LIFE EVENTS, SOCIAL SUPPORT AND DEPRESSION IN DEMENTIA

ALLYSON WAITE

D. Clin Psy

University College London

1998

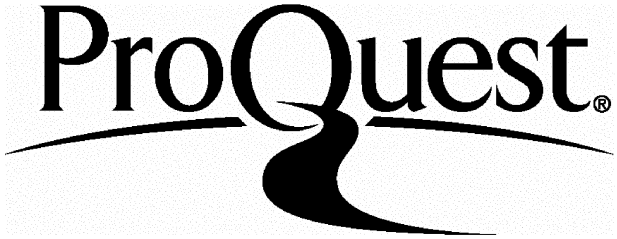


TABLE OF CONTENTS

Tables & Graphs

ABSTRACT

Recent research has highlighted the influence of psychosocial factors on the course of dementia and previous studies have demonstrated an association between the experience of life events and the onset of depression. This study aimed to investigate the inter-relationships between social factors, specifically life events, and depression in dementia sufferers and their carers. Seventy two dementia sufferers and their carers were interviewed using the Life Events and Difficulties Schedule (LEDS). Demographic information and data relating to quality of relationship between carers and dementia sufferers, social support and confiding relationships were collected. Depression in dementia sufferers was measured using the Cornell Scale for Depression in Dementia (CSDD) and in carers using self report methods. A sample of dementia sufferers were interviewed using qualitative methods to elicit their awareness and experience of stressful life events. The findings revealed a significant association between life events and depression in dementia sufferers. There was no relationship between quality of relationship, social support or confiding relationship and depression. Depression in carers was associated with two factors; the presence of depression in dementia sufferers and living with the dementia sufferer. Furthermore, the impact of carer depression appeared to mediate the association between life events and depression in dementia sufferers. There was no significant relationship between demographic factors, quality of relationship or social support and depression in carers. This study therefore supports the importance of psychosocial factors in dementia and the clinical implications of such are discussed.

ACKNOWLEDGEMENTS

There are several people I would like to thank in the course of preparing and conducting this research. Firstly, I would like to thank my research supervisors, Dr. Martin Orrell, Senior Lecturer, UCL, Department of Psychiatry and Behavioural Sciences and Dr Martin Skelton-Robinson, Consultant Clinical Psychologist, Woodland Centre, Hillingdon Hospital for their advice and support and helpful comments on reading drafts of this thesis. Secondly, I would like to thank Professor Paul Bebbington, Professor of Social and Community Psychiatry, UCL, Department of Psychiatry and Behavioural Sciences for his help in training on the use of the LEDS and in rating initial interviews. Thirdly, I would like to thank Ms. Paula Dunlop, Manager, Orme Lodge Day Centre, Stanmore, Mr. Chris Patterson, Manager, Herga Day Centre, Harrow and all the clinicians at Woodland Centre for their help in identifying suitable participants for this study. Fourth, I would like to thank the support staff at Woodland Centre, Hillingdon Hospital for their help. Finally, I would like to thank all those participants and their carers who gave their time to participate in this study.

CHAPTER ONE - INTRODUCTION

BACKGROUND AND OVERVIEW

Research of an objective and quantitative kind, into the impact of life events on mental health, is now firmly established as part of psychiatry. Though common-sense may suggest the likelihood of such a connection, it was not until the 1970's and as part of the legacy of the antipsychiatry movement of the 1960's, that biologically orientated psychiatrists began to accept the significant part played by life events in the aetiology of some major mental illnesses (Brown & Harris, 1978). Since Brown & Harris published their influential study, subsequent research has supported the relationship between stressful life events and the onset of depression (Cooke & Hole, 1983). In addition, increasing attention has been paid to clarifying this relationship as well in conditions other than depression e.g. schizophrenia and PTSD (Brown & Harris, 1989).

The area of life event research in the elderly in general, represents a complex scenario (Davies, 1993) and the influence of such psychosocial factors on dementia represents a relatively recent but important area of research. Comorbidity of depression and dementia is estimated at around 30% (Ballard et al, 1991) yet little is understood of the potential causes of these depressive symptoms, especially the influence of social factors. This chapter will begin by reviewing the available literature on the presentation of depression in dementia. Secondly, the literature on life event research will be reviewed in relation to older adults and dementia sufferers. Thirdly, theories and research findings on the

impact of psychosocial factors including life events on dementia sufferers will be discussed. Fourth, the influence of other social factors on depression, such as social support and its role as a potential mediator between stressful life events and the onset of depression in older adults will be reviewed. Finally, recent research from the caregiver literature will be reviewed in relation to life events, burden and carer depression.

Definitions

Dementia has been defined as the global impairment of higher cortical functions including severe short and long term memory loss and accompanied by disturbances of judgement, problem solving, abstract thinking and personality (American Psychiatric Association, 1987). Prevalence rates of dementia have been estimated at 5% in those over 65 and 20%, over 80 (Teri & Wagner, 1992).

Alzheimer's Disease

Alzheimer' Disease (AD) represents the most common form of dementia, accounting for almost 80% of all dementia's in older adults (Teri & Wagner, 1992). Characterised as an irreversible and degenerative dementia, it has an insidious onset, a gradually progressive course and currently no known aetiology or cure.

Multi-infarct dementia (MID)

Multi infarct dementia (MID) is thought to account for 10-20% of all dementia's (Fischer et al, 1990). In addition to the cognitive diagnostic criteria, there must be evidence of

cerebral vascular disease. In contrast to AD, onset is usually sudden and the course of the disease fluctuating rather than progressive, with an observed 'step wise' deterioration in functioning.

Depression

The definition of depression is varied, ranging from normal expression of sad mood to clinical depression. Diagnostic factors include a persistent and pervasive dysphoria, decreased interest and pleasure in normal activities and a number of other behavioural, cognitive, affective and somatic symptoms. Defining prevalence rates of depressive disorders is confounded by differences in classification in research studies between major depressive disorders (clinical depression) and symptoms of depression (dysphoria). Estimates of rates of major depressive disorders in older adults fall between 2 and 4% whilst for dysphoria the rates fall between 10 and 20% (Blazer et al, 1987).

DEPRESSION IN DEMENTIA

Prevalence

It is well established that symptoms of depression are common in patients with dementia, although estimates of reported prevalence vary widely between studies. In a review of studies, Burns (1991) found the frequency of reported depression in Alzheimer's disease ranged from 0% to 87% and Haupt et al (1985) found modal rates above 30%. Although less frequently studied, rates of depression among patients with multi-infarct dementia has been estimated at 0-30% (Ballard et al, 1993). Furthermore, rates of depression

among older adults with AD and MID are above that found in community samples of older adults without dementia (Fischer, 1990).

Aetiology

Despite its high prevalence, relatively little is known of the aetiological factors for depression in dementia and to date most research has focused on neurological and physical explanations for the high comorbidity. An overlap in the neuropathological and neurochemical substrates of depression and AD and cerebrovascular disease as well as factors such as family history have been most widely studied (Teri & Wagner, 1992). By contrast, relatively little is known of other causal factors and in particular psychological mechanisms which may contribute to aetiology. In a review of the literature, Ballard et al (1996) concludes that there is no association between demographic factors and incidence of depression in dementia sufferers although previous episodes of depression and family history are associated with higher rates of depression.

The relationship between severity of cognitive impairment and risk of depression has, however, been studied. Some studies have found increased depression in earlier stages of dementia (Ballard et al, 1996) although the research findings are inconclusive. Ballard et al (1993) found that patients with minimal dementia had more depressive symptoms than mild/moderate dementia but Verhey et al, (1987) found that depression scores did not correlate with severity of dementia. One theory suggested is based on the hypothesises that the degree of insight into cognitive deficits is related to the emergence of depressive

symptoms. During the initial stages of dementia, when insight is more, or at least, more assessable, it is speculated that depression may be an adjustment reaction to cognitive loss. As the course of dementia progresses however, level of insight declines and thus may be protective against depression. However, research findings do not support such a relationship (Verhey et al, 1993).

Assessment

A further difficulty facing researchers and clinicians is that the symptom profile of depression in dementia sufferers is not as yet clearly understood. There is considerable overlap between symptoms of depression and those of dementia and often it is difficult to determine how far observed symptoms relate to mood disturbance rather than the course of the dementia itself. There is also little normative data on the use of established measures of depression in older adults among people with cognitive impairment and evidence suggests that depressive symptoms may vary between those with cognitive impairment and those without. The development of scales to measure depressive symptoms specifically in dementia sufferers, such as the Cornell Scale for Depression in Dementia has aided the assessment process. Within the literature, there is some consensus that dysphoria and loss of interest are the most common symptoms of depression in dementia sufferers and psychomotor changes are reported in 50-60% of patients (Ballard, 1996). There is also a tendency for less 'psychological' symptoms such as guilt and a greater emphasis on marked mood reactivity (Merriam et al, 1988) whilst others have identified that symptoms such as loss of interest, decreased energy,

poor concentration and psychomotor disturbance increase at 15-34 month follow up (Burke et al, 1988). Forsell, (1993, cited in Ballard et al, 1996) undertook a principal components analysis of depressive symptoms in 224 cases of co-morbidity and identified two distinct clusters which appeared to be characterised by stage of dementia. The first was characterised by: loss of interest, psychomotor change, loss of energy, impaired concentration, and was associated with greater cognitive impairment. The second cluster was characterised by: dysphoria, reduced appetite, guilt and suicidal ideation, and was associated with patients with milder cognitive impairment. Whilst this is a significant step, the methodology has been criticised for its over inclusiveness of subjects such that some patients had a questionable diagnosis of dementia and may have simply been depressed or exhibiting symptoms of "pseudodementia". It is conceivable however, that although frequency of depressive symptoms do not vary according to the stage of dementia, the type of symptoms reported do. Perhaps as the disease progresses, articulation of such complex emotions as guilt become impossible but observable biological and behavioural symptoms are more evident.

In addition to the lack of clearly delineated symptoms, there is also the difficulty of accurately assessing symptoms. Depression is generally diagnosed by clinicians on the basis of the presence, duration and severity of symptoms. The memory loss characteristic of dementia makes the reliability of self report by patients with dementia questionable and research has consistently shown that patients frequently underestimate their symptoms. Ballard et al (1993) highlighted the tendency for patients with dementia to

give negative responses to the presence of symptoms even when they were reported as present by an informant. This finding is evident even in people with mild dementia (Teri & Wagner, 1992). In addition, Burns et al, (1990) identified that frequency of reported symptoms varied by informant, depending on whether they are carers, trained observers or patients. However, ratings of patient depression were similar in caregivers and trained clinicians (Teri & Wagner, 1991), suggesting that caregivers are able to act as surrogate reporters of depressive symptoms in dementia sufferers with reasonable accuracy (Lodgeson & Teri, 1995).

Impact of Comorbidity

Despite the difficulties of assessing depressive symptoms, there is a growing literature highlighting the importance of recognising affective problems in patients with AD. Firstly, there is an association between depressive symptoms in patients with dementia and additional behavioural and functional disturbances. Teri & Wagner (1992) reported that depressive symptoms were associated with an increase in behavioural disturbance, and may compromise cognitive function. Depression in AD can be a predictor of early institutionalisation (Haupt et al, 1995), perhaps in part due to the association between depression and greater impairment in functional abilities and activities of daily living (Burns et al, 1990). In addition, depressive symptoms in patients with dementia may exert a negative impact on caregivers. Drinka et al, (1987) found carer depression was associated with levels of patient depression. Depressive symptomatology in patients was also associated with greater stress and burden than either behavioural disturbances or

memory related problems (Teri et al, 1989, cited in Teri & Wagner, 1992). Finally, Burns (1991) found increased mortality rates among patients with concurrent depression and dementia.

In conclusion, depressive symptoms in dementia sufferers are common but treatable (Teri & Wagner, 1992). However, little attention has been paid to social factors, such as life events, social support and interpersonal relationships in the onset of depression in dementia sufferers. This is in contrast with populations without cognitive impairment which have shown that social factors, particularly life events can influence the onset and outcome of depression. Further research will potentially identify risk factors for depression as well as highlighting possible vulnerability factors. Such knowledge may aid appropriate clinical interventions and prevention and management strategies in order to improve quality of life for both the sufferer and their carers.

LIFE EVENTS AND DEPRESSION

Life events are defined as "stressors which by requiring adaptation and making demands on resources, cause or trigger psychological distress and the onset or relapse of psychiatric illness" (Creed, 1993). Although the aetiology of depression is varied, research into social factors has consistently demonstrated that life events may precipitate depression (Paykel, 1969). The pioneering work of Brown & Harris (1978) on the influence of psychosocial factors in depression implicated a direct causal relation. In their original study, Brown & Harris (1978) studied women aged 18-65 in the general

population. They found that in 68% of onset cases of depression, at least one severe life event was reported for the 38 weeks before onset, compared with 20% of non depressed women in the comparable time period and most of the difference in reporting of such life events was for the nine week period before onset.

Mechanisms of life events

Brown & Harris (1978) aetiological model of depression proposes an interaction between provoking agents, (such as life events and chronic difficulties) and vulnerability factors (such as a lack of a confiding relationship or poor self esteem) in the onset of depression. A prospective study of 400 women investigated the importance of long term severe and threatening life events in provoking cases of depression (Brown et al, 1987). This research highlighted that only 1 in 5 of those exposed to a life event went onto develop depression at caseness level. Therefore, other factors clearly interact to determine the onset of depression or not. The type of event, its developmental and social context, the perceived demand on physical and psychological resources as well as an individual's appraisal of the meaning of events, coping strategies and social supports may all be factors which determine whether or not an event becomes a stressor (Brewin, 1990).

In establishing the mechanisms through which life events cause depression, a number of factors have emerged as significant. Firstly, the degree of independence of life events. Independent events are defined as those events which are imposed upon the subject and outside of their the control (Brown & Harris, 1978). A criticism often levied at life

event research is that the direction of causality may be biased, in that depression may bring about life events. Research has suggested that rates of life events are higher in depressed than non depressed patients (Oei & Zwart, 1990). Focusing on independent events thus seeks to minimise bias in measurement of causality (Brown & Harris, 1989). Secondly, the degree of threat (or the negative emotional meaning) of events is critical. Only those events with a marked or moderate long term threat (that persisting one week after the event) played a causal role in depression whilst short term threat did not (Brown & Harris, 1978). Thirdly, only certain types of life events appeared to be of aetiological importance. Life events involving loss were central in precipitating depression in Brown & Harris's study (1978). It was hypothesised that such events may be associated with subsequent loss of self esteem and hopelessness, leading to depression. Further research has confirmed the aetiological significance of different life events in psychiatric disorders. Finlay-Jones & Brown (1982) distinguished between those events which involved loss and those involving threat. In a comparison of cases of anxiety and depression, they reported that 72% of anxiety cases could be attributed to a danger event whilst only 5% of anxiety cases could be attributed to a loss event. In contrast, 58% of depression cases could be attributable to a loss event and 37% to a danger event. Therefore, the occurrence of independent life events with severe and long term threat, such as a major loss, appears to be strongly associated with the onset of a depressive disorder.

Methodology

The aetiological significance of life events in the onset of depression has been criticised. In a review of studies, Cooke & Hole (1983) concluded that only 32% of psychiatric cases could be directly attributable to life events. The size of the association between stressful life events and depression has been disputed since the variance explained is as low as 10% in some studies (Andrews & Tennant, 1978). However, life event research has been plagued by methodological difficulties. The majority of studies of life events and depression have been case controlled which does not allow one to establish how individuals were before the life event, making the direction of causality difficult to establish (Orrell & Davies, 1994). Furthermore, variations in methodology between studies in terms of samples and measures used may account for these discrepant findings. Many studies employ the use of life event checklist approaches which have been found to be lacking in both validity and reliability (Creed, 1993). In addition, differences in defining, measuring and timing the onset of depression are common with some authors measuring clinical depression and others depressed mood (Brown & Harris, 1989). Well designed longitudinal studies using methodologically sound measures are needed to overcome these difficulties. Cooke et al, (1986) has summarised the criteria necessary to conclude a causal influence of life events and depression: there must be a clear statistical association between events and depression, evidence that the events led to the depression and not vice versa, satisfactory theoretical explanation for the events specifically leading to depression and an association between events and depression which is replicable across different populations and times.

LIFE EVENTS AND DEPRESSION IN OLDER ADULTS

The impact of a life event is dependent on its timing in relation to other events, to the person's appraisal of events and their stage in the life cycle (Neugarten, 1970). Life events in older adults by nature of their position in the life cycle are different in terms of prevalence, type and impact (Russo & Vitaliano, 1995). The notion of life events as developmental transitions suggests life events may be seen as potentially part of the adjustment process of ageing. Although the experience of loss events is likely to be greater in this age group, there is a suggestion that their impact may be different to that in younger adults. The social clock theory distinguishes "on time" and "off time" events (Rook et al, 1989). Stress is likely to be experienced if an event is "off time" whilst "on time" events are seen as expected and thus less stressful. A degree of resilience to stressful situations may develop with age (Orrell, 1994) but Murphy (1982) has pointed to the greater potential for social disadvantage among older populations which may increase vulnerability. These include poorer financial and housing status, decline of physical health and mobility, higher incidence of living alone with dispersed family networks, and a decline in social relationships. In a replication of the work of Brown & Harris (1978) the influence of these social factors in both the aetiology and outcome of depression in older adults was studied (Murphy, 1982, 1983). The rate of severe life events was significantly higher in the year before onset in the depressed sample compared to a matched community sample. In addition to the findings of Brown & Harris (1978), Murphy reported that physical ill health was an additional provoking agent

in the elderly. A lack of a confiding relationship was found to be a vulnerability factor to depression as in younger samples.

These findings have been replicated in other studies. Emmerson et al, (1985) compared life events in 101 depressed patients and 85 matched controls. The rate of severe life events in the depressed and non depressed group in the three month period was significantly different with 24% of the depressed group compared to 7% of the nondepressed group reporting at least one severe life event. In addition, the influence of a lack of confiding relationship as a vulnerability factor was further explored. Those who were depressed were significantly less likely to report such a relationship although there was also a significant effect of gender. Men who had no such confidant were significantly more likely to be depressed than women, with two thirds of the depressed sample reporting no confiding relationship. There was no significant difference in the numbers of depressed and non depressed women who reported a lack of a confiding relationship. Finally, Evans & Katona (1993) screened 408 primary care attenders and found depressive symptoms in 36%. Depression was significantly associated with life events (51% vs 31%) , chronic difficulties, poor physical health and a lack of a confiding relationship.

The occurrence of undesirable events has also been implicated in the relapse of depression in older women who had made initially good responses to treatment (Murphy, 1983). At one year follow up, a poor outcome was identified in two thirds of the sample.

This was significantly associated with the occurrence of severe life events during the follow up year; only 7% of those patients in the good outcome group experienced a severe life event in the intervening year compared to 24% of the poor outcome group. However, the hypothesis that a confiding relationship could prevent depression in the face of a severe and independent life event in the year was not supported.

PSYCHOSOCIAL FACTORS IN DEMENTIA

Life Events and Dementia

The impact of life events on dementia sufferers has largely been neglected in research. Despite the lack of an adequate model to explain the course of deterioration in dementia, little attention has been paid to the influence of such social factors. The importance of studying the impact of life events on sufferers of dementia has been highlighted by Orrell & Bebbington (1995a). They suggest three main mechanisms by which psychosocial factors may impact on the symptoms of an organic illness. Firstly, organic impairment may lead to a decreased ability to cope with the demands of the environment which in turn may lead to increased confusion in novel situations. Secondly, psychosocial stress may lead to permanent physiological changes through its effect on the immune system or neuro-endocrine response. Finally, psychosocial stress may change physiological tone that releases the consequences of organic change.

Furthermore, the effect of life events on dementia sufferers may depend on the type of life event and the degree of threat or change in environment that the event brings. Life

events resulting in social environment change may precipitate deterioration whilst events associated with severe threat may precipitate distress in the form of depression or anxiety (Orrell & Bebbington, 1995b).

Therefore, the impact of life events on dementia sufferers will be reviewed in three areas: on the aetiology of dementia, on the course of dementia and on co-morbidity of affective symptoms in dementia.

Cause

In terms of the aetiology of dementia, there is little evidence to support or refute the argument that stressful life events are significant factors in the genesis of dementia (Pitt, 1993). Jorm et al (1991) in a meta analysis of risk factors for AD concluded that there was no evidence from case controlled studies to support the hypothesis that life events were a significant risk factor. Nevertheless, there have been no adequate studies looking at life events leading up to the onset of dementia and the consequences of stress have been implicated in neuroendocrine cognitive impairment (O'Dwyer & Orrell, 1995).

Course

Psychosocial factors have been linked with deterioration and the course of dementia. An early study by Amster & Krauss (1974) investigated the relationship between mental deterioration and recent life crises. Using the Geriatric Schedule of Recent Experiences (GSRE) they compared 25 females with dementia and 25 fit female controls. They found

double the number of life crises in the previous year among the patient sample. However, the authors caution that the direction of causality is not clear since early symptoms of dementia may have led to a precipitation or exacerbation of life crises. Studies have also investigated the impact of enforced moves on patients with dementia. Anthony et al, (1987) reported a notable deterioration in behaviour and orientation and significant behavioural symptoms of depression up to 3 months following the move. Orrell & Bebbington (1995a) found that changes in social environment led to deterioration in functioning and increased probability of admission to hospital. Life events involving change therefore, appeared to cause deterioration in dementia sufferers, perhaps because of their limited ability to adapt to a changing social environment.

