (N = 39, baseline MMSE = 21.13; MMSE at 12 months 19.13) were included. This relative stability of MMSE was noted in both the high and low EE groups (high EE – from 21.7 at baseline to 19.9 at 12-month, and low EE – from 21.4 at baseline to 18.7 at 12-month).

This is in contrast to the study by Vitaliano *et al.* (1993), where the MMSE scores declined from 20.5 at baseline to 13.5 (Low EE group) and 15.5 (High EE group) over 15 to 18 months follow-up. Generally, for untreated mild to moderate Alzheimer's disease an annual decline in the MMSE score of around 4 points is considered average.

Non-cognitive symptoms in Alzheimer's disease are very common. In this sample, 71 out of 75 patients had one or more non-cognitive symptoms at baseline. However, the severity of these symptoms was mild, and they only became slightly worse over the 12-month follow-up (Table 5.4)

It is worth noting that at baseline, the high EE group patients had a slightly higher NPI score. This did not reach statistical significance, but the difference progressively widened at six and twelve months. It is possible that a persistently high EE environment leads to a progressive increase in the negative behaviour. It is also possible that the high EE carers rate the patients' behaviour more negatively, and this tendency increases with time.

It is also worth noting that, although neither GHQ nor NPI-DS scores were significantly different between high and low EE group, the NPI-DS scores for high EE group were marginally higher than those of the low EE group at each of the three points of assessments; this was not the case with the GHQ scores. Another hypothesis that can be raised is that the distress of the dementia carers is relatively specific to individual symptoms, and not a feature of their general health.

The BADL scores in this group also altered very little' from 16.39 at baseline to 19.35 at 12-month follow-up. The difference between the high and low EE groups was insignificant and inconsistent (the high EE group was marginally more impaired at baseline and twelve-month, and marginally less impaired at six-month follow-up). The BADL has been specifically developed for use in patients with dementia (Bucks *et al.* 1996), and has been shown to be sensitive to changes in mild to moderately severe AD (Byrne *et al.* 2000). It can therefore be said that there was little change in the dementia severity over the twelve-month follow-up.

## 6.4 Some methodological issues

### 6.4.1 Study design

A prospective cohort study would be the appropriate method to ascertain the influence of the exposure to an alleged factor such as EE on the occurrence of outcomes such as mortality or institutionalisation. However, a shorter (twelve-month) follow up may not be sufficient for enough outcomes to take place to allow for statistical comparison. Certain features of this sample would have made the probability of outcomes events happening in the first year even less likely. These include the mild to moderate levels of cognitive impairment; the patients being generally cooperative with the treatment and support; that they were relatively free of cerebrovascular and certain cardiac risk factors; they were well supported mostly by a cohabitant spousal caregiver but also by a wide range of formal help from various agencies.

As more and more patients with AD are likely to be treated with ChEI or other groups of anti-dementia drugs, there is a possibility that the course of AD on treatment may not progress as rapidly as in untreated patients. This would mean that future follow-up studies in similar subjects might need to be of longer duration for any differences to reach significance. It is possible that a similar study with more severely impaired dementia patients, patients with different types of dementia or those with significant non-cognitive or functional difficulties at baseline could yield different results.

### 6.4.2 Choice of outcome measures

The primary (survival or institutionalisation) and the secondary (formal help) outcomes chosen in this study were considered to be relevant, both clinically and from the service development perspective. They could however be construed as rather crude and unsophisticated. They may represent the end point of a number of other, more intermediate outcomes. Due to the complex interplay of a large number of psychosocial and biological factors in shaping the occurrence of the outcomes used in this study, not all such confounding factors were either measured or their effect controlled for.

Instead of these outcome measures, some other intermediate outcome measures could have been chosen. The examples include the markers of stress in the patients, the caregiver burden, the qualitative aspects of the relationship between the patient and the carer, or a more detailed economic analysis of the formal help received by the subjects. The latter is particularly noteworthy

because due to the diverse nature and extent of the formal help, it was not possible to compare individual aspects of it between the high and low EE groups. A detailed economic analysis would have allowed quantification of various formal help activities on some kind of economic continuum and could have allowed better comparison.

### 6.4.3 Information quality

Another issue to consider in this study is the informant fatigue and its effect on accuracy and comprehensiveness of the information. Ideally, multi-source information obtained over multiple short sessions may yield better quality and quantity of the information. This was not possible due to the resource limitations in this study.

We dealt with this issue in a pragmatic manner by allowing the carer to decide whether they wished to continue with the research assessment or to book another appointment, but the large number of assessment tools and the diverse manner in which they are rated can cause some uncertainty in the responders mind and may lead to erroneous responses.

# Chapter Seven

# Conclusions

The levels of expressed emotion of the informal carers of mild to moderately impaired AD sufferers, who were receiving ChEI treatment and follow-up from the old age psychiatry services, do not influence the course of AD over a twelve-month follow-up or its outcome over a two-year period from the baseline assessment. Considering that EE has been shown to influence the course and outcome of a number of other conditions, these negative results generate questions about why this might be. The limited literature of EE in dementia also suggests a lack of influence of EE on the risk of institutionalisation or death. Such lack of association between carer EE and mortality has been reported in other conditions such as CCF.

The importance and the popularity of the concept of EE are largely because of its predictive power and its amenability to therapeutic interventions. The evidence from the present study, suggesting that EE lacks such attributes in dementia sufferers in general and AD in particular, raises the possibility that the influence of EE on various conditions may be on a continuum, with certain illnesses (such as depression or eating disorders) being significantly influenced by it, but with others (such as dementia) being relatively unaffected.

The other possible reasons for this non-significant association include the limitations of the instruments used to measure the course and the outcome and

also the possibility that a well developed old age psychiatric services, with overwhelming majority of all the patients receiving some 'formal help', along with ChEI medication may have influenced the course and outcome in this group of patients and the carers and reduced any potential differences in the two groups. One way to investigate the longer term effect of EE on AD patients is to undertake a much longer term monitoring of their survival and domicile changes and undertake a survival analysis.

As the CFI used in this (and few other) study was modified for use in dementia subjects, the effect of those modifications on its ability to identify high EE carers also needs to be established. Another area of interest will be to investigate the appropriate cut-offs for optimal and meaningful differentiation between high and low EE subjects.

# Chapter Eight

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# Chapter Nine

# Appendices

9 Appendices

9.1 Ethical approval

9.2 Modified CFI

9.3 GHQ-12

9.4 MMSE

9.5 NPI and NPI-DS

9.6 BADL

9.7 OMFAQ summary physical health rating

9.8 Health and social care help

9.9 Letter on behalf of the consultant

9.10 Patient information leaflet

9.11 Carer Information leaflet

9.12 Consent form

**Appendix 9. 1**

# Leicestershire, Northamptonshire and Rutland Health Authority

NHS

From the office of Melanie Sursham
Direct Dial 0116 258 8610

Your Ref
Our Ref ms/bak

Gwendolen Road
Leicester
LE5 4QF

Tel: 0116 273 1173
Fax: 0116 258 8577
Mini Com: 0116 258 8640
DX 709470 Leicester 12

3 July 2002

Dr M Marudkar
Consultant in Old Age Psychiatry
Evington Centre
Gwendolen Road
Leicester LE5 4QG

Dear Dr Marudkar

**Influence of Carers' expressed emotion (EE) on the course and twelve-month outcome of patients with Alzheimer's Disease - our ref.no. 6681**

I have received a copy of your letter dated 29 May 2002 addressed to Dave Clark, Research & Development Manager and thank you for your helpful response to my letter dated 10 May 2002.

