

**MANAGEMENT OF THE BEHAVIOURAL
SYMPTOMS OF DEMENTIA AND THE
EFFECT ON CARERS**

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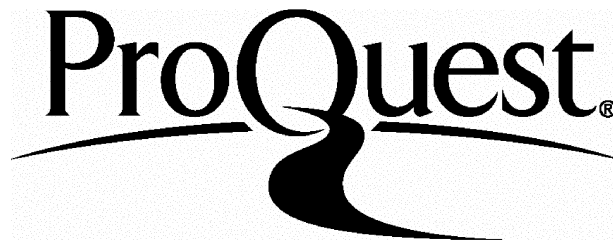
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PREFACE

The research work for this thesis took place between November 1991 and December 1993, while the author was employed as a clinical lecturer by firstly the Royal Free Hospital Medical School and latterly the University College Hospital Medical School. This had been preceded by a pilot study which was completed while the author was a registrar in psychiatry at the Royal Free Hospital between August 1990 and February 1991.

Dr Gill Livingston acted as supervisor throughout for the pilot study, the main study and in writing both up for publication. Professor Cornelius Catona was co-supervisor for the thesis. The author organised recruitment of dementia sufferers and their carers into both studies, completed the initial assessments and implemented the interventions. Follow up assessments were completed by research assistants Bernice Stone and Annie Shuttleworth. Bob Blizzard gave statistical advise and analysed the data, in discussion with the author.

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She also wishes to thank the Mental Health Foundation for funding the study, all the dementia sufferers and carers who took part in it and all the health care professionals who contributed to devising the intervention strategies, namely Dr Nori Graham, Inge Hyman, Hazel Fox and Helen Souris. She would also like to thank Bernice Stone and Annie Shuttleworth for so carefully completing the follow up assessments.

SUMMARY

Behavioural disturbance commonly complicates dementia and is associated with carer's psychiatric morbidity. This study hypothesised that behaviours specified by carers as distressing could be managed using individually designed care packages which could reduce such behaviours and improve carer mental health as compared to usual care.

People with dementia (PWD) and their carers were recruited. Carers were assessed using the General Health Questionnaire and the Geriatric Mental State (GMS) if over 65, or the Clinical Interview Schedule (from which a DSM IIR diagnosis was made) if under 65. PWD were assessed using the Mini Mental State Examination and the GMS. The Present Behavioural Examination was completed with each carer, who specified which behaviour(s) they found most distressing.

Care Packages for each couple were generated by a Multidisciplinary Team (Psychiatrists, Psychologists, Community Psychiatric Nurse, Occupational Therapist, Social Worker, Pharmacist).

Couples were divided into two groups: A and B. Group A care packages were implemented over sixteen weeks. Group B acted as controls. Then both groups were reassessed (reassessment 1) using the initial rating scales. Over the following sixteen weeks Group B Care Packages were implemented. Both groups were then reassessed again (reassessment 2).

At reassessment 1, compared to Group B, the behaviour of Group A dementia sufferers improved significantly ($p < 0.001$) as did the mental health of their carers ($p < 0.001$).

At reassessment 2, the behaviour of Group A dementia sufferers and the mental health of their carers remained improved. These variables were associated.

The intervention received by Group B couples neither improved carer mental health nor dementia sufferer behaviour.

In conclusion, behavioural complications of dementia can be reduced and this is associated with an improvement in carer mental health. Since no single intervention was significantly effective, it is likely that care packages succeeded because they were tailored to needs.

PREFACE

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PART 1

CHAPTER 1: INTRODUCTION

This chapter aims to place this thesis in context and so explain its relevance to the needs of elderly people in the community at present.

In the first section, demographic change is discussed since with an ageing population, there will be more people aged 65 years and over and subsequently greater numbers of people with dementia (1.1.1, 1.1.2).

The next section deals with the definition of dementia (1.1.3). The following two sections review the impact of dementia on the family and friends of dementia sufferers (1.1.4), and on society (1.1.5). Since this is influenced greatly by government policy to care for people at home for as long as possible, the NHS and Community Care Act (1989) is discussed next (1.1.6). Finally the aims and relevance of this thesis are reviewed (1.1.7).

1.1.1 THE AGEING POPULATION

Until the 18th century, life expectancy in Great Britain was 25-35 years of age (Midwinter 1989). However, it has risen over this century such that between the turn of the century and the mid 1980's, it has increased from 48.5 - 71.6 for men and from 51.4 - 77.6 for women (Warnes 1989). A recent report by the European Commission predicts that within the United Kingdom there will be a 43.6% increase in the population aged over 60 by the year 2025. The increase in life expectancy results from the decline in death rates particularly the fall in infant mortality such that death rates have fallen over the last century from over 30 to only 10 per thousand per year (Warnes 1989). There has also been a decline in birth rates. Thus the increase in the proportion of the population over 60, will be accompanied by a 2.8% decline in the working population aged 20-59, and a 8.2% drop in those aged under 20 (Bates 1996).

Not only are the numbers of elderly increasing, but the oldest of these (ie those over 85 years) are becoming a larger proportion of the total population over 65 years. Thus in 1985, 1.2% of the population were over 85 and in 1987 it was predicted that by 1996, this proportion would increase to 1.9%, a 50% increase in 10 years amounting to 400,000 more people in this age group (Office of Population Censuses and Surveys (OPCS) 1985, 1987)

1.1.2 THE AGEING POPULATION AND DEMENTIA

Jorm et al (1987), in a metanalysis of epidemiological studies into dementia, reported that dementia prevalence rates rise exponentially with age, doubling every 5.1 years. Thus the older the population, the higher the numbers of people with dementia. On the basis of epidemiological studies, prevalence rates are quoted as being about five percent of those over 65 years and 20% of those aged over 80 years (Copeland et al 1987, Livingston et al 1990).

Using 1980 rates as a baseline zero, a 30% increase in the numbers of people with dementia by the year 2025 is predicted (Jorm 1988).

1.1.3 DEFINITION OF DEMENTIA

The word "dementia" can be found as far back as the writings of Lucretius, and at that time it meant "being out of one's mind" (Berrios 1990). In 1684, Thomas Willis wrote about a condition which would now be called dementia saying that it was a "stupidity and foolishness" which "although it belongs to the rational soul, and signifies a defect in intellect and judgement, yet it is not improperly reckoned among the diseases of the head or brain; for as much as this eclipse of the superior soul proceeds from the imagination and the memory being hurt, and the failing of these depends upon the faults of animal spirits, and the brain itself". Thus, Willis recognised it as, at least in part, a disease of the brain, and even spoke of various aetiologies: "strokes or bruising of the head", "cruel diseases of the head", and "drunkenness and surfeiting". He also made an association with ageing itself saying "some at first crafty and ingenious, become by degrees and at length foolish, by the mere declining of age without any errors of living". It was not until the early 1900's that dementia came to have a more precise meaning as a disease in which there was an irreversible disorder of intellectual functions (Berrios 1990a).

In 1987, a consensus conference defined dementia as "a clinical state with many different causes, characterised by a decline from a previously attained intellectual level" (Office of the Medical Application of Research, 1987). It is the latter part of this definition that is at the centre of difficulties in diagnosing dementia. Many instruments designed to diagnose dementia infer the presence or absence of

cognitive impairment from current cognitive functioning. Thus those with high premorbid intelligence may score as non-cases on instruments designed to measure cognitive impairment even though there may be a decline from premorbid functioning. Conversely, those of lesser intellectual abilities or who have received little education may score as cases even when they do not have dementia. In medical practice, dementia is a clinical diagnosis made on the basis of history and mental state examination.

This allows a change in cognitive functioning or behaviour to be detected especially if there is an informant. Since dementia describes a variable clinical syndrome with multiple aetiologies, diagnostic criteria emphasise different features. For instance the Diagnostic and Statistical Manual 111-R (DSM 111R, American Psychiatric Association 1987) specifies that there must be demonstrable impairment in short and long term memory and impairment of higher cortical functioning which significantly interferes with work, social activities or relationships.

The International Classification of Disease (ICD 10, World Health Organisation 1992) states that dementia is a chronic or progressive brain disease affecting multiple higher cortical functions and specifies that changes in performance should not be used as criteria for dementia. Therefore, the two classification systems differ in that ICD 10 specifies either chronicity or progression which is not mentioned in DSM 111R, and DSM 111R includes deficits in functioning as an essential feature and this is specifically excluded as a criterion in ICD 10.

1.1.4 THE IMPACT OF DEMENTIA ON THE FAMILY AND FRIENDS OF DEMENTIA SUFFERERS

For many years it has been the stated policy of the government that elderly people should be maintained in the community rather than in residential care (HMSO 1981) and the NHS and Community Care Act (1989) (see 1.1.6) is the legislation which serves to implement this aim. Thus most people with dementia are cared for at home. In a classic early community study fewer than 20% were living in hospital or residential care (Kay et al 1964) and a more recent study reported similar results, that at least 80% of people with dementia were cared for in the community (Levin et al 1986). Informal carers (ie family members or friends) are known to be the main source of assistance for their dependent relatives and those

carers are usually women who receive little help from formal services (Jones and Vetter 1984).

Caring can have a profound impact upon a family both economically and psychologically. For example, the above study quoted that more than 11% of carers had given up work in order to care for their relative. Others may have reduced their hours of work or been paying for sitting services but these were not documented in the study. The psychological morbidity associated with caring is well documented and is discussed in detail in chapter 3.

1.1.5 THE IMPACT OF DEMENTIA ON SOCIETY

Health and social service use among elderly people with psychiatric illness living in the community is known to be high. One study found that those with depression had much greater contact with health services and those with dementia more contact with social services than people in the population as a whole (Mann et al 1990). 50% of those with dementia were receiving some help with social services. In terms of assessing the cost of this increased service use, one study estimated the economic burden of Alzheimer's Disease (Gray and Fenn 1993). A number of areas of provision were considered: hospital and residential care, general practice, day care, home care and informal care. The total cost of care amounted to around £1,039 million pounds for the year 1990/91 and state contributions to informal carers accounted for about six percent of this. This is likely to be an underestimate of the true cost of caring for people with dementia, since not all dementia is of the Alzheimer type and the study only included those people in whom Alzheimer's disease was listed on a death certificate. A recent study (Livingston et al 1997) assessed the financial cost of the domiciliary services received by a representative sample of people aged 65 years and over. The total cost of health and social services per month for those who were well was £32.52 whereas for those with dementia it was £194.70. These figures do not take into account accommodation costs or periods of inpatient and residential care so are likely to be an underestimate of the true cost. Services provided by social services such as having a home help or meals on wheels were associated with having dementia and the mean cost per person with dementia per month was £57.68 and £24.70 respectively.

Attending a day centre was associated with either suffering from dementia or an anxiety disorder but the

cost of the provision was greater for those with dementia (£71.35 vs £31.05 per person with the disorder per month) which is explained by the fact that a greater proportion of those with dementia than those with anxiety disorder were attending day care (25.6% vs 14.1%). The authors emphasise that the study costed services received rather than services required and it is possible that many were in receipt of inadequate levels of support. In addition, no account was taken of the costs to the carer. Thus these figures may underestimate the true cost of services required.

1.1.6 THE NHS AND COMMUNITY CARE ACT (1989)

Supporting physically and mentally ill people at home has been a consistent element of government policy at least since 1977 (Callaghan 1977). The effect on mental health provision has been a move away from isolated asylums and the development of psychiatric units that are part of district general hospitals within the communities in which patients live. Alongside reduced hospital provision, there has been a growth in community services.

The NHS and Community Care Act (1989) was introduced over three years between 1991 and 1993. One of its requirements is that a multidisciplinary assessment of need be made on all vulnerable individuals within the community which includes many of those with physical disabilities, learning difficulties or dementia. This is lead by social services who may ask for reports from health services to assist in drawing up a statement of need for a given individual. Social services also hold the budget from which the community provision is to be funded.

However, there is no obligation to provide the services set out in the statement of need. Thus, by statute, need is not necessarily followed by resources. Where there is a mismatch between them, the burden of the short fall may be born by informal carers (ie family members or friends).

The needs of carers have begun to receive greater attention and these are recognised in "The Carers Recognition and Services Act 1995", also known as the "Carers Act". The act entitles carers to an assessment in their own right from social services , who are then required to take account of the carers needs when they plan service provision.

However, as above, there is no obligation to fulfil these requirements.

1.1.7 THE AIM AND RELEVANCE OF THIS THESIS

With an ageing population, there are increasing numbers of people with dementia and given government policy to care for older people in the community, about 80% of older people with dementia live in their own homes supported to a great extent by informal carers (see 1.1.1 and 1.1.3). Therefore improving the community management of people with dementia is increasingly relevant.

The literature review in this thesis (chapters 2-5) explores behavioural manifestations of dementia, carer mental health, the links between them, and the efficacy of intervention studies. The hypothesis on which this thesis is based was formulated on the basis of the questions raised in this review as outlined below.

The impact of caring on carer mental health is such that many become depressed (1.3.1a). One of the factors associated with poor carer mental health is behavioural disturbance in the dementia sufferer (Graftesman et al 1994, Sanford et al 1975, Motenko 1989, O'Connor et al 1990, Pruchno and Resch 1989, Gilleard et al 1982, Gilleard et al 1984, Deimling and Bass 1986, Kinney and Paris Stephens 1989, Brodaty and Hadzi-Pavlovic 1990). Behavioural changes are common non-cognitive manifestations of dementia and since they afflict around 80% of sufferers referred to psychiatric services (Swearer et al 1988, Burns et al 1990) (see chapter 2), successful management of such difficulties is important. Given the association between behavioural disturbance in dementia and poor carer mental health, reduction of the former might improve the latter.

The link between behavioural disturbance in dementia and carer psychological morbidity is likely to be complex. Those carers who are more depressed might be expected to be less tolerant to behavioural disturbance and therefore to present to services more often. Thus the needs of both the dementia sufferer and the carer need to be considered in order to manage behavioural disturbance comprehensively. This study aimed to evaluate a multidisciplinary approach to the management of behavioural disturbance in dementia by addressing individually, both the behavioural difficulties of a person with dementia and

psychological morbidity of their carers. No previous intervention study has assessed the needs of both individually. In addition, this study aimed to implement individually formulated packages of care to subjects and carers in their own home. Previous studies have evaluated interventions which were group educational programmes plus or minus group support. Although some earlier studies have evaluated interventions administered individually, they have been designed to cater for carers needs in general.

Thus the hypothesis of this study was that individually formulated and administered packages of care designed to address both the behavioural difficulties of a person with dementia and the mental health needs of their carers, could effectively reduce such behavioural problems and improve carer mental health.

PART 1

CHAPTER 2: BEHAVIOURAL CHANGE IN DEMENTIA

Although the cognitive impairments in dementia are the defining (see 1.1.2) and perhaps most easily measurable aspects of the disease, there are many non cognitive aspects such as behavioural disturbance and personality change. These may lead to carer distress (see section 1.4.2) and to breakdown in community care (Sanford 1975).

The following paragraphs will review the nature of behavioural disturbance in dementia, its prevalence and its relation to the progress of the disease. In addition, literature on interventions aimed at modifying behavioural disturbance in dementia will be reviewed.

1.2.1 THE DEFINITION OF BEHAVIOURAL DISTURBANCE IN DEMENTIA

The term behavioural disturbance is vague and researchers vary as to which categories of behavioural change they include under this heading. Most studies use the term behavioural disturbance to describe observable behaviours such as aggression (verbal and physical), wandering and repetitive questioning but also include psychiatric symptoms such as delusions, hallucinations, depression and anxiety (Swearer et al 1988, Pruchno and Resch 1989, Burns et al 1990, Patel and Hope 1993). Some authors include cognitive aspects of the illness within their definition of behavioural disturbance such as "forgetting recent events" or items that are related to language difficulties such as "inability to express self" (Pruchno and Resch 1989). Others include dependence as measured by a limitation in the activities of daily living (O'Connor et al 1990).

More recently, since a consensus conference in 1996 in Lansdown Virginia, the term "behavioural and psychological symptoms in dementia (BPSD)" has been used to describe those manifestations of the disease other than cognitive and functional impairment. The work of Reisberg et al 1989 reported that functional and cognitive changes clustered together whereas those with BPSD do not and so concluded that BPSD was a distinct syndrome which should be studied independently of the cognitive and functional domains of the dementing process.

1.2.2 THE PREVALENCE AND NATURE OF BEHAVIOURAL DISTURBANCE IN DEMENTIA

It is difficult to separate discussion on the prevalence of behavioural disturbance in dementia from discussion of the nature of such disturbance, since prevalence is likely to vary with the definition of behaviour used as described above (see 1.2.1). Therefore, section 1.2.2a will consider prevalence of behavioural disturbance in general but the prevalence of specific behavioural changes such as aggression will be considered in section 1.2.2b where individual behaviours in dementia are discussed in more detail.

1.2.2a THE PREVALENCE OF BEHAVIOURAL DISTURBANCE IN DEMENTIA

The prevalence of behavioural disturbance in dementia is likely to vary not only with the definition used (see 1.2.1) but also the population studied and the severity of their illness (see section 1.2.3). There has been no study of behavioural change in an unselected sample of people with dementia, who are representative of this group as a whole (Sturmev 1994). Studies usually recruit selected samples of people with dementia such as those already referred to psychiatric services (Burns et al 1990, Swearer et al 1988), or from retrospective case note analysis of dementia sufferers who have died and on whom post mortem findings have confirmed a diagnosis of Alzheimer's disease (Jabeen et al 1993).

Within a population referred to psychiatric services, there is a general consensus that behavioural changes are common (Burns et al 1990, Swearer et al 1988) and this may be because behavioural disturbance is a factor which precipitated the carer to seek medical help (Sanford 1975). In one study, 83% of 126 dementia patients had one or more troublesome behaviours (listed below), 74% had two, and 55% had three or more (Swearer et al 1988). A further study examined all patients with NINCDS/ADRDA defined Alzheimer's disease known to a psychiatric catchment area (Burns et al 1990). Of 178 dementia sufferers, 20% had aggressive behaviours, 19% wandered, 7% were sexually disinhibited, and 48% were incontinent of urine. (No overall percentage of those with behavioural disturbance is given).

1.2.2b THE NATURE OF BEHAVIOURAL DISTURBANCE IN DEMENTIA

Table A (see end of chapter) summarises two studies which have made behavioural assessments on

patients with dementia (Swearer and Drachman 1988, Burns et al 1990) and gives the range of behavioural disturbances found with the frequency of each. Swearer et al (1988) report on a sample of 126 consecutive referrals to the University of Massachusetts Medical Centre Alzheimers and Related Disorders Research Clinic and describe behavioural change based on interviews with carers using a standardised but unspecified behavioural questionnaire. The authors report nine categories of behavioural disturbance: angry outbursts, assaultive/violent behaviour, bizarre behaviour, delusions/hallucinations, paranoia, phobia, dietary change, sleep disturbance, and incontinence. Burns et al (1990) examined a population of elderly people with dementia known to two hospitals serving a particular catchment area (inpatient, community and residential) using the Stockton Geriatric Behaviour Rating Scale (Meer and Baker 1966) (see 2.1.1c) . They list a similar spectrum of behavioural changes including aggression, wandering, incontinence, withdrawal/apathy, binge eating, hyperorality, going into rages, sexual disinhibition, misrecognition, and hypermetamorphosis (an excessive tendency to attend and react to every visual stimulus). In separate but related papers in the same series, Burns et al (1990) also considers depression and disorders of thought content. Since the authors differ as to how they assess behaviour, the terms used to describe behavioural disturbance also differs; for instance Swearer et al (1988) refer to "paranoia", whereas Burns et al (1990) refer to "paranoid ideation" and "delusions of suspicion". In addition, the authors group behaviours together in different ways; for example Swearer et al (1988) include delusions and hallucinations in a single category but Burns et al (1990) separate them. For these reasons, and because of the studies used different populations, the results can only be broadly compared (see table A).

A more recent study examined behavioural difficulties in a large community population (Leyketsos et al 2000). 1002 people (329 with dementia and 673 without dementia) were assessed using a psychiatric inventory. Apathy 27%, depression 24% and agitation/aggression 24% were the most common non-cognitive symptoms in those with dementia. This contrasts with both the above studies of referred populations where psychotic symptoms were more common but is probably more representative of the spectrum of symptoms in the community.