To help examine the influence of psychosocial factors on the course of dementia, Kitwood (1993) argues that historically, the study of dementia has been dominated by a biomedical model and the notion of social influences on the dementing process has been largely neglected. The work of Kitwood (1993) has attempted to develop an account of the dementing process and dementia care which incorporates the social with the neurological. He argues that traditional psychiatric thinking emphases pathological theories at the expense of the psychosocial. However, such theories are limited in their ability to fully explain the observed patterns of decline in dementia sufferers and it has now been established that patients with cognitive impairment are highly sensitive to social and environmental factors (Orrell, 1994) and that change in one's social environment and routine may lead to deterioration. Kitwood argues that the biomedical

model has a fundamental flaw in that it cannot equate the relationship between mind and brain and this is evident in three significant research findings. Firstly, the correlation, less than expected, between measures of dementia and the extent of neuropathology (Kitwood, 1993). Secondly, deterioration in functioning following an incident such as relocation occurs at a faster rate than can be attributed to progressive decline in neurological structures. Thirdly, the emergence of partial recovery of function in some patients cannot be purely explained by a progressive and irreversible neurological degeneration (Kitwood, 1996).

Therefore, Kitwood's theory helps to bridge the gap between the psychological and neurological and suggests that to fully understand the manifestation of the dementing process, five key interrelated factors need to be accounted for. Firstly, personality which encompasses both constitutional and learnt factors and includes coping style and defences against anxiety. Secondly, biography or the succession of life changes and personal history. Thirdly, physical health including the acuity of the senses. Fourthly, neurological impairment which varies according to type, location and intensity. Fifth, social psychology. Kitwood argues that social psychology "makes up the fabric of everyday life" and serves to enhance or diminish an individuals sense of self, value and security. This model thus explains the phenomena observed in the dementia in terms of the variability and unique course of the disease for each individual as an interplay between the neurological and the social influences. Despite some preliminary evidence that the course of dementia is influenced by social factors, there has been only a limited

amount of empirical study of this hypothesis. Often a person with dementia is seen only as an individual and their behaviour seen as a manifestation of a diseased brain. The social context and all this entails is ignored. Thus this model has attempted to observe dementia care using an ethological approach and has emphasised the importance of personhood. Kitwood (1992) defines the notion of 'personhood' as central to well-being, and notes this may often be unwittingly threatened in sufferers of dementia. This is due not only to neurological impairment but 'malignant social psychology' which undermines an individual's sense of self, and genuine neurological disability is further reinforced by interactions with others. A malignant social psychology is observed through the process of disempowerment or invalidation. A benign social psychology on the other hand may serve to maintain personhood where neurological impairment is offset by mutually reinforcing strategies such as validation. The importance of facilitating the latter has been an emphasis in the practice of good dementia care and in particular interventions such as validation therapy (Kitwood, 1996).

Comorbidity

To date only one study has investigated the impact of life events on affective symptoms in patients diagnosed with dementia. Orrell & Bebbington, (1995b) reported that independent, severely threatening life events were strongly associated with depressive symptoms in dementia sufferers. Using the LEDS interview (with informants) a comparison was made of life events between three groups; 70 patients with dementia

admitted to hospital, 50 patents with dementia living in the community and 50 control subjects. The number of life events occurring in the 6 months before an identified deterioration date were rated. Life events with severe threat were not significantly more frequent in the dementia patients who had been admitted to hospital compared to the other samples. However, depression in both dementia groups was significantly associated with the occurrence of independent and severe life events. Therefore, this research suggested that patients with cognitive impairment respond to stressful life events in much the same way as those without cognitive impairment. The findings of this study provide further evidence that events with a high level of threat appear to contribute to emotional changes in dementia sufferers. Life events involving threat may be more difficult for a person with dementia to adjust to or cope with because of cognitive deterioration and impairment in their ability to adapt to and process emotional responses (Gilhooly, 1994). As such this work suggests that the experience of life events may help to explain the high rate of depressive symptoms in dementia sufferers.

SOCIAL SUPPORT

There has been an increased interest in the role of social support in the prevention and in particular, course of psychiatric illness. Although it is difficult to prevent the occurrence of stressful life events, the study of factors which may mediate between stress and illness has considerable therapeutic implications. A study by Andrews et al (1978) examined the interactive effects of life event, coping style and social support on mental health. When

the effects of these three variables was combined, persons in the most ideal situation had a risk of mental health problems of 12.8 %, (half the risk of the general population). Conversely, those in the poorest situation (high life event stress, low social support and poor coping style) had a risk of 43.3 %, (nearly double that of the general population). Focusing on those factors conferring with increased vulnerability to psychiatric problems, (e.g. depression following life events), such as lack of social support may facilitate clinical interventions to ameliorate the effects of a severe life event on vulnerable persons. This section will address the literature concerning life events, depression and the role of social support as a mediating variable.

Definitions

The conceptualisation of social support is complex and is reflected in the many varied attempts to define and measure it. Two distinct schools of thought, a sociological and a psychological, have attempted a theoretical definition. The sociological perspective has focused on the structure and function of networks; the size and composition of the groups and the extent to which an individual's needs are met. Functions of support have been characterised to include: attachment, social integration, reassurance of worth, opportunity for nurturance, reliable, practical help and guidance (Brugha et al, 1987). In contrast, the psychological approach has attempted to evaluate the behavioural, cognitive and affective components of social support. The majority of empirical research has attempted to break down support into such components although the issues of quality of social support have been most widely addressed since little consistent evidence exists

to support any direct relationship between size of support networks and satisfaction with support (Lam & Power, 1991, Wenger, 1997).

One important distinction within this research lies between instrumental support and emotional support. It is generally considered that vulnerability to depression is most widely related to the lack of emotional support (Lam & Power, 1991, Brugha et al, 1987). In addition, this is clarified by the further distinction between perceived support and received support and there is mounting evidence to suggest that it is not simply whether an individual receives help but rather the belief that help is available which is most significant. A study of depressed and non depressed adults aged 65 - 84, found that the non depressed group had significantly higher levels of perceived emotional and practical support (Lam & Power, 1991) than the depressed group.

Most research investigating the relationships between social support and depression has been cross sectional. Therefore, problems are frequently encountered in attempting to assume direction of causality between life events, depression and social support. Since the quality of emotionally supportive relationships rather than the quantity are the critical factor, studies have focused on measuring perceived social support, a subjective phenomenon, which may be clouded by perception (Alloway & Bebbington, 1987). Depressed patients may view their social supports negatively, thus underestimating the extent of relationships available to them. In addition, depression itself may decrease the frequency and availability of support networks.

Models

Despite the difficulties in both defining and measuring social support, the question of the relationship between social support and health has been widely addressed in recent years (Russell & Cutrona, 1991) and two main theories have been proposed. Firstly, the buffer theory of social support which postulates that social support acts to lessen the negative impact of stressful life events on mental health. Secondly the direct effect model which predicts a positive relationship between social support and mental health independent of life event stress.

Many studies have explored these models with adults, though there are relatively fewer studies examining the relationships between social support, stressful life events and health outcomes in older adults. Of those studies, a number have found buffering effects of social support whilst others have found direct effects. Sherbourne (1992) examined this pattern across three age groups, finding that social support was beneficial for mental and physical health irrespective of age. Among those older adults with chronic illness, the majority reported good social networks and a high level of satisfaction. The mean level of emotional well-being for patients over 65 with high social support was higher than the level of any other age group lending some support to the first hypothesis. Numerous studies have attempted to provide support for the buffer theory of social support although evidence for this view is inconsistent (Alloway & Bebbington, 1987, Sherbourne, 1992). In part this may reflect methodological differences between studies

although indicating that any observed effects are "not of dramatic proportions" and potentially the result of spurious associations.

An alternative, process model has been proposed by Russell & Curtrona (1991) of the mechanism through which social support may affect adaptation to stress. In addition to mediating effects, several longitudinal studies of social support and stress have found that initial levels of social support are related to the subsequent experience of major life events (Gore, 1981) suggesting low support may act as a risk factor for subsequent experience of stressful experiences. Thus they hypothesised that a reciprocal relation between depression and stress exists in that poor mental health increases risk for stressful events which in turn increases the probability of depression. In a study of older adults, deficits in social support were found to have both direct effects on levels of depression at 1 year follow up although this was unrelated to the occurrence of major life events as predicted (Russell & Cutrona, 1991).

Social Support in Older People

The pattern of social relationships and support networks in the elderly has been described in a number of studies and patterns of social support appear to be distinct from those found in younger adults. Henderson et al (1986) found in a sample of 158 aged 70-79 and 116 aged 80+, fewer close or diffuse relationships were reported than in younger adults. However, they reported greater satisfaction with those relationships, a finding

supported by Wenger (1994). The size of social networks is generally dependent on a number of demographic factors such as age, gender as well as personality and cultural factors. The number of people in elderly persons' social networks has been estimated to fall between five and seven people, on average (Bowling, 1994) although this falls with increasing age. More importantly, perceived social support is not necessarily determined by the actual support resources available in one's network (Wethington & Kessler, 1986). However, despite it's importance, the perception of support has been less well studied. Perceived quality and accessibility to support has been reported to predict well being among a sample of elderly people whilst frequency of contact did not and poor social support has been associated with psychiatric morbidity in older adults (Bowling , 1994). Evidence for the buffer theory of social support is equally inconsistent in elderly samples, with Russell and Cutrona (1991) finding no support whilst Murphy, (1982) and Emmerson, (1987) reported the presence of a confiding relationship as protective against the onset of depression in the event of life events. Finally Bowling et al (1994) reported that physical health was a greater predictor of psychiatric morbidity than social support, even when controlling for life events, although satisfaction with support networks did have some explanatory power.

Research in elderly samples suggests depression has an impact on close social relationships. Henderson et al (1986) found a marked decrease in perceived availability of social interaction, compared with non depressed, which is consistent with patterns observed in younger samples. In addition, Murphy (1985) investigated the differences in

social supports in two groups of depressed patients: one group who had recovered from depression at one year follow up and the second who had remained ill or had relapsed. Social support was measured using the LEDS intimacy scale, she found a significant decline in the social relationships of the latter group. This sample also appeared more vulnerable to loss of relationships through death, moving or illness. In addition, the decline appeared to follow a major life event rather than be attributed directly to depression.

Social Support and Dementia

The study of support networks in dementia sufferers has been limited. However, cognitive impairment may create a barrier to the use of social resources. People with dementia may be less able to initiate help seeking and also have difficulties in maintaining reciprocal relationships. The seeking and provision of social support is to an extent dependent on the type of network available to an individual. People with dementia have reduced support networks which tend to revolve around personal care and 'surveillance' and are predominately family based with fewer contacts with networks such as friends and neighbours (Grant & Wenger, 1993). Furthermore, Henderson et al (1986) found that patients with dementia reported less social interaction outside of close ties and fewer opportunities for social relationships then they would like. Wenger (1994) reported a marked difference in the distribution of support network types between those identified with cognitive impairment and those without cognitive impairment. Dementia

sufferers were more likely to live with others and to have more contact with family members, but have less contact with friends, neighbours and community groups.

Social support has been defined as "an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of an individual over time" (Esser & Vitaliano, 1988). Therefore, in keeping with a psychosocial model of dementia, it is hypothesised that social support in dementia may potentially play a role in maintaining well-being. However, the impact of social support in dementia has had little investigation and there has been little research regarding the perceived quality of such relationships from the sufferer's perspective. To date, there has been no systematic investigation of the influence of a confiding relationship on depressive symptoms in dementia.

CAREGIVING, LIFE EVENTS AND DEPRESSION

Background

The quality of any caregiving relationship is likely to be a reflection in part of the carer's mental health. The impact of caregiving on carers has been widely studied and research supports the clinical observation that caregiving is associated with stress, burden and mental health problems (Gilhooly, 1994). Many attempts to elucidate which factors

contribute most to these findings have been made, such that concepts of subjective and objective burden have been differentiated and their physical and psychological correlates described. The focus of this section will be on depression in caregivers. Prevalence of depressive disorders in caregivers has been estimated at between 18% and 83% with many studies reporting rates of between 40 and 60%. (Redinbaugh et al, 1995). This contrasts sharply with prevalence rates for depression of 8% for non caregivers of similar age (Blazer & Williams, 1980). In addition, the finding that the ability to maintain care for an elderly person with dementia in the community is more highly correlated with the well-being of the caregiver than the severity of impairment of the dementia sufferer (Morris et al, 1988) makes the issue of depression in carers especially pertinent. However, attempts to understand the associations of depression in carers is complex and the research findings are often inconsistent. A number of variables appear to correlate with depression but many of these are interrelated, making it difficult to draw firm conclusions. The research literature, in the main, has tended to focus on demographic variables or factors related to the care giving relationship itself. However, other factors such as personality, life events and appraisal of the caregiving situation and coping style may all mediate the impact of caring.

The available evidence on the relationship between gender, age and depression in caregivers is inconclusive. Although gender differences in well-being are described with higher levels of depression reported in female carers, this finding is confounded by higher rates of depression in females more generally (Morris et al, 1991). Similar

difficulties are found in interpreting the evidence on their relationship between age of carer and depression (Shulz et al, 1995). More consistent, however are the findings that relationship to the patient is associated with carer depression. Generally, the greater the difference in familial relationship, the better the individuals well-being and attempts to explain this finding have focused on the differing degree of emotional investment in caregiving. In a review of available studies, Schulz et al, (1995) reported that spouses tended to report greater depression in five of the seven studies reviewed. In a comparison of adult children and spousal caregivers, George (1984) also reported poorer mental health in spouses. Both of these groups reported greater distress than more distant caregivers such as friends or extended family. Moreover, qualitative studies of marital intimacy report significant changes in the relationship as the course of dementia progresses and such changes would support these findings (Knight, 1991). Finally, a relationship between residence of patient and carer depression has been reported with live in carers reporting greater levels of depression (Brodaty & Hadzi-Pavoavic, 1990). The quality of the caregiving relationship has been found to be of central importance in mediating the degree of burden and well-being reported by carers. In particular the relationship prior to onset of dementia has a significant influence on the subsequent perception of burden. A poor premorbid relationship has been associated with greater depression (Kreigsman, 1994) and those reporting a poor relationship were more likely to favour institutional care. In terms of characteristics associated with the patient, factors such as severity of cognitive impairment or functional ability are poorly correlated with carer depression (Gilhooly, 1994). However, a consistent finding is the relationship

between behavioural disturbance in patients and depression in carers, with 9 of the 10 studies reviewed by Shulz, (1995) reporting significant associations.

The study of social factors on carer depression has received less attention in the literature although a few studies have addressed the impact of life events on carers in relation to perceived burden and carer well-being. Brown (1987) has commented that when a stressful life event occurs in the context of a chronic stressor (such as caregiving), it may "increase aspects of the stressor resulting in greater distress than if either occurred alone" so life events may have equal if not greater impact on depression in carers. Redinbaugh et al (1995) investigated the impact of life events and social support in three groups of caregivers: chronically depressed, episodically depressed and never depressed, over three years. Those with chronic depression were consistently different from the other two groups at each time point and had more negative life events, higher stress levels, lower levels of social support and negative reactions to patients disruptive behaviours. Other factors such as pre caregiving depression predicted depression during caregiving but 90% of the chronically depressed caregivers had no history of depression. Deficits in social support have long been associated with increased rates of depression following life events and these findings would suggest that poor social support in the face of the stress of caring and the occurrence of life events may increase vulnerability to depression. Furthermore, Reed et al (1990) examined the occurrence and impact of a number of life events including health difficulties, interpersonal relationships, and work stressors on caregivers. The findings revealed that caregivers reported more negative events and

rated them as more distressing than controls and it may be that the impact of life events in carers has greater impact.

However, by contrast, Russo & Vitaliano (1995) compared the frequency and the impact of life events in carers of dementia patients with matched controls and the role life events played in the burden reported by carers. The sample of 175 spousal caregivers and 92 matched controls were interviewed using the life events survey for older adults measured on the Life Experiences Scale (Kiyak et al, 1976 cited in Russo & Vitalino, 1995). Caregivers and controls did not differ in the rate of independent life events, suggesting that carers are not different from other older adults in terms of the frequency of life events. However, in this sample a decrease in social interaction was reported more frequently by the caregivers. This finding is significant given that other studies have found that caregiving is associated with a decline in social support and increased isolation and withdrawal (Morgan & March, 1992). From the stress buffering theory of social support it may be hypothesised that this will increase the probability for depression in the event of stressful life events. As in other groups, appraisal of the adequacy of social support has been found to mediate depression in caregivers (Hannappel et al, 1993).

There has been little research investigating the impact of carer depression on patients and vice versa. The concept of contagion suggests that individuals tend to 'pick up the mood' of those around them. Bookwala & Shulz (1995) have demonstrated that negative mood

in one partner may 'spill over' to the other, independent of other factors in elderly couples. In addition, relatives of patients with depression whose onset followed life events had higher rates of depression than those whose onset was not associated with life events (McGuffin et al, 1988). The authors concluded that liability to depression and even experiencing life events is familial. Given the high comorbidity of depression in dementia and the high prevalence of depression among carers, exploring any potential interrelationship would appear valuable and has not been systematically investigated in the literature.

The social deterioration of an older person with dementia has a significant impact on the carer. Studies using a more qualitative approach have attempted to clarify this (Gilhooly, 1994). In these studies it was noted that many carers spoke of caring for the 'body or shell' of their relative and behaved in many ways as if the patient were already 'socially' if not biologically dead. The term 'social death' has been defined as the way in which people think of a person they once knew as alive, now think of them for as 'dead' or non existent whilst anticipatory grief refers to the patterns of normal grieving and withdrawal observed in people with terminal illness prior to death. In a recent study (Sweeting et al, 1992 cited in Gilhooly, 1994), patterns of grieving were clearly observed whilst in relation to 'social death', three factors emerged: the carers anticipation of death and the feeling the patient had lived too long; the dementia sufferer's apparent lack of awareness and response to the environment; the carer's belief that in many ways their relative was already dead and that bodily death would be a welcome release.

Therefore, there is a need for greater understanding of factors which may lead to the breakdown of the caregiving relationship. Gilhooly (1994) argues that this should be qualitative in direction and include the views of patients with dementia. To date, research has focused separately on the sufferer and has been mostly on the physiological or cognitive aspects of carer burden. Perhaps due to the nature of dementia and memory decline, little faith has been put in the reliability of the views of people with dementia.

SUMMARY

Evidence that life events of a threatening nature are linked to symptoms of depression in persons with dementia (Orrell & Bebbington, 1995c) is a finding with considerable practical and theoretical interest. it highlights how we may have neglected the existence of normal psychological processes of a non cognitive nature where dementia is present. It provides support for Kitwood's argument that persons with dementia are not just responsive to but may have heightened responses to interpersonal and social events whilst giving impetus to clinicians to consider carefully the diagnosis and treatment of depression in the presence of dementia. In addition, it raises numerous theoretical questions (some of which the present study is designed to address). For example, How are threatening life events registered by people whose memory is failing?, Do the usual relationships between social support and vulnerability remain in people with dementia?, Are there vulnerability factors which are specific to person's with dementia? and What

part, if any, does the mood of the carer play in protecting against or contributing to depression in dementia sufferers?

AIM

The aim of this study therefore was to explore the interrelationships between social factors, specifically life events, and depression in dementia sufferers and their carers. The new areas of research that are examined in this study are the impact of social support on the response of person's with dementia to threatening life events; the impact of carer life events and depression in carers on a person with dementia; with a qualitative examination of what a person with dementia can relate about threatening life events. The specific research questions addressed by this study were as follows:

RESEARCH QUESTIONS

1. What is the association between life events and depression in dementia sufferers?

2. What is the relationship between carer depression and depression in dementia sufferers, particularly in the context of the sufferer experiencing a threatening life event?

3. Does a lack of perceived social support increase the risk of depression in dementia sufferers, particularly in the presence of a threatening life event?

4. Does carer depression decrease the perceived social support experienced by dementia sufferers, especially in the presence of a threatening life event?

5. Is there an association between life events in carers and depression in dementia sufferers, particularly in the context of a poor caregiving relationship?

6. Even in the presence of a mild/moderate dementia, is there some recollection of, and emotional reaction to a threatening life event? (whether or not this leads to the emergence of depressive symptoms).

CHAPTER TWO - METHOD

OVERVIEW

This study aimed to investigate life events, depression and social support in dementia sufferers. Participants were patients diagnosed with senile dementia attending outpatient or day centre services. Carers were interviewed about life events occurring in the six months prior to the interview date and a number of measures of mood, level of disability and social support were completed. In addition, a subgroup of patients were interviewed about recent life events using qualitative and checklist measures.

DESIGN

This study was cross sectional in design, investigating associations between life events and depression in people diagnosed with dementia. Subgroups of depressed and non depressed participants were identified and compared on a number of variables.