All the Committee's concerns have now been addressed and by Chairman's action formal approval is given for this study to proceed.

Yours sincerely

**P G Rabey**
**Chairman**
**Leicestershire Research Ethics Committee**

**(NB All Communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire, Northamptonshire and Rutland Health Authority. If however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way)**

## Appendix 9. 2

### CAMBERWELL FAMILY INTERVIEW

**INTRODUCTION**

FIRST STATE THE FOLLOWING:

DATE:
RESPONDENT:
CARER CODE:
RELATIONSHIP TO PATIENT:

In this interview, I will ask you some questions, which refer to the kinds of problems faced by carers and families of people with memory problems.

There are no right and wrong answers; I simply want to have your impressions of how the condition has developed and what it has been like coping with the problems over the last few months.

**BACKGROUND INFORMATION**
[Composition of the household, i.e. sharing the same cooking facilities]

1. Does your _____ live here with you?

2. Has that always been the case?

3. So, is it safe to say that during the last 3 months, your _____ has been living here with you?

4. Does anyone else live here besides you and your _____?

If No, Move On To '**Patient History**'

5. If so,

(i) How is [each person mentioned] related to you?
(ii) Roughly, how old is each person?
(iii) What does each person do for a living?
- Do they work?
- Are they still at school?
- Are they unemployed?

6. So, just to confirm, how many people live here in total?

**PATIENT HISTORY - PHYSICAL ILL HEALTH**

1. Does your _____ have any problems with their physical health? For example, heart problems, high BP, Diabetes, problems with their chest, deafness, infections, etc.

2. Has there been any changes in her/his physical health recently?

If No, Go To 4

3. If yes, have any of these problems affected his/her behaviour?

4. Has there been any change in his/her medication over the last few months?

If No Go To Next Section

5. Has the change in medication affected her/his behaviour at all?

**SECTION A - VERY IMPORTANT QUESTIONS**

1. I would like to begin by asking you when your _____'s memory problems first began?

2. So that was how long ago? years and months?

3. And, when did you first notice something different about your _____'s behaviour?

4. What brought the problem to your attention? [and /or: What kinds of behaviour were different?]

5. Can you GIVE ME AN EXAMPLE of her/his behaviour at the time (or GIVE ME AN EXAMPLE of how her/his behaviour had changed?)

6. How would you react?

**LAST 3 MONTHS**

1. How have things been over the last 3 months?

2. Has your _____ 's behaviour got any worse lately or harder to manage?

IF A LOT OF INFORMATION GIVEN SPONTANEOUSLY, ASK: How have you managed to deal with this - And Then Go To Next Section or proceed with 3.

3. Has there been any incidents or crises involving your _____ recently?

4. Or, has there been any kind of upset in the household during which time s/he was particularly forgetful and difficult to manage?

4. What happened?

5. During the last 3 months can you think of any thing else that has been different about your _____?

6. Can you give me an example what did s/he do?
   (a) When did s/he first begin to behave in this way?
   (b) How often does this happen?
   (c) How do/did you react?
   (d) How do/did the rest of the family who were around at the time react?
   (e) Have you found any way of managing or containing this?
   (f) What do/did you do?
   (g) Was it effective?

**FAMILY TIME BUDGET (Last 3 months)**

I now want to get an idea of how your _____ spends her/his day and of the amount of contact s/he has with each member of the household.

1. At what time would your_____ usually get up?

2. Would s/he eat breakfast? With you? With the rest of the family?

3. How would s/he spend the afternoon? [Are you with her/him in the afternoon?

4. In the evenings what would s/he do? Watch TV and chat to the rest of the family?

5. What time would s/he go to bed?

6. And how about weekends? Is your _____'s routine more or less the same or different?

[If different, repeat questions as above]

7. Does s/he go to a day-centre?

8. Roughly how often are you out of the house without your _____, say to go shopping, out in the evening or to church?

9. So then, roughly, how much time do you spend with your _____?
Most of the time with the exception of the odd morning or afternoon a week? Weekdays only?

10. How much time would each of the other members of the family spend with your _____?
Most evenings during the week and more time on weekends?

**SECTION A1 (IRRITABILITY)**

Okay, moving on. One of the ways which these problems can affect people is to make them more irritable. By this, I mean snappy, raising their voice, or flying off the handle at things that would not normally bother them.

1. How regularly would you say your _____ is irritable or snappy?

2. Can you give me an example of the type of thing that would make her/him irritable?

3. Is there any particular time of day or type of situation which sparks of this irritability [e.g. mealtimes, toileting]

If Information Is Given Spontaneously - Go To 9 otherwise proceed

4. Would s/he ever become cranky and refuse to cooperate with yours / others attempt to help her/him?

5. Does s/he ever criticize you and your attempts to help her/him?

6. Is s/he ever demanding of you with respect to the care you provide, demanding that you do such and such or that you do something in an unreasonably quick fashion?

7. What would happen if you did not do something s/he asked?

8. Is s/he snappy or cranky with anyone in particular? [Mention each member of household]

9. When was the last time that s/he was irritable? What happened?

10. Have you come up with a strategy for dealing with her/his irritability [even just ignoring]?

11.* Would you ever avoid things that may result in becoming irritable? (e.g. specific situations that may lead to ...)

12. How effective is this?

13. What do you think makes your _____ like this?

[14. Do you think s/he could do more to control this irritability?]

**SECTION A2 (QUARRELS)**

1. Most families have quarrels or arguments from time to time, apart from the sort of crankiness we have been talking about, has your _____ had any rows or quarrels with you or anyone else in the family?

If No Go To Next **Section A3** otherwise proceed

2. What would happen during these quarrels or arguments?

3. What happened the last time?

4. How long would a typical quarrel last? [only record if longer than half an hour]

5. What would happen following a quarrel or disagreement of this nature?

**SECTION A3 (NAGGING AND GRUMBLING)**

1. Apart from the quarrels we have just spoken about, do you ever nag or grumble at your_____ ?
[Just in case I need to explain, nagging involves moaning or just going on about something]

2. What sort of things do you complain about?
[2a. What would be the type of thing that you would say?]

4. How often has this happened in the last week? ...month?....3months?

5. Would others in the family ever nag or grumble at your _____?

6. (ASK IF APPROPRIATE) How much nagging or grumbling would there be between you and others in the household?

**SECTION B**

Now, we move on to some questions about the way your _____'s trouble with her/his memory may have affected her/him and about the sorts of behaviour people we see at the hospital sometimes have. Many won't apply to your however, I need to run through all the questions in order to get as full a picture as possible.
So, perhaps you could answer the following questions for me, bearing in mind that they refer to the last 3 months/[ the time around the incident] in particular.

**SECTION B1 (BODILY FUNCTIONS)**

SLEEP
1. Has/did your _____have any difficulty getting to sleep?

2. Does this happen often?

If Infrequently Go To 5

3. How do you cope with this problem occurring as frequently as it does?

4. Have you changed the way you do things because of this? For e.g. re-arranging your own or the children's bedtime?

5. Has your _____ ever been restless or wakeful during the night recently?

If No Go To 11

6. Would s/he do anything when s/he is awake at night? [e.g. get something to eat, make tea]

7. How often would s/he get up at night?

8. Does this affect you & the rest of the family? Would your ___s restlessness ever waken you or them up at night?

If No Go To 11

9. How do you react? How does the rest of the family react?

10. Have you changed the way you do things because of this? For e.g. changing sleeping arrangements, sleeping beside your _____ ?