By far the most exhaustive description of behavioural change in dementia has been made by Hope and

Fairburn in constructing the Present Behavioural Examination (PBE) (Hope and Fairburn 1992). Their 211 item rating scale was constructed following an extensive literature review, personal clinical experience, and detailed interviews with carers. It covers nine "domains": physical health, mental health, wandering/walking, eating, diurnal rhythms, aggressive behaviour, sexual behaviour, incontinence, and a miscellaneous group of behavioural abnormalities such as "mumbling" and "picking". Within each of these domains there are a large number of specific behavioural features to be assessed such that the details of an individuals behavioural disturbance can be recorded. Furthermore the frequency rating for each behaviour is on a seven point scale which allows measurement of change (see 2.2.8a).

Some authors have focused in depth on particular behavioural changes in dementia such as aggression (Patel and Hope 1993), psychotic symptoms (Jabeen et al 1992) (Burns et al 1990), depression (Burns et al 1990, Jabeen et al 1992) or personality changes (Petry et al 1988, Rubin et al 1987), inappropriate sexual behaviour (Burns et al 1990, Rabins et al 1982) or wandering (Rabins et al 1982). These behaviours have been extensively investigated in the literature and are therefore discussed individually below. Other behaviours such as sleep disturbance and altered eating behaviour are well documented and difficult to manage but have not been the focus of so much research.

AGGRESSION

Patel and Hope (1993) discuss some conceptual difficulties involved in rating aggressive behaviour. For instance, they suggest that the term "aggression" refers to a theoretical concept within which there are certain categories two of which are "aggressiveness" and "aggressive behaviour". The former refers to a disposition and so should be used to describe a personality trait and the latter should be reserved for acts of aggression. They also discuss the different ways in which the word may be used: some will use the term "aggressive" to describe a behaviour only if they think the aggressor intended harm but others will use it even when a person with dementia is too cognitively impaired for an intention to be meaningful. Finally, they explore the varying causes of aggressive behaviour in dementia, mentioning brain damage in terms of specific lesions, neurotransmitter changes, ictal states, acute confusional states, aggression secondary to psychotic experiences, and that arising for more psychological reasons such as in catastrophic reactions or misunderstandings.

A further difficulty in assessing aggressive behaviours is the range of terms and definitions used. For instance one study does not report a distinction between verbal and physical aggression, giving a single prevalence of 20% for aggressive behaviours, stating that these are acts that "result in or are liable to result in actual physical harm to another person" (Burns et al 1990). Patel and Hope (1993) also define aggression in physical terms but include not only aggression towards other people but also the "delivery of a noxious stimulus to another object, organism or self". However another study (Swearer et al 1988) distinguishes angry outbursts from assaultive behaviour, giving frequencies of 51% and 21% respectively. It may be that this study includes verbal aggression in the angry outburst category and physical aggression in the assaultive category but it is not clear. Likewise, in a study by Rabins et al (1982), carers were asked about behaviour problems in their relatives with dementia and divided the answers they received into the following categories: demanding/ critical behaviour, making accusations physical violence, and hitting. These categories had prevalence rates of 37%, 32%, 24% and 16% respectively and clearly there must be some overlap between them. Other work on aggressive behaviour in a small sample of 18 people with dementia reported a prevalence rate of 17%. Thus, in summary, those studies which examine rates of physical aggression in mixed community and residential samples of people with dementia referred to psychiatric services report rates of 17% - 24%.

A recent paper found an association between language impairment and aggression in people with Alzheimer's disease (Welsh et al 1996). The sample was very small, consisting of only 18 subjects, and were unrepresentative in that they had been selected for a drug trial. The findings, however, are interesting. Welsh et al (1996) found that impaired language expression correlated with verbal aggression and aggression toward objects, whereas impaired comprehension correlated with aggression towards other people. They suggest that for this may be because impaired language expression leads to frustration which is expressed as verbal aggression or aggression against objects whereas impaired language comprehension leads to misinterpretation of others communications which becomes expressed in aggression towards the person who has been misunderstood.

PSYCHOTIC SYMPTOMS

In considering the prevalence of psychotic symptoms in Alzheimer's disease, Burns et al (1990) examined a sample known to psychiatric services and recruited not only from the community, but also residential homes and hospital inpatients. They found that 16 % had delusions, 13% had visual hallucinations, 10% auditory hallucinations, and 30% had misidentification syndromes. Lower rates of psychiatric symptoms were reported by Jabeen et al (1992) from a retrospective analysis of case notes after death in a sample with neuropathologically confirmed Alzheimer's disease (11% delusions, 14% visual hallucinations, 3% auditory hallucinations, 6% misidentification syndromes). The reason for this discrepancy may be that in the former study, behavioural difficulties were prospectively enquired about whereas in the latter case note study, such disturbance was not a particular focus of attention at the time of documentation so may not have been recorded. Also, the two samples may have been at different stages of the disease which may alter either the prevalence or detection of such symptoms (see 1.2.3)

DEPRESSION

Depression commonly occurs in people with dementia and may be a presenting feature especially when it occurs for the first time after the age of 65 (Van Ojen et al 1995). It is difficult in diagnosing and therefore assessing the prevalence of depression in dementia is the overlap of symptoms between the two. For instance, a symptom such as loss of interest could be due to depression or dementia. A further difficulty is that people with dementia may forget to report symptoms such as depression or sleep disturbance and even when asked specifically, may deny them because they have not understood the question. This has created a need for specific scales to diagnose depression in this group of patients such as the Dementia Mood Assessment Scale (Sunderland et al 1988) which was derived from the Hamilton Dementia Rating Scale and the Cornell Depression Scale (Alexopoulos et al 1988). Both have a good interrater reliability but the sensitivity and specificity is not yet established. A further depression rating scale for people with dementia is the Depressive Signs Scale (DSS) (Katona and Aldridge 1985). The advantages of this scale are, firstly, that it utilises information from both the patient and either relatives or nursing staff/formal carers. Secondly, since it relies on signs rather than verbal expressions of low mood, it can be used to detect depression in people with dementia who are unable to express how they are feeling. The scale includes nine items: a sad appearance, alleviation of the sad appearance by external circumstances,

agitation, slowness of movement, slowness of speech, early wakening, loss of appetite, diurnal variation in mood (mornings worse), and loss of interest in surroundings. It has been validated against a depressed control group and its inter rate reliability is high (Spearman's correlation coefficient 0.98).

In addition to the above, a further difficulty in diagnosing depression in elderly people with dementia is that rating scales designed for a general adult population are poor detectors of depression in those over 65 which is the age group in which most people with dementia fall. For instance, community studies using the DSM 111R criteria to assess depression in the elderly report rates of 3%, whereas the Geriatric Mental State/Age cat system detected a rate of 10-15% (Blazer et al 1987).

Studies which examine for depression in samples of people with dementia, report different prevalence rates. Rates of 5%, 16%, 24% and 38% have been reported in different studies (O'Connor et al 1990, Jabeen et al 1992, Burns et al 1990, Cooper and Schwartz 1982). These differences may reflect the populations studied, in particular, the proportions of the samples that come from the community or hospital patient groups since depressed patients with dementia may be preferentially referred to clinical services. A further reason for the discrepancy between the work of Jabeen et al (1992) and Burns et al (1990) may be that (as outlined in the previous section) that the lower rate of 16% reported by Jabeen et al (1992) relied on retrospective case note recording and depression would only have been recorded if it was a particular focus of interest at the time of documentation.

Several studies have focused on differing rates of depression in different types of dementia. Cummings et al (1988), Rovner et al (1989), and Greenwald et al (1989) report higher rates of depression in those with vascular dementia than in Alzheimer's Diseases. Other studies have found no difference between the two types of dementia (Reding et al 1985, Ballard et al 1993, Verhey et al 1993), but two of these use samples in which patients with mixed Alzheimer's/Vascular dementia were included in the vascular group. Therefore, there may be higher rates of depression in those with a pure vascular dementia. It has been suggested that this may be because those with vascular dementia have greater degrees of physical disability (Cummings 1989). However a further possibility is that vascular lesions may involve the left frontal lobe so making people vulnerable to depression as has been reported in those who develop

affective disorder following a cerebral vascular accident affecting this part of the brain (Starkstein et al 1987). There also may be higher rates of depression in those with Lewy Body Dementia. McKeith et al (1992) reported that in their sample of dementia patients, 38% of patients with Lewy Body Dementia were depressed, while only 15% of the Alzheimer patients were depressed.

There are several ways in which dementia and depression may be associated. Firstly, given that in a population over 65, the prevalence of dementia is 5-10% (Cooper 1991) and that of depression about 15% (Copeland et al 1987), it would be expected that one percent would have both. Secondly, from a psychological perspective, the onset of dementia is a devastating life event incurring many losses and could therefore precipitate depression.

However there is no evidence to support a link between insight into the dementing process and becoming depressed (Verhey et al 1993, Ott and Fogel 1992). There is, however, an association between threatening life events in the lives of people with dementia and depressive symptoms suggesting that dementia sufferers are responsive to stress in the same way as cognitively intact people (Orrell and Bebbington 1995a). A parallel study had found that a group of cognitively intact people had had more life events over a given time period than a group of people with dementia suggesting that the above finding could not be confounded by or explained by an excess of life events occurring secondary to the difficulties resulting from having dementia (Orrell and Bebbington 1995b).

Lastly, there may be organic factors occurring as part of the brain degeneration involved in dementia which leads to symptoms of depression. The Dexamethasone Suppression Test (DST) (ie the non suppression by dexamethasone of endogenous cortisol production which suggests an abnormality in the functioning of the hypothalmpituitary axis) has widely used in the diagnosis of depression but has also been reported as abnormal in about 50% of people with dementia (Raskind et al 1982, Spar and Gerner 1982, Balldin et al 1983, Coppen et al 1983, Carnes et al 1983). A further study reported that those people with dementia who had an abnormal DST scored significantly more highly on the Depressive Signs Scale (DSS) (Katona and Aldridge 1985). Post mortem findings in people with dementia report low neuronal counts in the locus coeruleus (Zubenko and Moosey 1988, Zweig et al 1988, Forstl et al

1992), greater cell loss in the substantia nigra (Zubenko and Moosey (1988), and more cell loss in the raphe nucleus (Forstl et al 1992) in those who were also depressed. In the Zubenko and Moosey (1988) study, the differences in the cell counts in the substantia nigra were of sufficient magnitude to differentiate the depressed from the non depressed with 90% sensitivity and 95% specificity. A subsequent study reported a decrease in noradrenaline in the hippocampus and neocortex in those who were depressed (Zubenko et al 1990).

No association has been found between age (Zubenko and Moosey 1988), physical health (Ballard et al 1993), marital status (Forsell et al 1994), family history of dementia (Duara et al 1993), duration of dementia (Reding et al 1995), or gender (Reding et al 1995) and developing depressive symptoms in dementia. Since poor physical health and female gender have been linked to depression occurring in a population with no cognitive impairment, this suggests that there may be different pathological process underlying depression in dementia and depression in the cognitively unimpaired.

PERSONALITY CHANGE

There has, until recently, been no clear distinction made in much of the literature between personality and behavioural changes in dementia. For instance becoming more irritable is regarded as a change in personality by Petry et al (1988), but as a behavioural change by Hope and Fairburn (1992). However, a recent study defined personality changes in dementia as those behavioural changes which were "broad and consistent" (Jacomb and Jorm 1996). This is consistent with the changes focused on by Petry et al (1988) which were those relating to more subtle and pervasive changes such as becoming more passive and as such may represent the milder changes in behaviour seen in the earlier parts of the disease. Petry et al (1988) discuss the possible origins of personality change: these may be related to the topography of pathologic lesions in the brain but alternatively changes due to ageing itself might wrongly be ascribed to a disease process, and the premorbid personality of the dementia sufferer may be an important determinant of changes seen as the illness progresses. They examined the personalities of 30 people with dementia from the reports of their spouses, asking the latter to answer each question both currently and prior to the onset of the dementia. Control subjects were healthy retired people whose spouses answered the same questions both currently and prior to retirement. Personality assessments were made using a

scale of 18 dimensions examples of which are affectionate/cold, enthusiastic/listless, irritable/easy going. People with dementia were found to have an altered rating on twelve of the 18 items and there were no changes in the control group. The authors concluded that people with dementia may become more passive, more coarse and less spontaneous as a result of the disease but that in contrast, personality in normal ageing remains stable. Further work examined the progression of personality changes in dementia and reported that passive, agitated and self centred behaviours increased over time (Rubin et al 1987). Jacomb and Jorm (1996) conducted a two stage study, first examining the opinions of professional people working with dementia sufferers and secondly those of their carers, as to changes in personality. The study used a five factor model assessing personality in the following domains: extroversion, agreeableness, conscientiousness, intellect and neuroticism. Both groups described an association between having dementia, a decrease in the first four domains and an increase in the fifth. Although the adjectives used to describe personality traits are different between these studies, their findings are generally consistent.

SEXUAL BEHAVIOURS

The work of Burns et al (1990), examined the frequency of sexually inappropriate behaviour in dementia defined as exposing self, obscene sex language, masturbation, and propositioning others. The study also examined whether there was a relationship between this sexually inappropriate behaviour and other symptoms of the Kluver Bucy Syndrome. No frequency for the occurrence of inappropriate sexual behaviour is given but it was found to be correlated with hyperorality. However a previous study, also examining the Kluver Bucy Syndrome in dementia found that the other symptoms of the disorder (hyperorality, binge eating, withdrawal, rage, hypermetamorphosis (see 1.2.1b), and visual agnosia) were more common than inappropriate sexual behaviour which effected only 17% of their sample of patients with dementia selected for having at least one symptom of the disorder (Sourander and Sjogren 1970). A further study assessing behaviour problems cited by families of patients with dementia known to a university department of psychiatry, stated that only 2% reported sexually inappropriate behaviour as having occurred and no family reported that it was a problem (Rabins et al 1982). Given the understandable embarrassment at discussing such abnormalities, it is possible that such low rates represent an under reporting by relatives.

WANDERING

In the study mentioned above, wandering was cited as a problem by 70% of carers of dementia sufferers (Rabins et al 1982). Burns et al (1990), however, reported the behaviour in 20% of his sample. The reasons for the wide discrepancy may be the different samples assessed. Although both involved both inpatients and outpatients known to hospital psychiatry departments, the former was a single university department whereas the latter involved those known to the psychiatric services within a health authority so possibly involved a broader group of dementia sufferers. A further factor is that the latter sample was considerably larger containing about 170, whereas the former involved only 55. It is also possible that the two studies were using different definitions of wandering and neither paper precisely clarifies the definition they used.

1.2.3 RELATION OF BEHAVIOURAL DISTURBANCE IN DEMENTIA TO DISEASE SEVERITY

Behavioural disturbance has been considered a consequence of cognitive decline or, in contrast, a separate dimension of the dementing process which therefore need not progress at the same rate. Burns et al (1990), measuring cognitive decline and overall dementia severity using the Mini mental State Examination (MMSE), found that behavioural disturbance increased in parallel with cognitive impairment but that the association was particularly strong for aggression and wandering. Swearer et al (1988) reported that it was only assaultive behaviours that increased with the severity of dementia. The work of Petry et al (1987) found that of the 18 dimensions of personality changes they considered, only one, excitability, increased with increasing cognitive impairment as measured by the MMSE. As there is considerable overlap between behaviours described as "aggressive", "assaultive" and "excitable", it may be that these studies were all reporting similar findings using different terminology. Haley and Pardo (1989), however, suggest a different relationship between behavioural disturbance and cognitive decline in that they found that behavioural disturbance was greatest in the middle phase of the disease, preceded by deficits in instrumental activities of daily living and followed by physical dependency. As mentioned in 1.2.1 the work of Reisburg et al 1989 showed that the behavioural and psychological symptoms were a distinct syndrome from the cognitive and functional manifestations of the disease which might therefore

progress independently of cognitive decline.

1.2.4 MANAGEMENT OF BEHAVIOURAL DIFFICULTIES IN DEMENTIA

Strategies for managing behavioural disturbance in dementia include treating associated physical and psychiatric illness, drug treatments, behavioural therapy, case management and changing the environment (Livingston and Hinchliffe 1994). These will be reviewed below.

1.2.4a TREATING ASSOCIATED PHYSICAL AND PSYCHIATRIC ILLNESS

A study of psycho geriatric admissions for behavioural problems reported that 34.4% had untreated physical illness, 8.5% had drug toxicity, and 11.4% had psychiatric symptoms. Only 39% had behavioural disturbance associated with the dementia alone (O'Connor 1987). This highlights the importance of attending to the physical health problems of people with dementia as this may also have a positive impact on any behavioural disturbance.

1.2.4b DRUG TREATMENT

Drug treatment has been used for depression, psychotic symptoms, agitation, aggression and sleep disturbances. Those studies which reviewed the efficacy of neuroleptic medication on BPSD in general will be considered first followed by those which reviewed the effect of medication on particular syndromes such as depression.

There has been two large randomised control trials investigating the effect of the atypical neuroleptic risperidone on BPSD (De Deyn et al 1999, Katz et al 1999). Both studies involved institutionalised patients and concluded that low dose risperidone (1mg per day) was effective in reducing the severity and frequency of behavioural symptoms particularly aggression and psychosis. The work of De Deyn (1999) compared risperidone and haloperidol with a placebo. Risperidone and haloperidol were both effective but the latter was associated with extrapyramidal side effects and cognitive decline. However there was no difference in the cognitive deterioration of those on risperidone and those taking a placebo. A further study by Street et al (2000) in which the patients were randomised to different doses of olanzapine or a placebo for non-cognitive symptoms of dementia found that 5mg was superior to either

10 or 15mg of olanzapine in efficacy and tolerability and superior to placebo in efficacy.

DEPRESSION

As discussed in section 1.2.2b, depression is a common feature of dementia. Studies examining the efficacy of antidepressants in treating depression in dementia, have produced contradictory findings. Three studies reported that antidepressants were effective and a fourth reported that those treated with antidepressants did not improve to a significantly greater extent than those taking a placebo.

The first examined the effect of Citalopram, a selective serotonin reuptake inhibitor (Nyth and Gottries 1990). Ninety eight patients were recruited to this double blind study of whom 89 completed it. Sixty five of these had Alzheimer's Disease and twenty four had Vascular Dementia. They were assessed using the Montgomery Asberg Depression Rating Scale (MADRS) and assigned to either Citalopram or placebo groups. The MADRS is a ten item scale which is reliable and whose validity has been tested against the Hamilton Depression Scale with a reported correlation of 0.7 (Bowling 1991). It was designed specifically to measure change in depressive symptoms with treatment. After four weeks, those who had a diagnosis of Alzheimer's Disease had improved significantly ($p=0.05$) but those with Vascular Dementia remained depressed. Perhaps the smaller numbers in the vascular group partly account for there being no statistically significant change in this group.

The second study treated a sample of 694 elderly people with moclobemide, a reversible monoamine oxidase inhibitor (MAOI) (Roth et al 1996). DSM-IV diagnostic criteria were used and 511 patients fulfilled criteria for both depression and dementia and the remaining 183 scored were depressed with cognitive impairment but were not demented. Patients were assessed using the Hamilton Rating Scale (Hamilton 1967) for Depression. There was a significant improvement in the depression scores for both groups of patients treated with Moclobemide in comparison with the placebo group ($p=0.001$). The authors conclude that not only is moclobemide an effective treatment of depression in dementia but that it does not cause cognitive impairment.

The findings of the third study are less robust (Lawlor et al 1994). The authors assessed the effect of two

drugs known to act on the serotonergic system, Trazadone and Buspirone, comparing both with a placebo. The rating scales used were the Brief Psychiatric Rating Scale (Overall and Gorham 1962) and the Dementia Mood Assessment Scale (Sunderland et al 1988). The latter has not yet been shown to have satisfactory sensitivity and specificity (see 1.2.2b). Trazadone produced a small but significant reduction in both rating scales indicating that it may have reduced depressed mood but Buspirone was ineffective. The authors conclude that the size of the drug effect in this study was of doubtful clinical significance.