PARTICIPANTS

The participants for the study were from selected from two sources. Firstly, from outpatient referrals during the preceding 12 months to two multidisciplinary teams within an old age psychiatry service at Hillingdon Hospital. Secondly, from attenders at two day centres in Harrow for people diagnosed with a dementia. Ethical approval was obtained from Harrow & Hillingdon NHS trusts. Case notes were reviewed and clinicians approached with regards to the suitability of identified patients. Once identified,

dementia sufferers GP's were informed of their being approached for participation in the study.

Inclusion criteria:

1. Aged 65+
2. Diagnosis of primary degenerative dementia either Alzheimer's Disease (AD) or Multi-Infarct Dementia (MID): based on consultant diagnosis, DSM IV criteria plus a score of <24 on the Mini Mental State Examination (MMSE) (Folstein, 1975).
3. Availability of a suitable carer defined as somebody who had a significant relationship with the person, was able to give an accurate account of the person's life events and who saw them at least weekly.
4. Absence of severe physical illness likely to affect cognition.
5. Not living in a staffed residential unit.

In addition, some potential participants identified were excluded due to clinicians perceived tensions within the caregiving relationship or infrequency of contact. Initially, an exclusion criteria of a score <10 on the MMSE was included. This was intended to screen for those patients with severe dementia who would be unlikely to be able to participate in an interview due to the level of impairment in functioning. However, due to delays in recruitment, this criteria was dropped and all patients, irrespective of severity of dementia, were considered for inclusion in the study.

PROCEDURE

Once patients were identified as suitable and clinicians consented to them being approached for interview, information sheets and letters were sent to patients and their identified carer to invite them to take part in the study. Follow up telephone calls were made to the carer in order to answer any questions and arrange interview dates. In all but three cases, participants were interviewed in their own or carer's home for convenience. The remainder were interviewed at a day centre.

Each interview lasted between 45 and 90 minutes depending on the number of life events experienced and whether or not the patient themselves were interviewed. The purpose of the study was summarised and participants were given the opportunity to ask questions. Carers then gave written consent to participate. Where patients were interviewed, information was given and consent, written where possible, was obtained in the presence of the carer. Carers were interviewed, usually alone, in order to collect demographic information, life event details, social support information and depression ratings. In addition , carers completed self report depression scales. In those cases where patients were interviewed, this was either alone or in the presence of the carer. Interviews with patients lasted approximately 15 minutes and information was collected on life events, perceived social support and mood and MMSE. Once interviews were completed, the rating of life events was carried out by a panel of independent raters. All quantitative data were analysed using SPSS for windows. No formal analysis of the qualitative data

were carried out. Material obtained from these interviews was used to support and to illustrate quantitative findings.

MEASURES

Demographic information

This included marital status, accommodation (living alone/others), details of the level of formal support including frequency of attendance at day services, homehelp/paid carers, professional and voluntary services received, family history, physical health and details of family and social networks.

Clinical Dementia Rating (CDR)

This standardised scale was used to determine overall severity of dementia. It consists of a composite rating, derived from five separate areas: cognition, judgement, problem solving, level of personal care and social abilities (Hughes et al, 1982). A score of 0 in each category indicates normal function and 3, severe dementia. The measure has been widely used and it's valid and reliability demonstrated, with a significant correlation reported ($r = 0.6$) between carer's ratings of symptoms and those of a clinician (Brodaty & Hadzi-Pavlovic, 1990).

Cornell Scale for Depression in Dementia (CSDD)

This scale is a 19 item instrument specifically designed for the rating of symptoms of depression in patients diagnosed with dementia (Alexopolous et al, 1988). In this study it

was used in order to determine the presence of depression in dementia sufferers. The scale is clinician administered and items are constructed such that they can be rated on the basis of observation. The scale covers five domains: mood related signs, behavioural disturbance, physical signs, cyclic functions and ideational disturbance. The measure was administered in two stages with the carer interviewed initially followed by the patient themselves (where possible). Symptoms were described as they appeared on the scale and any discrepancies between the two interviews were clarified. The severity of each of the items was rated according to three grades: absent, mild/intermittent or severe. The scale has been demonstrated to have good reliability and validity (Teri & Wagner, 1991). High inter-rater reliability (k=0.67), internal consistency (coefficient alpha: 0.84) and sensitivity is reported. Total Cornell scale scores correlate (0.83) with depressive symptoms as classified according to research diagnostic criteria (Alexopoulos et al, 1998). Although designed as a rating scale rather than diagnostic instrument, the measure has been used to determine caseness (Vida et al, 1993). Receiver operating characteristic analysis indicated that for clinical purposes, a cutpoint of 7/8 was suitable for the detection of research diagnostic criteria major depression in mild to moderate Alzheimer's disease, yielding a sensitivity of 0.90 and a specificity of 0.75 (Vida et al, 1993).

Mini-Mental State Examintation (MMSE)

This is an 11-item, 30 point measure used to assess immediate and delayed memory, orientation, reading and oral comprehension, writing and visual-motor abilities. Widely

used, this scale screens for cognitive impairment (Folstein et al, 1975) and was used in this study to determine severity of cognitive impairment. In many cases, MMSE ratings were available in case notes and as such were not administered to the dementia sufferer if recent (within 6 months). The MMSE has been demonstrated as a valid test of cognitive function, with high levels of sensitivity for moderate to severe levels of cognitive impairment and is successful in separating those with cognitive disturbance from those without (Tombaugh & McIntyre, 1992). In addition, satisfactory test-retest reliability has been reported (>0.8) (Folstein, 1975).

Quality Of Relationship Scales (QoRS)

These scales were developed by Bergmann et al, (1984) to provide a brief assessment of the quality of the relationship between older psychiatric patients and their carers. Three domains: dominance-submissiveness, negative-positive communication, and autonomy-physical dependency are rated on a 7 point scale. Ratings in this study were made on the basis of report from interviews with carers to determine their perception of the caregiving relationship. Although there is limited psychometric evaluation, previous use of the measure indicates satisfactory inter-rater reliability (Bergmann et al, 1984).

Intimacy Scales (IS)

The LEDS schedule (Brown & Harris, 1978) includes questions about the quality of personal relationships (intimacy) which are used to rate the degree to which a confiding relationship is available. The measure has been demonstrated to have high reliability

and validity with adults and older adults (Murphy, 1985). Carers were asked about the perceived availability of a confiding relationship for themselves and for the person they cared for. Ratings were made on a four point scale:

A). = a close, intimate and confiding relationship with a spouse or cohabitant.

B). = a close, intimate relationship with someone whom they do not live with, i.e. sibling, child, friend, seen at least once weekly.

C). = a close, intimate relationship with the above but seen less than weekly.

D). = nobody available.

Social Support (OARS)

The social resources scale of the OARS Multidimensional Functional Assessment Questionnaire and Services Supplement (Fillenbaum, 1978) was administered as a measure of social support in dementia sufferers. The OARS instrument was developed to give a comprehensive profile of older people living in the community in terms of mental health, physical health, economic and social resources and activities of daily living. It permits both an overall assessment of individual functioning and a comprehensive assessment of services utilised (Fillenbaum, 1981) and has been extensively used in numerous research and clinical settings (Liang et al, 1989). The OARS was validated on three older populations, test-retest reliability is reported at 0.91 (Fillenbaum, 1981) and inter-rater reliability reported as ranging from 0.67 to 0.87 (Fillenbaum, 1981). Only the social resources scale was administered in this study, which measures both quantity and quality of relationships with family and friends. It

contains questions regarding levels of functional support, i.e. size of social network and frequency of contact as well as questions designed to elicit perceived emotional support. Sample items include, 'Do you feel you have someone to trust and confide in?' . Information regarding frequency of social contacts was collected in all cases but perceived social support was only collected in those cases where patients themselves were interviewed.

Bedford College Life Events and Difficulties Schedule (LEDS)

The LEDS is a method of eliciting, recording and dating the occurrence of life events using a semi structured interview covering a number of areas (Brown & Harris, 1978). This method is reliable, valid and appropriate for use with older populations (Murphy, 1982). Inter-rater reliability of the LEDS is estimated at 80% and is acceptable even after brief training of raters (Tennant et al, 1979) and reliability of the LEDS with an older sample is equal to that of younger samples (Wilkinson et al, 1986). In addition, age differences between raters and participants do not appear to affect the overall reliability of the ratings (Davies et al, 1987) and informants can provide accurate information about events (Murphy, 1982, Orrell, 1994).

The LEDS was adapted for use with an older sample, such that age inappropriate questions, e.g. questions relating to pregnancy were removed. Areas covered in the LEDS for this sample were as follows:

Health related problems including hospital admissions, accidents, falls

Deaths

Family related issues

Changes in roles/friendships

Separations/moves

Financial

Housing

Losses/crises

Employment (carers)

Other

Information regarding the occurrence of life events in the six months prior to the interview date was collected from carers/informants. Carers were asked for details of life events affecting the patient and those affecting the carer themselves and the events dated to the nearest month. In many cases i.e. where the participants were married there was considerable overlap between the events experienced by both carer and patient. Events were rated separately for their impact on the carer and the patient. Similarly events which appeared to impact solely on the carer (or the dementia sufferer) were rated individually for that person only.

Events were rated by a trained and independent panel of raters (Dr. M. Orrell, Dr. M. Skelton-Robinson, Prof. P. Bebbington). The life events were presented with socio-demographic information and the contextual background to each event but without details of the subjects emotional response to events. Events were rated for the degree of

long term 'threat' to the participant, defined as that threat persisting 1 week after the event. A score of 1-4 was given after discussion: 1 = marked threat, 2 = moderate, 3 = mild and 4 = little or no long term threat. In addition, the psychological status of the participant was withheld, i.e. carer or patient although the nature of some events made this impossible at times. The degree of 'independence' for each event was rated such that; 1 = independent, 2 = possibly dependent and 3 = dependent. This method represents an advance on checklist measures of life events enabling an objective measure of threat to be made without bias from the participant or interviewer.

List of Threatening Events (LTE)

This is a checklist of 12 events identified from a longer inventory (Brugha, 1985). This checklist has been validated against the LEDS and showed that it accurately covered 80% of items on the LEDS rated as carrying significant long term threat (Brugha, 1985). The version used in this study covered only those items appropriate to this age group with an added question to cover any other events. The measure was used in the qualitative interviews with dementia sufferers in order to prompt memories of life events.

Qualitative experience of life events

A sample of patients (41) who were willing and able to give consent were interviewed. A brief semi-structured questionnaire designed for this study which focused on recent life events was used. This questionnaire was used as a prompt for discussion in order to elicit the subjective meaning attributed to a threatening life event by the patients. All 41

dementia sufferers who were interviewed were asked about recent life events using open ended questions followed by prompts in the form of a checklist (Brugha, 1985). If participants reported the occurrence of life events, they were encouraged to expand on these using open ended questions relating to what happened, how it affected them and how they coped with life events. This aimed to ascertain the person's awareness, experience and memories of the life event, their lasting impressions and any coping methods employed following the event, particularly related to social support. If no events were recalled then information obtained from the carer's LEDS was used to prompt recall if possible. The results of the checklist were compared to that reported by carers on the occurrence of life events.

Carer measures - Beck Depression Inventory (BDI)

This is a standardised, reliable and valid self report measure of depressive symptoms in adults (Beck, 1988). Consisting of 21 items covering a range of depressive symptoms, the BDI provides a rating of severity of depression from 0 to 63 with a cut off point of 10/11 indicative of mild depression. (Beck, 1961). This measure was administered to all carers under the age of 65 in order to screen for depression. It was not administered to carers over 65 since it has been found to be less valid in older adults due to the reliance on somatic items in the measure.

Carer measures - Geriatric Depression Scale (GDS)

The GDS was developed as a measure of depressive symptoms specifically in older adults. The short form of the GDS, a 15 item self report scale with a yes/no format, has been demonstrated to have a high correlation with the original version (Sheikh & Yesavage, 1986) and has good internal consistency and validity (Hermann et al, 1996). In addition, the measure provides a cut-off score of 5/6 demonstrating a sensitivity of 85% and a specificity of 74% (Hermann et al, 1996). Sample items include: 'Are you in good spirits most of the time?' and 'do you think that most people are better off than you are?'. The measure has been found to have good concurrent validity with the Beck Depression Inventory (correlation coefficient = 0.84) (Ferraro & Chelminski, 1996) and is therefore also appropriate for use with a younger sample. Subsequently, this measure was administered to all carers regardless of age to screen for caseness of depression and was used in the analysis of data relating to carer depression.

CHAPTER THREE - RESULTS

OVERVIEW

This chapter will report on the main findings of this study in relation to the research questions. It will begin by summarising demographic factors and social support among this sample of dementia sufferers. Secondly, factors associated with depression in dementia sufferers, including life events will be reported. Thirdly, the demographic, social support and factors associated with carer depression will be described. Fourth, the relationship between life events, carer depression and depression in dementia sufferers will be addressed. Lastly, multivariate analysis of factors associated with depression in both dementia sufferers and their carers will be reported. Finally, the findings from the qualitative interviews will be summarised.

RESPONSE RATE

In total, 112 people were identified as potentially suitable for the study and were invited to take part. Of these 112, 4 had since died and 6 had been admitted to residential care. Of the remaining 102, 72 patients and their carers consented to the study, making a response rate of 70.5%. Of the total sample, 41 carers and dementia sufferers and 31 carers only were interviewed. Of the 30 people who declined to participate, 10 (25%) carers felt that the patient was too mentally confused or physically unwell to participate, 7 (17.5%) felt that discussing recent life events may cause the patient or themselves to become distressed and 13 (32.5%) gave no reason. There was no significant differences

between the participants and those who declined to participate, in terms of age, sex, MMSE score or diagnosis.

DEMOGRAPHIC DATA

Dementia sufferers

Of the total number of dementia sufferers in this study (n=72), 30 (41%) were male and 42 (59%) female. The mean age of the total sample was 80 (sd 5.2, range 66-94). Males had a lower mean age, 78 (sd 6.1) than females, 81 (sd 7.8) although this was not statistically significantly. In terms of DSM 1V diagnosis 50 (70%) were diagnosed with Alzheimer's Disease (AD) and 22 (30%) with Multi-Infarct Dementia (MID). The mean score on the Mini Mental State Examination (MMSE) was 14 (sd 5.2) with a range of 5-24. On the Clinical Dementia Rating Scale (CDR), 21 (29.2%) participants were rated as having mild dementia (CDR=0.5-1), 31 (43.0%) as having moderate dementia (CDR=2) and 20 (27.8%) as having severe dementia (CDR=3). The mean score on the CDR was 1.91 (sd 0.88). There was no significant relationship between gender and age on the MMSE, CDR or diagnosis. Table 1 shows data on marital status, ethnic origin and living status.

Of the total number of carers in this study (n=72), 58 (80%) were female and 14(20%) male. The mean age of carers was 64 (sd 13.7), range 29-90. A breakdown of the relationship of carers to dementia sufferers and frequency of contact can be found in Table 1.

TABLE 1: Socio - demographic characteristics of the total sample.

	Sample n = 72	
	N	**%**
Ethnic origin		
White UK/ Irish	66	91.7
White Other	4	5.6
Indian	2	2.7
Marital Status		
Married	34	47.2
Widowed	32	44.4
Divorced	3	4.2
Single	3	4.2
Living Status		
Alone	26	36.1
Spouse	32	44.4
Children	10	13.9
Grandchildren	2	2.8
Siblings	1	1.4
Friend	1	1.4
Carer Status		
Husband	9	12.5
Wife	24	33.3
Son	4	5.6
Daughter	23	31.9
Daughter in law	3	4.2
Brother	1	1.4
Sister	2	2.8
Other Relative	1	1.4
Friend	5	6.9
Frequency of contact		
Live in	46	63.9
Daily (non live in)	10	13.9
2-3 times weekly	13	18.0
4-6 times weekly	2	2.8
weekly	1	1.4

DEMENTIA GROUP

Social support

Data relating to perceived social support in terms of quantity and quality of support was measured using the OARS and LEDS intimacy scale. Data relating to the quantity of social support available to dementia sufferers was obtained from carers for the total sample (n=72). Data relating to the quality of social support was obtained from interviews with dementia sufferers (n=41).

Quantity of Social Support

Three questions measuring the amount of social support were analysed. When asked, *'How many people do you know well enough to visit or have visit you?'*, 7 (9.7%) reported none, 38 (52.8%), 1-2 people, 17 (23.6%), 3-4 people and 10 (13.9%) 5+ people and excluded contact with formal or professional carers. Secondly, *'How many times in the last week did you meet with someone who does not live with you?'*, 7 (9.7%) reported none, 20 (27.8%) once, 43 (59.7%) 2-6 times and 2 (2.8%) daily. Finally, *'How many times did you speak to friends/relatives on the phone in the last week?'*, 31 (43.1%) reported none, 19 (26.4%) once, 19 (26.4%) 2-6 times and 3 (4.2%) daily.

Perceived Quality of Social Support

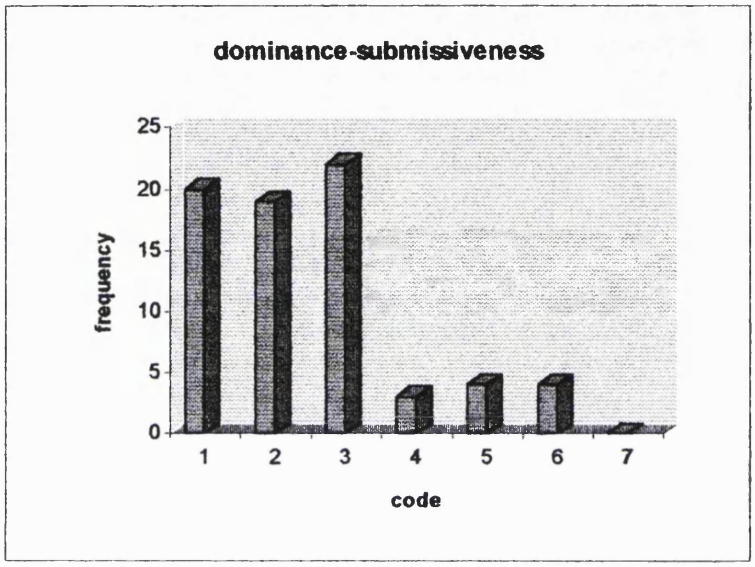
In order to evaluate the perceived social support in dementia sufferers, three questions from the OARS social resources questionnaire and the intimacy rating from the LEDS

(based on the perception of the dementia sufferers social support by the carer) were analysed. Firstly, when asked, *'Do you feel you have someone to trust and confide in?'*, 37 (90.2%) reported yes and 4 (9.8%) no. Secondly, *'Do you find yourself feeling lonely?'*, 5 (12.2%) reported quite often, 12 (29.3%) sometimes and 24 (58.5%) almost never. Finally, *'Do you see your friends and family as often as you would like to?'*, 28 (68.3%) reported yes and 13 (31.7%) no. Responses to the LEDS intimacy question for dementia sufferers (as perceived by carers) supported these findings with 54 (75%) reporting that there relative had a confidant seen daily, 13 (18.1%) seen weekly, 5 (6.9%) seen less than weekly and 0 having no confidant.

Quality of Relationship Scales (QoRS)

The QoRS scales were analysed in order to evaluate the quality of relationship between carer and dementia sufferers. Graph 1 shows that in the majority of cases, the carer felt that the dementia sufferer was largely in control of the relationship and only a small minority felt that the carer was generally in control. As expected, Graph 2 shows that the carer tended to be providing help for the dementia sufferer and almost no dementia sufferers were seen to be helping the carer. Lastly, graph 3 shows that to a large extent carers felt that the relationship was predominantly positive. However, there was an important minority (rating 5) where negative communication was a problem.

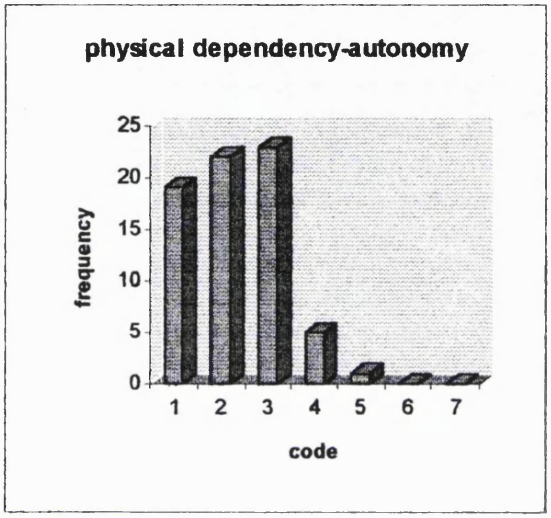
Graph 1: Dominance-submissiveness in carer-dementia sufferer relationship.



code:

1 = Patient controls every area of a relationship
2 = Patient generally in control of relationship.
3 = Patient mainly in control of relationship but some areas relative has control.
4 = Equal sharing of control, balance of power/independence.
5 = Relative mainly in control some areas patient has lot of control.
6 = Relative generally in control, some options left to patient.
7 = Relative controls every area of relationship.