11. Does s/he wake up early now?

If No Go To 15

12. Does it happen often?

13. How do you cope with this?

14. Have you changed the way you do things because of it? Maybe get up earlier yourself?

If No To All These Questions Move To Next Section Now

15. What do you think has caused this change in your _____ 's sleeping habits?

16. Do you think that there is anything that s/he could do to deal with it her/himself?

APPETITE

1. In general, has your eaten about the same amount as s/he did before the problems started?

2. Has s/he eaten roughly the same kinds of things?

3. Has his/her eating style changed at all?
   Does she eat at a faster rate than before?
   Does s/he ever spit out food?
   Does s/he ever use her/his hands to eat?

If No To All These Questions Go To Next Section Now

4. Has s/he ever done this in front of visitors or when you have been out?

5. Did this make you feel on edge?

6. Do you think s/he could have done more to control it?

SEXUAL BEHAVIOUR

Occasionally people with memory problems show a marked change in sexual behaviour? So,

1. Does your _ ever speak crudely, or talk inappropriately about sex?

If No Go To 4

2. How often does this happen?

3. How do you feel about this? How do you react?

4. Has s/he ever made [any inappropriate] advances to people s/he may not know very well?

If No Go To Next Section Now - B2

5. Has s/he behaved in this manner recently?

6. How would you react when s/he does this?

**SECTION B2 (MEMORY LOSS)**

I know that we mentioned memory problems a short while ago, but now 1 want to ask you a few specific questions about the type of problems your has been having with her/his memory.

1. Does your____ have difficulty finding her/him way about the neighbourhood e.g. to the shops or Post Office near home?

2. Does s/he have any difficulty finding her/his way about the home (or ward), e.g. finding the toilet?
If No Go To 5

3. When did s/he last have this type of difficulty?

4. How did you react, what did you say?

5. Would your _____have more difficulty remembering short lists of items e.g. shopping

6. Does s/he have difficulty remembering recent events e.g. when s/he last saw you, or what happened the day before?

7. Does s/he have any difficulty interpreting her/his surroundings? e.g. knowing where s/he is? Or discriminating between different types of people such as relatives, visitors, doctors?

8. (Ask if appropriate) How do you react, when, for example, s/he does not recognise members of the family?

9. Do you think that perhaps s/he could do more to control this aspect of her/him memory problem?

**SECTION B3 (DAILY ACTIVITIES)**

I am now going to move on to deal with a few questions related to your _____'s ability to look after her/himself?

1. Is s/he able to wash and dress her/himself without help?

2. Is s/he able to manage the stairs unaided?

If Person Appears To Be Able And Well Go To Next Section

3. How do you feel about providing this help as frequently as you do?

4. Is s/he able to use the toilet without help?

5. Are there problems with soiling or wetting?

If No Go To 8

6. Has s/he ever gone to the toilet in inappropriate places?

7. If yes, does s/he appear concerned or indifferent to what s/he has done?

8. Do you think s/he could do anything to manage these problems better?

**SECTION B4 (**

1. Moving on, would you say that your _____ ever seems disinterested in or unaware of her/his surroundings?

If No Go To 4

2. When did this first begin?

3. How do you cope with his/her disinterest

4. How would you describe your _____ 's spirits at the moment [low/high]? Have they ever been low?

5. Would/does s/he ever appears sad, tearful or depressed?

If No Go To 9

6. What makes you think this? [OBTAIN EXAMPLE]

7. How do you react?

8. What do you think caused your _____ to be like this?

9. Has s/he ever [reacted in what appeared to be an overly emotional way] become extremely distressed over something small, a failed attempt to do something [ e.g. a task/job around the house]?

10. How did you react?

11. Have there been times recently, when s/he has been very anxious or frightened?

If No Go To Next Section

12. What happened?

[13. If not spontaneously elicited - what caused her/him to become anxious?]

14. How did you cope with this?

**SECTION B5 (**

1. Has your ever become jealous of the way you treat others?
Your husband?
Your children?
Your / his(her) friends or relatives?

2. Has s/he ever accused you of things, for example: following or spying on her/him?

3. Has s/he ever been suspicious that people were against her/him? E.g. that people were stealing things (things that s/he has mislaid), following or spying on her/him, plotting against her/him? Is s/he suspicious about the neighbours?

Go To 5, if the answers to 1, 2 & 3 have been YES

4. Has s/he ever expressed any other strange or odd ideas? For example about being abandoned, about someone else living in the house, or about this house not being her/his home? [Include Capgras here - i.e. others being replaced by an impostor]

If No To Everything, Go To Next Section

5. How do you deal with this? How do you react in yourself?

6. What do you think has made your _____ express these odd ideas or makes these strange accusations?

7. Do you think s/he could do more to control these ideas?

**SECTION B6 (**

1. Has your _____ ever talked to her/himself at all or laughed at her/himself?

2. Do you think your _____ has heard or seen things which are not really there. For example, heard imaginary voices or seen imaginary things?

3. What do you say to her/him concerning these odd ideas?

4. How does s/he react?

[5. How do you deal with this?]

6. Do these ideas limit your _____ at all - such as not being able to get out?

7. Do these strange claims that your _____ makes limit you in any way, such as being unable to call to see friends together or have guests around to the house? [RATE MISIDENTIFICATIONS HERE IF THEY ARE MENTIONED]

**SECTION B7 (**

1. I know we talked about general irritability a while ago, but has your _____ ever been physically aggressive, for example hitting, kicking, scratching, pushing or spitting in an aggressive manner?

If No Go To 4

2. What happened?

3. How did you react [emotionally]?

4. Would s/he ever have been verbally aggressive with anyone, raised her / his voice in anger, used sharp words or threatened anyone?

If No Go To 7

5. Would this happen often?

6. How do you deal with it?

7. Would s/he ever have been destructive and knocked things about the house?

If No Go To Next Section

8. Has this happened recently?

9. How do you react?

**SECTION B8 (ASK FIRST IF S/HE HAS ANY PROBLEMS WITH MOBILITY)**

1. Does your _____ ever walk about the house or follow you around?

2. Does it make you feel on edge?

3. Does your ever behave in a dangerous manner? .... smoke in bed?... leave water taps running?.... leave electrical appliances turned on?

If No Go To Next Section

4. What happened the last time?

5. How do you react when this happens? [how does this make you feel?]

6. Do you think s/he could do more to make sure that her / his behaviour is safe?

**SECTION B9 (**

1. Is s/he ever restless or agitated, not being able to sit at peace?

2. When did this happen last time?

3. Does this make you feel uneasy or on edge at all?

4. Has s/he ever had times of being more talkative.... asking lots of questions?

5. Do you think s/he could do anything more to control this?

If No Go To 7

6. How do you react to her / his asking these questions?

7. Has s/he ever seemed particularly slow at doing things [e.g. dressing, shaving]

If No Go To 9

8. How do you cope with this?

9. Has your _____ got any unusual habits for e.g. would s/he ever move objects around or hoard them?

If No Go To Next Section

10. How do you manage to deal with these behaviours?

11. Do you think s/he could do more to control these actions?

**SECTION C**

**SCETION C1**

1. From your own point of view, what has been the most disturbing aspect of your _____'s problems?

If Response Is Quite Thorough Go To Next Section

2. Has it made any difference to your social life?

3. Has the amount of private time you allow for yourself changed?

**SECTION C2**

1. Has the amount of help your _____ gives you with regard to doing things around the house or garden, changed at all since the trouble began?