In contrast to the above studies, the work of Reiffler et al (1989), comparing Imipramine with a placebo and found that both produced equal improvements in depression. Subjects were volunteers attending hospital outpatients departments who had Alzheimer's disease. They were divided into a group who also met DSM-IV criteria for depression and those without coexistent mood disturbance. The subjects were then randomly assigned to an eight week double blind trial of either Imipramine or placebo. They were rated using the Hamilton Rating Scale (see 2.2.9) at outset and again at 2,4,6 and 8 weeks and results showed similar improvements in both Imipramine treated and placebo groups.

Depression in dementia is known to result in distress to sufferers (Burns 1991) and may detrimentally influence cognitive function (Greenwald et al 1989), activities of daily living (Fitz and Teri 1994) and can reduce life expectancy (Burns 1991). Therefore, in spite of the discrepancy in the findings of the studies listed above, it is important that patients are given every opportunity to benefit from treatment. The choice of anti depressant should be determined by the patients tolerance to it and the side effect profile.

PSYCHOTIC SYMPTOMS

Psychotic symptoms such as delusions and hallucinations have been considered more sensitive to the effect of neuroleptics than other behavioural disturbances for which this class of drugs are also used, such as agitation and unsociability (Schneider and Sobin 1994). Some studies have assessed the effect of particular neuroleptics in reducing psychotic symptoms. Haloperidol and thioridazine have been used most extensively (Schneider and Sobin 1992), although thioridazine is no longer used because of cardiotoxicity. In addition, thiothixine and loxapine have been examined individually and found to be

effective (Petrie et al 1982, Rada and Keelner 1976). Of nine studies reviewed by Schneider and Sobin (1994), none found that any particular neuroleptic was superior to others in effectiveness although these studies did not distinguish between psychotic symptoms and other behavioural disturbance. Very low dose depot antipsychotic drugs have been used to help with compliance in forgetful patients and may have the advantage of ensuring more stable blood levels (Howard and Levy 1993). A difficulty in assessing the efficacy of neuroleptics in the treatment of patients who may have poor recall of their symptoms, is distinguishing a true decrease in the severity of psychotic symptoms from the non specific effect of sedation.

Using neuroleptics in those with dementia can be problematic since this population is at particular risk of developing tardive dyskinesia, though such movements can occur in those with dementia who have never received neuroleptics (Kane and Smith 1982). A further problem is the reported association between neuroleptic drug use and accelerated cognitive decline. A recent study (McShane et al 1997) involving a two year follow up of 71 patients with dementia found that the 16 who were taking neuroleptic medication experienced twice the cognitive decline as those who were not as measured by the Mini Mental State Examination. This finding was independent of the behaviour problems for which the neuroleptics had been prescribed.

AGITATION AND AGGRESSION

The varying ways in which the term aggression is defined are discussed in section 1.2.1b. For the purposes of this section on the pharmacological management agitation and aggression, both are considered together since clinically they form a continuum.

Several classes of drugs have been used in the management of agitation and aggression in dementia. Sometimes a clear cause for such behaviour can be identified. Agitation and/or aggressive outbursts can occur in the context of acute confusional state and then management of the aggression involves diagnosing the cause of and treating the acute confusion. Similarly, if aggression occurs in the context of post ictal states, then it is important to control fitting as well as possible. Where ictal activity exists, anticonvulsants have been shown to reduce aggressive behaviour (Monroe 1975) and this may in part

explain why carbamazepine is effective. However the latter also effects the serotonergic system (see ahead). Where aggression is occurring secondary to psychotic symptoms, neuroleptic medication may reduce the psychosis and thereby the aggression (see above paragraph on psychotic symptoms).

In some cases, agitation and/or aggression in dementia appears to have no cause other than that of the brain damage incurred by the disease process. In such cases neuroleptics may be helpful by virtue of their non specific tranquillising effect although in some patients an exacerbation of their symptoms can occur (Risse and Barnes 1986). Based on the theory that aggressive behaviour is mediated by the serotonergic (5HT) system (Brown et al 1982), drugs which act on this system have been used, for instance trazadone, which has a 5HT re uptake blocking action, and buspirone, a 5HT agonist. Both have been reported to be effective in controlling aggressive behaviour in patients with dementia (Wilcock et al 1987). Fluoxetine, a selective 5HT reuptake inhibitor has been used successfully in the treatment of people with dementia who become agitated (Sobin et al 1989). As mentioned above, carbamazepine has been found to be effective in treating aggression in dementia (Risse and Barnes 1986) and this may be due to its 5HT enhancing activity.

Benzodiazepines have also been used in the management of agitation and/or aggression and appear superior to placebo (Kirven and Montero 1973). However, they can have a paradoxical effect such that they may worsen the agitation and/or aggression. They may also worsen cognitive impairment. In summary, in the management of aggression in people with dementia, if antipsychotics are ineffective or contraindicated for individual patients, drugs which enhance 5HT activity such as Fluoxetine, Buspirone, and trazodone have been found to be effective as has carbamazepine (Patel and Hope 1993).

SEXUALLY INAPPROPRIATE BEHAVIOUR

Such behaviour in dementia may occur secondary to frontal lobe damage, but may also have an aggressive component, especially in men. Neuroleptics have been used to treat this behaviour. Their mechanism of action remains unclear although they may have effect via a general tranquillising action or by increasing prolactin levels. There have been no trials of their effectiveness at treating this behaviour.

In cognitively intact men who fail to control their sexual impulses, hormonal treatments have been used. There is a single report which suggests that medroxyprogesterone, a drug which lowers testosterone levels, may be effective in reducing inappropriate sexual behaviour in people with dementia (Cooper 1987). Although those with mild disease may be able to consent to such treatment, the ethics of treating those who are unable to give consent with such medication remains unexplored.

SLEEPLESSNESS

Before pharmacological approaches are considered in the management of sleep disturbance in dementia, it is important that a behavioural approach is tried employing the principles of “sleep hygiene”. This will be discussed below (see 1.2.4c).

Neuroleptics, benzodiazepines, chlormethiazole, zopiclone and chloral hydrate have all been used (Mullan et al 1994) but there are no controlled trials of their effectiveness. Using drugs with shorter half lives is preferable to minimise daytime hangover.

1.2.4c BEHAVIOUR THERAPY FOR DEMENTIA SUFFERERS

Behavioural modification is an integral part of the management of behavioural difficulties in those with learning difficulties (Yule and Carr 1987), but has rarely been used with elderly people who have dementia.

Although it may be of benefit to this latter group, its usefulness may be limited by the fact that it relies on learning and therefore memory which will be increasingly impaired in people with dementia. Behavioural approaches rely on a thorough description of a given behaviour, also rating its frequency, severity, antecedents and factors which are noted to ameliorate it. Such information is essential if effective interventions are to be devised and tested. It is unknown how frequently behavioural modification is used by health care professionals working with dementia sufferers and their carers. Few studies have evaluated its effectiveness. Behavioural approaches employed in the management of aggression and sleep are discussed below.

AGGRESSION

A study of a group of six physically and verbally aggressive elderly men in hospital positively reinforced non-aggressive behaviour with a tangible reward (fruit, biscuits) while ignoring aggressive behaviour (Vaccaro 1988). Although behaviour improved for the duration of the study, it deteriorated again when the approach was discontinued.

SLEEPLESSNESS

People with dementia may cat nap during the day and then be wakeful throughout the night (day night reversal). This can be managed with certain behavioural/common sense measures referred to as "sleep hygiene" such as:

- a. Encouraging day time activity
- b. Discouraging day time sleeping
- c. Avoiding a bedtime drink in order to reduce the chance of waking at night to micturate.

There are no formal studies which assess the efficacy of these measures.

DISRUPTIVE VOCALISATIONS

People with dementia may make repetitive vocalisations. A study by Burgio et al (1996) explored a method of managing such behaviour following the observation that people with dementia who repetitively vocalised did so less while under a hairdryer. They referred to this type of noise as "environmental white noise". They studied the effect of audio tapes of similarly repetitive noises such as a gentle ocean or a mountain stream played via head phones to people with dementia. They found that this reduced disruptive vocalisations by 23% in the experimental group compared to a control group.

1.2.4d CHANGING THE ENVIRONMENT

There are four studies which assess the effect of environmental change on the behaviour of people with dementia. All involved people with advanced dementia living in hospital or residential settings. Three sought to reduce wandering/agitated behaviour and a fourth aimed to increase socialisation.

WANDERING

One study (Cohen-Mansfield and Werner 1998) reported that “enhanced environments” ie those that provided much sensory stimulation (visual, auditory and olfactory) lead to a reduction in pacing and agitation in people with advanced dementia. They compared non-enhanced corridors with two simulated enhanced environments using a multiple AB design. Results were promising in that there was a trend towards a reduction in such problem behaviour but this did not reach significance.

Two studies aimed to reduce wandering behaviour by placing strips of masking tape on the floor to form a grid pattern near the exit of the ward. This was based on the observation that people with dementia may perceive a two dimensional pattern as a three dimensional object. The first study used beige tape on a brown floor near an opaque door and reported that the exit contact for 8 patients fell from 98% to 42% (Hussian and Brown 1987).

The second study used black tape on a white floor near to a glass door and this lead to no reduction in the attempts to exit (Chafetz et al 1990). The reason offered for the discrepancy in the findings was that in the second study, the door was glass and being able to view the outside world may have enticed patients through it.

There are no studies examining the effect of such grid patterns in the home of someone with dementia.

A recent short report reviewed coping strategies adopted by informal carers looking after people with dementia in their own home who exhibited wandering behaviour (Dodds 1994). Some used a strategy which would fall into the category or "changing the environment" in that they simply locked either internal or external doors. Others used a pharmacological approach by giving medication or alcohol, while others employed a more behavioural strategy and sought to divert the carer through some activity. Thus some responses were creative but others maladaptive. The study highlights the difficulty in managing this behaviour and the guidance carers should receive in coping with it.

INCREASING SOCIAL BEHAVIOUR

A further study differed from those described above in that it aimed to increase the level of a desirable behaviour rather than decrease a problem behaviour. The authors sought to improve socialising behaviour in a group of people with dementia by rearranging furniture. Chairs were moved from a position along corridors to groupings around tables, and mealtime routines were changed to allow more time to eat. Before these changes were made, baseline ratings were collected on the frequency of tactile and verbal communication between the dementia sufferers. They were then divided into an experimental and control group, and the former received the changes in environment explained above. The frequency of communication increased in the experimental group and the authors concluded minor changes in environment can lead to therapeutic changes in the behaviour of people with dementia.

1.2.4e A CASE MANAGEMENT APPROACH

There is no formal definition of the case management approach but the principle of health professionals developing individualised care plans for their patients is a familiar one. Such care plans are now multi-disciplinary in nature and with the implementation of the Care Programme Approach following a directive from the Department of Health in 1991, have become obligatory since 1.10.1994.

In order to employ case management in the care of a person with dementia, a thorough assessment of their physical and mental difficulties, their social circumstances and their carers needs is required. Appropriate individualised care plans can then be drawn up and implemented. For instance, in managing a behavioural difficulty such as sleeplessness, sleep hygiene measures may be sufficient for some people whereas others may need a combination of such measures with a sedative drug. Thus, case management allows elements of all therapeutic approaches to be combined in a way which best satisfies the needs of an individual dementia sufferer and their carer. This point is made well by the work of Terri et al 1998 who after comparing haloperidol, trazadone, behavioural management and placebo in a group of people with dementia produced a “agitation protocol” combining all elements.

The work of Cohen-Mansfield (2000) highlighted the importance of individualising the management of behavioural problems in dementia. Cohen-Mansfield focused on understanding the behaviour in terms of

what the dementia sufferer was communicating via it. Three syndromes of behavioural and psychological symptoms of dementia (BPSD) were discussed as follows: physically aggressive behaviour was described as occurring in advanced dementia often precipitated by requiring assistance with personal care. It therefore follows that appropriate management lies in the skilful and sensitive handling of the patient by care staff. Physically non aggressive behaviour such as pacing and agitation was seen as an adaptive way of the individual providing stimulation for him or herself in a very deprived environment. A solution would therefore be the “enhanced environment” described in Cohen-Mansfield and Werner’s work (1998) mentioned previously. Verbal behaviours were thought to relate to discomfort of some sort either from physical pain, depression or feeling alone. Again this way of understanding the behaviour suggests solutions such as treating physical, mental and social causes.

This chapter highlights the need for case management in the management of behavioural problems in dementia including attention to untreated physical illness, treatment of any coexistent psychiatric symptoms (depression and/or psychosis), and considers both pharmacological and behavioural interventions. There are no intervention studies with dementia sufferers and their carers which evaluate the efficacy of such an approach.

Table A showing the range and frequency of behaviours reported in two studies on behavioural disturbance in dementia.

BEHAVIOUR	FREQUENCY (%)	
	SWEARER ET AL (1988)	BURNS ET AL (1999)
Angry outbursts	64 (51%)	
Assaultive/violent	27 (21%)	35 (19.7%)
Bizarre behaviour	26 (21%)	
Hallucinations	28 (22%)*	30 (16.9%)
Delusions	28 (22%)*	28 (16%)
Misidentification		54 (30%)
Depression		41 (24%)
Paranoia	40 (32%)	
Delusions of suspicion		10 (5.6%)
Paranoid ideation		36 (20.2%)
Phobia	31 (25%)	
Dietary change	57 (46%)	
Binge eating		17 (9.8%)
Hyperorality		11 (6.3%)
Sleep disturbance	55 (45%)	
Incontinence	16 (17%)	83 (47.7%)
Withdrawal/apathy		71 (40.8%)

* Swearer et al include delusions and hallucinations in a single category so the same figure of 22% refers to both together.

PART 1

CHAPTER 3: CARER MENTAL HEALTH

What is a carer? The Carers Recognition and Services Act (1996), commonly known as the Carers Act, defines a carer as someone who provides a “substantial amount of care on a regular basis for another person”. It states that a carer need not live with the person they care for, nor do they have to be the sole carer. The term does not include those employed to provide care or those working for volunteer agencies.

The definition used by the Carers National Association differs in that it does not focus on amount or regularity of care required. It states that a carer is someone who looks after a friend, relative or neighbour who cannot manage without help because of sickness, age or disability, Neither definition does justice to the complexities of being a carer and the changes that occur in the caring role as a dementia sufferer’s illness progresses. Eighty percent of people with dementia are supported in the community by informal carers (Levin et al 1986).

Research into the difficulties faced by carers uses neither of the definitions given above. There is much heterogeneity both within studies and between them as to who is included as a carer. Some studies include only those who live with the person they are caring for (Brodaty and Gresham 1989, Brodaty et al 1994, Mittleman et al 1993) whereas others include both those who live separately and those who live together (Haley et al 1987). Similarly, some studies include only those who are spouses (Mittleman et al 1993), but others include any carer who is a family member (Gilhooly 1984, George and Gwyther 1986).

Many studies have sought to determine whether caring for another person is associated with psychological distress and morbidity. Those caring for dementia sufferers have been studied extensively, perhaps because of the particular difficulties that exist in caring for people who have the combination of memory impairment, behavioural change and loss of independence in activities of daily living. A further impetus for this work may be the ageing population leading to increasing numbers of elderly people and therefore greater numbers of people with dementia. As a result there is a growing need to examine the issues relating to caring for them in the community.

This chapter will review the studies which describe the prevalence and nature of the distress associated with caring for someone with dementia. It will also focus on the effect of social support on carer well-being and characteristics of the carer that might increase their vulnerability to mental health problems. Features of the dementing illness that may affect carer well-being such as severity of cognitive impairment or behavioural disturbance, will be explored in chapter 4.

1.3.1 THE NATURE AND PREVALENCE OF CARER MENTAL HEALTH PROBLEMS

The nature of psychological disturbance in carers will be considered first (sections 1.3.1a and 1.3.1b) and the prevalence of this disturbance discussed afterwards (1.3.1c).

1.3.1a INSTRUMENTS USED TO ASSESS THE NATURE OF PSYCHOLOGICAL DISTURBANCE IN CARERS OF DEMENTIA SUFFERERS

In considering the nature of psychological disturbance in carers, it is necessary to review the instruments used to measure it; some measure distress, some psychiatric symptoms and others psychiatric diagnosis. These three categories will be discussed below.

MEASURING CARER DISTRESS

Those instruments that measure psychological distress in carers of dementia sufferers have been specifically designed for this purpose. They are composite measures of psychiatric symptoms, social restrictions and financial strain. These are the Relatives Stress Scale (Green et al 1982), the Strain Scale (Machin 1980) and the Burden Interview (Zarit et al 1980) and each of these will be discussed in turn.

The Relatives Stress Scale (RSS) is a 15 item questionnaire designed to measure stress by adding together items eliciting the carer's mood state, negative feelings towards the care recipient and the restriction caring places on social life. The Strain Scale not only enquires into feelings of anxiety and depression but also into disturbed sleep, lack of holidays and financial difficulties. Items are coded as occurring "never" (zero points), "sometimes" (1 point) or "often" (two points) with a maximum score of 26 points. The Burden Interview is a 22 item questionnaire examining the perceived impact of caring on

caregivers financial status, physical health, emotional health and social activities. Although it is used in several studies on carers (Zarit et al 1986, Zarit et al 1980) it is not used to explore the nature of their psychological disturbance but more to look for factors associated with “burden”.

MEASURING CARER PSYCHOLOGICAL SYMPTOMS

The Brief Symptom Inventory (Derogatis and Spencer 1982), and the Short Psychiatric Evaluation Scale (Pfeiffer 1975) were both designed to measure psychiatric symptoms and have been used in studies of those caring for dementia sufferers. Both have been used extensively in other research and population norms have been established.

The Brief Symptom Inventory is a 53 item questionnaire with 9 subscales (somatisation, obsessive/compulsive, interpersonal sensitivity, depression, anxiety, hostility, paranoid ideation and psychoticism). Each item is rated on a five point scale of distress from “not at all” (0) to “extremely” (4). Three global indexes can be derived: the global severity index, the positive symptom total and the symptom distress index. It has been validated against the Minnesota Multiphasic Personality Inventory with which it correlates highly (Hathaway and McKinley 1990). The Short Psychiatric Evaluation Scale is a 15 item scale designed to measure psychiatric symptoms indicative of psychiatric disorder (Pfeiffer 1975).

The Older Americans Resources and Services Schedule (OARS) (Fillenbaum 1978, Fillenbaum and Smyer 1981) differs from the rating scales mentioned above in that it measures psychiatric symptoms and intellectual impairment. It rates these on a scale of 1-6, such that a high score can indicate psychiatric symptoms and/or mental impairment.

The General Health Questionnaire (GHQ) (Goldberg and Hillier 1979) (see 2.1.10) has been used to assess carer mental health in a number of studies (Gilleard et al 1984, Eagles et al 1987, O’Connor et al 1990). This records psychiatric symptoms, according a point to each positive answer. Scores of greater than four indicate psychiatric “caseness” but the instrument does not allow a precise diagnosis, such as depression, to be made. It has been extensively tested for reliability, validity and sensitivity to change

and the results are good (Goldberg 1972, 1978, Goldberg and Huxley 1980).

Finally the Clinical Interview Schedule (CIS) (Goldberg et al 1970) has also been used to measure psychiatric symptoms in carers of dementia sufferers. It has been found to have good reliability when used with both lay interviewers and psychiatrists and a revised version now exists (CIS-R) (Lewis et al 1992), but has only been validated for assessing people under the age of 65. The interview asks questions over the time frame of the last seven days covering the following domains: somatic symptoms, fatigue, concentration and forgetfulness, sleep problems, irritability, worry about physical health, depression, depressive ideas, worry anxiety, phobias, panic, compulsions, obsessions and a screening section for psychotic disorder involving questions regarding elation and ideas of reference. Positive answers to questions in each area are then summated to give a score that is a measure of caseness but is not diagnostic.

CARER PSYCHIATRIC DIAGNOSIS

Work which has assessed those caring for dementia sufferers using diagnostic instruments has focused on those measuring depression.