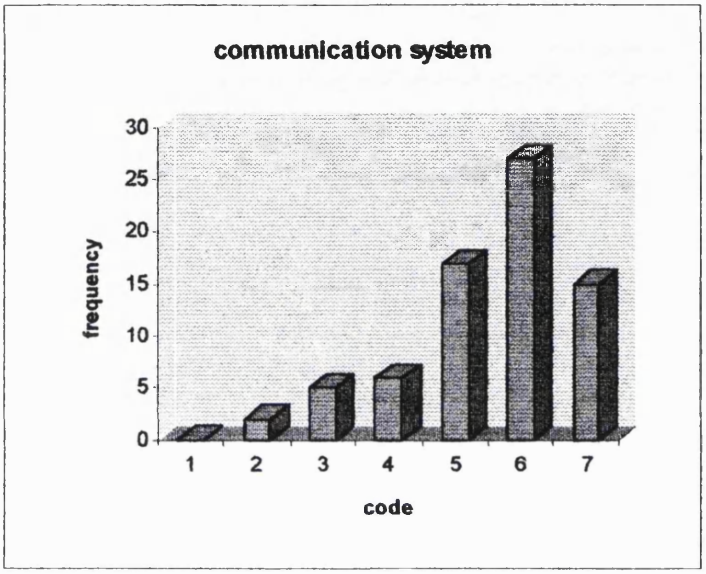
Graph 2: Physical dependency - autonomy in the carer - dementia sufferer relationship.



Code:

1 = Relative gives patient a great deal of physical care daily.
2 = Relative gives patient some daily help although patent independent in self care.
3 = Relative gives patient some help less than daily.
4 = Relative and patient are independent of each other or give mutual help.
5 = Patient gives relative some less than daily.
6 = Patient gives relative some daily help although relative independent in self care.
7 = Patent gives relative a great deal of physical care daily.

Graph 3: Communication system in the carer - dementia sufferer relationship:



Code:

1 = Constant negative communication, criticism, punishment, withdrawal.
2 = Frequent verbal aggression/withdrawal. Little reward for partner.
3 = Much verbal punishment/withdrawal, but some reward.
4 = Equal amounts of negative verbal communication/withdrawal and positive communication.
5 = Mainly positive communication, some negative verbal communication/withdrawal.
6 = Predominately positive warm communication, occasional negative verbal communication.
7 = Almost continual positive reward, loving, almost no withdrawal from relationship.

DEPRESSION IN DEMENTIA SUFFERERS

Demographic factors

The Cornell Scale was used as a measure of depression in dementia sufferers. The mean score for the total sample (n=72) was 7.08 (sd 4.86), range = 0 - 20. A score of >7 has been determined as a cut off score for depression on this measure (Vida et al, 1994). The scale was also recoded into depressed/not depressed and on the basis of this cut off score, 29 (40.2%) of the dementia sufferers were classified as depressed. The mean score for the non depressed sample was 3.79 (sd 2.08) whilst for the depressed group, the mean score was 11.96 (sd 3.45). There were no significant differences between the depressed and non depressed samples in terms of age, gender, diagnosis, MMSE or CDR scores. Details of the incidence of depression in dementia sufferers can be found in Table 2.

Table 2: Rate of depression in dementia sufferers by gender.

	Male	Female	Total
Depressed	13 (43.4%)	16 (38.1%)	29 (40.2%)
Not Depressed	17 (56.6%)	26 (61.9%)	43 (59.8%)

Life events

Of the sample of dementia sufferers (n=72), 50 (69.5%) had experienced at least one life event in the 6 months prior to interview date. Life events were recoded into those events which were both independent (rated as 1) and severe in terms of threat. A severe threat

included those events rated as a 1 (marked) or 2 (moderate) on the LEDS contextual rating method. Thirty four (47.2%) of dementia sufferers had one or more independent and severely threatening life events in the preceding six months. Only those events which met this criteria were included in analysis of the relationship between life events and depression. Table 3 shows data on the frequency, type and focus of these life events, indicating events which were focused on dementia sufferer only, carer only or joint events. The rate of joint life events in this sample was 59.3%

Table 3: Frequency of severe and independent threatening life events in total sample (dementia sufferers, carers and joint events):

Type of life event	dementia only	carer only	joint event	% joint events
ill health	7	6	15	53.5%
bereavement	6	4	14	58.3%
separation/divorce	1	0	1	50.0%
accidents/falls	2	1	2	40.0%
family worries	2	2	8	66.6%
friends worries	0	1	1	50.0%
financial	1	2	1	25.0%
housing	0	0	1	100%
moves	0	0	1	100%
occupational	0	1	0	0.00%
crime	0	2	0	0.00%
other crises/emergency	0	2	2	50.0%
TOTAL	**19**	**21**	**46**	**59.3%**

Life events and depression

The first research question addressing the association between life events and depression in dementia sufferers was explored. The frequency of severe and independent life events for three time periods, 0-3 months, 4-6 months and 0-6 months prior to interview date

was compared with depression/non depression as shown in Table 4. The results revealed a significant association between the occurrence of life events in the depressed group for 0-3 months ($\chi 2$=7.65, df=1, p=0.005) and 0-6 months ($\chi 2$= 4.32, df =1, p=0.03). There was no significant difference between the depressed and non depressed group in terms of the occurrence of life events for the period 4-6 months ($\chi 2$=0.350, df=1, p= 0.55). In addition, t-tests revealed a significantly higher depression score for those experiencing at least one life event in the 0-6 month period, mean = 8.26 (sd 5.55) compared to a mean of 6.02 (sd 3.09) in those not experiencing a life event (t = -1.96, p=0.05). There was also a significant difference in mean depression score between the two groups for the 0-3 month period, 8.76 (sd 5.42) for the depressed group compared to 6.13 (sd 4.28) for the non depressed group, (t=2.28, p=0.02). Therefore, an association between life events and depression in dementia sufferers was found. Table 4 shows data on life events and depression in dementia sufferers in 0-3, 4-6 and 0-6 months. Given that the significant association between life events and depression was for 0-3 months prior to interview, this variable was used in all further analysis of the data involving life events in dementia sufferers.

Table 4: Rates of depression and life events among dementia sufferers across three time periods:

	0 - 3 mths		**4 - 6 mths**		**0 - 6 mths**	
	Events	*No events*	*Events*	*No events*	*Events*	*No events*
Depressed	16 61.5%	13 28.3%	10 45.5%	19 38.0%	18 53.0%	11 29.0%
Not depressed	10 38.5%	33 71.7%	12 54.5%	31 62.0%	16 47.0%	27 71.0%
Total	26 $\chi 2$= 7.65 p=0.005	46	22 $\chi 2$=.350 p=0.55	50	34 $\chi 2$=4.32 p=0.03	38

In order to investigate the possibility that depression results from an accumulation of life events within this time period, a correlation between total number of life events and Cornell score was performed which was not significant (0.23, p=0.15). Therefore, it would seem that the presence of one severe and independent event alone is significantly associated with depression.

Social support and depression

In order to investigate whether a lack of social support increased the risk of depression in dementia sufferers following a life event, data relating to perceived social support were analysed. Comparisons of the perceived social support and Cornell scores were investigated. There was no significant relationship between the perceived presence/absence of a confiding relationship and depression/no depression ($\chi 2$=0.17,

df=1, p=0.67) or satisfaction with frequency of contact with relatives and depression ($\chi 2$=0.15, df=1, p=0.69). The relationship between the LEDS intimacy scale, feeling lonely and depression was investigated using Mann-Whitney U. No relationship was found between loneliness and depression (U=147.0, p=0.18) or between lack of intimacy and depression (U=556.0, p=0.30). Finally, the relationship between quantity of social support and depression were investigated in terms of the number of people available in the social network. There was no significant relationship between quantity of social support and depression. (U=481.5, p=0.07). Table 5 shows data on these results for depressed and non depressed dementia sufferers.

Table 5: Dementia Sufferer's responses to perceived social support measures by depression.

	Depressed	**Not depressed**
Perceived Confidant	1 (7.01%)	3 (11.1%)
No confidant		
Confidant	13 (92.9%)	24 (88.9%)
Lonely		
Quite often	2 (14.3%)	3 (11.1%)
Sometimes	6 (42.9%)	6 (22.2%)
almost never	6 (42.9%)	18 (41.9%)
Satisfaction with frequency contact with friends/relatives		
Not satisfied	5 (35.7%)	8 (29.6%)
Satisfied	9 (64.3%)	19 (70.4%)
LEDS intimacy scale		
Nobody	0	0
Confidant seen <weekly	3 (10.3%)	2 (4.7 %)
Confidant seen >weekly	6 (20.7%)	7 (16.3%)
Confidant seen daily	20 (69.0%)	34 (79.1%)

Life events, social support and depression.

In order to investigate whether social support was a protective factor against depression in the context of a life event, cross tab analyses were performed on the data. Given the uneven distribution of scores in the other measures, satisfaction with frequency of contact was used as a measure of perceived social support. The analysis did not reveal any significant relationship between life events (0-3 months) and depression when perceived social support was controlled for. However, there did appear to be a positive link between satisfaction with social support and the experience of life events (0-3 months), independent of depression. The trend, although not statistically significant, suggested that 75% of those experiencing life events were satisfied with their social support, compared to 65% of those not experiencing life events who were satisfied with their social support. For the depressed sample, 75% of those people with life events were satisfied with social support whilst 50% of those without life events were satisfied with social support. In terms of the non depressed sample, 75% of those with life events were satisfied with social support compared to 25% of those without life events. A breakdown of the relationships between depression, life events and social support can be found in Table 6:

Table 6: Relationship between life events (0-3 months), depression and satisfaction with social support in dementia sufferers:

	All		**Depressed**		**Not Depressed**	
	No events	*Events*	*No events*	*Events*	*No events*	*Events*
Not satisfied	10(34.5%)	3(25.0%)	3(50%)	2(25%)	7 (30.4%)	1(25.0%)
Satisfied	19(65.5%)	9(75.0%)	3(50%)	6(75%)	16(69.6%)	7(75.0%)

CARERS AND DEPRESSION

Demographic factors

Carer depression was measured by the GDS in all carers and the BDI only in those under 65. A correlation of the BDI with the GDS was 0.8 (p=0.000) indicating acceptable concurrent validity between the two scales. Therefore, since the GDS was available for all carers, only this measure of depression was used in all further analyses. The mean GDS score for the sample of carers was 4.31 (sd 3.39, range 0-14). Using the GDS cut of score of >5, 31 (43.1%) of carers were classified as depressed. The mean score for the depressed sample was 7.54 (sd 2.46) and for the non depressed sample was 1.87 (sd 1.30). There were no significant differences between the depressed and non depressed groups in terms of gender, age, spouse/non spouse or severity of dementia of the person they cared for as measured by the CDR total score and MMSE or quality of relationship. Table 7 shows data on the incidence of depression in carers.

Table 7: Rates of depression in carers and dementia sufferers by gender:

	Male	Female	Total
Depressed	6 (40.0%)	25 (43.8%)	31 (43.1%)
Not Depressed	9 (60.0%)	32 (56.2%)	41 (56.9%)

There was an association between live in carers and depression scores in this sample of carers. Of the carers who were depressed (n=31), 27 (87.1%) were live in carers and 4 (12.9%) were non live in carers which was statistically significant (t= -3.84, p= .000). The mean GDS score for live in carers (n = 46) was 5.28 (sd 3.54) whilst for non live in carers the mean GDS score was 2.62 (sd 2.33). This suggests that live in carers are more likely to be depressed than carers who do not live in. In addition, given that there was no significant relationship between spouse or non spouse and depression this would appear to be true for all carers whether spouses or other.

Carer life events and carer depression

Of the sample of carers (n=72), 45 (62.5%) experienced at least one life event in the 6 month period prior to interview. In terms of independent and severely threatening life events in carers, the rate was 35 (48.6%) in the 0-6 month period. The association between life events and depression in carers was investigated using cross tab analysis. This did not reveal any significant relationship between life events and depression in carers during the 0-6 month period. In addition, there was no significant difference in

mean scores on the GDS between those experiencing life events, 4.60 (sd .58) and those not, 4.05 (sd 3.23). Table 8 shows data on the rates of life events and depression in carers.

Table 8: Rates of life events and depression in carers, 0-6 month period.

	0-3 mths		**4-6 mths**		**0-6 mths**	
	Events	*No events*	*Events*	*No events*	*Events*	*No events*
Depressed	14 46.2%	17 37.0%	7 46.7%	24 42.1%	18 51.4%	13 35.1%
Not Depressed	12 53.8%	29 63.0%	8 53.3%	33 57.9%	17 48.6%	24 64.1%
Total	26 $\chi2$=1.92 p=0.16	46	15 $\chi2$=0.10 p=0.75	57	35 $\chi2$=0.79 p=0.37	37

Given the finding of a significant relationship between depression and live in carers, cross tab analysis of life events and depression was repeated for live in carers only (n=46). However, these findings were not significant ($\chi2$=0.790, df=1, p=0.37) suggesting that being a live in carer has no influence on the relationship between depression and life events in carers.

Carer social support and carer depression

The availability of a confiding relationship in carers was measured using the LEDS intimacy scale and the majority of carers had a confiding relationship whom they saw daily (56.9%). In addition, there was a significant relationship between carer depression

and the lack of a confiding relationship, (U=358.0, p=0.007). Those with a confiding relationship who was seen daily had a lower mean depression score, 3.29 (sd 3.31) than those carers who reported seeing a confidant less than weekly, 5.23 (sd 3.30) or nobody at all, 8.67 (sd 4.93). Table 9 shows data on the frequency of responses to this scale for depressed and non depressed carers.

Table 9: Carers responses to the LEDS intimacy scale.

	All	Depressed	Not depressed
No confidant	3 (4.2%)	2 (6.5%)	1 (2.4%)
Confidant seen<weekly	13 (18.1%)	9 (29.0%)	4 (9.8%)
Confidant seen>weekly	15 (20.8%)	10 (32.3%)	5 (12.2%)
Confidant seen daily	41 (56.9%)	10 (32.3%)	31 (75.6%)
	n = 72	n = 31	n = 41

THE RELATIONSHIP BETWEEN DEPRESSION IN DEMENTIA SUFFERERS AND DEPRESSION IN CARERS

In order to investigate whether there was a relationship between depression in carers and depression in dementia sufferers, cross tabs analysis was performed using a depressed/ non depressed dichotomy. There was no significant association between carer depression and dementia sufferer depression in the total sample, ($\chi 2$=2.90, df=1, p=0.08). In addition, there was no significant correlation between total GDS score and total Cornell score (0.10, p=0.38). However, given the finding that live in carers were more depressed, the analysis was repeated separating live in (n=46) from non live in carers (n=26). This revealed a significant association between depression in carers and depression in dementia sufferers when carers were live in ($\chi 2$=4.62, df=1, p=0.03). No such

association was found for non live in carers ($\chi 2$= 0.11, df=1, p=0.73). It would seem therefore that there is an association between depression in carers and depression in dementia sufferers only if they live together. Table 10 shows data on the rates of depression in carers and dementia sufferers.

Table 10: Rates of depression in carers and dementia sufferers by resident/non resident status:

	Live in		**Non live in**		**All**	
	Carer depressed	*Carer not depressed*	*Carer depressed*	*Carer not depressed*	*Carer depressed*	*Carer not depressed*
Patient Depressed	14 (51.9%)	4 (21.1%)	2 (50.0%)	9 (40.9%)	16 (51.6%)	13 (31.7%)
Patient not depressed	13 (48.1%)	15 (78.9%)	2 (50.0%)	13 (59.1%)	15 (48.4%)	28 (68.3%)
	n = 46 p = 0.03		n = 26 p = 0.73		n = 72 p = 0.08	

Carer depression, dementia sufferer depression and life events

Secondly, the relationship between carer depression and depression in dementia sufferers in the context of the dementia sufferer experiencing life events (0-3 months) was investigated. Analysis of the impact of life events on depression in dementia sufferers was repeated controlling for the effect of carer depression. Cross tab analyses were performed when carers were depressed (n=24) and when carers were not depressed (n= 48). The findings revealed that if carers were depressed, there was a significant relationship between life events and depression in dementia sufferers ($\chi 2$=3.89, df=1,

p=0.04). There was no significant relationship between life events and depression in dementia sufferers when carers were not depressed ($\chi 2$=0.40, df=1, p=0.52). Thus, it would appear that depression in carers may be an important mediator of the effects of severe and threatening life events on dementia sufferers. Therefore, it would appear that depression in carers is associated with depression in dementia sufferers in the context of the latter experiencing a life event. Table 11 shows data on the relationship between life events (0-3 months), carer depression and dementia sufferer depression.

Table 11: Relationship between depression in carers and dementia sufferers in the context of dementia sufferer's life events (0-3 months).

	Carer depressed		**Carer not depressed**	
	Life events	*No events*	*Life events*	*No events*
Dementia sufferer depressed	10 (76.9%)	6 (33.3%)	6 (46.2%)	7 (25.0%)
Dementia sufferer not depressed	3 (23.1%)	12 (66.7%)	7 (53.8%)	21 (75.0%)

Finally, the impact of joint events on carer depression and dementia sufferer depression was investigated. Cross tab analysis was carried out on the data comparing the relationship between depression/no depression in both carer and dementia sufferer, selecting joint events (n= 26) and no joint events (n=46). This revealed a significant association between carer and dementia sufferer depression in joint events, when life events had impacted on both carers and dementia sufferers ($\chi 2$=4.01, df =1, p= 0.04).

Where life events impacted solely on carers or solely on dementia sufferers, there was no overlap in depression ($\chi2$=0.20, df=1, p=0.64). However, it is important to consider that this finding may be confounded by live in or non live in status since it is conceivable that joint events are more likely in those people who live together.

Impact of carer depression on perceived social support in dementia sufferers

Exploring whether depression in carers decreased the perceived social support experienced by dementia sufferers in the presence of a life event was investigated in three stages. Firstly, the relationship between carer depression and perceived social support (satisfaction with frequency of support) was investigated using cross tab analysis. This suggested that there was no significant relationship between the two variables ($\chi2$=0.55, df=1, p=0.45). Secondly, the analysis was repeated separating live in (n=31) and non live in carers (n=10). Again, there was no significant relationship between carer depression and perceived social support in either live in ($\chi2$ =0.00, df=1, p= 0.95) or non live in carers ($\chi2$=2.36, df=1, p=0.12). Finally, the analysis was repeated comparing carer depression and perceived social support in the context of the dementia sufferer experiencing life events (0-3 months) (n=16) or not (n=25). Again, there were no significant associations between these variables ($\chi2$=0.41, df=1, p=0.51) and ($\chi2$=0.03, df=1, p=0.86). Therefore, no associations were found, suggesting that there is no relationship between carer depression and perceived social support in dementia sufferers. Details of the relationship between carer depression, perceived social support and dementia sufferer life events can be found in Table 12.

Table 12: Life events in dementia sufferers (0-3 months), satisfaction with perceived social support and carer depression:

	All		**Life events**		**No events**	
	satisfied	*not satisfied*	*satisfied*	*not satisfied*	*satisfied*	*not satisfied*
Carer depressed	12 (75.0%)	4 (25.0%)	5 (83.3%)	1 (16.7%)	7 (70.0%)	3 (30.0%)
Carer not depressed	16 (64.0%)	9 (36.0%)	4 (66.7%)	2 (33.3%)	12 (63.2%)	7 (36.8%)
	n = 41		n = 16		n = 25	

Quality of relationship and depression in dementia sufferers

In order to investigate whether life events in carers impacted on dementia sufferers only when there is a poor quality of relationship, the communication question of the Bergmann scales was used as a measure of overall quality of carer/dementia sufferer relationship. This variable was recoded into good (6-7) and bad (1-5) communication on the basis of the degree of negative communication in the relationship and used in all subsequent analyses. On this basis, 30 (41.7%) were classified as having a poor relationship and 42 (58.3%) as having a good relationship. There was no significant relationship between quality of relationship and total depression score in dementia sufferers ($t=2.65$, $p=0.18$).

In order to investigate whether life events in carers impacted on dementia sufferers, cross tab analysis were used to compare life events/no life events in carers and depression/no depression in dementia sufferers. There was no significant association between these variables ($\chi2$=0.03, df=1, p=0.84). The analysis was repeated separately for those dyads reporting a good relationship which was non significant ($\chi2$=1.98, df=1, p=0.15) and for those dyads reporting a poor relationship which was also not significant ($\chi2$=1.47, df=1, p=0.22). In addition, there was no significant relationship between live in /non live in carers and good/poor communication ($\chi2$=1.98, df=1, p=0.15) suggesting that quality of relationship is not affected by being a live in carer. Therefore, no associations were found, suggesting no relationship between quality of relationship, carer life events and dementia sufferer depression. Table 13 shows data on these relationships.

Table 13: Relationship between carer life events, dementia sufferer depression and quality of relationship.