If No, Clarify And Then Move On To Next Section

2. In what way?

3. How do you manage now?

4. Does getting any of these things done around the house ever lead to a disagreement between you and your _____?]

**SECTION C3 (Medication)**

1. Does your _____ take any prescribed drugs or pills?

2. Does s/he take this medication without any difficulties?

3. Do you have to remind her/him to take this medication - or help in any other way with its administration?

4. What do you say or do? - How does your _____ respond?

**SECTION C4 (MARITAL ONLY - ASK ONLY IF CARER IS SPOUSE)**

1. Has the way your looks after her/his [side of] financial matters changed since their memory problems started?

2. Who mainly looks after the money matters nowadays?

If Looking After Money Matters Unchanged Move To Next Section

3. How do you feel about these arrangements?

4. Do they ever lead to disagreement?

5. Has there been any change in the money coming into the household since your _____'s memory problems began?

6. What effects has this change had?

7. How have you found the task of assuming these new roles and responsibilities?

**SECTION C5 (FOR SPOUSAL CARERS ONLY - VERY IMPORTANT QUESTIONS)**

The following questions concern the relationship between yourself and your how well you get along together?

1. Are there any thing which you and your _____ enjoy doing together in the evenings or at the weekends? E.g. watching TV, sitting & chatting, playing games, hobbies

2. In general, how well would you say you get along together?

3. Would you generally be able to tell when s/he was pleased or when s/he was feeling down? Read her/his moods?

4. Over the past year, have you been apart for any reason?

If No Go To Next Section

5. How long was this for?

6. How did you feel about it?

**SECTION C6 (AFFECTION/WARMTH/INTEREST - MARITAL ONLY)**

1. Does your _____ express as much interest in you and the things you do, as s/he did before the problems started?

If Answer Is Comprehensive Enough - Go To 4

2. Does s/he show you as much affection nowadays? Has the amount of affection that s/he shows you changed at all in the last year?

If Amount Of Affection Has Remained Constant Go To 4

3. How do you feel about the change?

4. Has the way you feel about your _____ changed at all since the trouble began? In what way?

**SECTION C6 (AFFECTION/WARMTH/INTEREST - NON-SPOUSAL CARERS)**

1. Can you tell me a little bit about how you and _____ get along?

2. Do you find her/him a friendly person?

3. Is s/he easy to get on with?

4. Can you get close to him/her?

5. Have you felt any differently towards him/her since the trouble began?

6. Has the amount of affection you feel for _____ changed?

7. Have you behaved any differently towards her/him since the trouble began?

8. Has s/he behaved any differently towards you since the trouble began?

9. Has the amount of affection/ interest/attention _____ has shown you changed at all since the memory problems began?

10. Are you satisfied with the amount of affection/ interest/attention s/he shows you?

11. If there has Been A Change - how do you feel about the change? (Find out, without asking, of it bothers him/her)

**SECTION C7 (ADDITIONAL QUESTIONS - FOR ALL CARERS)**

1. What do you think has made your _____ like this?

2. Do you think s/he could do more to control it?

3. How do you think her/his condition will progress in the future?

4. Would you like your _____ to stay here with you for as long as possible? (End of Interview)

**Appendix 9. 3**

General Health Questionnaire (GHQ-12) Serial Number: _____

**Please read this carefully:**

We should like to know if you have had any medical complaints, and how your health has been in general. Please answer ALL the questions simply by underlining the answer, which you think most nearly, applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

**Have you recently -**

1 Been able to concentrate on whatever you're doing?
A) Better than usual B) Same as usual
C) Less than usual D) Much less than usual

2 Lost much sleep over worry?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

3 Felt that you are playing a useful part in things?
A) More so than usual B) Same as usual
C) Less useful than usual D) Much less than usual

4 Felt capable of making decisions about things?
A) More so than usual B) Same as usual
C) Less so than usual D) Much less capable

5 Felt constantly under strain?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

6 Felt you couldn't overcome your difficulties?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

7 Been able to enjoy your normal day-to-day activities?
A) More so than usual B) Same as usual
C) Less so than usual D) Much less than usual

8 Been able to face up to your problems?
A) More so than usual B) Same as usual
C) Less able than usual D) Much less able

9 Been feeling unhappy and depressed?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

10 Been losing confidence in yourself?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

11 Been thinking of yourself as a worthless person?
A) Not at all B) No more than usual
C) Rather more than usual D) Much more than usual

12 Been feeling reasonably happy, all things considered?
A) More so than usual B) About same as usual
C) Less so than usual D) Much less than usual

**Appendix 9. 4**

## MINI-MENTAL STATE EXAMINATION

Serial Number _____

Name:.....

Examiner:..... Date: / /

*(1) ORIENTATION*

What is the (year) (season) (date) (month) (day)? [ ] 5

Where are we (country) (county) (town) (hospital) (clinic)? [ ] 5

*(2) REGISTRATION*

Name 3 objects. One second to say each then ask subject to repeat them. One point for each correct answer. Then repeat until all 3 are learnt - record trials. [ ] 3

Trials [ ]

*(3) ATTENTION AND CONCENTRATION*

Serial 7's - 1 point per correct response (stop after 5)
OR spell 'WORLD' backwards [ ] 5

*(4) RECALL*

Ask subject to recall 3 objects from (2). [ ] 3

*(5) LANGUAGE AND PRAXIS*

Name a pencil and a watch [ ] 2

Repeat the following "No ifs ands or buts" [ ] 1

Follow a 3 stage command "Pick up this paper with your right hand, fold it in half and put it on the floor" [ ] 3

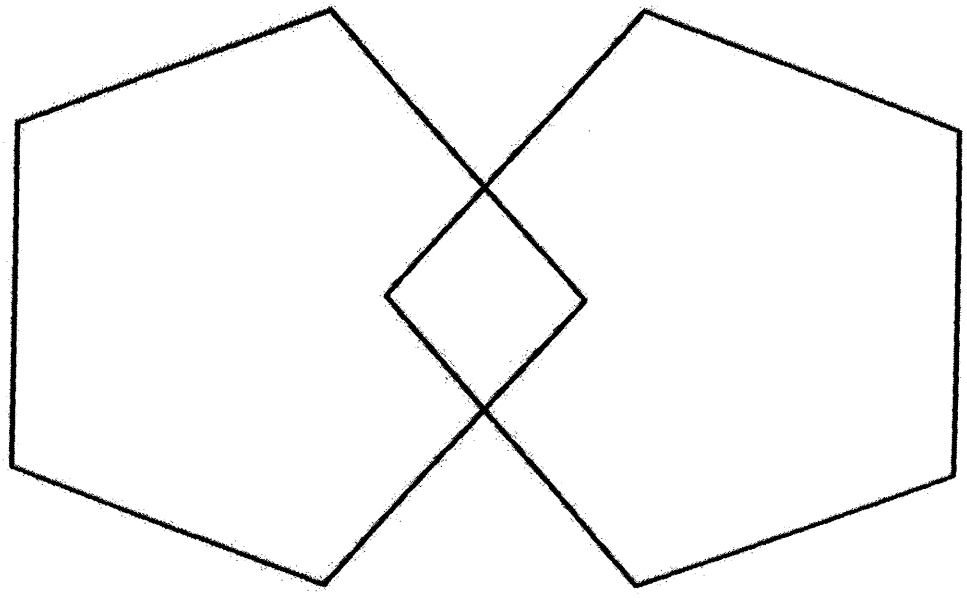
Read and obey the following "Close your eyes" [ ] 1

Write a sentence [ ] 1

Copy a design [ ] 1

**TOTAL:** **[ ] 30**

# Close your eyes



Write a sentence -

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI)