The Beck Depression Inventory (Beck et al 1961) is a 21 item self report instrument for assessing mood which has a satisfactory validity and reliability. Each item is given a score from 0-3 such that the maximum score is 63. A score of over 10-15 indicates mild depression, 15-20 moderate depression and 25 upwards severe depression. The scale is less reliable in adults over 65 (Bowling 1991) because it contains many questions on somatic symptoms which elderly people may rate positively because of their physical health. This is clearly a drawback in research on carers of dementia sufferers, many of whom will also be elderly.

A further instrument for measuring depression is the Centre for Epidemiological Studies Depression Index (CES-D) (Radloff 1977). This is a 20 item self report depression scale with a cut point of 16 for depressive symptomatology. Its results correlate highly with that of the Beck Depression Inventory and the Zung Depression Scale (Weissman et al 1975).

The Zung Depression Scale is a self rating scale (Zung 1965). The scale consists of 20 statements about depressive feelings or symptoms. For each statement there are four response categories relating to the amount of time the symptom or feeling is experienced (eg “some of the time”, “most of the time”) such that each item scores from 1-4. The interpretation of the scores is based on norms which are given in the scales manual and these were based on the scores of adults aged 20-64 years so may not be accurate for either younger or older people. It has been correlated highly with the Hamilton Depression Scale, but there is little evidence of the scale’s reliability.

The Short CARE (Comprehensive Assessment and Referral Evaluation) (Gurland et al 1984) differs from the above in that it is a semi-structured interview designed for people over 65. It includes diagnostic scales for dementia and depression which have been validated against psychiatric assessments with levels of agreement of 0.73 (Toner et al 1988).

1.3.1b THE NATURE OF PSYCHOLOGICAL DISTURBANCE IN CARERS OF DEMENTIA SUFFERERS

Eagles et al (1987a) studied a sample of carers recruited from a general practice catchment area and found that although those caring for people with dementia were generally non-cases on the GHQ, their RSS scores were significantly greater than those caring for the physically disabled. A study by O’Connor et al (1990) reported similar results, that those caring for dementia sufferers had higher strain scale scores than those of a control group although their GHQ scores were not significantly different. Thus, both of these studies indicated that the carers were experiencing adverse psychological consequences as a result of caring but this did not lead to psychiatric illness.

Those studies which measure psychiatric symptoms in carers of dementia sufferers report high levels in carers. Using the Brief Symptom Inventory, Bergstone et al (1988) reported higher levels of psychological symptomatology in a community sample of those caring for people with dementia than in the general population. The Short Psychiatric Evaluation Scale (Pfeifer 1975) was used in a study by George and Gwyther (1986) and similarly found that a group of carers on the mailing list of the Duke

University Family Support Programme had three times as many “stress symptoms” as an age and sex matched comparison group.

A further study (Gilhooly 1984) made within group comparisons on the mental health of carers according to their sex, relationship to the care recipient, satisfaction with help received from other relatives and duration of caring but did not compare the mental health of carers with that of a control group. This study reported a different result from that found in the two studies mentioned above, concluding that, in general, carers were in good mental health according to the OARS (see 1.3.1a) and the highest score was four, indicating definite but not severe psychiatric symptoms and/or cognitive impairment.

Several studies have used the GHQ to assess carer mental health (Gilleard et al 1984, Eagles et al 1987, O’Connor et al 1990). The first of these reported a high rate of GHQ caseness in carers although the remaining two studies did not (see 1.3.1c).

Finally, in assessing depression in carers of dementia sufferers, Haley et al (1987) examined a group of carers recruited from the local branch of the Alzheimer’s Disease Society and newspaper and radio advertising, using the Beck Depression Inventory (1.3.1a). Forty three percent of carers scored in a range consistent with mild or moderate depression. Similar results were found by Pruchno and Resch (1987). Using the Centre for Epidemiological Studies Depression Index (CES-D) (Radloff 1977) they found carers of dementia sufferers significantly more depressed than a matched sample of non-carers. Both these studies used highly selected samples, from a support group and from community outreach respectively. However, the study of Livingston et al (1996) (1.3.1c), assessed a representative sample of carers in the community and found that 32% were depressed according to the Short CARE (Gurland et al 1984).

In summary, there is a general consensus in the literature that carers of dementia sufferers experience some form of psychological distress and may develop psychiatric illness. It is uncertain what scales designed specifically for carers, such as the Burden Interview or the Relatives Stress Scale, are actually measuring in psychological terms since they are composite measures of both psychological symptoms

and social difficulties. Carers who score as significantly more “stressed” or “strained” than non-carers may fail to score on conventional measures of caseness such as the GHQ and cannot be said to be psychiatrically ill. Three authors have published work using diagnostic scales and all report higher levels of depression in carers of people with dementia than controls, in spite of employing varying sampling procedures and using different rating scales.

It is clear from the carer literature that although care giving may be a risk factor for developing depression, not all carers are adversely effected by the task. It is possible that the social support a carer receives may act as a protective factor, reducing the psychological morbidity they experience during the course of their care giving role. This will be explored in section 1.3.2. Alternatively, it may be that certain carers are at greater risk because of their individual characteristics (discussed in sections 1.3.3. a-f) or because of particular features of the dementing illness in the person for whom they are caring (discussed in chapter 4).

1.3.1c PREVALENCE OF PSYCHOLOGICAL DISTURBANCE IN CARERS OF DEMENTIA SUFFERERS

There are many studies which assess the prevalence of carer psychological morbidity as opposed to carer distress. Gilleard et al (1984) reported on the carers of a group of dementia sufferers referred to psychiatric services and found that 57% - 73% of them score as cases on the General Health questionnaire (Goldberg and Hillier 1979) (see 1.3.1a). These rates of psychological morbidity are very high, but the population of carers may not be representative of those caring for dementia sufferers in the community. Since this sample included only carers whose relatives with dementia had been referred to psychiatric services, it would have been expected to include a disproportionate number of those experiencing difficulties in the caring situation and therefore who were particularly distressed.

A second study, also assessed carer psychological morbidity in carers of dementia sufferers referred to psychiatric services (Coope et al 1995). The case notes of a consecutive series of referrals were reviewed, and those people who fulfilled CAMDEX (Cambridge Examination For Mental Disorders In The Elderly) (Roth et al 1986) criteria for dementia and were living with a carer were included in the

study. The CAMDEX is a diagnostic scale which consists of a 60 item cognitive examination (CAMCOG), a section for rating the interviewer's observations, a physical examination, laboratory and radiological tests, current medication, and a structured interview with an informant. It has a high inter-rater reliability and the CAMCOG component has a diagnostic sensitivity of 92% and specificity of 96%. Carers were assessed using the Geriatric Mental State (Copeland et al 1976) (See 2.2.5a and b, 2.2.8b, 2.2.9). The study reported that 28% of carers were cases of depression and a further 12% were subcases. In addition, 4% were cases of anxiety, and 18% had subcase levels. The prevalence of case depression exceeds that reported in community samples (Copeland et al 1987).

A further study, on a more representative sample was that of Levin et al (1986). This larger study (see ahead for numbers involved) was conducted by the National Institute of Social Work (NISW). A list of elderly people in contact with health or social services providers (eg. general practitioners, geriatricians, psychiatrists, home helps, day centres, community nursing services) were drawn from three London boroughs. All were screened for confusion using "NISW noticeable memory and orientation problems" scale which is a list of six questions which enquired about memory difficulties, doing everyday tasks, knowing the time of day, orientation in place, recognising familiar people and being able to follow a conversation. Those who were confused according to this scale and had a named "supporter" in the community, who may or may not have been living with them, numbered 900 people. From this group, a random sample of 150 were chosen. The elderly people who scored as confused on the initial screen, were further assessed using a standardised semi structured diagnostic interview, the Geriatric Mental State (Copeland et al 1986) (See 2.2.5a and b, 2.2.8b, 2.2.9). Carers were assessed using the GHQ (1.3.1a). The results showed that overall 32% of carers had GHQ scores in caseness range. Those who were caring for someone with dementia had significantly higher GHQ scores than those caring from someone with no psychiatric illness. Thus, even in this more representative sample of carers, psychological morbidity was high.

More recently, another prevalence study has been published which is the most detailed to date on the subject in that it compares the mental health of people who live with someone who does not require caring for (referred to as co-resident) and those who live alone with that of three categories of carer:

those caring for people with dementia, other psychiatric disorders or with physical disability (Livingston et al 1996). Also it is the most rigorous in terms of ensuring a representative community sample since it recruited people by door knocking an area, so did not rely on general practice patient lists which can be inaccurate. The study made diagnostic assessments on each carer using the Short CARE (Comprehensive Assessment and Referral Evaluation) (Gurland et al 1984) in those over 65 (see 1.3.1a), and for those under 65, the Revised Clinical Interview Schedule (CIS-R) (Lewis et al 1992) (see 1.3 1a) with some additional questions such that an ICD 10 diagnosis could be made. Thus, it is not directly comparable with the other three studies, but it has the advantage of making specific diagnoses. The study reported that overall, carers were no more psychiatrically ill in terms of symptoms or specific syndromes, such as depression, than co-residents. However, those caring for people with a psychiatric disorder had a higher rate of both depression and anxiety disorder than co-residents and those caring for someone with dementia had the highest rate of depression (32%). The rates of depression in those caring for someone who was physically disabled were low, suggesting that this type of caring may be associated with a reduced risk of psychological morbidity. However, they were not significantly lower than that found in co-residents.

Not all studies report an increase in psychological morbidity in dementia sufferers. One study analysed carers selected from a general practice catchment area and found that care GHQ scores neither reached caseness nor distinguished between those caring for someone with cognitive impairment according to the Mental Status Questionnaire (MSQ) (Pfeiffer 1975) from those whose relatives were physically disabled (Eagles et al 1987a). The MSQ (see 2.2.5a) is a ten item screening test and within the cognitively impaired group, only 5.7% scored low enough to suggest a diagnosis of dementia. Thus the low rates of psychological morbidity may have been because few of the carers were caring for someone who actually had a dementing illness. A further study by the same author and published in the same year, compared the GHQ score of elderly people living with a spouse who was cognitively impaired with one who was cognitively intact and found that they were almost equal (Eagles et al 1987b). Supporting this finding, a third study also recruiting from a general practice, reports no significant difference in the GHQ scores of those caring for people with dementia diagnosed using the Mini Mental State Examination (Folstein et al 1976) (see 2.1.1c) compared with a sample who were caring for cognitively intact people (O'Connor et

al 1990).

Some of the discrepancies in these results may be explained by the sampling procedure. Although only one study used a highly selected sample of carers whose relatives have been referred to psychiatric services (Gilleard et al 1984), a further study only recruited from helping agencies (Levin et al 1989), three studies were based on those who were on the list of local General Practitioners (Eagles et al 1987a and b, O'Connor et al 1990) and only one ensured an unbiased and completely representative sample of carers living in the community (Livingston et al 1996). A further possibility is the use of different instruments. However, all use well recognised instruments for measuring both dementia and carer psychological morbidity, so again, this cannot fully explain the discrepancy. As mentioned above, the lack of psychological morbidity in carers reported by Eagles et al (1987a) may be explained by the fact that only 5.7% of the care recipients had screening test scores consistent with dementia, although this explanation accounts for only one study.

1.3.2 CARER CHARACTERISTICS ASSOCIATED WITH PSYCHOLOGICAL MORBIDITY

A consideration of the findings of research into the characteristics of carers associated with greater psychological morbidity is clouded by several methodological issues. Studies approach measuring such morbidity in different ways as outlines in 1.3.1. Also, since most research has used unrepresentative samples of carers, factors associated with morbidity may reflect selective sampling rather than a true association (Brodaty and Hadzi-Pavlovic 1990).

1.3.2a CARER GENDER

Most studies conclude that women are more vulnerable than men to the psychological symptoms and/or morbidity associated with caring. Most female carers are spouses. Thus, separating the effect of being female from that of being a spouse, is problematic.

Of nine studies published which consider the effect of carer gender, three consider only spouse carers (Pruchno and Resch 1987, Fitting et al 1986, Zarit et al 1986), and a further one analyses spouse carers



separately (O'Connor et al 1990). The first of these finds greater levels of depression in wives than husbands according to the CES-D (see 1.3.1a), and the second reports the same result using the Minnesota Multiphasic Personality Inventory. This scale is used to generate psychological descriptions and includes a depression scale (Hathaway and McKinley 1943, 1990). Zarit et al (1986) found that wives had higher burden scores than husbands when initially assessed, but that at two year follow up, their scores were the same. O'Connor et al (1990) found that wives caring for moderately demented husbands had both higher strain and GHQ scores than their male counterparts.

Those studies which recruit mixed samples of both spouse and non spouse carers report similar results. The work of Gilhooly (1984, 1986) in which only 25% of the carers were spouses, finds lower morale in female carers as measured by the Kutner Morale Scale (Kutner et al 1956) but no difference in their mental health as measured by the OARS (see 1.3.1a). Using the Brief Symptom Inventory (see 1.3.1a) and a sample in which 52% were spouse carers, Bergstone et al (1988) reported that women had elevated scores on subscales measuring anxiety and hostility. In addition, women over 65 also had higher depression scores. Gilleard et al (1984) assessed a group of carers of which an unspecified number were spouses using the GHQ and found that women had significantly higher ratings. Using the Short Care (see 1.3.1a), Livingston et al (1996) found that female carers of people with dementia had higher rates of depression than male carers, women living with a co-resident or women living alone.

Only one study contradicts the general consensus that women carers are more vulnerable to psychological symptoms than men. Brodaty and Hadzi-Pavlovic (1990) assessed a self selected group of 146 carers who were members of the Alzheimer's Disease and Related Disorders Society using the GHQ and the Zung depression scale and found similar scores for men and women. It is difficult to explain why the findings of this study are dissimilar to the rest. All of the studies mentioned use samples that are selective (from support group attenders or groups referred to hospital services) so it is possible that the work of Brodaty and Hadzi-Pavlovic involved a different sample from the other studies, although this is not clear from the description of the recruitment procedure. Also, it may be that the Zung is not a particular good measure of depression in the elderly (see 1.3.1a). It has been reported that the convergent validity of the Zung scale with physicians judgement is lower than with that of the CARE

which was specifically designed for the elderly (kappa 0.29 versus kappa 0.46) (Toner et al 1988).

In conclusion, women caregivers report more psychological symptoms than men. Despite using different rating scales, and variously recruited samples from support groups to day hospital populations, in all but one study, women have consistently been in poorer mental health. It may be that women carers who are also spouses are particularly vulnerable and this will be discussed in 1.3.2b.

In a review article, Morris et al (1988a), consider the reasons why female caregivers may be more adversely affected by their role. Firstly, it is established that in the general population, women suffer more psychological illness than men. However, the excess morbidity among women carers is greater than could be explained by this alone (Morris et al 1991). It has been suggested that women find it harder to benefit from both formal and informal social support, perhaps because they find it harder to hand over the responsibility of care giving and feel guilty about not providing care themselves (Zarit et al 1986). Linked to this are differences in the socialisation of men and women which may mean that women find caring more emotionally demanding because they see it as an extension of their nurturing role, whereas men may take a more practical, problem solving approach conceptualising caring as a job of work to be done.

Younger women carers may also find they have conflicting duties such as caring for children and pursuing their own career, so that caring becomes yet another responsibility. Other authors have suggested that women may use less effective coping strategies than men (see 1.3.2e) and are more likely to use “avoidance coping” (wishing a problem would go away), whereas men use “active coping” to a greater extent (Billings and Moos 1981): the former coping style has been associated with higher levels of distress (Pett et al 1988). Finally, Fitting et al (1986) reported that men were much more likely than their female counterparts to report an improvement and less likely to report a decline in their marital relationship following the onset of a dementing illness. Thus, the challenge of a care giving role may be suited to the needs of some male carers.

1.3.2b RELATIONSHIP TO THE DEMENTIA SUFFERER AND CARER MENTAL HEALTH

Much of the research into the mental health of carers considered samples of spouse carers only. However, some work does compare the well-being of spouse carers with that of other caregivers (Brodaty and Hadzi-Pavlovic 1990, George and Gwyther 1986). The former found spouse carers to have higher GHQ scores than other groups, although their Zung depression scores were not significantly different. The latter study reported that spouses had poorer mental health as measured by a greater number of stress symptoms. Other work has looked more broadly at the role of blood tie in relation to carer psychological morbidity and reports that a closer blood tie is associated with poorer carer mental health (Gilhooly 1984).

Perhaps a closer family relationship is associated with greater psychological morbidity because it is more painful to witness a mental deterioration in a person one has had an intimate relationship with (see 1.3.2d). However, this contrasts with grieving after death where coping with loss is complicated by ambivalence during life. A further possibility is that a close relative carer may become more actively involved with providing care so finding care giving tasks harder to relinquish, such that they become more distressed Gilhooly 1986). Finally, family relationship is confounded by living arrangements (George and Gwyther 1986) as those with a close relationship are more likely to be co-resident.

1.3.2c CO-RESIDENCE AND CARER MENTAL HEALTH

Three studies have compared the mental health of carers living with the person for whom they are caring with those who live separately. One study found that co-resident carers had significantly higher GHQ scores than those living separately and that there was a trend for GHQ and Zung depression scores to fall with increasing geographical distance between carer and care recipient (Brodaty and Hadzi Pavlovic 1990). Other work quoted previously reported that co-resident children had significantly higher strain scale scores than those living separately (O'Connor et al 1990). Finally, the work of Gilhooly (1984) found that co-resident carers had slightly lower morale and mental health than non-resident carers but in neither case did this reach statistical significance.

Thus, most of the studies which consider the effect of coresidence on carer mental health find it to be

detrimental. This is to be expected given that those living with a person with dementia are likely to be more involved with the caring role for a greater number of hours each day. In addition, they are more likely to be spouses or to have a close blood tie and so have several risk factors for psychological morbidity.

1.3.2d INTIMACY AND CARER MENTAL HEALTH

A number of studies have examined whether the quality of the premorbid relationship between carer and dementia sufferer is associated with carer psychological well-being. It is possible that feeling a great emotional bond with the sufferer allows the carer to receive more gratification from the task and to resent it less and this may be protective of their mental health. Alternatively, those carers who have had a more intimate relationship may experience greater distress as this relationship is eroded by the progressive nature of a dementing illness, so putting them at greater risk of psychological morbidity.

Horowitz and Shindleman (1983) examined 203 caregiver/care recipient pairs (9% spouses) and reported that those carers who felt more affection for the person for whom they cared had lower levels of “perceived stress”. The work was entirely qualitative involving open ended questioning and no standard rating scales. Although the care recipients had some activity limitation, no assessment was made of their cognitive functioning and most of them did not live with the caregiver. Thus it is likely that the sample involved many subjects who were cognitively intact. However, similar findings were reported in a sample of which all care recipients had dementia (Gilleard et al 1984): those carers who rated their premorbid relationship with the dementia sufferer negatively, had high GHQ score. Alternatively, having a high GHQ score, indicating psychological morbidity may cause a carer to rate relationships negatively as part of their generally negative thought content.

A further study focused particularly on intimacy between spouse caregivers of dementia sufferers (Morris et al 1988b). Intimacy was measured using the assessment scale developed by Waring and Patten (1984). This consists of 24 statements covering eight areas of intimacy; affection, cohesion, expressiveness, compatibility, conflict resolution, sexuality, autonomy and identity. The instrument was administered twice in order to assess both past and present intimacy. Carer mental health was measured

using the Beck Depression Inventory and a seven point self rating strain scale. A behavioural assessment of the dementia sufferer was made using the Problem Checklist (Gilleard 1984). This instrument rated the frequency and severity of 34 abnormal behaviours commonly seen in dementia such as “temper outbursts” and “repeated questioning”. Correlational analyses showed that caregivers who experienced lower levels of intimacy both before the onset of dementia and currently, had higher levels of depression and perceived strain. Those carers who had experienced a greater loss of intimacy also had higher levels of depression but not of strain. The latter finding is consistent with work relating depression to loss of any description (Parkes 1972, Bowlby 1980). Thus the study concludes that a poorer premorbid relationship or a greater loss of intimacy are risk factors for carer depression. Finally, this study also found a negative correlation between intimacy and behavioural problems indicating that spouses were more intimate with dementia sufferers who had fewer behavioural problems. This will be discussed further in section 1.4.2.