	All		**Poor relationship**		**Good relationship**	
	Carer life events	*Carer no events*	*Carer life events*	*Carer no events*	*Carer life events*	*Carer no events*
Dementia sufferer depressed	15 (51.7%)	14 (48.3%)	11 (73.3%)	6 (40.0%)	7 (39.8%)	5 (21.7%)
Dementia sufferer not depressed	20 (46.5%)	23 (53.5%)	4 (26.7%)	9 (60.0%)	12 (63.2%)	18 (78.3%)

MULTIVARIATE ANALYSIS

Dementia sufferers and depression

Logistic Regression

Finally, in order to investigate the possible influence of other factors on depression in dementia sufferers, a logistical regression analysis was performed. The dependent variable was the presence/absence of depression. The independent variables entered were chosen on the basis of hypothesised predictors of depression. The aim was to ascertain whether life events were linked to depressive symptoms when the effects of other variables were controlled for. A previous regression analysis was performed including variables relating to perceived social support. There was no significant association between these variables and depression. Therefore, in order to maximise the total number of cases included in the regression analysis, no social support variables were included. The independent variables entered were: age, gender, CDR, MMSE, carer depressed/not depressed, live in/non live in carer, QoRS (good/bad), absence/presence of severe and independent life event in 0-3 months. In the first analysis all variables were entered and the relative contributions of each variable can be found in Table 14. From this regression, it can be seen that when all variables are included in the model, only presence of a severe/independent life event (0-3 months) reached statistical significance as a predictor of depression in dementia sufferers.

Table 14: Logistic regression analysis investigating variables associated with depression in dementia sufferers.

Variable	B	R	Signif.
Age	.020	.000	.596
CDR total score	.034	.000	.399
Live in/not live in carer	-0.69	.000	.294
Carer depressed/not depressed	1.05	.102	.082
Life events/no events	1.36	.204	.013
Sex	-.256	.000	.666
MMSE total score	.042	.000	.525
Good/poor relationship	.240	.000	.786
Constant	-3.689		.329

The analysis was repeated using a forward stepwise selection procedure to select out (in order) all those variables which did not make a significant contribution to the goodness of fit of the model. The final results can be found in Table 15. As a result of this procedure, all variables, except for the presence/absence of life events were removed. These two variables correctly classified 72.2% of the sample as depressed/not depressed.

Table 15: Logistic regression analysis likelihood ratios using forward stepwise selection procedure for variables associated with depression.

Term removed	Log Likelihood	-2 Log L Ratio	df	Significance of Log LR
LIFE EVENTS	- 48.537	7.650	1	0.005

Carer depression

Logistic Regression

In order to investigate the possible influence of other variables on carer depression, a logistic regression was performed with presence/absence of depression as the dependent variable. The independent variables entered were those which were hypothesised to have a potential influence on carer depression. The independent variables were dementia sufferer depression/no depression, CDR total score, carer sex, carer age, live/not live in, presence/absence of carer life events in 0-6 months. In the initial analysis, all variables were entered and the relative contributions of each can be found in Table 16. From this regression, it would appear that when all variables were accounted for, only being a live in carer was associated with depression in carers.

Table 16: Logistic regression analysis looking at variables associated with depression in carers.

Variable	B	R	Sig
Sufferer depressed/not depressed	1.069	.114	.069
Carer life events/no events	.560	.000	.335
Carer sex	-.322	.000	.664
Carer age	-.026	.000	.345
CDR total score	.903	.000	.204
Live in/not live in carer	2.566	.283	.001
Constant	-1.546		.521

The forward stepwise selection procedure was used to select out (in order) all variables which did not make a significant contribution to goodness of fit of the model. The final

results can be found in Table 17. As a result of this analysis, all events except for live in and depression/no depression in the dementia sufferer were removed. These two variables predicted 70.8% of the sample as depressed/not depressed.

Table 17: Logistic regression analysis likelihood ratios after forward stepwise procedure for variables associated with carer depression.

Term Removed	Log Likelihood	-2 log L Ratio	df	Significance
Sufferer depressed	- 42.438	4.105	1	0.042
Live in carer	- 47.755	14.919	1	0.001

QUALITATIVE ANALYSIS

This section will report the degree of concurrence between carers and patients in recalling life events. Secondly, illustrative comments from these interviews on the experience and recall of life events will be given and on the coping strategies employed to cope with such life events. Of the sample who completed the interviews (n = 41), 10 cases had no life events in the 0-6 month period prior to interview. Therefore, of the remaining 31 cases, carers reported a total of 51 severe and threatening life events in the 0-6 month period prior to interview. Using a cross check between the LEDS information obtained by carers and the checklist obtained from dementia sufferers, a percentage agreement between the two was established. This provided an estimate of the degree of concurrence of reporting of life events. Of those dementia sufferers experiencing life events, there was a 59% agreement between carers and dementia sufferers whilst 41% of life events were not recalled by the dementia sufferer even after prompting. The

following comments taken from interviews with dementia sufferers illustrate the themes of difficulty adjusting, feeling unhappy and loss which emerged in these interviews.

Themes

In response to her husband's hospital admission for an operation, one 68 year old woman, reported: " I do remember going to see him in hospital and praying for him. I do remember feeling down in the dumps, I'm not doing as much now as I used to. He has taken over most things and it was difficult when he was in hospital, but I'm feeling better now." *(MMSE = 18, depressed).*

In response to the death of her sister, one woman, aged 86, described: "I don't remember when she died, we had been very close when we were younger but I hadn't seen her since she had been ill. I hadn't seen her for a long time, but I didn't feel that upset because she was ill, I do miss her"*(MMSE = 20, depressed).*

Following the death of her son in law, one woman, 82 remarked: "It's hard to adjust to it, it's very sad. He was only young. It's difficult to do anything about it, my memory is not as good as it used to be." *(female, 82, MMSE = 12, depressed).*

In response to the death of her neighbour of 40 years, one woman, 79 reported:

"When E..... died, I was very upset, we were rather friendly. We used to see each other for company. We had always been here." *(MMSE = 14, not depressed).*

Following the death of his wife, 5 months previously, one man, 82 described: "I lost my wife a few weeks ago, no maybe two months, it is very difficult. She was ill, very ill. I

try not to think, my daughter is here but we were married years, I don't know. It's very difficult." *(MMSE =16, depressed).*

In addition, some dementia sufferers mentioned life events in addition to those mentioned by carers. Although the reliability of this information in terms of accuracy and dating events may be inconsistent, the results indicate that life events have an emotional impact on dementia sufferers whether or not this is recognised by carers:

A 72 year old man remembered: " I stopped bowling because of a bad back, I used to be one of the best players, played all my life, I want to play again, keep going even if walking is more painful". *(MMSE = 20, not depressed.)* and another added: "I went to the day centre. I don't like it. I've got family, I don't like it, I'm determined not to go. I didn't stay, I'm not going to go again. *(male, 82, MMSE = 16).*

Coping with life events:

Finally, these comments illustrate something of the coping strategies used by people with dementia in the face of life events.

" I usually try to keep things to myself or I pray. I try not to get upset about things I can't do anything about" *(female, 68, MMSE = 18).*

" I don't know, I do think about things at times but my daughter does a lot of things. I don't know what I would do. She talks to me on the phone". *(female, 86, MMSE = 20).*

"When things are stressful, I try to get on with it, I'm not one to talk really but I do a little bit of grumbling now and then". *(female, 82, MMSE =17).*

"I would find somebody to talk to. I have company at X (day centre). I'm not lonely". *(female, 84, MMSE = 15).*

"I don't know what I would do if X wasn't there, who else would come, I'm not sure what to do. But I don't really have problems now." *(female, 68, MMSE = 11).*

"I don't keep anything from my wife, nothing is troubling me really, not to my knowledge that she doesn't know about. I'd be in a poor way without her. I don't know how she puts up with me at times. *(male, 85, MMSE = 21).*

CHAPTER FOUR - DISCUSSION

OVERVIEW

This study aimed to explore the inter - relationships between social factors, specifically life events, and depression in dementia sufferers and their carers. This chapter will begin by reviewing the main findings of this study in relation to the research questions. Following this the limitations of this study, the implications of the findings for clinical practice and suggestions for further research will be addressed.

DEPRESSION IN DEMENTIA SUFFERERS

In terms of the characteristics of this sample, they would appear to be comparable to the community sample of dementia sufferers in Orrell's (1994) study of life events and dementia in terms of age and gender. The finding that 40.9% of the sample of dementia sufferers were depressed is slightly higher than that reported in other studies where the average rate of prevalence is around 30% (Teri & Wagner, 1992, Ballard et al, 1993) although rates of 40-50% have been reported (Vida et al, 1993). In addition, Orrell (1995a) reported depressive symptoms in 20% of dementia patients and in 26% of community dementia controls. The higher than average prevalence of depression in this sample may be in part a reflection of the difference in sample selection and measures of depression used. Ballard et al (1996) reported a higher prevalence of depression among samples in contact with clinical services than in community samples. Given that the sample in this study were recruited from day centres and outpatient services, this may explain the higher than average rates of prevalence. In addition, many studies have used

DSM IV criteria or research diagnostic criteria for major depression. The Cornell scale is primarily used as a measure of depressive symptomatology and not as a diagnostic tool. Therefore, the rates of depression in this sample as measured by the Cornell may include some people who would not meet the criteria for clinical depression. However, standard criteria which relies on interview methods may miss depression in the severe dementia group.

The finding that severity of dementia was unrelated to depression is in keeping with other studies (Fitz & Teri, 1994, Haupt et al, 1995) as is the lack of association between age and gender and depressive symptoms (Ballard et al, 1996). In this study, rates of depression were not related to diagnosis. The rate of depression in Alzheimer's Disease (AD) was 40% and in Multi Infarct Dementia (MID) 40.9%. However, other studies have reported a much higher prevalence in patients with AD than MID (Cummings et al, 1987). The fact that different diagnostic criteria were used might have important implications in this respect, e.g. persons with MID are more likely to have problems with expression and comprehension of language and so self report may underrate symptoms.

Life events and depression in dementia

This study found a significant relationship between life events and depression in dementia sufferers. The proportion of this sample reporting at least one severe and independent life event in the 6 months prior to interview was higher in the depressed group than the non depressed. This supports the findings of other studies on the

relationship between life events and depression in the elderly (Murphy, 1982, Emmerson et al, 1989). Only those life events which were rated as both severe and independent were included in the analysis and the rate of such life events for the total sample (42.7%) falls between the 48% found by Murphy (1982) and 38% reported by Emmerson et al (1989). In addition, the most frequently reported events were bereavement and ill health which was in keeping with that reported by other studies of life events in this age group; for example, these events were the most frequently reported in a sample of 188 persons over 65 (Linn, 1980).

The finding of a significant association between life events and depression in dementia sufferers replicates the findings of Orrell & Bebbington (1995c). Their study reported a consistent excess of severe and threatening life events in those dementia sufferers with depressive symptoms. In this study, a significant association between life events and depressive symptoms was found for the 0-6 month period, but more specifically, for the 3 months prior to interview. During this period, 61.5% of the depressed group reported at least one life event compared to 38.5% of the non depressed group. The significance of 0-3 months has been reported in the work of Brown & Harris (1978) and Emmerson (1989). However, the rate of life events in this time period is far greater than that reported in either of these studies (42%) and (24%) respectively or the 40% found in dementia sufferers with depression (Orrell & Bebbington, 1995a). In contrast to this study, Orrell & Bebbington (1995c) found a significant association between life events and depression to be related to the 4-6 months prior to interview. Some studies have

even suggested that events occurring 2-7 months before interview are less strongly associated with depression than those 8-13 months beforehand. (Tennant, 1979).

One possible explanation for this difference may relate to the smaller number of life events occurring in the 4-6 months prior to interview in this sample. It is conceivable that taken together the impact of life events on depression may span a 6 month period and thus it is not clear where the major effect lies.

Furthermore, it would appear that the occurrence of only one severe and independent life event is associated with depression in this sample. This study did not find a cumulative effect of life events since a comparison of the number of life events with total depression score did not yield any associations. Similar conclusions were drawn by Brown & Harris with a younger sample (1978) although it is contrast with that reported by Linn (1980) who reported a cumulative effect of stressful life events.

SOCIAL SUPPORT AND DEMENTIA SUFFERERS

There was no association found between social support and depression following life events in dementia sufferers. Descriptions of the support networks of dementia sufferers have shown that people with dementia tend to have smaller networks than those without dementia (Grant & Wenger, 1993). The majority of people in this study lived with a carer (63.8%) and reported at 1-2 people in their social network (52.8%). Wenger (1994) has reported that social support in people with dementia is confined in the main to close

family members rather than friends, neighbours and wider networks. There was a similar pattern in this study, although the majority of people (59.7%) had spent time with people they didn't live with at least twice in the previous week. However, since this included attendance at day centres, this may have overestimated the degree of contact with supports other than formal services. Family support appeared critical for most dementia sufferers living in the community. Wenger (1994) also found 63% of the dementia sufferers and Orrell & Bebbington (1995c) noted 70% of dementia sufferers had contact with a relative daily. This study indicates that older people with dementia do not lose overall social support although the nature of that support may have changed.

There were no significant associations between depression and social support in dementia sufferers on any of the measures. Other studies have reported that a lack of social support is associated with depression. Loneliness and a lack of satisfaction with frequency of contact with relatives and friends have been associated with depression in elderly samples without dementia (Prince et al, 1997) and Cohen (1993 cited in Ballard et al, 1996) identified a greater risk of depression in those dementia patients living alone.

In this study, no associations were found between lack of perceived social support and depression in dementia sufferers in the presence of a threatening life event. This is in contrast to many other studies which support the importance of a confiding relationship as protective against depression in both young (Brown & Harris, 1978) and elderly samples (Murphy, 1982, Emmerson, 1989). However, some studies have not supported

the stress buffering hypothesis in elderly samples (Russell & Curtona, 1991). The relationship between perceived social support and dementia sufferers has been neglected in research and so there is little with which to compare the findings of this study.

There are several potential explanations for a lack of association between depression and social support in this study. Firstly, this may be a reflection of the sample chosen. Of this sample, 63.8% of dementia sufferers lived with their main carer, and the reported levels of perceived social support were high. Only 4 (5.6%) of the 41 dementia sufferers interviewed reported that they did not have a confiding relationship and the majority (58.5%) reported never feeling lonely and being satisfied with the frequency of contact with relatives or friends, (68.3%). As such, it is conceivable that the sample size of those reporting poor social support was too small to have any significant association with life events and depression. Secondly, in order to be selected for participation in this study, an inclusion criteria was the availability of a carer seen at least once weekly. Therefore, this sample of dementia sufferers were biased to some extent by the inclusion criterion towards those with relatively good social support. However, in order to elicit reliable and accurate information on life events it was essential that this sample had a carer who was in frequent and close contact in order to know of such occurrence of life events. Thirdly, this may reflect the design of the study. Measurement of depression and social support was current whilst life events were measured retrospectively. Brown (1978) suggests that it is the mobilisation of support in the face of a life event that is

crucial to preventing the onset of depression which is best observed longitudinally rather than taking cross sectional measures and extrapolating to the past.

Finally, the measure of perceived social support used in this study may have been inadequate. The OARS has not been standardised for use with people suffering from cognitive impairment. Although perceived social support is the factor most associated with a stress buffering hypothesis (Sherbourne, 1992), it may be that it is difficult to elicit such a concept in people with dementia using this measure. The concept of perceived social support in people with dementia has not been systematically investigated and it is conceivable that people with cognitive impairment may appraise social support differently. Henderson (1986) has described the problems of self reported information on social support in dementia sufferers. Using the Interview Schedule for Social Interaction (ISSI), he described availability and perceived adequacy of social support in an elderly sample with dementia. He found that people with dementia did not report any lack of a confiding relationship overall. However, there was an association with severity of dementia and satisfaction with support. Those with a moderate/severe dementia reported being dissatisfied with their social interaction although satisfied with the availability whilst those with a mild dementia reported less availability of social interaction. He argues that self reported information collected from dementia sufferers may be distorted either at random or systematically in one direction. This is evident in depressed patients who report their social resources in a negative light (Brugha et al, 1982). However, in this study information on the quantity of social support available was

collected from interviews with carers. Although not a direct measure, the levels of social support reported, do indicate that dementia sufferers were well supported.

An interesting finding to emerge from this study was the relationship between social support and life events, (independent of depression). Those people reporting a greater degree of contact with others reported a greater number of life events. This suggests that interaction with others increases the likelihood of experiencing life events. Furthermore, in those people experiencing life events there was a trend towards reporting greater satisfaction with social support. In this sample, 75% of dementia sufferers having life events reported satisfaction with social support compared to 65% not having life events. In addition, there was no significant difference between the depressed and non depressed dementia sufferers satisfaction with social supports in those having had life events.

CARER DEPRESSION

The sample of carers in this study would appear to be representative of that found in other studies of caregiving in terms of age, gender and living arrangements (Ballard et al, 1995, Redinbaugh, 1995). Of this sample, 45.8% were spouses, 41.7% children or children's spouses, 4.2% were siblings, 1.4% other relatives and 6.9% friends. The majority of carers were over 65 (54.2%) and female (79.2%). Using the cut off score for the GDS, 43.1% of the sample could be classified as depressed compared to rates of 40-60% reported in other studies (Redinbaugh, 1995). No demographic factors appeared to be related to carer depression in this sample. This contrasts with the ubiquitous finding

in the literature is that men and women react to the caregiving role differently. Gilhooly (1994) reported female carers as more likely to report symptoms of depression than male carers whilst Harper & Lund (1990) reported that female spouse caregivers are more likely to be influenced by affective disturbance in dementia sufferers. However, a lack of association in this study may result from the relatively small numbers of male carers in the cohort.

Other studies have also noted that live in carers were more likely to report depressive symptoms than non live in carers (Brodaty & Hadzi-Pavlovic, 1990, Ballard et al 1995). Given that live in carers spend greater periods of time with the dementia sufferer and may have greater responsibility in performing caregiving tasks, this finding makes intuitive sense. Being a live in carer is further influenced by the nature of ones relationship to the dementia sufferer and spousal caregivers report higher depression than non spouses (Shulz, 1995). However, in this sample, there was no association between spouse/non spouse status and depression. Perhaps live in carers are more likely to report depressive symptoms, regardless of their relationship to the dementia sufferer.

An unexpected finding was that there was no association between carer life events and carer depression. The chronic strain of caregiving may hypothetically make caregivers more vulnerable to the impact of life events, so predisposing them to depression. The rate of life events, independent of caregiving, in this sample were not dissimilar to that reported by Russo & Vitliano (1995). However, other studies have found a relationship

among caregivers (Redinbaugh et al, 1995) or an even greater incidence of negative events among carers (Reed et al, 1990). The finding that there was no significant differences in the incidence of life events in the depressed and non depressed group in this sample is not easy to explain. Of the sample reporting life event (n=35), 51.4% were classified in the depressed group and 48.6% classified as not depressed. One possibility is that this sample of carers were relatively well supported. Other studies have demonstrated a positive correlation between carers social support and emotional well-being (Fiore et al, 1986 cited in Hannappel et al, 1993) and low levels of social support have been associated with elevated depressive symptoms in chronically depressed caregivers (Redinbaugh, 1995). In this study, information about the availability of a confiding relationship for the carer revealed that 77.8% felt that they had a confiding relationship whom they saw at least weekly and only 6.9% reported the absence of any such relationship. The sample in this study were selected from those in contact with clinical services and nearly half the sample of dementia sufferers were attenders at day centres. Perhaps, the level of both formal and informal support available served to lessen the impact of life events on carers mood. Another possibility is that caring for someone with a dementia is itself a constant strain and burden which for the vulnerable carer, or in a vulnerable relationship, dwarfs any single adverse life event in determining the quality of the carers' mental health.

RELATIONSHIP BETWEEN CARER DEPRESSION AND DEPRESSION IN DEMENTIA SUFFERERS

The association between caregiver depression and depression in dementia sufferers has not been systematically investigated in the research literature. Other studies have reported an increased risk of depression in relatives of patients who experienced life events in the three month period prior to onset of depression (McGuffin et al, 1988) and therefore, there was reason to hypothesise that links may be found between dementia sufferers and their caregivers. This study found a significant relationship between carer depression and depression in dementia sufferers in the event of sufferer life events.

The finding that dementia sufferer depression is a risk factor for carer depression is an important finding. Although there was no direct association between depressive symptoms in carers and dementia sufferers, the association appeared to be mediated by other variables. The impact of depressive symptoms in dementia sufferers on carers mood was found only when carers were living with the dementia sufferer. Therefore, it would seem that there is an interaction between being a live in carer and patient depression on carer mood. Although both have separate influence on carer mood, it would seem that their effect is mediated through an interaction of the two; if patients are depressed and the carer is a live in carer, it would be hypothesised that there is a greater risk of depression in the carer.

The interaction between depressive symptoms in carers and dementia sufferers also appears to be in both directions. The finding that carer depression mediated the effect of life events on dementia sufferers was interesting. Depressive symptoms in dementia sufferers were only associated with life events when carers reported depressive symptoms. There is a need to separate out these factors, in order to get a clearer understanding if the direction of causality and mechanism of influence. One possible explanation is the finding that joint life events were related to depression in dementia sufferers. It is conceivable that the higher incidence of such events for live in carers may explain the observed relationship. The finding that carer depression is related to depression in dementia sufferers in the context of a life event, fits with the work of Bookwala & Shulz, (cited in Shulz, 1995). They reported that negative affect in one partner may "spill over" to the other although it would appear that the impact of this differs between carers (who may become depressed) and dementia sufferers (who may become depressed only in the context of life events). Furthermore, a study of risk factors for carer distress and burden also revealed that depression in dementia sufferers was the most consistent and powerful predictor of psychological morbidity in carers (Donaldson et al, 1998).