## A. Delusions

1. Does the patient have beliefs that you know are not true? For example insisting that people are trying to harm him/her or steal from him/her. Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I'm interested if the patient is convinced that these things are happening to him/her ☐ yes ☐ no ☐ n/a

| | | yes | no |
|---|---|---|---|
| 2. | If yes, does the patient believe that he/she is in danger - that others are planning to hurt him/her? | ☐ | ☐ |
| 3. | Does the patient believe that others are stealing from him/her? | ☐ | ☐ |
| 4. | Does the patient believe that his/her spouse is having an affair? | ☐ | ☐ |
| 5. | Does the patient believe that unwelcome guests are living in his/her house? | ☐ | ☐ |
| 6. | Does the patient believe that his/her spouse or others are not who they claim to be? | ☐ | ☐ |
| 7. | Does the patient believe that his/her house is not his/her home? | ☐ | ☐ |
| 8. | Does the patient believe that family members plan to abandon him/her? | ☐ | ☐ |
| 9. | Does the patient believe that television or magazines are actually present in the home? (Does he/she try to talk or interact with them?) | ☐ | ☐ |
| 10. | Does he/she believe in any other unusual things that I haven't asked about? | ☐ | ☐ |

**11.Frequency of delusions:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - once or more per day ☐

**12.Severity of delusions:**

Mild - delusions present but seem harmless and produce little distress in the patient ☐

Moderate - delusions are distressing and disruptive ☐

Marked - delusions are very disruptive and are a major source of behavioural disruption. (If PRN medications are prescribed, their use signals that the delusions are of marked severity) ☐

**13.Distress:** How emotionally distressing do you find the behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## B. Hallucinations

1. Does the patient have hallucinations such as false visions or voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has actually died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds, or visions ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient describe hearing voices or act if he/she hears voices? | ☐ | ☐ |
| 3. Does the patient talk to people who are not there? | ☐ | ☐ |
| 4. Does the patient describe seeing things that are not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc)? | ☐ | ☐ |
| 5. Does the patient report smelling odours not smelled by others? | ☐ | ☐ |
| 6. Does the patient describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her? | ☐ | ☐ |
| 7. Does the patient describe tastes that are without any known cause? | ☐ | ☐ |
| 8. Does the patient describe any other unusual sensory experiences? | ☐ | ☐ |

**9.Frequency of the hallucinations:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - once or more per day ☐

**10.Severity of the hallucinations:**

Mild - hallucinations are present but harmless' and produce little distress in the patient ☐

Moderate - hallucinations are distressing and disruptive to the patient ☐

Marked - hallucinations are very disruptive and are a major source of behavioural disturbance. (PRN medications may be required to control them) ☐

**11.Distress:** How emotionally distressing do you find the behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## C. Agitation/Aggression

| | ☐ yes | ☐ no | ☐ n/a |
|---|---|---|---|
| 1.Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle? | | | |

| | yes | no |
|---|---|---|
| 2. If yes, does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes? | ☐ | ☐ |
| 3.Is the patient stubborn, having to have things his/her way? | ☐ | ☐ |
| 4.Is the patient uncooperative, resistant to help from others? | ☐ | ☐ |
| 5. Does the patient have any other behaviours that make him/her hard to handle? | ☐ | ☐ |
| 6.Does the patient shout or curse angrily? | ☐ | ☐ |
| 7.Does the patient slam doors, kick furniture, throw things? | ☐ | ☐ |
| 8.Does the patient attempt to hurt or hit others? | ☐ | ☐ |
| 9.Does the patient have any other aggressive or agitated behaviours? | ☐ | ☐ |

**10.Frequency of agitation/aggression:**

| | |
|---|---|
| Occasionally - less than once per week | ☐ |
| Often - about once per week | ☐ |
| Frequently - several times per week but less than every day | ☐ |
| Very frequently - once or more per day | ☐ |

**11.Severity of the agitation/aggression:**

| | |
|---|---|
| Mild - behaviour is disruptive but can be managed with redirection or reassurance | ☐ |
| Moderate - behaviours disruptive and difficult to redirect and control | ☐ |
| Marked - agitation is very disruptive and a major source of difficulty: there may be a threat of personal harm. Medications are often required | ☐ |

**12.Distress:** How emotionally distressing do you find the behaviour?

| | |
|---|---|
| Not at all | ☐ |
| Minimally | ☐ |
| Mildly | ☐ |
| Moderately | ☐ |
| Severely | ☐ |
| Very severely or extremely | ☐ |

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## D. Depression/Dysphoria

| | ☐ yes | ☐ no | ☐ n/a |
|---|---|---|---|
| 1. Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed? | | | |
| | | yes | no |
| 2. If yes, does the patient have periods of tearfulness or sobbing that seem to indicate sadness? | | ☐ | ☐ |
| 3. Does the patient say or act as if he/she is in low spirits? | | ☐ | ☐ |
| 4. Does the patient put him/herself down or say that he/she feels like a failure? | | ☐ | ☐ |
| 5. Does the patient say that he/she is a bad person or deserves to be punished? | | ☐ | ☐ |
| 6. Does the patient seem very discouraged or say that he/she has no future? | | ☐ | ☐ |
| 7. Does the patient say that he/she is a burden to the family or that the family would be better off without him/her? | | ☐ | ☐ |
| 8. Does the patient express a wish for death or talk about killing him/herself? | | ☐ | ☐ |
| 9. Does the patient show any other signs of depression or sadness? | | ☐ | ☐ |

**10.Frequency of depression/dysphoria:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**11.Severity of the depression/dysphoria:**

Mild - depression is distressing but usually responds to redirection or reassurance ☐

Moderate - depression is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate ☐

Marked - depression is very distressing and a major source of suffering for the patient ☐

**12.Distress:** How emotionally distressing do you find the behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## E. Anxiety

| | ☐ yes | ☐ no | ☐ n/a |
|---|---|---|---|
| 1. Is the patient very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the patient afraid to be apart from you? | | | |
| | | yes | no |
| 2. If yes, does the patient say that he/she is worried about planned events? | | ☐ | ☐ |
| 3. Does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense? | | ☐ | ☐ |
| 4. Does the patient have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than nervousness? | | ☐ | ☐ |
| 5. Does the patient complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? (Symptoms not explained by ill health)? | | ☐ | ☐ |
| 6. Does the patient avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds? | | ☐ | ☐ |
| 7. Does the patient become nervous and upset when separated from you (or his/her caregiver)? (Does he/she cling to you to keep from being separated?) | | ☐ | ☐ |
| 8. Does the patient show any other signs of anxiety? | | ☐ | ☐ |

**9. Frequency of the anxiety:**

| | |
|---|---|
| Occasionally - less than once per week | ☐ |
| Often - about once per week | ☐ |
| Frequently - several times per week but less than every day | ☐ |
| Very frequently - essentially continuously present | ☐ |

**10Severity of the anxiety:**

| | |
|---|---|
| Mild - anxiety is distressing but usually responds to redirection or reassurance | ☐ |
| Moderate - anxiety is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate | ☐ |
| Marked - anxiety is very distressing and a major source of suffering for the patient | ☐ |

**11.Distress:** How emotionally distressing do you find the behaviour?

| | |
|---|---|
| Not at all | ☐ |
| Minimally | ☐ |
| Mildly | ☐ |
| Moderately | ☐ |
| Severely | ☐ |
| Very severely or extremely | ☐ |