Similar results to the above study were found in two further studies using different research instruments Brodaty and Hadzi Pavlovic 1990, Motenko 1989). In the first of these, the quality of the relationship premorbidly and currently was measured on a visual analogue scale. All premorbid relationships were rated as satisfactory but where there had been a greater deterioration in the relationship, there was an associated increase in carer psychological morbidity according to both the GHQ and the Zung Depression Scale. In the second, the author measured carer well-being according to the Deputy Psychological Well 984) which Being Index (Deputy 1 is a 22 item instrument with six sub scales measuring anxiety, depression, general health positive well-being, self control and vitality. Marital closeness, gratification’s from care giving, and the meaning of care giving was also assessed. Marital closeness was measured by asking the question “Before your husband got sick, which three people were you closest to? And now?” Gratification from care giving was measured using the question “People say that even though care giving is difficult and exhausting there are moments of warmth, comfort and pleasure. Is this true for you most of the time, some of the time, a little of the time or none of the time?”. The meaning of care giving was judged as being one of three: reciprocity, responsibility or tender loving care. Carer well-being was positively associated with finding gratification in care giving. Gratification was associated with marital closeness. The lowest gratification scores were reported in those who had

experienced a decline in their marital closeness, they were highest in those who continued to be close and in the middle range in those who had never been close. Gratification from care giving was also associated with viewing caring as loving and nurturing rather than as a responsibility.

On the work of Gilhooly (1984) reported no association between the quality of the relationship between carer and dementia sufferer and carer mental health as measured by the OARS. The reason for this difference in result may lie in the method for assessing the quality of the relationship. In most studies, this is measured by directly questioning the carer, but in the Gilhooly study it is rated by the author herself, on a five point scale, based on answers to unspecified questions concerning the relationship at various times during the carer's life. It is debatable which method is preferable since, although the former seems a potentially more accurate assessment of relationship quality, the latter has the advantage of being less affected by current carer mental state.

Thus, in summary, for those who care for dementia sufferers, a good premorbid relationship seems to be protective of mental health while paradoxically, a decline from a previously high level of intimacy may be a risk factor for depression. However, as all the studies are cross sectional rather than longitudinal, the direction of causality is uncertain. It is possible that depressed carers report poorer premorbid relationships or a decline in intimacy as part of a generally negative thought content, rather than a poor relationship making a carer vulnerable to depression.

1.3.2e COPING STRATEGIES AND CARER MENTAL HEALTH

The effect of coping style on carer well-being has been studied by Pruchno and Resch (1989). They viewed coping as being either emotion focused (the regulation of one's emotional response to a problem) or problem focused (altering the problems causing the distress). Carers' coping styles were rated according to a 34 item coping scale measuring wishfulness (wished you could change the situation or the way you felt), acceptance (accepted the situation and refused to let it get to you), intrapsychic coping (imagined a better time or place than the one you are in), and instrumental thinking (made a plan of action and followed it, creative problem solving). Instrumental coping and acceptance were associated

with lower CES-D scores (see 1.3.1a).

Similar findings were reported by Williamson and Schulz (1993). They considered three different “stressors”: memory deficits, loss of communication, and the general decline in a loved one. Coping strategies were examined with regard to their appropriateness for dealing separately with each of these. Wishfulness was associated with depressive symptoms as measured by the CES-D in all categories. In relation to memory difficulties, acceptance as a coping strategy was associated with fewer depressive symptoms and direct action with more of them. Acceptance was also helpful in coping with decline of a loved one and seeking social support was associated with further reduction in depressive symptoms. Consistent with this was the finding that stoicism (keeping feelings to oneself and not letting others know how distressed you are) was associated with greater depression. The study is valuable in highlighting that coping strategies must be judged in relation to their suitability to the problem being encountered and perhaps it is the ability to use different coping strategies in a flexible way that is associated with mental well-being.

1.3.2f PERSONALITY AND CARER MENTAL HEALTH

The personality of carer has been considered in several studies in terms of their concept of causality and control over negative life events. Pagel et al (1985) asked 68 spouse caregivers to rate both their perception of control and their causal attributions regarding changes in the behaviour of the person with dementia for whom they were caring. Perceived lack of control was consistently related to depression as measured by both the Beck (see 1.3.1a) and the Hamilton (see 2.2.9) rating scales. Caregivers tended to be more depressed if they thought that their spouse’s behaviour was caused by themselves. This tendency to self-blame was also associated with higher levels of anxiety and hostility. These personality traits may be associated with depression in the general population and not only in those people who care for someone with dementia (Beck 1970). Thus, caring may be the precipitant of depression in someone who is, by virtue of personality, predisposed to developing it.

1.3.2g CONCLUSION: CARER CHARACTERISTICS ASSOCIATED WITH PSYCHOLOGICAL MORBIDITY

There are factors related to the caregiver which are associated with carer psychological morbidity and particularly depression: these are female sex, spouse status, family relationship, co-residence, poor premorbid relationship, a decline from a previously high level of intimacy, the use of emotion focused coping strategies, and certain personality traits such as a tendency to feel out of control and to blame oneself. Chapter 5 will consider the characteristics of the dementia sufferer which may also be related to carer psychological morbidity.

1.3.3 SOCIAL SUPPORT AND CARER MENTAL HEALTH

Many studies have examined the relationship between the social support received by a carer and their mental health. In this review, two categories of social support are considered: informal support refers to support from friends and relatives, and formal support describes help provided by social services.

1.3.3a INFORMAL SUPPORT AND CARER MENTAL HEALTH

Informal support can be measured quantitatively in terms of the number of visits from family or friends (Zarit et al 1980) or qualitatively in terms of the content of the contact and how gratifying and helpful the carers experience the support they receive. It cannot be presumed that contact with friends and family is necessarily supportive and it may even be counterproductive as carers may feel criticised and find it an added burden. In addition, support received may not be of a uniform quality. Furthermore, both quantitative and qualitative measures of social support are unable to address whether support has been provided in response to carer distress or whether its availability has acted to protect against such distress and this complicates assessment of the relationship between them.

Several studies have examined the relationship between the number of visits carers receive from family members and their mental health. Zarit et al (1980) reported that carer burden as measured by the burden interview was less in those who received more visits from family members. Other work reports a different result: Gilleard (1984) found no relationship between family support/contact and carer GHQ score and Gilhooly (1984) reported that support from friends and family were not related to carer morale

according to the Kutner Morale Scale (Kutner et al 1956) or carer mental health as measured by the OARS (see 1.3.1a). However, Gilhooly (1984) did find an association between satisfaction with help received from relatives, (a rating that may reflect the quality of the help received) and both carer morale and mental health. This association bears two interpretations: dissatisfaction may cause poor mental health or reflect it.

A study by Morris et al (1989) addressed the limitations in numerical measurement of social support by using a social support scale derived from the Californian Human Population Questionnaire (Berkman 1983). This allowed assessment of emotional, instrumental and financial help received, and of the social web of relationships surrounding the carer. The results of this study found that those carers with greater informal support had lower scores on the Beck Depression Inventory (BDI) (see 1.3.1a) and lower measures of strain.

1.3.3b FORMAL SUPPORT AND CARER MENTAL HEALTH

The relationship between formal support and carer mental health is confounded by the same issues that confound the relationship of informal support and carer mental health: the distressed carer may be receiving more support and then that support might reduce their distress to the levels of those carers who were initially less distressed so masking, any relationship which might exist between formal support and carer well-being.

This issue is partly addressed by the work of Levin (1986) who reported that carer GHQ scores decreased over a one year follow-up period, if they were receiving formal support in the form of a home help, a community psychiatric nurse, day care, respite care or attendance allowance. In combining these various forms of social support, the study does not allow the effect of practical help, nursing input and financial assistance to be considered separately. However, given its follow-up design, it does point to a potential protective role for formal support services in reducing carer psychological morbidity. It is not stated whether this study found relationship between carer GHQ score and social support at initial interview.

A further study considered the above mentioned forms of support separately (Gilhooly 1984) comparing

those carers receiving a form of support with those who were not : results showed that having a home help was associated with better carer morale according to the Kutner Morale Scale (Kutner et al 1956) and better carer mental health as measured using the oars (1.3.1a). Visits from a community psychiatric nurse were associated with better carer morale but there was no association with carer mental health. Receiving meals on wheels or the dementia sufferer attending a day hospital were correlated with neither measure of carer well-being. Perhaps having a home help and having a community nurse visiting were effective forms of social support because they involved spending more time with carers and so were more personal, attending to the individual concerns of carers. In contrast, meals on wheels and day hospital provision may not involve the carer in any one-to-one help.

Other work has assessed formal support differently. For instance, Morris et al (1989) recorded visits made by general practitioners, district nurses, health visitors, social workers, home helps, chiropractors, hairdressers and meals on wheels and each were given a score according to the frequency of contact and then all scores were summated to give an overall rating for formal support. A similar system was used by Gilleard (1984) who measured formal support by using a professional care index which was compiled by summing all contact with professional services but no details are given of exactly what services are included within this. The two studies measure carer mental health differently. The former used the Beck Depression Inventory (BDI) (see 1.3.1a) and a seven point strain scale. No association was found between amount of formal support received and the carers' BDI scores but greater formal support was associated with less strain. The latter study used the GHQ to rate carer mental health and found that there was no association between GHQ score and formal support. Thus the consensus from these two studies is that there is no link between formal support and carer mental health but it is not possible to compare this directly with the work of Gilhooly and Levin because of the different ways formal support is measured.

Thus, in conclusion, given the different ways formal support is measured in the studies discussed above, and given the complex interaction that may exist between support and carer mental health, the relationship remains uncertain and can only be resolved by longitudinal studies. Carer support groups and their impact on carer mental health is discussed in chapter 5.

PART 1

CHAPTER 4 CHARACTERISTICS OF THE DEMENTIA SUFFERER AND CARER MENTAL HEALTH

Research examining the relationships between the characteristics of people with dementia and the mental health of their carers has focused on four variables pertaining to the dementia sufferer: cognitive impairment, behavioural disturbance, level of dependence in activities of daily living and duration of illness.

Here are two methodological difficulties in comparing and summing this work. Firstly, the studies use different measures for these variables and some use scales which are composite measures of several of the variables listed above. For instance, Pruchno and Resch (1989) rate behavioural difficulties according to a list of 34 items derived from the "caregiver literature" which include questions relating to changes in cognition, mood, social performance and physical health. These are then divided into three categories of behaviour: forgetful, asocial and disorientated. Although this procedure for assessment is rigorous, it is not comparable with other studies. "Getting lost in the house" is rated as a disorientated behaviour, but others might regard it as forgetful. Similarly, the work of George and Gwyther (1986) recorded the "severity of symptoms displayed" in the person with dementia from a list of 32 symptoms "reported in the literature as characteristic of Alzheimer's disease and related disorders" and summed these into a single global measure of severity. It is not clear to what extent this is measuring cognitive, behavioural or functional changes in the sufferer since no further details are given.

Secondly, behavioural assessment is further complicated by the fact that it is usually rated from information supplied by the carer. thus it relies heavily on the carer's observational accuracy and current mood. Some behavioural assessment scales such as the Problem Checklist asks questions which assess the carers reaction to an item of behaviour such as whether the dementia sufferer has behaviours which are irritating or embarrassing (Gilleard 1984). Thus, the assessment of behaviour becomes, to some extent, a measure of the carer's own mental state.

The following sections will consider the research evidence for a relationship between carer mental health

and the four variables in the dementia sufferer listed above: cognitive impairment, behavioural disturbance, level of dependence in activities of daily living and duration of illness.

1.4.1 COGNITIVE IMPAIRMENT AND CARER MENTAL HEALTH

Eight studies have considered the relationship between the severity of cognitive impairment and carer mental health. Three studies report that they are not associated (Zarit et al 1980, Gilhooly 1984, Brodaty and Hadzi-Pavlovic 1990), four that they are directly related (Graftesmen et al 1994, Eagles et al 1987, O'Connor et al 1990, Donaldson et al 1998) and one that they are related in an indirect way (Deimling and Bass 1986).

Three studies (Zarit et al 1980, Gilhooly 1984, Eagles et al 1987) assessed cognitive impairment using the Mental Status Questionnaire (MSQ) (Kahn et al 1960) (see 2.25a). This is a 10 item screening questionnaire which covers orientation in time and place, date of birth, current prime minister and previous prime minister. It has been found to be highly associated with a psychiatrist's evaluation of the presence and severity of a chronic brain syndrome (Kahn et al 1960b), but it is not a diagnostic instrument and a low score does not necessarily indicate dementia. Also, given its brevity, it can only be a limited measure of the severity of cognitive impairment. A further three studies used the Clinical Dementia rating Scale (CDR) (Hughes et al 1982) (Brodaty and Hadzi-Pavlovic 1990), Graftesmen et al 1994, O'Connor et al 1990). This is a global dementia staging system pooling information from patients and informants on six areas of mental function: memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care. Although not diagnostic, it is a good measure of dementia severity. Finally, Deimling and Bass (1986) measured "cognitive incapacity" using an eight item instrument the details of which are not specified. Thus, the three instruments for measuring cognitive impairment are not directly comparable.

Zarit et al (1980) using the Mental Status Questionnaire (MSQ) (Kahn et al 1960) to measure cognitive impairment and found no correlation with carer distress as assessed by the Burden Interview (see section 1.3.1a). Gilhooly (1984) reported the same result also using the MSQ to measure cognitive impairment but using the OARS (see 1.3.1) to assess carer well-being. Finally, Brodaty and Hadzi-Pavlovic rated

people with dementia according to the CDR. They assessed carer mental health using both the GHQ and the Zung Depression Scale and found no association between these scores and the severity of dementia.

Considering the studies that report a relationship between the severity of cognitive impairment and carer well-being. Graftesmen et al (1994) reported a positive association between mild dementia as measured by the CDR and carer burden as rated by asking the carer five questions about their mood and how they were coping. O'Connor (1990) reported an association between those behaviours associated with forgetfulness (but not cognitive impairment as such) and both higher strain and GHQ scores. Thus, although this implies a link between carer morbidity and cognitive impairment, the findings do not show an association between carer mental health and the severity of cognitive decline. However Donaldson et al 1998 report of a relationship between higher mini mental state examination score in dementia sufferers and higher GHQ scores in their carers. Lastly, Eagles et al (1987b) found a positive association between the MSQ score of wives (who may not have dementia for reasons given above) and the psychological morbidity of their husbands as measured by the GHQ and the Leeds Depression Scale (Snaith et al 1976).

Those studies that report a relationship between cognitive impairment and carer mental health have used representative community samples. Those that find no association have recruited samples selected from a support group register or from a day hospital. It may be that attending a support group or day hospital masks an association between cognitive impairment and carer mental health because the carers selected in this way are a more homogenous group consisting of those who are distressed and seeking services. Alternatively, the assistance of a support group or day hospital may improve carer mental health so disguising a relationship between it and severity of cognitive impairment.

Deimling and Bass (1986) reported that there is no direct relationship between cognitive impairment and carer well-being but concluded that it does exert an indirect effect via its association with impaired social functioning and disturbed behaviour. This highlights a difficulty referred to earlier, that although cognitive change and behavioural disturbance can be assessed separately they are nonetheless, related to each other (see section 1.2.3).

1.4.2 BEHAVIOURAL DISTURBANCE IN DEMENTIA AND CARER MENTAL HEALTH

Of thirteen studies reviewed below, eleven find an association between behavioural disturbance and carer well-being (Grafteson et al 1994, Sandford et al 1975, Motenko 1989, O'Connor 1990, Pruchno and Resch 1989, Gilleard et al 1982, Gilleard et al 1984, Deimling and Bass 1986, Kinney and Paris Stephens 1989, Brodaty and Hadzi-Pavlovic 1990, Donaldson et al 1998). However, two of these conclude that they are less important than carer characteristics (Motenko 1989, Brodaty and Hadzi-Pavlovic 1990).

GENERAL BEHAVIOURAL DISTURBANCE AND CARER MENTAL HEALTH

Four studies listed above reported an association between the general degree of behavioural disturbance and carer distress (Graftstom et al 1994, Kinney and Paris Stephens 1989, Motenko 1989, Donaldson et al 1998). The first found “dementia related symptoms” (not specified) to be associated with positive answers to five questions on carer burden. The second reported an association between caregiver “hassles” as a result of behavioural changes in the care recipient and a scale for measuring symptoms of psychological distress called the SCL-90-R (Derogatis 1983). The study defined hassles as “irritants – things that annoy or bother you” and behavioural changes included losing things, yelling/swearing, not co-operating repetitive questioning, wandering and hiding things. The third found an association between a 17 item dementia symptom questionnaire (unspecified) and “care frustration” (Motenko 1989). Frustration was measured using a 9 item Likert scale asking caregivers about certain emotions relation to the care recipients illness (anger, resentment, shame, regret, overwhelmed, afraid, guilty, resigned, hopeful). Lastly, a later study found a relationship between this third behaviour as measured by mouse pad and carer GHQ (Donaldson et al 1998).

SPECIFIC BEHAVIOURAL PROBLEMS AND CARER MENTAL HEALTH

Two studies by Gilleard et al (1982, 1984a) reported that “demand” behaviours (demands attention, disrupts social life, creates clashes, noisy, always questions) were associated with poorer carer well-being than those reflecting “dependency” (needs help with dressing, feeding, washing, not safe outside, cannot be left alone”, “disability” (incontinence, not able to manage stairs, needs to be helped into bed)

or “disturbance” (accusations, temper outbursts, aggression). In the first study “demand” behaviours were found to be associated with strain as measured by carer self reports of combination of “burden”, “ability to cope”, and “negative mood ratings” and in the second they were related to higher carer GHQ scores. The association with demand behaviours is also reported by Brodaty and Hadzi Pavlovic (1990). They report no association between general behavioural disturbance as measured by a problem behaviour checklist and carer well-being as measured by either the GHQ or the Zung depression scale, but find an association between demand behaviours and carer GHQ.

A fourth study reported an association between carer morbidity as measured by the CES-D (1.3.1a) and asocial behaviours (losing temper, verbal abuse, embarrassing the caregiver) (Pruchno and Resch 1989). Other categories of behavioural disturbance, namely forgetful and disorientated behaviours were associated with “perceived burden”, “consequences of caring” and “restrictions on the carers social life” but not with carer depression. In this study, burden was assessed by asking the carer to rate how burdened they felt on a scale of 1-5. “Consequences of caring” were assessed by asking the carer about 12 emotions felt as a result of caring e.g. guilty, irritable, and overwhelmed. “Restrictions in social life” referred to a decrease in the carer’s participation in 13 social activities.

The work of Deimling and Bass (1986) supports the findings of Pruchno and Resch (1989) in reporting that disruptive behaviours (swearing, striking family members) are particularly associated with carer depression as measured by the Zung depression scale. They also find a lesser but significant association with impaired social functioning.

In a further study, the authors examine four problem categories, “dependency”, “disturbed behaviour”, “forgetfulness” and “inertia” and find that all are related to carer strain as measured by the Strain Scale but not to carer GHQ (O’Connor et al 1990). However, although the authors do not state how each behaviour is categorised, they report that “disturbed behaviours” which may be the same as those described as “disruptive” by other authors have the strongest association with carer strain. Of note, they also find a strong association with physical dependency which is not found in other work (Gilleard 1982) (see 1.4.3).

A different approach to assessing behaviour was taken in a study by Sanford (1975). This author questioned relatives who had brought those they were caring for to hospital, saying that they could not cope. Of those that gave behavioural problems in the care recipient as a reason for this, the most common problems were faecal incontinence and sleep disturbance. Not all the care recipients had dementia and no assessment was made of the caregivers well-being but the study highlights the subjective impact of these behaviours on the carer's ability to cope at home. Faecal incontinence and sleep disturbance were not considered separately in the studies discussed above.