Successfully identifying those carers who may have an increased vulnerability to depression may help to target interventions to assist in preventing the breakdown of the caregiving relationship. This study suggests that living with a dementia sufferer and cormorbidity of depression in the dementia sufferer are significant risk factors for carer

depression. There has been little investigation of the relationship between depression in carers and dementia sufferers and this study suggests that this would be a logical and valuable line of enquiry to pursue in further research.

In terms of the relationship between depression in the carer and perceived social support experienced by the dementia sufferer in the presence of a life event, no significant associations were found. However, there did appear to be a trend towards a relationship between carer depression and availability of social support although this was not statistically significant. When carers were depressed, 64% of the dementia sufferers were satisfied with the social support whilst when carers were not depressed this figure rose to 77%.

Quality of relationship

The quality of relationship between caregiver and dementia sufferer has been reported as an important mediator of emotional distress (Morris et al, 1988). It is also critical in maintaining a person with dementia in the community (Bergmann et al, 1984). He found that lower levels of positive communication were associated with poorer outcome at 3 months. In this study, the communication question of the Bergmann scale was taken as a measure of overall quality of relationship. This was subdivided into good and poor communication based on the degree of negative verbal communication reported. In this study there was no relationship between quality of relationship and depression in either carers or dementia sufferers. Other studies (Morris et al, 1998) have suggested that the

presence of a poor premorbid relationship was significantly associated with carer burden and depression. In addition, poor relationships between carers and dementia sufferers has been shown to influence attitudes to continued care giving. Hirschfield (1981, cited in Gilhooly, 1994) argues that the current relationship between the two is the crucial variable in determining a families ability to continuing to care for a dementia sufferer at home.

In addition, Orrell & Bebbington (1995b) investigated the relationship between carer-patient relationship and admission to hospital in dementia sufferers and reported that a high level of conflict in the relationship between carer and dementia sufferer was a significant risk factor for deterioration of functioning in dementia sufferers and in presentation to services. There has been little research addressing the impact of dementia on family relationships (Blliesznер & Shifflet, 1990) although the concept of expressed emotion (EE) is one theoretical explanation for this observed relationship. Originally found to be a factor in predicting relapse among schizophrenics, the predictive value of expressed emotion in family care of the dementing elderly has been studied (Gilhooly, 1994). Gilhooly & Whittick (1989) reported a significant correlation between carers psychological well-being and expressed emotion. In the sample of carers, being female, those reporting least contact with friends and a poor quality of relationship between carer and dementia sufferer were associated with greater frequency of critical comments. In addition, Bledin et al (1990) found high EE was associated with a higher level of distress and strain in daughters carers.

However, in this study, there was no evidence to support that a poor relationship mediated the effect of carers life events on depression in dementia sufferers. Furthermore, there were no significant relationships between carers life events and depression in dementia sufferers.

MULTIVARIATE ANALYSIS

The logistic regression analysis of depression in dementia sufferers supports the finding that psychosocial factors have a significant association with comorbidity of depression. The experience of a severe and independent life event in the 0-3 months prior to interview was the only risk factor for depressive symptoms in this sample of dementia sufferers.

The logistic regression analysis of depression in carers found only two factors associated with depression in this sample: i) living in and ii) depressive symptoms in the dementia sufferer.

QUALITATIVE ANALYSIS

The final aim of this study was to investigate the recollection of and experience of life events in dementia sufferers using a qualitative interview. Of those persons interviewed (41) there did appear to be a recollection of life events which corresponded to that reported by carers in 59% of cases. Therefore, the impact of life events on dementia

sufferers appears to be recalled with appropriate cueing and a substantial proportion of life events were recalled in people with a mild/moderate dementia. Furthermore, the coping strategies employed by people with dementia were revealed in the qualitative comments. It is hard to know whether such strategies reflect long term coping mechanisms of the individuals interviewed or have developed as a result of having a dementia. Many people reported that they tried not to think about things or would turn to their carer for support at such times. Although the accuracy of events recalled by dementia sufferers may be questioned, many events were distressing to the person, though not recognised as such by carers.

Other studies have demonstrated that people with dementia may recall unusual or emotive events (Williams & Garner, 1998). A study of the effects of emotional involvement on memory retention among Alzheimer's patients was investigated following the Kobe earthquake in Japan (Ikeda et al, 1998). Fifty one subjects who experienced the earthquake were assessed 6-10 weeks after the disaster using semi structured interviews. A total of 86.3% were able to remember the earthquake compared to only 31.4% remembering a routine scan from the same time period. There was no relationships between severity of dementia and recall. In addition, the results highlighted that people may remember the personal ordeal rather than the factual details of an event. Therefore, it would appear that people with dementia have improved memory for emotional material and that personal memories with strong emotion are retained relatively well despite severe memory loss (Ikeda et al, 1998).

It is important to consider that many of the participants in the current multiple life events or that the severity of dementia may have confounded the findings. Those people interviewed were most likely to have a mild dementia and therefore, it is likely that their recall of events would be higher. Given the difficulties inherent in interviewing someone with a more severe dementia, it is not possible to know of the impact of life events in people with greater cognitive impairment.

LIMITATIONS OF THIS STUDY

Methodological Issues

Firstly, it is important to consider the sample included in this study. The response rate of in this study was adequate (70.5%) and a variety of factors were associated with non participation. A minority of participants who were identified as suitable for inclusion in the study, declined to take part because of experiencing recent life events. Therefore, it remains possible that people who chose to participate in this study had fewer life events than those who did not. Alternatively, those who declined due to recent stressful events may have been more likely to be depressed. Their inclusion in the study may have served to enhance the associations found.

This study found significant associations between life events and depression in dementia sufferers. However, the cross sectional design of this study precludes the direction of

causality being firmly established. There has been a good deal of uncertainty about the aetiological link between life events and depression in general and whilst this study has supported the association between the two in people with dementia but cannot confirm a direct causal relationship. Another factor which reduces the ability to confirm causality is that the onset of depression in this sample was not dated. There are difficulties in dating depression in dementia sufferers, and it might be argued that depression may have been related to the incidence of life events. By including only independent life events, those events which may have resulted from either low mood or dementia were excluded from analysis. Despite this, others have argued that factors such as background (Kahana, 1992, cited in Russo & Vitaliano, 1995) and personality (Poulton & Andrews, 1992, cited in Russo & Vitalino, 1995) may make an individual predisposed to life events. Events which were possibly dependent were excluded from the analysis but some of these events may have been independent and their exclusion may have reduced the statistical power of the analysis.

Furthermore, this study did not consider the existence of a history of depression in either dementia sufferers or carers. It is likely that a previous history of depression would have been a significant risk factor for the onset of later depression in either case and may have confounded the impact of life events on depression to a degree. Furthermore, it may have been useful to collect information on the duration of caregiving in order to see whether this had any association to depressive symptoms in carers.

The method of eliciting life events used in this study was reliable, valid and has distinct advantages over checklist approaches. Nevertheless, some events may have been forgotten although this has not been reported in other studies (Orrell, 1994). Secondly, the dating of life events may have biased in that participants included events mistakenly in the 0-6 month period which may have overestimated the prevalence of life events.

There has been little research on the accuracy of phenomenological, autobiographical and family history obtained from people with dementia. Ballard (1991) studied the concordance of information between 92 dementia sufferers and their relatives. The level of agreement between patient and carers responses was determined by comparing answers on the personal history section of the CAMDEX interview. The overall percentage agreement was 76%, and the patients positive hit ratio (the percentage agreement for which the patient answered positive) was 93% but the relative's positive hit ratio (the percentage agreement for all the questions which the relative answered positively) was 40%. This study concluded that positive responses made by dementia sufferers were more likely to be accurate but that negative responses were likely to be erroneous. Furthermore, the percentage agreement varied from 89% for past history to 44% for current mental functioning and there was no association between diagnosis or severity of dementia and percentage agreement. This suggested that dementia sufferers tend to underreport information. As such the use of prompting in the qualitative interview in this study may have helped to maximise recall. Partridge et al, (1990) have highlighted the need for appropriate information cueing in order to obtain the most accurate response from dementia sufferers.

It is possible that this sample of dementia sufferers were not representative of dementia sufferers overall. They were chosen from referrals to clinical services and all had a carer. Therefore it is not possible to generalise these findings to those dementia sufferers without such supports or those who are not in contact with services. The high level of social support in this group may potentially account for the lack of significant findings in relationship to life events and depression. There may also have been a social desirability factor, i.e. dementia sufferers may have responded in such a way as to overemphasise their satisfaction with support.

It may have been useful to examine the type of life events most associated with depression in dementia sufferers. Loss has been most widely associated with depression (Finlay-Jones & Brown, 1981), and studies with the elderly have reported both the incidence of bereavement and poor health as most influential in differentiating depressed and non depressed groups (Prince et al, 1997). Murphy (1982) concluded that depression in the elderly is "closely associated with adversity; events involving loss or threat of loss were implicated as in younger people". In addition, physical health was seen as an important provoking factor, perhaps through its perceived meaning for the individual of impending decline and death. The frequency of reporting of such events in this sample was high. It would be interesting to note if certain types of loss events were particularly salient in persons suffering with dementia who develop depression.

IMPLICATIONS

This study has highlighted a number of issues relating to the relationships between life events, social supports and depression in dementia sufferers and their carers. The finding that life events are significantly associated with the occurrence of depressive symptoms in dementia sufferers has several implications. Setting aside the somewhat academic doubt about direction of causality, it provides further evidence that people with a cognitive impairment are sensitive to distressing experiences and react in a similar manner to those who are cognitively intact. This has implications for the treatment of depression in both carers and dementia sufferers.

Depressive symptoms in dementia are potentially reversible by pharmacological or psychotherapeutic interventions. To date most emphasis has been placed on pharmacological management (Teri & Wagner, 1992). However, there is very limited research on the use of nonpharmacological methods of depression treatment in dementia sufferers. Given the relationships found between depression in carers and dementia sufferers and the impact of life events, this suggests that psychosocial factors may be vitally important in the aetiology of depression in both groups. Interventions with carers aimed at reducing depression and improving behavioural features of the carer relationship such as communication may well be the most efficacious means to enhance the well being of dementia sufferers. Information provision, carer training programmes and carers support groups have been found to reduce carer depression (Knight et al, 1993). Proper outcome studies of such interventions would help confirm these

inferences. In addition, the concept of contagion of mood reported by Bookwala & Shulz, (1995) suggests that where there is depression in both partners, it should be tackled simultaneously by pharmacological and/or psychological methods.

FUTURE RESEARCH

Research investigating the influence of psychosocial factors on depression in dementia sufferers is recent but has demonstrated important findings. Replication of this study with larger samples of dementia sufferers may serve to establish the aetiological role of life events in depression among people with dementia. Dating the onset of depressive symptoms through the use of informants and prospective studies may help to clarify the causal role of life events and depression in dementia sufferers. Linn (1980) has identified that the effects of life events are mediated by individual factors such as personality, social support and coping strategies. "The amount of control and choice available to a person who is undergoing a stressful life event needs to be considered in determining the effects of such stress. Also, the amount of support and personal resources available to the person who is undergoing the stress needs to be considered in evaluating the magnitude of stress". Given that the experience of cognitive impairment inherent in dementia may impact on all these factors, it is conceivable that one may be predisposed to a greater risk of psychological ill health following life events. At present, very little is known about how much the life events impact on people with dementia, the protective or vulnerability factors which may mediate their impact or the long term effects of such events. More research is also required on the coping strategies employed by people with

dementia which may mitigate or potentially prevent depressive episodes arising in the face of severe life events.

The relationships between depression in dementia sufferers and carer depression also needs to be further investigated. Although this study found an important association, this needs replication and consideration of other factors which may mediate this relationship. Finally, the concept of perceived social support has not been studied in people with dementia. There is a need to address the definition and measurement of this concept in people with dementia and how it may differ from that in people without cognitive impairment. So far only the type and structure of social networks have been investigated (Wenger, 1994). This research suggests that a fundamental difference exists in the nature of support networks between elderly people with dementia and those without. Since people with cognitive impairments have networks characterised by close family supports, it is possible that this may affect their views of the quality of social support. There is a need for future research to be both quantitative and qualitative in methodology. At present very little is known about the experience of social relationships in people with dementia. Given the importance of social stimulation on cognitive and functional ability as well as mood, this line of enquiry warrants further investigation.

CONCLUSIONS

This study aimed to investigate the relationships between life events, social support and depression in dementia sufferers and their carers. Several significant findings emerged.

Firstly, there was a significant relationship between depression and the occurrence of severe and independent life events in dementia sufferers. However, no other factors such as social support, quality of relationship or demographic factors predicted depression in dementia sufferers. This supports Kitwoods (1997) view that psychosocial factors are key to the understanding of the dementia process.

Secondly, depression in carers was unrelated to carer's life events, intimacy or quality of relationship. It was however, predicted by two factors; depression in the dementia sufferer and living with the dementia sufferer. It would appear that being a live in carer is associated with a risk of depression in the carer and this in turn is associated with a risk of depression in the person with dementia. There may be a more complex relationship between dementia sufferers and carers, life events, quality of relationship and other psychosocial factors. However, the explanations above are more parsimonious and are also supported by the available evidence.

There are a number of clinical implications from these findings. Firstly, that dementia sufferers are sensitive to social factors, particularly life events and practitioners need to be aware that depression is not only common but is often related to such stresses. Secondly, not only are dementia sufferers sensitive to life events but despite their failing memory, they are often able to recall the life events to some degree and relate the distress experienced as a result of them. Mental health staff and researchers need to understand this and acknowledge it, in dementia, as part of ordinary human experience despite the

evident memory difficulties. Thirdly, carers are more at risk of depression if the dementia sufferer is depressed and practitioners should be particularly vigilant to the possibility of depression in both parties, if one is depressed and particularly if they live together.

These findings have important implications for understanding the aetiology of depression in both dementia sufferers and their carers and highlights the potential effects of psychosocial factors on the course of dementia. Furthermore, this may have implications for the prevention and treatment of depression in the context of dementia, and for the better management of persons with dementia through interventions targeted at carers. Depression in dementia sufferers and carers is amenable to treatment and this study suggests that psychosocial as well as pharmacological interventions may be efficacious.

REFERENCES

Alexopolous, G.S., Abrams, R.C., Young, R.C. & Shamoian, C.A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry, 23,* 771-784.

Alloway, R. & Bebbington, P. (1987). The buffer theory of social support - a review of the literature. *Psychological Medicine, 17,* 91-108.

American Psychiatric Association (1987). *Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised.* American Psychiatric Association, Washington, DC.

Amster, L.E. & Krauss, H.H. (1974). The relationship between life crises and mental deterioration in old age. *International Journal of Ageing and Human Development, 8, 1,* 51-55.

Andrews, G., Tennant, C., Hewson, D.M. & Vaillant, G.E. (1978). Life event stress, social support, coping style and risk of psychological impairment. *Journal of Nervous and Mental Disease, 166, 5,* 307-316.

Anthony, K., Proctor, A.W., Silverman, A.M. & Murphy, E. (1987). Mood and behaviour problems following the relocation of elderly patients with mental illness. *Age & Ageing, 16,* 355-365.

Ballard, C.G., Bannister, C. & Oyebode, F. (1996). Review: Depression in dementia sufferers. *International Journal of Geriatric Psychiatry,* 11, 507-515.

Ballard, C.G., Cassidy, G., Bannister, C. & Mohan, R.N.C. (1993). Prevalence, symptom profile and aetiology of depression in dementia sufferers. *Journal of Affective Disorders, 29,* 1-6.

Ballard, C.G., Chithiramohan, R.N., Ghandy, S., Bannister, C., Davis, R. & Todd, N.B. (1991). Information reliability in dementia sufferers. *International Journal of Geriatric Psychiatry, 6,* 313-316.

Ballard, C.G., Saad, K., Coope, B., Graham, C., Gahir, M., Wilcock, G.K. & Oyebode, F. (1995). The aetiology of depression in the carers of dementia sufferers. *Journal of Affective Disorders, 35,* 59-63.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J. & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4,* 561-571.

Beck, A.T., Steer, R.A. & Garbin, M.G. (1988). Psychometric properties of the Beck Depression Inventory: twenty five years of evaluation. *Clinical Psychology Review, 8,* 77-100.

Bergmann, K., Manchee, V. & Woods, R.T. (1984). Effects of family relationships on psychogeriatric patients. *Journal of the Royal Society of Medicine, 77,* 840-844.

Blazer, D.& Williams, C.D. (1980). Epidemiology of dysphoria and depression in an elderly population. American Journal of Psychiatry 137, 387-394 (cited in Evans, S.M.B. & Katona, C.M.D.,1993).

Bledin, K., MacCarthy, B., Kuipers, L.& Woods, R. T. (1990). Daughters of people with dementia: expressed emotion, strain and coping. *British Journal of Psychiatry,* 157, 221-227.

Blieszner, R. & Schifflet, P.A. (1990). The effects of Alzheimer's disease on close relationships between patients and caregivers. *Family Relations, 39,* 57-62.

Bookwala, J. & Shulz, R. (in press). Contagion among elderly couples, *Psychology and Ageing* (cited in Shulz, et al, 1995).

Bowling, A. (1994). Social networks and social support among older people and implications for emotional well being and psychiatric morbidity. *International Review of Psychiatry, 6,* 41-58.

Brewin, C.R. (1990). Cognitive Foundations of Clinical Psychology. Lawrence Erlbaum, Hove. cited in Orrell, M.W. (1994). Life events in the elderly. *International Review of Psychiatry, 6,* 59-71.

Brodaty, H. & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. *Australian and New Zealand Journal of Psychiatry, 24,* 351-361.

Brown, G. & Harris, T. (1978). *Social Origins of Depression.* (London, Tavistock).

Brown, G. & Harris, T. (1989). *Life Events and Illness.* (London, Guildford Press).

Brugha, T., Conroy, R., Walsh, N., Delaney, W., O'Hanlon, J., Dondero, B., Daly, L., Hickey, N. & Burke, G. (1982). Social networks, attachments and support in minor affective disorders: a replication. *British Journal of Psychiatry, 141,* 249-255.

Brugha, T., Bebbington, P.E., MacCarthy, B., Sturt, E. & Wykes, T. (1987). Social networks, social support and the type of depressive illness. *Acta Psychiatrica Scandanavia, 76,* 664-673.

Burns, A., Jacoby, R. & Levy, R. (1990). Psychiatric phenomena in Alzheimer's disease. *British Journal of Psychiatry, 152,* 72-94.

Burns, A. (1991). Affective Symptoms in Alzheimer's Disease. *International Journal of Geriatric Psychiatry, 6,* 371-376.

Cohen, D. & Eisdorfer, C., Gorelick, P., Luchins, D., Freels, S., Semla, T., Paveza, G., Shaw, H. & Ashford, J.W. (1993). Sex differences in the manifestations of Alzheimer's disease. Journal of the American Geriatric society, 41, 229-232. (cited in Ballard et al 1996).

Cooke, D.J. & Hole, D.J. (1983). The aetiological importance of stressful life events. *British Journal of Psychiatry, 143,* 141-152.

Creed, F. (1993). Life events and physical illness. *Journal of Psychosomatic Research, 2,* 113-123

Cummings, J. L., Miller, B., Hill, M. A. & Neshkes, R. (1987). Neuropsychiatric aspects of multi-infarct dementia and dementia of the Alzheimer type. *Archives of Neurology, 44,* 389-393.

Davies, A.D.M. (1993). Life events in the normal elderly, in Copeland, J.R.M., Abou-Saleh, M.T. & Blazer, D. (Eds). *The Psychiatry of Old Age.* (Chichester, John Wiley. (cited in Orrell, M.W. & Davies, A, D, M., 1994).

Davies, A.D.M., Saunders, C. & Newton, T. (1987). Age differences in the rating of life- stress events: Does contextual detail make a difference? *British Journal of Clinical Psychology, 26,* 299-303.

Donaldson, C., Tarrier, N. & Burns, A. (1998). Determinants of carer stress in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 13,* 248-256.

Drinka, J.K., Smith, J.C. & Drinka, P.J. (1987). Correlates of depression and burden for informal caregivers of patients in a geriatrics referral clinic. *Journal of the American Geriatrics Society, 35,* 522-525.

Emmerson, J.P., Burvill, P.W., Finlay-Jones, R. & Hall W. (1989). Life events, life difficulties and confiding relationships in the depressed elderly. *British Journal of Psychiatry, 155,* 787-792.

Esser, S.R. & Vitaliano, P.P. (1988). Depression, dementia and social supports. *International Journal of Ageing and Human Development, 26, 4,* 289-301.

Evans, S. & Katona, C. (1993). The epidemiology of depressive symptoms in elderly primary care attenders. *Dementia, 4,* 327-333.