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## F. Elation/Euphoria

1. Does the patient seem too happy or cheerful for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or find humour where others do not? ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient appear to feel too good or to be too happy, different from his/her usual self? | ☐ | ☐ |
| 3. Does the patient find humour and laugh at things that others do not find funny? | ☐ | ☐ |
| 4. Does the patient seem to have a childish sense of humour with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others? | ☐ | ☐ |
| 5. Does the patient tell jokes or makes remarks that have little humour for others but seem funny to him/her? | ☐ | ☐ |
| 6. Does the patient play childish pranks such as pinching or playing "keep away" for the fun of it? | ☐ | ☐ |
| 7. Does the patient "talk big" or claim to have more abilities or wealth than is true? | ☐ | ☐ |
| 8. Does the patient show any other signs of feeling too good or being too happy? | ☐ | ☐ |

**9. Frequency of the elation/euphoria:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**10.Severity of the elation/euphoria:**

Mild - elation is noticeable to friends and family but is not disruptive ☐

Moderate - elation is notably abnormal ☐

Marked - elation is very pronounced; patient is euphoric and finds nearly everything to be humourous? ☐

**11.Distress:** How emotionally distressing do you find this behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## G. Apathy/Indifference

1. Has the patient lost interest in the world around him/her? Has he/she lost interest in doing things or lack of motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent? ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient seem less spontaneous and less active than usual? | ☐ | ☐ |
| 3. Is the patient less likely to initiate a conversation? | ☐ | ☐ |
| 4. Is the patient less affectionate or lacking in emotions when compared to his/her usual self? | ☐ | ☐ |
| 5. Does the patient contribute less to the household chores? | ☐ | ☐ |
| 6. Does the patient seem less interested in the activities and plans of others? | ☐ | ☐ |
| 7. Has the patient lost interest in friends and family members? | ☐ | ☐ |
| 8. Is the patient less enthusiastic about his/her usual interests? | ☐ | ☐ |
| 9. Does the patient show any other signs that he/she does not care about doing new things? | ☐ | ☐ |

**10. Frequency of the apathy/indifference:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**11.Severity of the apathy/indifference:**

Mild - apathy is noticeable but produces little interference with daily routines: only mildly different from patient's usual behaviour; patient responds to suggestions to engage in activities ☐

Moderate - apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members ☐

Marked - apathy is very evident and usually fails to respond to any encouragement or external events ☐

**12.Distress:** How emotionally distressing do you find this behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## H. Disinhibition

1. Does the patient seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others? ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient act impulsively without appearing to consider the consequences? | ☐ | ☐ |
| 3. Does the patient talk to total strangers as if he/she knew them? | ☐ | ☐ |
| 4. Does the patient say things to people that are insensitive or hurt their feelings? | ☐ | ☐ |
| 5. Does the patient say crude things or make sexual remarks that they would not usually have said? | ☐ | ☐ |
| 6. Does the patient talk openly about very personal or private matters not usually discussed in public? | ☐ | ☐ |
| 7. Does the patient take liberties or touch or hug others in a way that is out of character for him/her? | ☐ | ☐ |
| 8. Does the patient show any other signs of loss of control of his/her impulses? | ☐ | ☐ |

**9. Frequency of the disinhibition:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**10.Severity of the disinhibition:**

Mild - disinhibition is noticeable but usually responds to redirection and guidance ☐

Moderate - disinhibition is very evident and difficult to overcome by the caregiver ☐

Marked - disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress? ☐

**11.Distress:** How emotionally distressing do you find this behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## I.Irritability/Lability

1. Does the patient get irritated and easily disturbed? Are his/her mood very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks, we are interested to know if the patient has abnormal irritability, or rapid emotional changes different from his/her usual self? ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient have a bad temper, flying "off the handle" easily over little things? | ☐ | ☐ |
| 3. Does the patient rapidly change moods from one to another, being fine one minute and angry the next? | ☐ | ☐ |
| 4. Does the patient have sudden flashes of anger? | ☐ | ☐ |
| 5. Is the patient impatient, having trouble coping with delays or waiting for planned activities? | ☐ | ☐ |
| 6. Is the patient cranky and irritable? | ☐ | ☐ |
| 7. Is the patient argumentative and difficult to get along with? | ☐ | ☐ |
| 8. Does the patient show any other signs irritability? | ☐ | ☐ |

**9. Frequency of the irritability/lability:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**10.Severity of the irritability/lability:**

Mild - irritability or liability is noticeable but usually responds to redirection and reassurance ☐

Moderate - irritability or liability are very evident and difficult to overcome by the caregiver ☐

Marked - irritability or liability are very evident they usually fail to respond to any intervention by the caregiver, and are a major source of distress? ☐

**11.Distress:** How emotionally distressing do you find this behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI) (cont.)

## J. Aberrant Motor Behaviour

1. Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads? ☐ yes ☐ no ☐ n/a

| | yes | no |
|---|---|---|
| 2. If yes, does the patient pace around the house without apparent purpose? | ☐ | ☐ |
| 3. Does the patient rummage around opening and unpacking drawers or closets? | ☐ | ☐ |
| 4. Does the patient repeatedly put on and take off clothing? | ☐ | ☐ |
| 5. Does the patient have repetitive activities or habits that he/she performs over and over? | ☐ | ☐ |
| 6. Does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc? | ☐ | ☐ |
| 7. Does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot? | ☐ | ☐ |
| 8. Does the patient do any other activities over and over? | ☐ | ☐ |

**9. Frequency of the abberant motor behaviour:**

Occasionally - less than once per week ☐

Often - about once per week ☐

Frequently - several times per week but less than every day ☐

Very frequently - essentially continuously present ☐

**10.Severity of the abberant motor behaviour:**

Mild - abberant motor behaviour is noticeable but produces little interference with daily routines ☐

Moderate - abberant motor behaviour is very evident can be overcome by the caregiver ☐

Marked - abberant motor behaviour is very evident, it usually fail to responds to any intervention by the caregiver, and is a major source of distress? ☐

**11.Distress:** How emotionally distressing do you find this behaviour?

Not at all ☐

Minimally ☐

Mildly ☐

Moderately ☐

Severely ☐

Very severely or extremely ☐

Patient No ☐☐☐☐☐

# Neuropsychiatric Inventory (NPI)

## Scoring

| Behavioural Domain | NA | Absent | Frequency | Severity | Freq. x Sev. | Distress |
|---|---|---|---|---|---|---|
| A. Delusions | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| B. Hallucinations | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| C. Agitation/Aggression | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| D. Depression/Dysphoria | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| E. Anxiety | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| F. Elation/Euphoria | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G. Apathy/Indifference | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| H. Disinhibition | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I. Irritability/Lability | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| J. Aberrant Motor Behaviour | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Appendix 9. 6**

Activities of Daily Living (The Bristol ADL Scale)
Client Initials_____ S. No_____
This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or the other.
For each of the following 20 activities, statements A) to E) refer to a different level of ability.
Thinking of the last 2 weeks, tick the box that represents your relative's / friends ability.
Only one box should be ticked for each activity.
(If in doubt about which box to tick, choose the level of ability which represents their *average* performance over the last 2 weeks)

1) FOOD
   A) Selects and prepares food as required.
   B) Able to prepare food if ingredients set out.
   C) Can prepare food if prompted step by step.
   D) Unable to prepare food even with prompting and supervision
   E) Not applicable

2) EATING
   A) Eats properly using correct cutlery
   B) Eats appropriately if food made manageable and/or uses spoon
   C) Uses fingers to eat
   D) Needs to be fed
   E) Not applicable.