The general consensus of the above studies is that those behaviours described as disruptive or demanding are most strongly associated with carer distress. More precisely, the distressing behaviours are those in which the dementia sufferer is "noisy", "always questions", makes "accusations", or is verbally or physically "aggressive". These behaviours are associated with carer psychiatric morbidity (whether measured by the GHQ, the Zung Depression Scale or the CES-D) (See 1.3.1a) and measures of carer distress such as "strain" or "burden".

In contrast to the above, two studies report no relationship between carer distress and any behavioural disturbance in the person with dementia (Zarit et al 1980, Zarit et al 1986). The former rated behaviour using the Memory and Behaviour Problem Checklist (Zarit et al 1980, Zarit 1982), from which memory and behavioural aspects can be analysed separately. The study concluded that the severity of behavioural problems was not related to carer burden as measured using the Burden Interview. However, in a subsequent study the same author found that although carer burden was not related to dementia sufferers' behaviour per se, it was related to the "cross product" of the frequency of problem behaviours and the individual carer's tolerance to them (i.e. to the frequency of those behaviours carers reported finding most distressing). Although this finding is reported in only one study which used a non-validated measure of carer distress, it highlights the importance of the interaction between factors relating to individual carers with those of the dementia sufferers.

In summary, most of the literature supports a relationship between carer psychological morbidity and

behavioural disturbance in the dementia sufferer (Graftesmen et al 1994, Sanford et al 1975, Motenko 1989, O'Connor et al 1990, Pruchno and Resch 1989, Gilleard et al 1982, Gilleard et al 1984, Deimling and Bass 1986, Kinney and Paris Stephen 1989, Brodaty and Hadzi-Pavlovic 1990). Certain behaviours, namely those described as demanding or disruptive may be more associated with carer morbidity, than those associated with dependency or disability (Gilleard et al 1982, Gilleard et al 1984). It may be that carers differ in their response to certain behavioural changes, and that carer psychological morbidity is greatest when a carer is trying to manage a behaviour they find particularly distressing (Zarit et al 1986).

1.4.3 PSYCHIATRIC SYMPTOMS IN THE DEMENTIA SUFFERER AND CARER MENTAL HEALTH

One study considered the impact of psychiatric symptoms mainly depression and psychotic symptoms and carer mental health (Donaldson et al 1998). Carer GHQ was found to be related to depressed mood (as measured by the Cornell Scale for Depression in Dementia Alexopoulos 1998) and the occurrence of psychotic symptoms as measured by the sub section of mouse pad related to delusions, hallucinations, misidentifications and reduplications.

1.4.4 IMPAIRMENT IN ACTIVITIES OF DAILY LIVING (ADL) AND CARER MENTAL HEALTH

Seven studies have examined the relationship between the physical dependency of the person with dementia and the mental health of their carers. In the absence of cognitive impairment, caring for a physically dependent person may be associated with better mental health than that of the general population (Livingston et al 1996). However, for a person with dementia, attending to their physical needs may be met with a lack of co-operation or even hostility, so making the task a more arduous one.

Four studies report that greater physical dependency is associated with poorer carer well-being (Deimling and Bass 1989, Motenko 1989, O'Connor et al 1990, Graftsrom et al 1994). All studied large numbers of dementia sufferers and their carers living at home and the latter two included representative community samples. Deimling and Bass (1989) rated ability in activities of daily living (ADL) in six areas, bathing, dressing, toileting, feeding and two relating to mobility generating a score between one

and six. Greater impairment in ADL was associated with carer depression as measured by the Zung Depression Scale. Motenko (1989) measured ADL in a similar fashion to the previous author but with a score range from zero and ten. The study found that ADL impairment was associated with greater levels of carer frustration (see section 1.4.2). O'Connor et al (1990) included measures of physical dependency as part of an overall behavioural assessment and reported a relationship with carer strain but not with carer GHQ. Graftsrom et al (1994) measured ADL in a standard way according to Katz et al (1963). This gives levels of impairment increasing from A-G and the author found that measures of carer burden peaked at impairment level E. They conclude that burden may peak before the end of the scale because people with end stage dementia may become less resistant to the efforts of others to attend to their physical dependency needs.

Three studies have reported no association between physical dependency and carer well-being (Zarit et al 1980, Gilhooly 1984, Kinney and Paris Stephens 1989). The first studied a community sample of dementia sufferers and their carers. It is not stated how they were recruited. No association was found between Lawtons (1971) measures of Physical and Instrumental Activities of daily living (PADL and IADL) and carer burden. Gilhooly (1984) studied a day hospital population of dementia sufferers and their carers and also found no association between PADL and IADL and carer well-being as rated by the OARS. Finally, Kinney and Paris Stephens (1989) rated ADL impairment on a 12 item scale but found no association between hassles associated with impaired ADL and psychological symptoms as measured by the SCL-90-R (Derogatis 1983).

Even allowing for the various methods used to rate ADL and carer distress, it is difficult to account for the different results of the studies mentioned above. Although most considered community samples, only two involved representative samples and these both reported an association between increasing ADL impairment and poor carer well-being. However, these studies did not take account of relevant help received from social services such as home care or a laundry service. Such help would clearly reduce the impact of ADL impairment on the carer and so differences in the availability of such help may account for the discrepancy of the findings.

1.4.5 ILLNESS DURATION AND CARER MENTAL HEALTH

Different studies have reported that longer illness duration is either positively or negatively associated with carer mental health or not associated with it at all.

It might be thought that a carer would become increasingly distressed and tired over time. However, only one study reports this (Graftsrom et al 1994), finding that “burden” increased as the illness progressed in severity and duration. In this study, carer burden was measured by asking questions concerning the carer’s perception of how caring affected them in five domains: physical and psychological stress, social limitations, limitations in the emotional relationship with other family members and close friends, limitations in the practical possibility of having contact with relatives and close friends and increase in the conflict with other family members.

Two studies reported an improvement in carer well-being with a longer duration of illness. Brodaty and Hadzi-Pavlovic (1989) found lower GHQ scores and Gilhooly (1984) found better carer morale as measured by the Kutner Morale Scale (Kutner et al 1956) and scores on the OARS assessment scale (see 1.3.1a). The authors suggest that carers adapt to their role over time, such that their mental health improves.

A further study found no association between duration of illness and carer well-being as measured using the Short Psychiatric Evaluation Scale (Pfeiffer 1975) (George and Gwyther 1986). The findings of Motenko (1989) are mixed, reporting that with longer duration of illness, carers’ gratifications and frustrations both decrease.

One explanation for these contradictory findings may be that the task of caring for someone with dementia may change over time as the illness develops. Carer well-being may be lower when confronting new difficulties and then improve when these resolve. The studies discussed above report group findings which may blur the changes in the well-being of individual carers over time. In addition, these studies are cross sectional, asking carers to rate duration in months and/or years. Since the onset of dementia is often uncertain and its progress over time unpredictable, these factors may alter associations

between illness duration and carer well-being. There are no longitudinal studies which would clarify this. Finally, it may be that those carers who are most distressed give up caring, so masking an association between duration and carer mental health.

1.4.6 CONCLUSION

Of all the factors relating to the dementia sufferer's illness discussed above, the most robust association with carer psychological morbidity is that of behavioural disturbance. With regard to physical dependency, the severity of cognitive impairment and the duration of illness, different studies report contradictory findings. All the studies which consider the impact of these factors on carer mental health are cross sectional. Longitudinal studies would assist in clarifying the relationship between them.

PART 1

CHAPTER 5: INTERVENTIONS STRATEGIES WITH CARERS OF DEMENTIA SUFFERERS

There is a growing literature on the effectiveness of intervening with those who care for dementia sufferers. Many studies are entirely qualitative, and provide no outcome data. Those that are more experimental differ widely in their methodology. The study design and results are summarised in Table B (see end of chapter) and discussed in the rest of the chapter.

1.5.1 DIFFERENCES IN THE INCLUSION CRITERIA FOR CARERS

The effects of caring, as measured by carer mental health varies with certain personal and demographic details of the carer and these have been discussed in detail in sections 1.3.2 a-f. In summary, female carers have poorer mental health than male carers (O'Connor et al 1990, Fitting et al 1986, Gilhooly et al 1984) and spouse carers have been shown to have higher rates of psychological morbidity than other relatives (Brodaty and Hadzi Pavlovic 1990). Co-resident carers have poorer mental health than those who live apart (O'Connor et al 1990, Fitting et al 1986, Brodaty and Hadzi Pavlovic 1990). Other factors which may be important include whether the caregiver is the person who is taking foremost responsibility for providing care (primary carer) and how much time the caregiver and care recipient spend together.

Studies vary in the extent to which they standardise their inclusion criteria for carers, or take account of the factors considered above which are associated with a greater risk of psychological morbidity. Such factors may be important determinants of mental health at outset and they may also determine the extent to which a carer is able to benefit from a given intervention. The following sections summarise and contrast the inclusion criteria in the published studies.

1.5.1a CARER GENDER

None of the intervention studies take account of the sex of the carer or attempt to standardise the numbers of men and women in the control and intervention groups. Two studies mention the greater levels of psychological morbidity reported in female carers and so confine their sample to daughter and

daughter in law carers (Toseland et al 1990, Toseland and Smith 1990).

1.5.1b RELATIONSHIP BETWEEN CARER AND CARE RECIPIENT

In terms of the familial relationship between the carer and care recipient, one author confines herself to spouse carers (Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996) and many other studies include only carers who are family members (Toner et al 1987, Glosser & Wexler 1985, Haley et al 1987, Aronson et al 1984, Marples 1986, Safford 1980, Kahan et al 1985, Toseland and Smith 1990, Toseland et al 1990, Zarit et al 1987). However, in the work of Schultz et al (1993), 47% of the carers were friends or relatives other than children or spouses.

None of this work assesses the quality of the emotional relationship between caregiver and care recipient, either premorbidly or while providing care. Although it is not known whether this might effect the capacity to benefit from an intervention programme, feeling affection for the person cared for has been associated with lower carer "perceived stress" (Horowitz and Shindleman 1983), and greater intimacy has been linked to better mental health (Morris et al 1988).

1.5.1c CO-RESIDENCE, PRIMARY CARER STATUS, AND THE TIME THE CARER AND SUFFERER SPEND TOGETHER

The issue of co-residence, the time carer and sufferer spend together and primary carer status are all inter-related. Five studies specify that all carers were primary caregivers who lived with the dementia sufferer (Brodaty and Gresham 1989, Brodaty et al 1994, Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996). Schmidt and Keyes (1985) stated that their sample of carers were all also primary carers and 80% were spouses so probably lived together. In contrast, Haley et al (1987) used a group of family caregivers, some of whom may have been primary carers, and set a lower limit of at least weekly contact. Similarly, Schultz et al (1993) included a diverse group of carers, of whom 25% lived with the care recipient and 50% cared for relatives. 20% of those caring for relatives were spouses but the issue of how many carers were primary carers was not discussed. Two further studies specified that 25% and 50% of their carers respectively took foremost responsibility for caring (Kahan et al 1985, Glosser & Wexler 1985). Other studies were family based so included primary carers and other family members

(Aronson et al 1984, Marples 1986, Safford 1980).

1.5.2 DIAGNOSIS OF THE CARE RECIPIENT

The diagnosis of the care recipient is likely to contribute to the mental health of their caregivers. A recent study compared the mental health of those caring for people with a psychiatric illness (depression or dementia) with those caring for someone who was physically disabled (Livingston et al 1996). Rates of depression as measured by the Short CARE (Comprehensive Assessment and Referral Evaluation) (Gurland et al 1984) (see 1.3.1a) for those aged 65 and over, and according to ICD 10 criteria (see 1.1.3) for those under 65, were found to be 24% for those caring for someone with a psychiatric illness but only 8% in those caring for a physically disabled person. Within the group caring for those with mental health problems, rates of depression were greater for those caring for someone with dementia (32%) than for those caring for someone with depression (18%).

Since the appropriateness of any intervention for a carer may depend on the illness/disability the care recipient is experiencing, it is important that intervention studies clarify the care recipients diagnosis. In addition, given that caring for someone with dementia has been associated with greater psychological morbidity than that found in other groups of carers (Livingston et al 1996), it is important that intervention studies particularly address their needs. Most of the intervention studies discussed below have restricted their sample to carers of dementia sufferers, and specify how the diagnosis of dementia was made. Brodaty and Gresham (1989) include carers of people with DSM111R dementia (American Psychiatric Association 1987) (see 1.1.3). Brodaty et al (1994) studied carers of people with moderate dementia according to the Clinical Dementia Rating Scale (CDRS) (Hughes et al 1982). This instrument assesses cognitive and functional skills so allowing a global assessment of illness severity to be made. Other studies have included carers of subjects who have been diagnosed as having dementia after assessment at a hospital or research centre (Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996, Schmidt and Keyes 1985, Kahan et al 1985) or by a psychiatrist (Toner et al 1987). In several studies, however, it is not clear how the diagnosis of dementia was made (Safford 1980, Aronson et al 1984, Marples 1986, Glosser and Wexler 1895, Haley et al 1987). Brodaty and Gresham (1989) only included subjects who fulfilled DSM111R criteria for a diagnosis of dementia but excluded those carers

who were looking after a relative who was either aggressive or wandered. Since there is an association between certain forms of behavioural disturbance in dementia (particularly those involving aggression) and poor carer well being (see section 1.4.2), it is possible that this study excluded those carers who were most distressed (Gilleard et al. 1984)

Of note, one intervention study involved caregivers of people with both physical and mental illnesses; some had arthritis, or mobility problems, others were depressed, and only 24.5% had a diagnosis of dementia (Schultz et al 1993). Other intervention studies (Toseland and Smith 1990, Toseland et al 1990) specified that the care recipients included were frail elderly people who had two or more chronic illness but did not require that dementia was one of them. As discussed at the beginning of this section, the psychological morbidity of those caring for people with varying difficulties are likely to differ considerably and this may alter their need for and response to intervention programmes.

1.5.3 RECRUITMENT

None of the intervention studies to date have used a representative community sample of those caring for people with dementia. Several studies have drawn their sample from carer support groups (Haley et al 1987, Brodaty et al 1994, Schmidt and Keyes 1985) so will include those carers aware of the diagnosis of the person for whom they care and of the need for both to receive help and support. Other studies have recruited from publicity campaigns so attracting only those carers who are informed and motivated to respond to them (Toseland and Smith 1990, Toseland et al 1990). Both these methods of recruitment are likely to include those carers who are more able to develop their own coping strategies even without intervention. Those studies which recruited from hospital services (Toner et al 1987, Kahan et al 1985, Glosser and Wexler 1985, Aronson et al 1984) may represent a different group of carers, in that they have been selected by the care recipient's need for and acceptance of hospital assessment. These carers are likely to be distressed by the difficulties which prompted hospital referral. In general, it is not stated how the samples are collected and whether all consecutive referral are asked to take part. All these factors which select for particular sufferers and carers may have a bearing on the carers response to intervention.

1.5.4 INTERVENTION PROGRAMMES

Intervention programmes may be rated quantitatively in relation to time input or quantitatively in terms of their content and the skill with which they are delivered. A further consideration is whether they are group based or administered individually.

Time spent with a carer and care recipient is a straightforward measurement. Most intervention studies to date have recorded the number of sessions, the length of the sessions and the time scale over which they were administered (see 1.5.4b). One author conducted an intervention programme that had no time limit (Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996). Qualitative analysis of an intervention would be more complicated in that it would require that a detailed record of the content of each session was made. It might also involve examining the skill with which an intervention was delivered. This would be very lengthy as sessions would need to be tape recorded or videoed and then assessed by independent raters.

In spite of the practical difficulties involved in making qualitative assessments of interventions with carers, it is important in order to evaluate what interventions are of benefit. For instance would time with a supportive person be sufficient or does some form of practical help, emotional support, or behaviour modification need to take place.

1.5.4a GROUP BASED VERSUS INDIVIDUAL INTERVENTIONS

The majority of the interventions are group based (Kahan et al 1985, Glosser and Wexler 1985, Brodaty and Gresham 1989, Brodaty et al 1984, Schultz et al 1993, Haley et al 1987, Schmidt and Keyes 1985, Aronson et al 1984, Marples 1986, Safford 1980). These can address the issues that are common to many carers but are not tailored to the differing needs of individuals nor can they account for individuals varying capacity to benefit from a group situation. However, it is possible that the above intervention studies encouraged carers to raise individual issues in the setting of a support group (as happens in local Alzheimer Disease Society support groups) although this is not clarified.

Seven studies have focused on the needs of individual carers (Mittleman et al 1993, Mittleman et al

1995, Mittleman et al 1996, Mohide et al 1990, Toseland and Smith 1990, Toseland et al 1990, Marriot et al 2000). Family work occurred as part of the intervention programme in the work of Mittleman et al but in all the other studies the interventions were administered to individuals as opposed to groups of carers.

Two further studies compare the effectiveness of group and individual interventions (Toseland et al 1990, Zarit et al 1987). This is discussed in section 1.5.5d)

1.5.4b TIME INPUT OF THE INTERVENTION PROGRAMMES

The time course of the intervention programmes has varied considerably between studies. Many are structured as a 6-8 week course of weekly sessions lasting from 1-2 hours each giving a total time input of 12-16 hours (Kahan et al 1985, Glosser and Wexler 1985, Marples 1986, Safford 1980). Others are longer, lasting from 3-6 months with a total time input of 18-39 hours (Brodaty et al 1994, Schultz et al 1993, Schmidt and Keyes 1985). In a further study, carers received 14 intervention sessions over a 28 week period but no information is given about the length of each session (Marriot et al 2000) and so no total time input can be estimated. In the work of Mittleman et al (1993, 1995, 1996) the time input of the intervention had no upper limit, in that carers were encouraged to contact the "counsellor" whenever they had a problem. In the case of one descriptive study, sessions lasting one and a half hours occurred at weekly intervals and it was planned that the sessions should continue after the study ended (Aronson et al 1984).

1.5.4c THE CONTENT OF THE INTERVENTION

Interventions studies with carers of dementia sufferers have included various components: education about dementia; techniques for managing behavioural difficulties; practical advice on financial and legal aspects; information about day care and respite facilities and emotional support. These are considered below.

EDUCATION

Education was a component of many intervention studies (Brodaty et al 1994, Schultz et al 1993,

Brodsky and Gresham 1989, Toner et al 1987, Haley et al 1987, Kahan et al 1985, Glosser and Wexler 1985, Marriott et al 2000). This was delivered verbally as teaching sessions in most cases and also included written material in two studies (Brodsky et al 1994, Marriott et al 2000). In another study the entire intervention used only written material (Toner et al 1987). The education package consisted of an explanation of the brain changes that occur in dementia and how this might lead to alterations in personality, memory and behaviour in the sufferer.

TECHNIQUES FOR MANAGING BEHAVIORAL DIFFICULTIES

Techniques for managing behavioural problems were a focus of several intervention programmes (Haley et al 1987, Kahan et al 1985, Glosser and Wexler 1985, Safford 1980, Marriott et al 2000). However, these give little detail as to the precise strategies used. For instance, in one paper, readers are told that one of the goals for each group of 10-20 participant carers was to learn "skills for managing behavioural, legal/financial, social and interpersonal problems" (Glosser and Wexler 1985). In another, the management of behavioural problems is covered in didactic information sessions in which carers are taught about the medical and neurological aspects of Alzheimer's disease (Kahan et al 1985). Since behavioural disturbance in dementia is both individual and situational, it is questionable how effectively behavioural difficulties could be addressed in the group settings described in these papers. However, general principles such as avoiding confrontation might be helpful and carers could advise each other from their own experience on how to cope with particular difficulties. One study included role play, as well as advice on managing problem behaviours, in order to help carers gain confidence in managing them (Marriott et al 2000).

PRACTICAL ADVICE ON FINANCIAL MATTERS, LEGAL ISSUES AND DAY CARE

Several studies have included practical advice on finance, legal matters, day care, home nursing, and residential care as a component of their intervention programme (Haley et al 1987, Kahan et al 1985, Glosser and Wexler 1985, Safford 1980, Marriott et al 2000). Such information is invaluable to some carers but others might be unable to use it without practical support from, for instance, a community psychiatric nurse or social worker.