Ferraro, F.R. & Chelminski, I. (1996). Preliminary normative data on the Geriatric Depression Scale - Short Form (GDS - SF) in a young adult sample. *Journal of Clinical Psychology, 52(4),* 443-447.

Fillenbaum.G. (1978). Duke University Centre for the Study of Ageing and Human Development. (1978). *Multidimensional Functional Assessment: The OARS Methodology, A Manual.* Durham, North Carolina: The Centre for the Study of Ageing and Human Development.

Fillenbaum, G. & Smyer, M. (1981). The development, validity and reliability of the OARS multidimensional functional assessment questionnaire. *Journal of Gerontology, 36,* 4, 428-434.

Finlay-Jones, R. & Brown, G.W. (1981). Types of stressful life event and the onset of anxiety and depressive disorders. *Psychological Medicine, 11,* 803-815.

Fiore, J., Coppel, D.B., Becker, J. & Cox, G.B. (1986). Social support as a multifaceted concept: examination of important dimensions for adjustment. American Journal of Community Psychology, 14,1, 93-111. (cited in Hannappel et al, 1993).

Fischer, P., Simamyi, M. & Danielczyk, W. (1990). Depression in dementia of the Alzheimer's type and in mullet-infarct dementia. *American Journal of Psychiatry, 147,* 1484-1487.

Fitz, A.E. & Teri, L. (1994). Depression, cognition and functional ability in patients with Alzheimer's Disease. *Journal of the American Geriatric Society, 42,* 186-191.

Folstein, M. F., Folstein, S.E. & McHugh, P.R. (1975). "Mini Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189-198.

Forsell, Y., Jorm, A.F., Fratiglioni, L., Grut, M. & Winblad, B. (1993). Application of DSMIII criteria for major depressive episode to elderly subjects with and without dementia. *American Journal of Psychiatry, 150,* 1199-1202. (cited in Ballard et al, 1996).

Gilhooly, M.L.M. & Whittick, J. (1989). Expressed emotion in caregivers of the dementing elderly, *British Journal of Medical Psychology, 62,* 265-272.

Gilhooly, M.L.M.., Sweeting, H, N., Whittick, J.E. & McKee, K. (1994). Family care of the dementing elderly. *International Review of Psychiatry, 6,* 29-40.

Gore, S. (1981). Stress-buffering functions of social support: An appraisal and clarification of research models. In B.S. Dohrenwend & B.P. Dohrenwend (Eds), Stressful life events and their contexts. New York: Neale Watson Academic Publications.

Grant G. & Wenger, C.G. (1993). Dynamics of support networks: Differences and similarities between vulnerable groups. *Irish Journal of Psychology*, Special Issue on *Psychological Aspects of Aging: Well being and Vulnerability, 14, 1,* 79-98.

Hannappel, M., Calsyn, R.J. & Allen, G. (1993). Does social support alleviate the depression of caregiver of dementia patients? *Journal of Gerontological Social Work, 20, (1/2),* 35-51.

Harper, S. & Lund, D.A. (1990). Wives, husbands and daughters caring for institutionalised dementia patients: towards a model of care-giver burden. *International Journal of Ageing & Human Development, 30,* 241-262.

Haupt, M., Kurz, A. & Greifenhagen, A. (1995). Depression in Alzheimer's disease: Phenomenological features and association with severity and progression of cognitive and functional impairment. *International Journal of Geriatric Psychiatry, 10,* 469-476.

Henderson, A.S., Grayson, D.A., Scott, R., Wilson, J., Rickwood, D. & Kay, D.W.K. (!986). Social support, dementia and depression among the elderly living in the Hobart community. *Psychological Medicine, 16,* 379-390.

Herrman, N., Mittmann, N., Silver, I.L., Shulman, K.I., Busto, U.A., Shear, N.H. & Naranjo, C.A. (1996). A validation study of the Geriatric Depression Scale short form. *International Journal of Geriatric Psychiatry, 11,* 457-460.

Hirschfield, M.J. (1981). Families living with senile brain disease. Dissertation submitted for Degree of Doctor of Nursing Science, University of California. (cited in Gilhooly et al, 1994)

Hughes, C., Berg, L., Danzeiger, W., Coben, L. & Martin, R. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry, 140,* 566-72.

Ikeda, M., Mori, E., Hirono, N., Imamura, T., Shimomura, T., Ikejiri, Y. & Yamashita, H. (1998). Amnesic people with Alzheimer's disease who remembered the Kobe earthquake. *British Journal of Psychiatry, 172,* 425-428.

Jorm, A.F., Van Dutin, C.M., Chandra, V., Fratiglioni, L., Graves, W.A., Heyman, A., Kokmen, E., Kondo, K., Mortimer, J.A., Rocca, W., Shalat, S.L., Soinen, H. & Hofman, A. (1991). Psychiatric history and related exposures to risk factors for Alzheimer's disease: a collaborative reanalysis of case control studies. *International Journal Of Epidemiology, 20,* 2, 43-47. (cited in Orrell & Davies, 1994).

Kahana, E. (1982). Stress research and ageing: complexities, ambiguities, paradoxes and promise. In Wykle, M., Kahana, E. & Kowal, J. (Eds). *Stress and health among the elderly,* 239-256. (New York: Springer) (cited in Russo & Vitaliano, 1995).

Kitwood, T. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12,* 269-287.

Kitwood, T. (1996) . A dialectical framework for dementia. In Woods R.T.(ed) *Handbook of the clinical psychology of ageing.* (John Wiley & Sons Ltd).

Kitwood, T. (1997). *Dementia Reconsidered.* Open university Press: Buckingham.

Kiyak, A., Lioang, J. & Kahana, E. (1976). Methodological enquiry into the schedule for recent life events. Paper presented at the 84th Annual convention of the American Psychological Association. Washington DC. (cited in Russo & Vitaliano, 1995).

Knight, B.G., Lutzky, S.M. & Macofsky, U. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontological Society of America, 33, 2,* 240-246.

Kreigsman, D.M.W., Penninx, B.W.J. & Van Eijk, J.T.M. (1994). Chronic disease in the elderly and its impact on the family: A review of the literature. *Family Systems Medicine, 12,* 3, 249-267.

Lam, D.H. & Power, M.J. (1991). Social support in a general practice elderly sample. *International Journal of Geriatric Psychiatry, 6,* 89-93.

Liang, J., Levin, J.S. & Krause, N.M. (1989). Dimensions of the OARS mental health measures. *Journal of Gerontology, 44,* 5, 127-138.

Linn, M.W., Hunter, K. & Harris, R. (1980). Symptoms of depression and recent life events in the community elderly. *Journal of Clinical Psychology, 36,* 675-682.

Livingstone et al. (1996). Depression and other psychiatric morbidity in carers of elderly people living at home. *British Medical Journal, 3, 12,* 153-156.

Lodgeson, R.G. & Teri, L. (1995). Depression in Alzheimer's disease patients: Caregivers as surrogate reporters. *The American Geriatrics Society, 43,* 150-155.

McGuffin, P., Katz, R. & Bebbington, P. (1988). The Camberwell collaborative depression study. III. Depression and adversity in the relatives of depressed patients. British Journal of Psychiatry, *152,* 775-782.

Merriam, A.E., Aronson, M.K., Gaston, P., Wey, S. & Katz, K. (1988). The psychiatric symptoms of Alzheimer's disease. *Journal of the American Geriatrics Society, 36,* 7-12.

Morgan, D.L. & March, S.J. (1992). The impact of life events on networks of personal relationships: A comparison of widowhood and caring for a spouse with Alzheimer's disease. *Journal of Social and Personality Relationships, 9,* 563-584.

Morris, R.G., Morris, L.W. & Britton, P.G. (1988). Factors affecting the emotional well-being of caregivers of dementia sufferers. *British Journal of Psychiatry, 153,* 147-156.

Morris, R.G., Woods, R.T., Davies, K.S. & Morris, L.W. (1991). Gender differences in carers of dementia sufferers. *British Journal of Psychiatry, 158, (*suppl. 10), 69-74.

Murphy, E. (1982). Social origins of depression in old age. *British Journal of Psychiatry, 141,* 135-142.

Murphy, E. (1983). The prognosis of depression in old age. *British Journal of Psychiatry, 142,* 111-119.

Murphy, E. (1985). The impact of depression in old age on close social relationships. *American Journal of Psychiatry, 142, 3,* 323-327.

Neugarten, B.L. (1970). Dynamics of the transition of middle age to old age: adaptation and the life cycle. *Journal of Geriatric Psychiatry, 4,* 71-87.

O'Dwyer, A.M. & Orrell, M.W. (1994). Stress, ageing and dementia. *International Review of Psychiatry, 6,* 73-83.

Oei, T.I. & Zwart, F.M. (1990). To what extent does age influence the reporting of life events? *Australian and New Zealand Journal of Psychiatry, 24,* 91-95.

Orrell, M.W. (1993). *Life events and senile dementia.* Thesis submitted for Ph.D. University of London.

Orrell, M.W. & Davies, A.D.M. (1994). Life events in the elderly. *International Review of Psychiatry, 6,* 59-71.

Orrell, M.W. & Bebbington, P. (1995a). Life events and senile dementia. I. Admission, deterioration and social environment change. *Psychological Medicine, 25,* 373-386.

Orrell, M.W. & Bebbington, P. (1995b). Social factors and psychiatric admission for senile dementia. *International Journal of Geriatric Psychiatry, 10,* 313-323.

Orrell, M.W. & Bebbington, P. (1995c). Life events and senile dementia: Affective symptoms. *British Journal of Psychiatry, 166,* 613-620.

Paykel, E.S. (1969). Life events and depression: a controlled study. *Archives of General Psychiatry, 21,* 753-760.

Partridge, F.M., Knight, R.G. & Feehan, M. (1990). Direct and indirect memory performance in patients with senile dementia. *Psychological Medicine, 20,* 111-118.

Pitt, B. (1992). Social factors and old age, in: Bhurgra, D. & Leff, J. (Eds). *Social Psychiatry,* 315-330. (London Blackwell Scientific).

Poulton, R. & Andrews, G. (1982). Personality as a cause of adverse life events. *Acta Psychiatrica Scandinavia, 85,* 35-38. (cited in Russo & Vitaliano, 1995).

Prince, M.J., Harwood, R.H., Blizard, R.A., Thomas, A. & Mann, A.H. (1997). Social support deficits, loneliness and life events as risk factors for depression in old age. The Gospel Oak Project VI. *Psychological Medicine, 27,* 323-332.

Redinbaugh, E.M., McCallum, R.C. & Kiecolt-Glaser, J.K. (1995). Recurrent syndromal depression in caregivers. *Psychology and Ageing*, 10(3), 358-368.

Reed, B.R., Stone, A.A. & Neale, J.M. (1990). Effects of caring for a demented relative on elders' life events and appraisals. *The Gerontological Society of America*, 30, 2, 200-205.

Rook, K.S., Catano, R. & Dooley, D. (1989). The timing of major life events: effects of departing from the social clock. *American Journal of Community Psychology, 17,* 233-258.

Russell, D.W. & Cutrona C.E. (1991). Social support, stress and depressive symptoms among the elderly: Test of a process model. *Psychology and Ageing, 6, 2,* 190-201.

Russo, J. & Vitaliano, P.P. (1995). Spouse caregivers of persons with Alzheimer's disease. *Experimental Ageing Research, 21,* 273-294.

Sheikh, J.I. & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. *Clinical Gerontologist, 5,* 165-173.

Sherbourne, C.D., Meredith, L.S., Rogers, W. & Ware, J.E. (1992). Social support and stressful life events: age differences in their effects on health related quality of life. *Quality of Life Research, 1,* 235-246.

Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist, 35, 6,* 771-791.

Tennant, C., Smith, A., Bebbington, P. & Hurry, J. (1979). The contextual threat of life events: the concept and its reliability. *Psychological Medicine, 9,* 525-528.

Teri, L. & Wagner, A.W. (1991). Assessment of Depression in patient's with Alzheimer's disease: Concordance among informants. *Psychology and Ageing, 6, 2,* 280-285.

Teri, L. & Wagner, A. (1992). Alzheimer's disease and depression. *Journal of Consulting and Clinical Psychology, 60, 3,* 379-391.

Tombaugh, T.N. & McIntyre, N.J. (1992). The Mini Mental State Examination: A comprehensive review. *Journal Of The American Geriatric Society, 40,* 922-935.

Verhey, F.R.J., Rozendaal, N., Rudolf, W.H.., Ponds, M. & Jolles, J. (1993). Dementia, awareness and depression. *International Journal of Geriatric Psychiatry, 8,* 851-856.

Vida, S., Des Rosiers, P., Carrier, L. & Gauthier, S. (1993). Depression in Alzheimer's Disease: Receiver operating characteristic analysis of the Cornell Scale for Depression in Dementia and the Hamilton Depression Scale. *Journal of Geriatric Psychiatry and Neurology, 7,* 159-162.

Wenger, C.G. (1994). Support networks and dementia. *International Journal of Geriatric Psychiatry, 9,* 181-194.

Wilkinson, S.J., Downes, O.J., Davies, M.G. & Davies, A.D.M. (1986). Rating reliability for life events and difficulties in the elderly. *Psychological Medicine, 16,* 101-105.

Williams, D.D.R. & Garner, J. (1998). People with dementia can remember: Implications for care. *British Journal of Psychiatry, 172,* 379-380.

APPENDICES

Appendix 1

Letters - Ethics

HARROW RESEARCH ETHICS COMMITTEE
(Chairman: Dr David Lubel)
Room 6BB 014
Northwick Park Hospital
Tel: 0181-869-2688
Fax: 0181-869-2174

NORTHWICK PARK & ST. MARK'S
NHS TRUST
WATFORD ROAD HARROW
MIDDLESEX HA1 3UJ

23 June 1997

Miss Allyson Waite
25A Queen's Road
Enfield EN1 1NF

Dear Miss Waite

Ethical Submission No. 2321: Life events & depression in dementia

I refer to your letter of 3 June 1997. I am pleased to inform you that this study has now been approved by Chairman's action which allows you to proceed with it and I will be writing to you again as soon as Chairman's action in this case is formally endorsed at the next meeting of the Committee.

Yours sincerely,

Brian Saperia
Secretary

HILLINGDON
HEALTH AUTHORITY
Kirk House 97-109 High Street
Yiewsley West Drayton Middlesex UB7 7HJ
Tel: 01895 452000 Fax: 01895 452108

01895 452000 Ext 3006

4 June 1997

Ms Allyson Waite
Clinical Psychologist in Training
25a Queens Road
Enfield
Middlesex EN1 1NF

Dear Ms Waite

ETHICS COMMITTEE SUBMISSION **838**
An evaluation of the relationship between life events and depression in dementia sufferers

With reference to the above submission to the Local Research Ethics Committee, I am pleased to confirm that this was approved at the meeting held on 3 June 1997. You may proceed with your proposed study subject to the following conditions:-

1 A copy of the letter from Dr Palmer in support of your study (dated 27 May 1997) with her signature should be lodged with the Committee.

2 A brief report on the project (say 1-2 sides of A4 paper) should be submitted to the Ethics Committee at the end of the project or annually in the case of an ongoing study.

3 Should you leave your current post before completing the project, the Ethics Committee will need to be advised of whether the project is to continue and the name of the practitioner who will undertake the project in future. If a project is discontinued some written information on progress to date should be deposited with the Secretary of the Committee to be kept on file.

Should you have any query about these points please do not hesitate to discuss them with me or the Chairman. In addition you may wish to refer to detailed guidance issued by the Royal College of Physicians on Ethics Committees in Medical Research, a copy is available for perusal in the Postgraduate Medical Centre Library, or we have a copy here. Also, enclosed with this letter you will find a copy of the Annex to Directive 91/507/EEC on the conduct of clinical trials.

Yours sincerely,

Joann Durrant - Committee Clerk

Appendix 2

Letters - Participants/Carers

Dear .....

I understand that you are a main carer for..... who has been in touch with the Old Age Psychiatry Service (Woodland Centre), Hillingdon Hospital during the last year.

The mental health professional with whom they were in touch ( ) has agreed that I can contact them and ask if they would be willing to take part in a study that I am carrying out.

The study will be looking at how older people with memory problems are affected by life events such as moving house or being ill. As part of the study, I also need to interview some people who have not experienced any such events, so I would like them to take part whether or not such events have recently happened.

I have written to..... inventing them to take part and perhaps you would discuss the idea with them. The study applies to people who have a regular carer and as such, I would be interested in interviewing yourself as well.

Enclosed is an information leaflet about the study. I can answer any further questions about it when we meet.

I will ring you and ..... in a few days to see if you are happy to take part and if so, to arrange a meeting either at your home or if your prefer, at the hospital.

Thankyou for your help.

Yours sincerely

Allyson Waite
Clinical Psychologist (in training).

Dear .....

You have been in touch with the Old Age Psychiatry Service (Woodland Centre), Hillingdon Hospital during the last year.

The mental health professional with whom you were in touch ( ) has agreed that I can contact you and ask if you would be willing to take part in a study that I am carrying out.

The study will be looking at how older people with memory problems are affected by life events such as moving house or being ill. As part of the study, I also need to interview some people who have not experienced any such events, so I would like you to take part whether or not such events have recently happened to you.

The study only applies to people who have a regular carer and I have also written to ..... to ask them to take part. Perhaps you would discuss the idea with them.

Enclosed is an information leaflet about the study. I can answer any further questions about it when we meet.

I will ring you and your carer in a few days to see if you are happy to take part and if so, to arrange a meeting either at your home or, if your prefer, at the hospital.

Thankyou for your help.

Yours sincerely

Allyson Waite
Clinical Psychologist (in training).

Appendix 3

Information sheets/consent forms

PLEASE READ CAREFULLY

Participants information sheet

Information:

My name is Allyson Waite and I am a psychologist carrying out some research into how older people with memory problems are affected by life events. Life events are things that happen to us, for example, moving house, becoming ill or having someone close to you die. These things affect people in different ways and I am interested to know whether any such things have happened to you recently and if so, how you feel now. Therefore, I would like to ask some questions about any events which have happened to you in the last six months. Sometimes when people face difficulties such as these, it is helpful to have someone close with whom you can talk to about how you feel. I would like to speak to you about your relationships with people close to you and how these may help you when you face difficulties in your life. I would also like your permission to talk to your main carer about these things too.

What does it involve?

The interview would take place whilst you are at home or at the day centre and will last for about half an hour. The interview with your carer would take place beforehand. The interview involves answering a few questions about the amount of support you feel you have when there are difficulties in your life. I will be able to go through the questions with you and help you with any problems you have with them. Your answers will be confidential and your name will not be used at all in the study.

If you have had difficulties recently in your life, I would be interested in talking to you in more detail about what happened, how you feel now and what has helped you to cope since then. Again, this information would be confidential.

Taking part

It is up to you whether or not you wish to take part in this survey and you are free to withdraw from the study at any time. Your decision will not affect any services that you may receive in any way. If you would like to discuss this more with myself in any more detail before making a decision please feel free to contact me on .....

Interview code.....

Participants consent form

A. Researcher: Allyson Waite (Clinical Psychologist in Training).

I confirm that I have explained this study both verbally and in writing to you in the presence of your main carer and am satisfied you understand the research.

Signature.....Date.....

B. To be completed by the participant/carer:

Delete as necessary

1. Have you read the information sheet about this study? YES / NO
2. Have you had an opportunity to ask questions and discuss this study? YES / NO
3. Have you had satisfactory answers to all your questions? YES / NO
4. Have you received enough information about this study? YES / NO
5. Do you understand that you are free to withdraw from this study:
   - at any time
   - without giving a reason
   - without affecting any services you may recieve YES / NO
6. Do you agree to take part in this study? YES / NO

Signed.....Date.....

Name.....

C. To be completed by main carer:

I was present while this study was explained by the researcher to the participant who was given the oppoertunity to ask any questions s(he) wished.

Signed.....Date.....

Carers information sheet
PLEASE READ CAREFULLY
Information:

My name is Allyson Waite and I am a psychologist carrying out some research into how older people with memory problems are affected by life events. Life events are things that happen to us, for example, moving house, becoming ill or having someone close to you die. These things affect people in different ways and sometimes people can very unsettled emotionally afterwards. I am interested to know whether any such things have happened to the person you care for and yourself in the last six months recently and if so, how you both have been affected by them.

Sometimes when people face difficulties such as these, it is helpful to have someone close with whom you can talk to about how you feel. I would like to speak to you about whether you feel that the person you care for is able to discuss difficulties they have with you. I would also like to discuss with the person themselves about the support they feel they have and how this helps them cope with any difficulties.

There is very little understanding at the moment of why some people with memory problems may become depressed and others not. Understanding more about the possible reasons, will be very useful in planning ways to help people and their carers when they do face difficulties in their life.

What does it involve?

The interview would take place at your home or at the day centre, whichever would be most convenient. It will last for 60 minutes at the most. The interview with the person you care for will take place afterwards. The interview involves answering a few questions about any life events that have happened to the person you care for and yourself in the past six months. Also, there will be some questions which you complete about your mood at present and the relationship you have with the person you care for. I will be able to help you with any problems you have with the questions. Your answers will be strictly confidential and your name will not be used at all in the study.