3) DRINKS
   A) Selects and prepares drinks as required
   B) Can prepare drinks if ingredients left available
   C) Can prepare drinks if prompted step by step
   D) Unable to make a drink even with prompting and supervision
   E) Not applicable

4) DRINKING
   A) Drinks appropriately
   B) Drinks appropriately with aids (beaker/straw)
   C) Does not drink appropriately even with aids but attempts to
   D) Has to have drink administered (fed)
   E) Not applicable

5) DRESSING
   A) Selects appropriate clothing and dresses self
   B) Puts clothes on in wrong order and / or back to front and /or dirty clothing
   C) Unable to dress self but moves limbs to assist
   D) Unable to assist and requires total dressing
   E) Not applicable

6) HYGINE
   A) Washes regularly and independently
   B) Can wash self if given soap, flannel, towel etc.
   C) Can wash self if prompted and supervised
   D) Unable to wash self and need full assistance
   E) Not applicable

7) TEETH
   A) Cleans own teeth / denture regularly and independently
   B) Cleans teeth / denture if given appropriate items
   C) Requires some assistance if prompted step by step
   D) Full assistance given
   E) Not applicable

8) BATH/SHOWER
   A) Bath regularly and independently
   B) Needs bath to be drawn / shower turned on but washes independently
   C) Needs supervision and prompting to wash
   D) Totally dependent, needs full assistance
   E) Not applicable

9) TOILET / COMMODE
   A) Uses toilet appropriately when required
   B) Needs to be taken to the toilet and given assistance
   C) Incontinent of urine OR faeces
   D) Incontinent of urine AND faeces
   E) Not applicable

10) TRANSFERS
   A) Can get in and out of chair
   B) Can get in to a chair but needs help to get out
   C) Needs help getting in and out of chair
   D) Totally dependent on being put in to and lifted from chair
   E) Not applicable

11) MOBILITY
   A) Walks independently
   B) Walks with assistance, i.e. furniture, arm for support
   C) Uses aids to mobilise i.e. frame, sticks, etc
   D) Unable to walk
   E) Not applicable

12) ORIENTATION – TIME
   A) Fully oriented to time / day / date etc.
   B) Unaware of the time / day etc. but seems unconcerned
   C) Repeatedly asks time/ day / date
   D) Mixes up day and night
   E) Not applicable

13) ORIENTATION –SPACE
   A) Fully oriented to surroundings
   B) Oriented to familiar surroundings only
   C) Gets lost in home, i.e. needs reminding where bathroom is, etc.
   D) Does not recognise home as own and attempts to leave
   E) Not applicable

14) COMMUNICATION
   A) Able to hold appropriate conversation
   B) Shows understanding and attempts to responds verbally with gestures
   C) Can make self understood but difficulty understanding others
   D) Does not respond to, or communicate with, other.
   E) Not applicable

15) TEPEPHONE
   A) Uses telephone appropriately, including obtaining correct number
   B) Uses telephone if numbers given verbally / visually or pre-dialled
   C) Answer telephone but does not make calls
   D) Unable / Unwilling to use telephone at all
   E) Not applicable

16) HOUSEWORK / GARDENING
   A) Able to do housework / gardening to previous standard
   B) Able to do housework / gardening but not to previous standard
   C) Limited participation even with a lot of supervision
   D) Unwilling / Unable to participate in previous activities
   E) Not applicable

17) SHOPPING
   A) Shops to previous standard
   B) Only able to shop for one or two items with or without a list
   C) Unable to shop alone but participates when accompanied
   D) Unable to participate in shopping even if accompanied
   E) Not applicable

18) FINANCES
   A) Responsible for own finances to previous level
   B) Unable to write cheques but can sign name and recognises money value
   C) Can sign names but unable to recognise money values
   D) Unable to sign or recognise money values
   E) Not applicable

19) GAMES / HOBBIES

A) Participates in past-times / activities to previous standard
B) Participates but needs instructions / supervision
C) Reluctant to join in, very slow, needs coaxing
D) No longer able or willing to join
E) Not applicable

20) TRANSPORT

A) Able to drive, cycle, or use public transport independently
B) Unable to drive but uses public transport of bikes etc.
C) Unable to use public transport alone
D) Unable / Unwilling to use transport even when accompanied
E) Not applicable

**Appendix 9. 7**

## OMFAQ Physical Health Rating Scale.( Summary rating)

Serial Number _____

RATE THE CURRENT PHYSICAL FUNCTIONING OF THE PERSON BEING EVALUATED ALONG THE SIX-POINT SCALE PRESENTED BELOW. CIRCLE THE ONE NUMBER WHICH BEST DESCRIBES THE PERSON'S PRESENT FUNCTIONING.

1. *In excellent physical health*
   Engages in vigorous physical activities, either regularly or at-least from time to time.

2. *In good physical health*
   No significant illness or disabilities. Only routine medical care such as annual check-ups required.

3. *Mild physically impaired.*
   Has only minor physical illnesses and / or disabilities that might benefit from medical treatment or corrective measures.

4. *Moderately physically handicapped.*
   Has one or more physical disabilities that are either painful or that require substantial medical treatment.

5. *Severely physically handicapped.*
   Has one or more illnesses or disabilities that are either severely painful or life threatening, or that require extensive medical treatment.

6. *Totally physically handicapped.*
   Confined to bed and require full time medical assistance or nursing care to maintain bodily functions.

Extent of Health and Social Care Input

Serial Number.....

Appendix 9. 8

- Please indicate which of the following health and / or social services is the patient receiving

| Services | Monday | | | Tuesday | | | Wednesday | | | Thursday | | | Friday | | | Saturday | | | Sunday | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | M | A | E | M | A | E | M | A | E | M | A | E | M | A | E | M | A | E | M | A | E |
| Home care Agency | | | | | | | | | | | | | | | | | | | | | |
| Mobile meal / lunch club | | | | | | | | | | | | | | | | | | | | | |
| Day care / day hospital | | | | | | | | | | | | | | | | | | | | | |
| Other local facilities | | | | | | | | | | | | | | | | | | | | | |
| Informal support | | | | | | | | | | | | | | | | | | | | | |
| Nursing intervention | | | | | | | | | | | | | | | | | | | | | |
| Others | | | | | | | | | | | | | | | | | | | | | |
| others | | | | | | | | | | | | | | | | | | | | | |

- Which of the following follow-up visits are taking place? (circle that applies) None GP CPNs SW OT Psychologist Psychiatrist Voluntary services Others(specify)

| • In the last 6 months has the patient had | No | Yes (describe how long and how often) |
|---|---|---|
| 1. Hospital admission(s)? | | |
| 2. Respite admissions(s)? | | |
| 3. Others periods of significant break in the caring role? | | |

**Appendix 9. 9**

25/11/04

To

Dear

**Re.: A study of the Influence of Carer's Expressed Emotion on the course and 12-month outcome of patient with Alzheimer's dementia.**

The purpose of this letter is to inform you about the above referred research study that is being done by Dr Mangesh Marudkar, Prof James Lindesay and Ms Penny Wakefield from the University of Leicester and the Leicestershire Partnership NHS Trust. This is a PhD research project and the above team of researchers are keen to include carers and patients who are willing to participate in this study.

They have approached me to ask whether they could contact you and give you more information about this study; and also seek your willingness to participate in this study. I am writing to you so that I could establish your willingness to be contacted by them.

I am enclosing two information leaflets about the study. The Local Research Ethics Committee of the Leicestershire Partnership NHS Trust has approved this study and these information leaflets.

In the coming few days one of the above researchers will contact you to offer you any clarification that you may want regarding the study. They will also seek your consent to participate in this study, unless of course you notify the researchers **(on 0116 2251229)** or me about your unwillingness.