EMOTIONAL SUPPORT

A central focus of many intervention programmes has been the emotional needs of carers. Some focused on stress management and coping skills (Haley et al 1987, Schultz et al 1993, Brodaty and Gresham 1989, Brodaty et al 1994, Kahan et al 1985, Marriott et al 2000). All these studies with the exception of Kahan et al (1985) and Marriott et al (2000) also provided supportive psychotherapy within a group setting as did Schmidt and Keyes (1985) and Glosser and Wexler (1985).

All the studies mentioned above evaluate interventions that have many components to them. A recent meta-analytic study of intervention with caregivers (Knight et al 1993) guarded against this approach of multifaceted interventions which throw in "everything but the kitchen sink" as the authors considered this unhelpful to the progress of science. They concluded that more studies are needed which compare theoretically grounded interventions separately. Whereas, it is clearly important to assess separately the effects of specific interventions, it is perhaps unlikely that the impact of single interventions are going to be the same for different carers managing relatives who may have different problems. Therefore, it seems likely that individualised interventions strategies may ultimately prove to be the most effective.

1.5.4d THE PROFESSION OF THE WORKER(S) IMPLEMENTING THE INTERVENTION

As the intervention programmes focused on a number of areas, many employed a number of people from varying disciplines to implement different components of them. Most studies used a combination of social workers, nurses, psychologists and psychiatrists (Kahan et al 1985, Glosser and Wexler 1985, Haley et al 1987, Schmidt and Keyes 1985, Aronson et al 1984). Although this allows the carers to benefit from the expertise of different professional groups, a possible drawback of this approach is that it does not encourage a relationship between the carer and the professional worker. Such a relationship might facilitate the discussion of more difficult or painful issues and provide a person to whom carers could turn for help. In a recent study, all components of the intervention programme, carer education, stress management and coping skills training were provided by one person, a clinical psychologist, so allowing a therapeutic relationship to develop (Marriott 2000). Other studies used counsellors whose professional backgrounds are not specified (Brodaty and Gresham 1989, Schultz et al 1993, Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996, Marples 1986).

One study compared the effectiveness of professionals and peers at providing individual counselling for caregivers (Toseland and Smith 1990). The carers were all daughters or daughters in law, and the care recipients were described as "frail elderly" but not specified as having dementia. The measures employed, in this study, to compare caregivers well-being before and after counselling were the Zarit Burden Interview (Zarit et al 1980) (see 1.3.1a), the Brief Symptom Inventory (Derogatis and Spencer 1982) (see 1.3.1a) and the Bradburn Affect Balance Scale (Bradburn 1969). The last of these is a measure of overall emotional well being and has good construct validity and test-retest reliability (Bradburn 1969). The scale consists of 10 items, five concerning negative affect and five relating to positive affect. Each is rated on a four point scale. The study showed that both peer and professional counselling was significantly more effective than no treatment. Peer and professional counselling led to similar improvements in the Zarit Burden Interview Score and the Bradburn Affect Balance Scale Score. The results using the Brief Symptom Inventory showed that whereas both peer and professional counselling were equally successful at reducing the overall score (ie the Global Distress measure) and the anxiety subscale, only the professional counselling significantly reduced the depression and hostility subscale scores. This suggests that although peer counselling can be effective in improving emotional distress, it may not be effective in reducing depressive symptoms. Also, as the care recipients in this study did not have dementia, the results may not apply to this group of caregivers.

1.5.5 OUTCOME OF THE INTERVENTION STUDIES

Several intervention studies have simply described the intervention programme they had devised. These were not experimental so they neither used a control group nor provided outcome data (Safford 1980, Marples 1986, Aronson et al 1984, Schmidt and Keyes 1985). In their conclusion, the authors of these papers affirm the importance of support group interventions for carers based on their personal experience of running them. Those studies which evaluate the efficacy of an intervention programme do so in four ways:

1. According to rates of institutionalisation
2. From the unstructured reports of carers

3. By change in carer mental health as measured by a rating scale
4. By comparing two different intervention strategies as opposed to comparison between a single intervention and a control group (Zarit et al 1987, Toseland et al 1990). These studies compare individual/family with group based interventions and use a range of outcome measures including those listed in 2 and 3 above. They also measure change in social support. A comparison of the efficacy of individual and group based interventions is considered separately in section 1.5.5d.

1.5.5a RATES OF INSTITUTIONALISATION

Four studies have examined rates of institutionalisation. Both found a lower rate following intervention when compared to a control group (Brodaty and Gresham 1989, Mittleman et al 1993, Mittleman et al 1995, Mittleman et al 1996). The former reported that 80% of the intervention group members were still living in the community at 30 month follow up, compared with only 35% in the control/waiting list group. The work of Mittleman et al has extended over a long time period but in her 1993 publication only 10% of the treatment group but 23% of the control group were living in residential care 12 months after the study started. In spite of finding a similar outcome, the interventions employed were very different. Brodaty and Gresham (1989) implemented a group based programme that involved education about dementia, stress management, techniques for managing difficult behaviours and group support. However Mittleman et al (1993) developed an individual and family based intervention that focused on education and counselling.

1.5.5b CARER REPORTS

Seven studies asked carers whether they found the intervention programme helpful, and all reported that carers felt they had benefited from them (Glosser and Wexler 1985, Schulz et al 1993, Haley et al 1987, Brodaty et al 1994, Zarit et al 1987, Toseland et al 1990, Toseland and Smith 1990). However one of these did not use a control group (Glosser and Wexler 1985), and another was controlled but did not randomly assign carers to the control and intervention groups (Schulz et al 1993). The authors explained that random assignment was not possible because of the constraints imposed by caregivers circumstances, such as geographical location and carer employment. Whereas this can be understood

pragmatically, the point of random allocation is to prevent such factors having an effect on outcome. In a further study, recruitment to the control group occurred 6 months before the study began, although the authors stress that they were recruited from the same sources as those who were later recruited into treatment groups (Toseland and Smith 1990). In a parallel study by the same author, it is stated that participants were randomly assigned to control and treatment groups within the "constraints of their schedules and the county in which they lived" (Toseland et al 1990).

Three studies were randomised controlled trials (Haley et al 1987, Brodaty et al 1994, Zarit et al 1987). The first of these asked carers to rate overall satisfaction on a scale of 1-5. Seventy six percent of participants endorsed the highest level of satisfaction. In the second study, 62% reported that the intervention programme had been valuable, 18% reported that they had found it irrelevant and 20% made no comment. Finally, in the third study, carers were asked to make a global rating of change following intervention, on a seven point scale from very much better (7) to very much worse (1). The scores for change ranged from 4.5-5.5. These positive evaluations cannot be attributable to an improvement in carer mental health as in all three studies this failed to improve (see 1.5.5c and d). However the results suggest that the carers valued the support they received and found it helpful.

1.5.5c CHANGE IN CARER MENTAL HEALTH

Nine studies measured outcome in terms of change in carer mental health according to a rating scale (Toner et al 1987, Kahan et al 1985, Brodaty and Gresham 1989, Brodaty et al 1994, Schultz et al 1993, Haley et al 1987, Zarit et al 1987, Toseland et al 1990, Mittleman et al 1995). All of these were controlled, although in one case the control and intervention groups were significantly different at outset according to their GHQ score (Toner et al 1987) and in another two random allocation of carers into control and intervention groups was either uncertain (Toseland et al 1990) or did not happen for the reasons described above (Schultz et al 1993).

Four controlled studies measured carer mental health using the General Health Questionnaire (GHQ) (Goldberg and Hillier 1979) (see section 1.3.1a). Three of these reported a fall in GHQ score following intervention (Toner et al 1987, Brodaty and Gresham 1989, Marriott et al 2000). The interventions

implemented were very different. The first only provided written information for carers. The second provided a group programme of education, stress management, techniques for managing difficult behaviours and group support. The third study provided an operationalised intervention involving carer education, stress management and coping skills. The fourth study found no change following intervention (Brodaty et al 1994) although the intervention had all the same components as the second study which reported a positive outcome (Brodaty and Gresham 1989).

There are four further studies which measure change in carer mental health using depression scales namely the Zung Depression Scale (Kahan et al 1985) (see section 1.3.3a), and the Beck Depression Inventory (Haley et al 1987) (see 1.3.1a) (Marriot et al 2000) and the Geriatric Depression Scale (Yesavage et al 1983). The first two instruments have been criticised for being unsuitable in the assessment of depression in the elderly (see 1.3.1a) (Bowling 1991) but the last instrument was specifically designed for use with elderly people. Kahan et al (1985) reported a fall in the Zung depression score, although Haley et al (1987) find no change in the Beck score, Marriot et al (2000) report a significant reduction. The studies of Kahan et al (1985) and Haley et al (1987) implement similar intervention programmes in that they both were group based, last about 16 hours in total, and involving education about dementia, practical advice and techniques for managing difficult behaviours. Differences between the studies are that Kahan et al (1985) provided stress management and taught coping skills and Haley et al (1987) provided group support. This may account for the difference in outcome but a further possible explanation is the use of different instruments. The study by Marriot et al (2000) assessed carers individually and implemented a longer intervention involving carer education, stress management and coping skills. The work of Mittleman et al (1995) involved no limit in terms of time and was a multi-faceted intervention involving individual and family counselling, support group sessions and the continuous availability of counsellors to help with crises as they occurred.

Two further studies compare change in carer mental health in relation to interventions delivered either individually or in a group setting. The outcome of these studies is discussed separately below (1.5.5d).

A final consideration in assessing the benefit of interventions with carers, is the duration of any

improvement in their mental health. Components of intervention programmes such as education about dementia, stress management and coping skills may be of benefit long after the intervention is complete since the knowledge and skills acquired could be useful as the dementia progresses. However the need for emotional support is likely to continue as is the help required in managing behavioural difficulties, which are likely to change over time. Thus, a 6-8 week programme may be sufficient to effect a short term improvement in carer well being, without being of long term benefit. One study addresses duration of improvement in mental health (Brodaty and Gresham 1989). Twelve months after the intervention finished, carer psychological morbidity as measured by the GHQ was better than 6 months afterwards, suggesting a long term effect of the intervention programme.

1.5.5d COMPARISON OF INDIVIDUAL AND GROUP BASED INTERVENTIONS

In the conclusion of their study, Brodaty et al (1994) suggested that group interventions with carers fail to improve carer well because they are unable to cater for the needs of individual carers. They state that further studies are needed to evaluate the effect of intervention studies which are implemented individually. However, studies of individual intervention strategies have also had variable results and these are discussed below (see Table B for summary of methodology and results).

In one study by Mittleman et al (1993) mentioned earlier, individual counselling served to delay institutionalisation, but had no effect on carer depression as measured by the Geriatric Depression Scale (Yesavage et al 1983). However further work by the same author reported a decrease in depression using the same measuring scale.

The work of Mohide et al (1990) compared conventional community nursing care with an experimental intervention consisting of caregiver focused health care, education about dementia, regular respite, attending a self help support group and assistance with problem solving. This package of care was delivered individually in the home. All care recipients had dementia and all caregivers lived with the dementia sufferer. Following the intervention, carers in the experimental group were found to have no reduction in depression according to the Centre for Epidemiological Studies Depression Scale (CES-D) (see section 1.3.1a) or in anxiety according to the State-Trait Anxiety Inventory (Spielberger et al 1968).

However using a measure of quality of life devised by the author called the Caregiver Quality of Life Instrument (Mohide et al 1988), there were improved ratings for the experimental group but scores for the control group showed a deterioration.

A further study (Zarit et al 1987), also with primary caregivers of dementia sufferers compared interventions designed to be similar in content but delivered either in a group setting or in individual and family counselling sessions. Each received eight sessions covering education about dementia, management of behavioural problems, and ways to access formal and informal support. Thus the difference between the treatments was in their mode of delivery rather than in their content. In the support group, the facilitator used interactions between carers to achieve therapeutic goals whereas in the individual/family group the focus was on the carers needs and involving other family members. Carer psychological well being was measured using the Burden Interview (Zarit and Zarit 1982), and the Brief Symptom Inventory (Derogatis and Spencer 1982) (see 1.3.1a). Although scores for both of these measures decreased following intervention, this did not differ significantly from the changes seen in the control no treatment group. Distress caused by memory and behaviour problems measured using the Memory and Behaviour Problem Checklist (Zarit and Zarit 1982) also did not differ between treatment groups. Only one difference between the group support and individual counselling treatments was significant and that was that members of the latter group reported feeling more supported.

A fourth study differs from the two discussed previously in that carers were limited to daughters and daughters in law only, and the care recipients were "frail elderly" but not specified as having a dementing illness (Toseland et al 1990). It is similar to the study of Zarit et al (1987), in that the study compares individual counselling with group counselling while keeping the length and content of the interventions the same. The details given regarding the intervention are sparse except that counsellors used validation of the caregiving experience, encouragement and praise, and affirmation of the carers ability to cope. Measures used for assessing carer psychological well being were the Zarit Burden Interview (see 1.3.1a), the Bradburn Affect Balance Scale (1.5.4d) and the Brief Symptom Inventory (see section 1.3.1a). Following intervention, the scores for the Bradburn Affect Balance Scale did not differ between treatment groups but the Zarit Burden Inventory Scores fell significantly more in those receiving

individual rather than group counselling although neither treatment option differed significantly from that seen in the control group. The results for the Brief Symptom Inventory scores showed that those in both intervention groups had lower total scores than those in the control group, but were not significantly different from each other. However, when the subscales of the Brief Symptom Inventory were compared, those in the individual counselling group had lower scores than the control group on seven subscales, but the group counselling group had a lower score than the individual counselling group on only one subscale. Although individual counselling seemed superior in reducing psychological symptoms, the group counselling participants experienced greater expansion in both their formal and informal social support. Both treatment groups were equally satisfied with the help they received.

There is a further study which evaluated a family intervention involving carers who scored as cases according to the General Health Questionnaire and dementia sufferers who fulfilled DSM-IV criteria for a dementing illness of the Alzheimer's type (Marriot et al 2000). The term "family intervention" suggests that members of the dementia sufferers family other than just the primary carer were involved but this is not clarified. The description of the intervention programme concentrates on the primary carer and describes three components: carer education, stress management and coping skills. It is delivered in 14 sessions at two week intervals. Following the intervention, carers had significantly lower GHQ scores, levels of GHQ caseness and Beck depression scores than did control group carers. Interestingly although no component of the intervention directly involved the dementia sufferer, a consequence of the intervention was that the number of psychiatric and behavioural symptoms reported by the carer as occurring in the dementia sufferer declined. This may be because the intervention, via role play, involved assisting the carer develop skills for managing problem behaviours or simply reflect the carers improved mental health.

A recent meta-analysis reviewed 20 interventions studies with caregivers reported that individualised interventions could be moderately successful in improving carer well being (Knight, Lutzky and Macofsky-Urban 1993). They compared studies using "effect size", which is the difference between the change in the intervention group and the control group divided by the standard deviation. Thus an effect size of zero indicates no difference and an effect size of 1 is considered strong, 0.5 moderate and 0.3

weak. The outcomes were rated according to Zarits Burden Inventory (see 1.3.1a) or "emotional dysphoria" which is the term used by the authors to bring together many measures of carer psychological morbidity including depression scales, symptom scales such as the Brief Symptom Inventory, and life satisfaction measures. The study reports that the effect sizes for individual interventions were approximately twice as large as for group interventions (burden: 0.41 vs 0.15, emotional dysphoria: 0.58 vs 0.31 respectively).

Thus there is evidence that individually administered interventions are superior to those delivered in a group setting in terms of their efficacy in improving carer burden, and emotional dysphoria (Knight et al 1993), and according to other measures such as quality of life (Mohide et al 1990), and feeling supported (Zarit et al 1987). However there is less evidence that they are superior in terms of their effect on carer mental health.

1.5.5e SUMMARY

Overall given the many differences in the methodology of these studies, and the quantitative and qualitative differences in the interventions implemented, the outcome data, where it exists, is inconclusive.

There are only two randomised controlled trials of intervention programmes using instruments that are valid and reliable, carers who are primary carers living with a care recipient who has dementia, and involving sufficient sample sizes (Brodaty and Gresham 1989, Brodaty et al 1994). As mentioned above, the latter study concludes by suggesting that the lack of efficacy of their intervention may be because it was group based so could not cater for the needs of individual carers and care recipients.

There are several studies which compare individual and group based interventions and these produce little evidence to suggest that the latter are more effective although a meta-analytic review of intervention studies concluded that individual interventions were more effective. These comparison studies compare interventions with a similar content being delivered in a different way. Thus, although the interventions may have been administered individually, they were designed on the basis of group needs so were

probably fairly uniform in content. Thus, the intervention was not designed to cater for the needs of individual carers.

1.5.6 CONCLUSION

In order to expand on the work done to date, there is a need for future studies to assess the needs of individual carers in their own home so that their particular difficulties can be addressed in context and intervention strategies devised. These could then be implemented on an individual basis so that the pace and the length of the intervention could vary according to the needs of the carer. In addition, ideally the sample of subjects and carers should be recruited in an epidemiologically sound way so that particular groups of carers such as those who attended carers groups or those whose relatives have been referred to psychiatric services are not over-represented. Finally if a detailed account was kept of the intervention as it was being implemented, a qualitative assessment could be made. If the interventions were effective, it would be useful to perform multivariate analyses in order to examine what components of a package of measures might be particularly effective.