If the person you care for has had difficulties recently, I would be interested in talking to them in more detail about what happened, how they feel now and what has helped them to cope. Again, this information would be strictly confidential.

Taking part

It is up to you whether or not you wish to take part in this survey and you are free to withdraw from the study at any time. Your decision will not affect any services that you or the person you care for may receive in any way. If you would like to discuss this more with myself in any more detail before making a decision please feel free to contact me on

.....

Interview code.....

Carers consent form

Researcher: Allyson Waite
Clinical Psychologist in Training

To be completed by carer:

	Delete as necessary
1. Have you read the information sheet about this study?	YES / NO
2. Have you had an opportunity to ask questions and discuss this study?	YES / NO
3. Have you received satisfactory answers to all your questions?	YES / NO
4. Have you received enough information about this study?	YES / NO
5. Do you understand that you are free to withdraw from this study: - at any time - without giving a reason - without affecting any services recieved	YES / NO
6. Do you agree to take part in this study?	YES / NO

Signed.....Date.....

Name.....

Researcher's signature.....

Appendix 4

DSM 1V criteria - AD/MID

Diagnostic criteria for Dementia of the Alzheimer's Type

A. The development of multiple cognitive deficits manifested by both
   (1) memory impairment (impaired ability to learn new information or to recall previously learned information)
   (2) one (or more) of the following cognitive disturbances:
      (a) aphasia (language disturbance)
      (b) apraxia (impaired ability to carry out motor activities despite intact motor function)
      (c) agnosia (failure to recognize or identify objects despite intact sensory function)
      (d) disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C. The course is characterized by gradual onset and continuing cognitive decline.

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:
   (1) other central nervous system conditions that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, normal-pressure hydrocephalus, brain tumor)

(continued)

☐ Diagnostic criteria for Dementia of the Alzheimer's Type *(continued)*

(2) systemic conditions that are known to cause dementia (e.g., hypothyroidism, vitamin B_{12} or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)
(3) substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g., Major Depressive Disorder, Schizophrenia).

Code based on type of onset and predominant features:

With Early Onset: if onset is at age 65 years or below

290.11 With Delirium: if delirium is superimposed on the dementia

290.12 With Delusions: if delusions are the predominant feature

290.13 With Depressed Mood: if depressed mood (including presentations that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.

290.10 Uncomplicated: if none of the above predominates in the current clinical presentation

With Late Onset: if onset is after age 65 years

290.3 With Delirium: if delirium is superimposed on the dementia

290.20 With Delusions: if delusions are the predominant feature

290.21 With Depressed Mood: if depressed mood (including presentations that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.

290.0 Uncomplicated: if none of the above predominates in the current clinical presentation

Specify if:

With Behavioral Disturbance

Coding note: Also code 331.0 Alzheimer's disease on Axis III.

Diagnostic criteria for 290.4x Vascular Dementia

A. The development of multiple cognitive deficits manifested by both
   (1) memory impairment (impaired ability to learn new information or to recall previously learned information)
   (2) one (or more) of the following cognitive disturbances:
      (a) aphasia (language disturbance)
      (b) apraxia (impaired ability to carry out motor activities despite intact motor function)
      (c) agnosia (failure to recognize or identify objects despite intact sensory function)
      (d) disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C. Focal neurological signs and symptoms (e.g., exaggeration of deep tendon reflexes, extensor plantar response, pseudobulbar palsy, gait abnormalities, weakness of an extremity) or laboratory evidence indicative of cerebrovascular disease (e.g., multiple infarctions involving cortex and underlying white matter) that are judged to be etiologically related to the disturbance.

D. The deficits do not occur exclusively during the course of a delirium.

Code based on predominant features:

290.41 With Delirium: if delirium is superimposed on the dementia

290.42 With Delusions: if delusions are the predominant feature

290.43 With Depressed Mood: if depressed mood (including presentations that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.

290.40 Uncomplicated: if none of the above predominates in the current clinical presentation

Specify if:

With Behavioral Disturbance

Coding note: Also code cerebrovascular condition on Axis III.

Appendix 5

Demographic information sheet

DEMOGRAPHICS

ID number .....

Consent obtained .....

Participant interviewed .....

Carer interviewed .....

Date of Birth ..... Age .....

Sex .....

Personal history

Education .....
Occupation .....
Physical health .....
Previous psychiatric .....

Family history

Parents .....
Siblings .....
Marital Status .....
Children .....

Social Situation

Housing .....
Condition .....

Support services level of support: 4-full 3-major 2-minor 1-contact only

Home Help	.....
Meals on wheels	.....
Day centre	.....
Social worker	.....
District nurse	.....
CPN	.....
Voluntary worker	.....
Relatives	.....
Other	.....

Informant	.....
Cohabitee	.....
Frequency of contact	.....
Date of onset of illness	.....
Date of diagnosis	.....
Level of dependency	3-severe 2-moderate 1-mild 0-nil

Mood
Irritable / suspicious .....
Depressed / withdrawn .....

Cognition
Memory, orientation, confusion.....

Behaviour
Restless / wandering .....
Aggressive / disinhibited .....

Self care
hygiene/appearance .....
sleep .....
continence .....

Other .....

Quality of R/S · A DSM-IV-3
B CONT
C PHYS DEP

MMSE : . . . . . .
DSM IV : . . . . . .

Appendix 6

Cornell Scale for Depression in Dementia

NAME

Hospital no.

CORNELL SCALE FOR DEPRESSION IN DEMENTIA		RATER'S INITIALS	DATE DAY / MO. / YR.

PATIENT STATUS AT TIME OF EVALUATION (Check one)
☐ 0 INPATIENT ☐ 1 NURSING HOME RESIDENT ☐ 2 OUTPATIENT

SCORING SYSTEM
a = UNABLE TO EVALUATE 0 = ABSENT 1 = MILD OR INTERMITTENT 2 = SEVERE

	RATINGS SHOULD BE BASED ON SYMPTOMS AND SIGNS OCCURRING DURING THE WEEK PRIOR TO INTERVIEW. NO SCORE SHOULD BE GIVEN IF SYMPTOMS RESULT FROM PHYSICAL DISABILITY OR ILLNESS.	WRITE SCORE BELOW.
A. MOOD-RELATED SIGNS	1. ANXIETY (Anxious expression, ruminations, worrying)	
	2. SADNESS (Sad expression, sad voice, tearfulness)	
	3. LACK OF REACTIVITY TO PLEASANT EVENTS	
	4. IRRITABILITY (Easily annoyed, short tempered)	
B. BEHAVIORAL DISTURBANCE	5. AGITATION (Restlessness, handwringing, hairpulling)	
	6. RETARDATION (Slow movements, slow speech, slow reactions)	
	7. MULTIPLE PHYSICAL COMPLAINTS (Score 0 if GI symptoms only)	
	8. LOSS OF INTEREST (Less involved in usual activities) (Score only if change occurred acutely, i.e., in less than 1 month)	
C. PHYSICAL SIGNS	9. APPETITE LOSS (Eating less than usual)	
	10. WEIGHT LOSS (Score 2 if greater than 5 lb. in 1 month)	
	11. LACK OF ENERGY (Fatigues easily, unable to sustain activities) (Score only if change occurred acutely, i.e., in less than 1 month)	
D. CYCLIC FUNCTIONS	12. DIURNAL VARIATION OF MOOD (Symptoms worse in the morning)	
	13. DIFFICULTY FALLING ASLEEP (Later than usual for this individual)	
	14. MULTIPLE AWAKENINGS DURING SLEEP	
	15. EARLY MORNING AWAKENING (Earlier than usual for this individual)	
E. IDEATIONAL DISTURBANCE	16. SUICIDE (Feels life is not worth living, has suicidal wishes, or makes suicide attempt)	
	17. POOR SELF-ESTEEM (Self-blame, self-depreciation, feelings of failure)	
	18. PESSIMISM (Anticipation of the worst)	
	19. MOOD-CONGRUENT DELUSIONS (Delusions of poverty, illness, or loss)	

COMMENTS (Please date and sign all comments) CHECK IF NONE ☐

Appendix 7

Geriatric Depression Scale

GERIATRIC DEPRESSION SCALE

This is a self rating scale, but subjects might need some guidance

(Yesavage 1988)

Are you basically satisfied with your life?	Yes/NO
Have you dropped many of your activities and interests?	YES/No
Do you feel that your life is empty?	YES/No
Do you often get bored?	YES/No
Are you in good spirits most of the time?	Yes/NO
Are you afraid that something bad is going to happen to you?	YES/No
Do you feel happy most of the time?	Yes/NO
Do you often feel helpless?	YES/No
Do you prefer to stay at home, rather than going out and doing new things?	YES/No
Do you feel you have more problems with memory than most?	YES/No
Do you think it is wonderful to be alive now?	Yes/NO
Do you feel pretty worthless the way you are now?	YES/No
Do you feel full of energy?	Yes/NO
Do you feel that your situation is hopeless?	YES/No
Do you think that most people are better off than you are?	YES/No

Answers indicating depression are in capitals. Each answer scores one point.
Scores above 5 indicate probable depression.

Yesavage J.A. (1988) Geriatric Depression Scale. Psychopharmacol. Bull. 24, 709-170

Appendix 8

OARS measure

PRELIMINARY QUESTIONNAIRE
[ASK QUESTIONS 1-10 AND RECORD ALL ANSWERS. (ASK QUESTION 4a ONLY IF SUBJECT HAS NO TELEPHONE.) CHECK CORRECT (+) OR INCORRECT (−) FOR EACH AND RECORD TOTAL NUMBER OF ERRORS BASED ON TEN QUESTIONS.]

CARD 1

1	0		
+	−		
		1. What is the date today? _____ Month Day Year	19
		2. What day of the week is it? _____	20
		3. What is the name of this place? _____	21
		4. What is your telephone number? _____	22
		5 a. [ASK ONLY IF SUBJECT DOES NOT HAVE A PHONE.] What is your street address? _____	23
		5. How old are you? _____	24
		6. When were you born? _____ Month Day Year	25
		7. Who is the president of the U.S. now? _____	26
		8. Who was the president just before him? _____	27
		9. What was your mother's maiden name? _____	28
		10. Subtract 3 from 20 and keep substracting 3 from each new number you get, all the way down. _____ [CORRECT ANSWER IS: 17, 14, 11, 8, 5, 2.]	29
		_____ Total number of errors.	30-31

1. Telephone number [IF SUBJECT IS RELIABLE TRANSFER FROM PRELIMINARY QUESTIONNAIRE; OTHERWISE, OBTAIN FROM INFORMANT OR LOOK ON TELEPHONE.]

2. Sex of Subject
   0 Male

CARD 1

3. Race of Subject
   1 White (Caucasian)
   2 Black
   3 Oriental
   4 Spanish American (Spanish surname)
   5 American Indian
   6 Other
   - Not answered

   32

4. [GET FROM PRELIMINARY QUESTIONNAIRE IF SUBJECT IS RELIABLE; FROM INFORMANT IF NOT.]
   a. When were you born? _____ (Month) (Day) (Year) Mo Day Yr 34-35 36-37 38-39
   b. How old are you? _____ 40-42

5. How far did you go (have you gone) in school?
   1 0-4 years
   2 5-8 years
   3 High school incomplete
   4 High school completed
   5 Post high school, business or trade school
   6 1-3 years college
   7 4 years college completed
   8 Post graduate college
   - Not answered

   43

SOCIAL RESOURCES

Now I'd like to ask you some questions about your family and friends.

6. Are you single, married, never married, widowed, divorced or separated?
   1 Single (never married)
   2 Married
   3 Widowed
   4 Divorced
   5 Separated
   - Not answered

   44

7. Who lives with you?
   [CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING.]

1	0	
YES	NO	
		No one

1 YES	0 NO		CARD 1
		Husband or wife	46
		Children	47
		Grandchildren	48
		Parents	49
		Grandparents	50
		Brothers and sisters	51
		Other relatives [Does not include in-laws covered in the above categories.]	52
		Friends	53
		Non-related paid* helper [*Includes free room]	54
		Other [SPECIFY.] _____	55

8. How many people do you know well enough to visit with in their homes?
   3 Five or more
   2 Three to four
   1 One or two
   0 None
   - Not answered

   56

9. About how many times did you talk to someone—friends, relatives, or others on the telephone in the past week (either you called them or they called you)? [IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES.]
   3 Once a day or more
   2 2-6 times
   1 Once
   0 Not at all
   - Not answered

   57

10. How many times during the past week did you spend some time with someone who does not live with you; that is you went to see them or they came to visit you, or you went out to do things together?

CARD 1

   1 Once
   0 Not at all
   - Not answered

   58

11. Do you have someone you can trust and confide in?
   1 Yes
   0 No
   - Not answered

   59

12. Do you find yourself feeling lonely quite often, sometimes, or almost never?
   0 Quite often
   1 Sometimes
   2 Almost never
   - Not answered

   60

13. Do you see your relatives and friends as often as you want to, or not?
   1 As often as wants to
   0 Not as often as wants to
   - Not answered

   61

14. Is there someone who would give you any help at all if you were sick or disabled, for example your husband/wife, a member of your family, or a friend?
   1 Yes
   0 No one willing and able to help
   - Not answered

   62

   [IF "YES" ASK a. AND b.]

   a. Is there someone who would take care of you as long as needed, or only for a short time, or only someone who would help you now and then (for example, taking you to the doctor, or fixing lunch occasionally, etc.)?
      3 Someone who would take care of Subject indefinitely (as long as needed)
      2 Someone who would take care of subject for a short time (a few weeks to six months)
      1 Someone who would help the Subject now and then (taking him to the doctor or fixing lunch, etc.)
      - Not answered

      63

   b. Who is this person?

      Name _____

      Relationship _____

      64

Appendix 9

Quality of Relationships Scale

7.1.3 Assessment of quality of family relationships

A. Dominance-submissiveness in a particular relationship

1. Patient controls every area of a relationship.
2. Patient generally in control but relative able to set some limits.
3. Patient mainly in control but there are some areas where the relative has a lot of control.
4. Equal sharing of control; balance of power or independence.
5. Relative mainly in control but there are some areas where the patient has a lot of control.
6. Relative generally in control, but options left in some areas to the patient.
7. Relative controls every area of a relationship.

B. The Communication System in a particular relationship

1. Constant negative communication by punishing, hurtful criticism or by withdrawal. Some physical aggression.
2. Frequent verbal aggressiveness or withdrawal from the relationship. Little reward for the partner in the relationship.
3. A lot of punishment used - verbal or in the form of withdrawal, but some reward in the relationship.
4. Equal amounts of negative verbal communication/withdrawal and warm positive communication.
5. Mainly warm positive communication but some negative verbal communication or withdrawal also.
6. Predominantly warm positive communication but occasional negative verbal communication in the relationship.
7. Almost continual positive reward system: devoted, loving, almost no cross words or withdrawal from the relationship.

C. Physical dependency - Autonomy in a particular relationship

1. Relative gives patient a great deal of basic physical care each day e.g., dresses, washes, feeds, toilets, etc.
2. Relative gives patient some daily help with shopping, cooking, cleaning etc. although the patient is independent in self care from day to day.
3. Relative gives patient some help from time to time (less than daily) with cleaning, cooking shopping, bathing etc.
4. Patient and relative are completely independent of each other in terms of day to day living activities, or give each other equal amount of help.
5. Patient gives relative some help from time to time (less than daily) with cleaning, cooking shopping, bathing etc.
6. Patient gives relative some daily help with shopping, cooking, cleaning etc. although the relative is independent in self care from day to day.
7. Patient gives relative a great deal of basic physical care each day e.g., dresses, washes, feeds, toilets, etc.

Appendix 10

Life Events and Difficulties Schedule

L.E.D.S.

A. HEALTH DATE

1. Have they (you) any long-standing/chronic health problems?
(interferes with daily activity, i.e. heart problems, arthritis, bad back).

.....
.....
.....
.....

2. Have they (you) been ill/ had health troubles in the past 12 months?
(how serious/how long for)

.....
.....
.....
.....
.....

3. Have they (you) been admitted to hospital in the past 12 months?
(emergency/planned/how long)

.....
.....
.....
.....
.....

4. Has anyone in their (your) family been ill/had health problems in
the past 12 months?
(children/spouse/how serious/emergency/missed work/how long)

.....
.....
.....
.....
.....

5. Have they (you) or anyone close to them (you) been admitted to hospital in past
12 months?
(why/routine or emergency/how long for/what changes for them (you)/how

involved were they (you)/medical outlook) DATE

.....
.....
.....
.....

6. Is anyone close to them (you) a worry for other reasons?
(mental health/suicide/age/drinking/gambling/disability)

.....
.....
.....
.....

7. Have there been any accidents in the past 12 months?
(road/home/children/falls/anything like that?)

.....
.....
.....
.....

8. Have there been any pregnancies/births in their (your) family in the past 12 months?
(planned/anyone lost a baby/miscarriage/still birth)

B. DEATHS

1. Are their (your) parents still alive?
(death of parents/cause/date/ age/subjects age)

.....
.....
.....
.....

2. Have they (you) ever been widowed/lost any close friend/relative/children?

.....
.....
.....
.....

3. Have there been any other deaths in the past 12 months? DATE
(they (you) present/expected/lead up/involvement)

.....
.....
.....
.....

C. ROLE CHANGES/FRIENDS/LEISURE

1. Has anyone in their (your) family got married/engaged in the past 12 months?
(expected/involvement/children/friends)

.....
.....
.....
.....

2. Has anyone got separated divorced in the past 12 months?
(expected/involvement)

.....
.....
.....
.....

3. Has anyone retired in the past 12 months?
(expected/changes in routine/finance)

.....
.....
.....
.....

4. Has anyone started school/college/exams in past 12 months?

.....
.....

5. Have they (you) made new friends in the past 12 months? DATE

.....
.....

6. Have they (you) lost contact with friends/family or changed frequency of contact in the past 12 months?
(moved away/left home)

.....
.....
.....
.....

7. Have there been any changes to their (your) leisure time in the past 12 months?
(not enough time/money/new hobbies)

.....
.....
.....
.....

8. Have they (you) had a holiday in the past 12 months?
(how was it/unexpected/important things happen whilst away)

.....
.....
.....
.....

D. MARITAL/RELATIONSHIP

If married Dates?
Previous relationship/marriage?

1. Have they (you) been separated from spouse for any length of time in the past 12 months?
(permanent divorce/separation/dates)

.....
.....
.....
.....

2. Have there been any changes in their (your) relationship in the past

12 months? DATE
(rows/major decisions/problems)

.....
.....
.....
.....
.....

E. FINANCES

1. Have they (you) had any money worries/change in finances in the past 12 months?
(meeting commitments/no work)

.....
.....
.....
.....

2. Have they (you) claimed any benefits in the last 12 months?

.....
.....

F. HOUSING

1. How long have they (you)lived in present home?

.....

2. Has there been any change in their (your)housing in the past 12 months?
(moved)

.....
.....
.....

3. Have there been any difficulties in the past 12 months?
(repairs/landlord/neighbours/area)

.....
.....
.....
.....

G. CRISES/FORECASTS/NEWS DATE

In the past 12 months:

1. Have there been any crises or emergencies?
(involving them(you)/how involved)

.....
.....
.....
.....

2. Been a victim of crime? (Burglary/Attacked)
Fire?
Lost any pets?

.....
.....
.....

3. Any very good/bad news? Had to break any news to someone else?

.....
.....

4. Any unexpected news regarding future events (moving house/redundancy)?
or things which were a shock/ (news of an affair/stealing/debt)
(involving them/you)

.....
.....
.....
.....

4. Any contact with the police? Social services ?
Legal troubles (going to court)?

.....
.....
.....

H. MISCELLANEOUS DATE

In the past 12 months has there been :

1. Any major disappointments not already mentioned?

.....
.....

2. Any major decisions made?

.....
.....

3. Anything especially nice not already mentioned/given you pleasure? (winning money/new clothes/furniture)

.....
.....
.....

CARERS ONLY:

I. EMPLOYMENT

1. Employed/not - job/length of time/enjoy

.....

2. Have there been any changes in your employment in the past 12 months? (redundancy/promotion/change in hours/responsibility)

.....
.....
.....
.....
.....

3. Have there been any difficulties in your work in past 12 months? (conflicts/sickness)

.....
.....

DATE

.....

.....

4. Any of the above in relation to spouse?

.....

.....

.....

Notes:

PT INTIMACY RATING : A - D

CF INTIMACY RATING : A - D

A : name spouse/friend - cohabiting - daily
B : confiding r/s with friend/s-in/child - weekly
C : < weekly
D : no-one

Appendix 11

Qualitative interview

QUALITATIVE INTERVIEW

1. Can you tell me about any events that may have happened in your life in the last six months?

2. Have you had any stressful events/experiences. Has anything happened which has upset you?

   Serious illness involving your self (falls)
   Serious illness involving friend/relative
   Death of close relative (spouse/child)
   Death of close friend/other relative
   Separation
   Serious problem with relative/friend/neighbour
   Major financial crises
   Police/legal involvement
   Something valuable lost/stolen

3. When did this happen?

4. How has it affected your daily life?

5. Is it on your mind a lot?

6. Did you talk to anyone about it?

7. What do you do to cope with difficult events?