Please remember that by agreeing to participate in the above study you will be helping the researchers complete their study.

**Your participation or refusal does not affect in anyway the treatment that your relative / friend is receiving or may receive in the future.**

Thank you

Yours sincerely

(Consultant Name)

Consultant Psychiatrist

**Appendix 9. 10**

## PATIENT INFORMATION LEAFLET

Following information refers to the study titled **"Influence of Carers' Expressed Emotion on the course and 12-month outcome of patients with Alzheimer's Disease."**

This study focuses on persons who are suffering from Alzheimer's Dementia and also carers who look after them. Because currently you have been diagnosed as suffering from Alzheimer's Dementia, we request you to participate in this study.

This study is being carried out by **Dr. Mangesh Marudkar** (Consultant in Psychiatry for the Elderly, Leicestershire Partnership NHS Trust), Ms Penny Wakefield (Research Associate, Division of Psychiatry for the Elderly, University of Leicester) and **Professor James Lindesay** (Professor of Psychiatry for the Elderly and Head Department of Psychiatry, University of Leicester)

In the following paragraphs, we have tried to give some important information related to this study to help you decide whether you wish to participate.

**If you have any further questions or comments please do not hesitate to contact the principle investigator Dr. Mangesh Marudkar, at Evington Centre, Gwendolen Road, Leicester or phone (0116) 225 1229, or Fax (0116) 225 1266 or e-mail mangesh.marudkar@leicspart.nhs.uk.**

**Q1) What is the purpose of the study?**

- The purpose of this study is to investigate whether and how a psychological concept called 'Expressed Emotion' of your carer influences the symptoms and the course of the illness over a 12-month period.

**Q2) What will be involved if I take part in the study?**

- As a patient, you will be interviewed once by the investigator. The interview should not last more than 5 to 10 minutes and will be focused on assessment of your memory.

**Q3) Will information obtained in the study be confidential?**

- All the information will be dealt with in confidence according to the Data Protection Act of 1984.

- Confidentiality will only be breached in the interest of health or safety of either yourself or someone else.

- Identity of any individual patient or carer will not be revealed in any document / publication related to the study.

**Q4) What if I am harmed by the study?**

- Medical research is covered for mishaps in the same way, as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

- This study does not involve any medical, including psychological treatment. Your treatment will be unaffected by either your agreement or refusal to participate in this study.

**Q5) Will I receive out of pocket expenses for taking part in the study?**

- You will not receive any out of pocket expenses for taking part in the study.

- Patients will be interviewed during their visit to the day care.

**Q6) What happens if I do not wish to participate in this study or wish to withdraw from the study?**

- If you do not wish to participate in this study or if you wish to withdraw from the study, you may do so without justifying your decision and your future treatment will not be affected.

-----x-----

**Appendix 9. 11**

## CARER INFORMATION LEAFLET

Following information refers to the study titled **"Influence of Carers' Expressed Emotion on the course and 12-month outcome of patients with Alzheimer's Dementia."**

This study focuses on persons who are suffering from Alzheimer's Dementia and also carers who look after them. Because currently either you have been looking after some one who suffers from such a problem, we request you to participate in this study.

Dr. Mangesh Marudkar (Consultant Old Age Psychiatry, Leicestershire Partnership NHS Trust) Ms Penny Wakefield (Research Associate, Division of Psychiatry for the Elderly, University of Leicester) and Professor James Lindesay (Professor of Psychiatry for the Elderly and Head Department of Psychiatry, University of Leicester) are carrying out this study.

In the following paragraphs, we have tried to give some important information related to this study to help you decide whether you wish to participate.

**If you have any further questions or comments please do not hesitate to contact the principle investigator Dr. Mangesh Marudkar, Evington Centre, Gwendolen Road, Leicester LE5 4QG or phone (0116) 225 1229, or Fax (0116) 225 1266 or e-mail mangesh.marudkar@leicspart.nhs.uk.**

**Q1) What is the purpose of the study?**

The purpose of this study is to investigate whether and how a psychological concept called 'Expressed Emotion' in the carers of patients with Alzheimer's Dementia influences the symptoms and the course of the illness over a 12-month period.

**Q2) What will be involved if I take part in the study?**

- As a carer, you will be interviewed, separate from the patient. The interview will have two main parts.

- One of them involves assessment of Expressed Emotion. For accurate assessment of Expressed Emotion, it is essential to record this part of the interview on an audio-tape. This part of the interview should last for around 45 to 60 minutes.

- The second part of the interview will focus on the difficulties and problems experienced by you as a carer and the patient, and some information about your general health. This second part of the interview will not be recorded on an audio-tape. This part of the interview should last for about 15 – 20 minutes.

- The patient will be interviewed once by the investigator. The interview should not last more than 5 to 10 minutes and will be focused on assessment of memory.

- If you agree a follow-up interview will be arranged at 6 months and then 12 months after the initial interview. Follow-up interview will be much shorter and will generally not involve any audio recording.

**Q3) Will information obtained in the study be confidential?**

- All the information will be dealt with in confidence according to the Data Protection Act of 1984.

- The audiotapes will only be used for assessment of Expressed Emotion and for establishing the reliability of the assessment i.e. two expert clinicians will rate the same recorded interview and then the two rating will be compared to see if rating matches with each other. After the ratings are done, the audiotapes will be stored according to the Data Protection Act of 1984.

- Confidentiality will only be breached in the interest of health or safety of either you or someone else.

- Identity of any individual patient or carer will not be revealed in any document / publication related to the study.

**Q4) What if I am harmed by the study?**

- Medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

- This study does not involve any medical, including psychological treatment. Treatment of patient will be unaffected by either your agreement or refusal to participate in this study.

**Q5) Will I receive out of pocket expenses for taking part in the study?**

- You will not receive any out of pocket expenses for taking part in the study.

- Patients will be interviewed during their visit to the day hospital.

- For the carers, car mileage or public transport charges from home can be reimbursed for you to visit the hospital for the purpose of the interview or if you prefer, you can be interviewed at your home.

**Q6) What happens if I do not wish to participate in this study or wish to withdraw from the study?**

- If you do not wish to participate in this study or if you wish to withdraw from the study, you may do so without justifying your decision and any future treatment will not be affected.

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**Appendix 9. 12**

Leicestershire Partnership NHS
NHS Trust

**Mental Health Services for Older People**
**The Evington Centre**
**Gwendolen Road**
**Leicester LE5 4QG**

## CONSENT FORM

**"Influence of Carers' Expressed Emotion on the course and 12-month outcome of patients with Alzheimer's Disease."**

*Principal Investigator - Dr. Mangesh Marudkar, Consultantr in Psychiatry for the Elderly*

*Co-investigator – Ms Penny Wakefield, Research Associate, Division of Psychiatry for the Elderly, University of Lericester*

I agree to take part in the above study as described in the patient and carer information leaflet.

I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may wish to view relevant sections of my medical records, but that all the information will be treated as confidential.

I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I have read the patient information leaflet on the above study and have had the opportunity to discuss the details with Dr. Marudkar / Ms Penny Wakefield and ask any questions. The nature and purpose of the tests to be taken have been explained to me and I understand what will be required if I take part in the study.

Signature (patient)..... (carer) .....

Date ..... Date .....

Name in BLOCK LETTERS

..... .....

I confirm that I have explained the nature of the study, as detailed in the patient information leaflet, in terms, which in my judgment are suited to the understanding of the patient and the carer.

Signature of the investigator..... Date .....

Name in BLOCK LETTERS .....