TABLE B: Studies of intervention strategies with carers of dementia sufferers

REFERENCE	SAMPLE RECRUITMENT	DEFINITION OF CARER	DIAGNOSIS OF SUBJECT	CONTENT OF INTERVENTION	IMPLEMENTATION a) individual or group b) by who	TIME COURSE	CONTROL GROUP (YES/NO)	RANDOM-ISATION (YES/NO)	OUTCOME (OBJECTIVE)	OUTCOME (SUBJECTIVE)
Safford (1980)	Not clear	- primary carers only - all relatives	Dementia (not clear how diagnosis was made)	- Education - Practical advice - Group Support	- Group based - Developed by social worker - Unclear who implemented it	- 2 hourly sessions - weekly for 6 weeks = 12 hours	No control group	N/A	NONE	NONE
Aronson et al (1984)	Hospital referrals	- all primary carers - all relatives	Dementia (not clear how diagnosis was made)	- Group support	- Group based - By psychiatrist, psychologist, nurse and social worker	- 1 ½ hourly sessions - Weekly - Ongoing	No control group	N/A	NONE	NONE
Kahan et al (1985)	Hospital referrals	- 25% primary carers - all relatives (19/40 spouses) - 50% live with subject	Dementia (hospital diagnosis)	- Education - Practical advice - Managing stress - Developing coping skills - Techniques for managing behavioural difficulties	- Group based - by social worker	- 2 hourly sessions - 8 sessions = 16 hours	No control group	N/A	↓ Zung depression score ↓ for family burden ↑ for knowledge	NONE
Glosser & Wexler (1985)	Hospital referrals	- 50% primary carers - all relatives (58% children, 27% spouses, 15% siblings/in laws)	Dementia (not clear how diagnosis was made)	- Education - Practical advice - Techniques for managing behavioural difficulties - Group support	- Group based - by psychologist and social worker	- 2 hourly sessions - 8 sessions = 16 hours	No control group	N/A	NONE	Positively regarded
Schmidt & Keyes (1985)	Support group attenders Hospital referrals	- all primary carers - all relatives (8/10 spouses) - not clear whether live together	Dementia (hospital diagnosis)	- Group support	- Group based - Psychiatrist and social worker	- 1 ½ hourly sessions - weekly = 39 hours	No control group	N/A	NONE	NONE
Marples (1986)	Not clear	- all primary carers - all relatives	Dementia (not clear how diagnosis was made)	- Education - Group support	- Group based - by unspecified personnel	- 90 minute sessions - weekly - for 8 weeks = 12 hours	No control group	N/A	NONE	NONE

REFERENCE	SAMPLE RECRUITMENT	DEFINITION OF CARER	DIAGNOSIS OF SUBJECT	CONTENT OF INTERVENTION	IMPLEMENTATION a) individual or group b) by who	TIME COURSE	CONTROL GROUP (YES/NO)	RANDOMISATION (YES/NO)	OUTCOME (OBJECTIVE)	OUTCOME (SUBJECTIVE)
Toner et al (1987)	Hospital referrals	- all primary carers - all relatives - all living with subject or nearby	Dementia (psychiatrist's diagnosis)	- Education (written material only)	- No personnel	time between initial assessment and follow up was 5 weeks	YES (but those in intervention groups had higher GHQ scores at outset)	NO (patients matched according to physical dependency)	↓GHQ score	NONE
Haley et al (1987)	Support group attenders	- all relatives - contact at least weekly	Dementia (not clear how diagnosis was made)	- Education (written and teaching) - Practical advice - Group support - Techniques for managing behavioural difficulties	- Group based - by nurses, social worker, psychologist	- 1 ½ hourly sessions - 11 sessions over 3 months = 16 ½ hours	YES	YES	Beck Depression Inventory - no change Social network - no change	Positively regarded
Zarit et al (1987)	Outreach: by contacting local agencies serving older people newspaper items asking for volunteers	- all relatives - all primary carers - 80% live together	Dementia < 20 on MMS < 8 on MSQ	- Education - Management of behavioural problems - Identification of supports - Delivered in either a) support group setting b) by individual counselling	- Group and individually based interventions compared - by unspecified therapists	-1 hourly sessions - weekly -8 sessions = 8 hours	YES	YES	↓ Burden Interview (significant) ↓ Brief Symptom Inventory (but not significant)	Those receiving individual counselling felt more supported
Brodsky & Gresham (1989)	Members of an Alzheimer Association Publicity campaign	- all primary carers - all living with subject	Dementia (DSMIII-R criteria) (excluded the most behaviourally disturbed)	- Admission to hospital - Education - Managing stress - Group support (some family work) - Techniques for managing behavioural problems - Developing coping skills	- Group based intervention - by unspecified personnel	Unclear	Waiting list control group	YES	↓ GHQ score ↓ Institutionalisation	NONE

REFERENCE	SAMPLE RECRUITMENT	DEFINITION OF CARER	DIAGNOSIS OF SUBJECT	CONTENT OF INTERVENTION	IMPLEMENTATION a) individual or group b) by who	TIME COURSE	CONTROL GROUP (YES/NO)	RANDOMISATION (YES/NO)	OUTCOME (OBJECTIVE)	OUTCOME (SUBJECTIVE)
Toseland et al (1990)	Publicity campaign by media Contacting social services	- all daughters or daughters-in-law - all primary carers - not clear how many lived with subject	"Frail elderly" - not specified as having dementia - two or more chronic illnesses	- Validation and confirmation of care giving experience - Encouragement and praise - Affirmation of ability to cope	- Group and individually based interventions compared - by unspecified therapists (highly trained)	- 2 hourly sessions - weekly - for 8 weeks = 16 hours	YES	NO (randomised within the constraints of personal schedules and county of origin)	Bradburn Affect Scale - no change Zarit Burden Interview - ↓ (no difference between intervention and control groups) Brief Symptom Inventory - ↓ (no difference between intervention groups)	Positively regarded (by both intervention groups with no difference between them)
Toseland & Smith (1990)	Publicity campaign by media Contacting social services	- all daughters or daughters-in-law - all primary carers - not clear how many lived with subject	"Frail elderly" - not specified as having dementia - two or more chronic illnesses	- Unspecified counselling	- Individual intervention - comparison of counselling by peers with professional counselling	- 1 hourly sessions - weekly - for 8 weeks = 8 hours	YES	NO (those in control group recruited at a different time although by the same method)	Bradburn Affect Balance scale- no change Zarit Burden interview - no change Brief Symptom Inventory - no change	Positively regarded
Mohide et al (1990)	Not clear ("from an urban centre")	- all primary carers - all lived with subject	Dementia ≥ 8 on DRS < 19 on MMS stage 5 on Reisburg Scale	- Education and reading material - Advice on behavioural problems - Group support - 4 hours respite per week	- Individually based intervention - by nurses	- weekly visits - for 6 months	YES	YES	CES-D - no change State Trait Anxiety Inventory - no change Caregiver Quality of Life - ↑	NONE
Mittleman et al (1993)	Hospital referrals Alzheimer Association members Day Centre attenders	- all primary carers - all spouses - all living with subject	Dementia (hospital diagnosis)	- Education - Individual and family counselling	- Implemented to individuals and their families - by unspecified counsellors	- variable	YES	YES	↓ Institutionalisation	NONE

REFERENCE	SAMPLE RECRUITMENT	DEFINITION OF CARER	DIAGNOSIS OF SUBJECT	CONTENT OF INTERVENTION	IMPLEMENTATION a) individual or group b) by who	TIME COURSE	CONTROL GROUP (YES/NO)	RANDOMISATION (YES/NO)	OUTCOME (OBJECTIVE)	OUTCOME (SUBJECTIVE)
Shultz et al (1993)	Publicity campaign	- 50% relatives - 25% lived with subject	Dementia (24.5%) Depressed (30%) Mobility problems (25%)	- Education - Managing stress - Developing coping skills - Group support	- Group based - by unspecified personnel	- 2 ½ hourly sessions - 9/4 ½ months = 22 ½ hours	YES	NO (said to be not possible because of differing caregiver circumstances)	↓ State Anxiety Score	Positively regarded
Brodsky et al (1994)	Support group attenders	- all primary carers - all living with subject	Dementia (according to Clinical Dementia Rating Scale [CDRS])	- Education (written and teaching) - Managing stress - Developing coping skills - Techniques for managing behaviour - Group support	- Group based intervention - by social worker and other unspecified co-ordinator	- 18 hours over 4 months	Waiting list control group	NO (allocation into control and intervention groups according to which support group attended)	GHQ - no change	Positively regarded
Mittleman et al (1995)	Hospital referrals Alzheimer's Association members Day centre attendees	- all primary carers - all spouses - all living with subject	Dementia (hospital diagnosis)	- Individual spouse and counselling sessions - Weekly support group - Continuous availability of counsellors to help in crises - Education	- To individual spouses and their families - Unspecified counsellors (experienced)	- unlimited	YES	YES	↓ Score	None
Mittleman et al (1996)	Hospital referrals Alzheimer's Association members Day centre attendees	- all primary carers - all spouses - all living with subject	Dementia (hospital diagnosis)	- Individual and family counselling sessions - Weekly support group - Continuous availability of counsellors to help in crises - Education	- To individual spouses and their families - Unspecified counsellors (experienced)	- unlimited	YES	YES	↓ Institutionalisation	None
Marriot et al (2000)	Hospital referrals	- all primary carers - all living with subject	DSMIII-R dementia of the Alzheimer's type	- Carer education (written and teaching) - Stress managing - Coping skills training	- Family intervention by clinical psychologist	- 14 sessions over 28 weeks	YES	YES	GHQ ↓ GHQ caseness ↓ Beck Depression scores ↓	None

PART 2

INTRODUCTION

SUMMARY OF PART 1

Previous literature has established that behavioural difficulties are common in dementia (Burns et al 1990, Swearer and Drachmann 1988) and that they have an adverse effect on carer well being (see 1.4.2). Where carer mental health is compromised, and fails to improve with intervention, this has been found to predict institutionalisation (Gilleard 1987). Thus with an ageing population, a consequent increase in the numbers of people with dementia, and government policy to care for elderly people in the community (NHS and Community Care Act 1993), there is a growing need to manage behavioural problems in dementia in a community setting. Some of the studies on managing behavioural problems in dementia have focused on single treatment strategies such as drug treatment (Lawlor et al 1994, Howard and Levy 1993) or behavioural interventions (Vaccaro 1988). Other work has focused on improving carer well being but the interventions have also involved sessions on managing behavioural problems (Brodaty and Gresham 1989, Brodaty et al 1994). These have mostly been group based delivering a fixed number of sessions on different aspects of dementia to a selected group of carers. Interventions with carers are reviewed in part 1.5.1-6; it is concluded that there is no consensus in the literature as to what measures are effective in improving carer mental health and that further studies are needed which evaluate the efficacy of interventions which are both individually designed to meet the needs of carers and individually implemented. The aim of this thesis was to conduct such a study.

OUTLINE OF PART 2

In the first instance, a pilot study was performed. The hypothesis was that behavioural disturbance in dementia could be effectively managed either pharmacologically or by behavioural techniques and that where this was successful, carer psychological morbidity would reduce. The methodology of this study, the results and the discussion are included in chapter 1. There were certain limitations to this study and with the experience gained from it, a further substantive study was planned (subsequently referred to as "the main study"). The hypothesis was refined such that the main study was an evaluation of a multi-disciplinary, case management approach to managing behavioural difficulties in dementia (using pharmacological, behavioural or social interventions as appropriate) and there were

two outcome measures: change in the behaviour of the dementia sufferer and change in carer mental health. Individual packages of care were devised which were tailored to the needs of dementia sufferers and their carers and these were implemented in the setting of their own homes. This second study is described in chapter 2, the results are given in chapter 3 and the discussion in chapter 4.

CHAPTER 1 THE PILOT STUDY

2.1.1 DESIGN OF THE STUDY

2.1.1a HYPOTHESIS

The hypothesis was that behavioural disturbance in dementia sufferers could be successfully managed using pharmacological or behavioural treatments and that this would lead to an improvement in the psychological health of their carers.

2.1.1b RECRUITMENT

The pilot study recruited people with dementia living with carers in the community and attending a local day centre. This decision was made, in part, for pragmatic reasons. The research project had funding for just six months and good working relationships already existed with the day centre in question so reducing the time needed to recruit people into the study. However a further reason for choosing a day centre sample was to see if day centre staff could help implement behavioural change. Carers were approached individually and if they were interested in taking part in the study they were asked to sign a consent form. Initial assessment involved interviewing both the carer and the person with dementia.

2.1.1c INSTRUMENTS USED IN ASSESSMENT

Carers were first interviewed using the General Health Questionnaire (see 1.3.1a) as a measure of probable psychiatric morbidity. This was chosen because it concentrates on broader components of psychiatric morbidity such as anxiety and depression and was designed to be used in community settings. A further advantage of this scale is that it exists in many shortened forms and although this shortening slightly compromises validity and reliability it is appropriate for use with frail elderly people because it is less arduous to complete. This becomes an ever more important consideration in designing research projects that involve many instruments. The GHQ has been widely used in other studies with carers of dementia sufferers, and so a further reason for choosing this instrument was to allow comparison with other studies. The version GHQ-28 was used which was specifically designed for research purposes, has four subscales measuring somatic symptoms, anxiety and insomnia, social dysfunction and severe depression; it has a cutpoint for caseness of 4-5. Carers were then asked to

complete the Stockton Geriatric Behaviour Rating Scale (SGBRS) (Meer and Baker 1966) which is a questionnaire designed to detect behavioural disturbance in people with dementia from carer reports. The instrument has 33 items and includes four subscales measuring physical disability (PD), apathy (AP), communication failure (CF), and socially irritating behaviour (SIB). It was chosen because it was the most detailed behaviour assessment questionnaire available at the time. Following completion of the SGBRS, carers were asked if there were any behaviours they found particularly distressing or hard to manage.

People with dementia were assessed using the Short CARE (Comprehensive Assessment and Referral Evaluation) (Gurland et al 1977)(see 1.3.1a) and the Mini Mental State Examination (Folstein et al 1975) (see below). A diagnosis of dementia was made using the former instrument. This is a semi-structured instrument derived from the core CARE (Golden et al 1984). The instrument focuses on diagnosing dementia and also depression which is important because of the detrimental effect low mood can have on cognitive performance. The advantage of the shortened version is that it takes about 30 minutes or less to complete whereas the core CARE can take over an hour. The CARE interview has been tested against psychiatric assessments and shows satisfactory levels of agreement of 0.73 (Toner et al 1988).

The Mini Mental State Examination (MMSE) was used to assess dementia severity. It consists of a series of short subtests designed to elicit information about orientation, registration, attention, calculation ability, recall, language and praxis. Summing the points assigned to each subtest produces a score from 0-30. A score of 23 or lower suggests sufficient cognitive decline that a diagnosis of dementia is likely. The instrument is quick to administer and so is often used as a screening instrument for cognitive impairment and for serial assessments. Its validity has been established by correlation with other psychometric tests and neuroimaging and high test-retest and inter-rater reliabilities have been established (Cockrell and Folstein 1988). A drawback of the instrument is that performance may be influenced by educational level so that it is not a good diagnostic instrument and a different cutpoint of seventeen has been suggested for those with less than nine years of education (Cockerall and Folstein 1988). It was chosen in this study, not as a diagnostic instrument but in order to assess

dementia severity.

2.1.1d PLANNING AND IMPLEMENTING THE INTERVENTION

In cases where carers reported behaviours they were finding distressing or difficult to manage, the specific behaviours were monitored by carers and in some instances by day centre staff also. To establish a baseline over a two week period, charts were kept noting the time each episode of behaviour occurred, its duration and antecedents.

A decision was then made by the author in conjunction with the supervising consultant, as to whether the behaviour was most appropriately managed psychologically or pharmacologically. In the former case behavioural interventions were planned with a psychologist. In the latter, a drug was prescribed after discussion with the general practitioner caring for the dementia sufferer. The interventions were then implemented by the author and throughout the intervention period the same charts as used in the baseline assessments were kept to record any changes in behaviour. Finally, the rating scales used in the initial assessment were repeated.

2.1.2 RESULTS OF THE PILOT STUDY

2.1.2a DEMOGRAPHY

The sample consisted of 16 subjects. 12 were women and four were men. The mean age was 77 years. One subject had pre-senile dementia (aged 33). Fifteen subjects were cared for by relatives (10 spouses, four children, and one sibling. The remaining subject was cared for by an adult fosterer. During the study, four subjects were lost to follow up: two died, one entered residential care and one was admitted to hospital.

2.1.2b INTERVENTIONS IMPLEMENTED

Seven carers reported that they had problems coping with specific behavioural difficulties. Of the seven, one died, one entered residential care and another did not wish to proceed with the intervention. The remaining four cases form too small a group to warrant statistical analysis, but are described below.

CASE 1

The carer of an 82 year old lady (MMSE 12) reported that her incessant talking was very irritating. During the assessment period, it was noted that she was unable to bring her thoughts to a conclusion. The carer was taught to interject with a relevant question requiring a simple answer. Using this technique, he was able to take control and reduce her excessive chatter. His GHQ fell from 20 to six.

CASE 2

An 89 year old lady (MMSE 12) had a disturbed sleep pattern and 80% of the time woke between 3.00am and 4.30am despite night sedation. Measures taken were to reduce her fluid intake after 8.00pm, toilet her before bedtime and to prevent her sleeping during the day by teaching her carer distraction techniques. Following the implementation of this programme, she slept until 5.00am more than 80% of the time. Her carer's GHQ fell from 26 to zero.

CASE 3

A 76 year old lady (MMSE 5) was generally restless and paced up and down throughout the day. Her husband found this particularly troublesome when she awoke early in the morning. After commencing Temazepam 20mg nocté, she woke before 5.00am only half as often as before (ie from 60% - 30% of nights). His GHQ fell from seven to three.

CASE 4

An 81 year old lady (MMSE 11) had spontaneous outbursts of verbal and physical aggression. After starting Thioridazine 10mg bd these ceased completely. However, despite this his GHQ increased from two to four, both scores being below "caseness" level.

2.1.2c RESULTS OF MORBIDITY MEASURES

Table C (see end of chapter) shows the means and standard deviations of each variable at the start of the study (time 1) and at reassessment (time 2). For the 12 cases seen on both occasions, the standard errors of the difference in scores over the study period are given, with t and p values as measures of

significance.

In spite of there being no significant change in Mini Mental State score, or in the measures of behavioural disturbance according to the Stockton Geriatric Behaviour Rating Scale, the GHQ score fell over the study period by a mean of 10 points ($p=0.007$). In the two cases receiving a psychological intervention, the score fell by a mean of 20 points, compared to a fall of only three points in those receiving no intervention. For the two cases prescribed medication, carer GHQ fell by four points and increased by two points respectively.

2.1.3 DISCUSSION

This study investigated the use of psychological and pharmacological methods of managing behavioural difficulties in dementia and monitored associated changes in carer morbidity. Carer mental health was assessed using only the GHQ. Although this gave a score which was a valid and reliable measure of psychiatric caseness, it did not allow a diagnosis to be made. Without a diagnosis, no treatment strategy directed at managing carer mental health problems could be implemented and this limited the scope of the study.

The Stockton Geriatric Behaviour Rating Scale (SGBRS) was found to be a blunt instrument for detecting behavioural disturbance in people with dementia. There are many behaviours which it does not include such as wandering and repetitive questioning. In addition, it has a three point frequency rating which gives little scope for measuring change. In this study, behavioural difficulties were detected in only four cases and in three of these, carers reported additional distressing behaviours which were not elicited using the SGBRS. It is possible that if a more detailed behavioural assessment procedure has been used in this study, more behavioural disturbance would have been detected in this group of dementia sufferers.

This study lacked a control group such that any changes in the behaviour of the dementia sufferer or the mental health of the carer could have resulted from the passage of time rather than participation in the study.

In three cases the study found an association between a clinically significant improvement in the behaviour of the dementia sufferer and a fall in carer GHQ score. However this might be explained by the emotional support carers received during the study rather than being a true association between behavioural disturbance and carer mental health. This possibility is increased by the fact that the GHQ scores fell most in those receiving psychological interventions which involved greater time input than in those receiving pharmacological ones.

When the study was being planned, it was envisaged that day centre staff might be able to monitor behaviour and implement behavioural modification techniques. It quickly became evident that this was not possible since they were too busy to spend time carefully observing one person. Furthermore, many of the carers reported behaviours in their relatives which were confined to the home environment and so best dealt with in the domestic setting. For instance, repetitive questioning can be very irritating for a carer who spends hours alone with their relative, but ceases to be a problem in a day centre where there are many staff to share any difficulties which arise.

During the study it became evident that the rationale of using either behavioural or pharmacological interventions in the management of behavioural problems was too restrictive. In a clinical setting, the needs of dementia sufferers and their carers would have been better served by a flexible approach which incorporated a range of measures according to clinical response. Finally, of 16 dementia sufferers recruited into the study, 4 (25%) were lost to the study even within a short follow up interval of 3 months; two died and two entered residential care. These subjects all had advanced disease, scoring less than eight on the Mini Mental State Examination. It was important to consider ways of reducing this high drop out rate in the main study in order to be able to evaluate the effect of intervention on as many dementia sufferers as possible.

2.1.4 CONCLUSION

The pilot study highlighted the following difficulties which were then addressed in the design of the main study.

1. Limitations of the instruments used

As explained above, the GHQ is a sound but limited measure of carer mental health since it does not allow a psychiatric diagnosis to be made. Therefore, in the main study further assessment of carer mental health was made using the Geriatric Mental State (GMS) (Copeland et al 1976). This instrument is discussed further in sections 2.2.5a and b, 2.2.8b and 2.2.9).

The SGBRS did not provide a sufficiently detailed assessment of behaviour for a study which focused on the management of behavioural difficulties since there were some common behaviours that it did not include (eg wandering) and its three point frequency rating was insufficient to measure change. This was replaced in the main study by the Present Behavioural Examination (Hope and Fairburn 1992) which is discussed in section 2.2.8a.

2. Deficiencies in the design of the pilot study

The pilot study had no control group but this was addressed in the main study which used a waiting list control group.

Since day centres proved to be an unsatisfactory setting for the assessment and modification of behavioural difficulties, they were not incorporated in the design of the main study. Instead, all behavioural assessments and management strategies were implemented in the home of the dementia sufferer and their carer.

The pilot study did not allow the effect of interventions implemented on carer mental health to be distinguished from the possible benefits of spending time with a supportive person. This was addressed in the main study by recording in the form of a diary the time spent and content of each intervention implemented, so that possible associations between aspects of the intervention and outcome in terms of carer mental health could be detected.

Since using either a pharmacological or behavioural approach to managing behavioural problems was

found to be too restrictive, this was replaced in the main study by developing individual packages of care which incorporated pharmacological, behavioural and social measures as appropriate.

The 25% drop out rate occurred exclusively in those scoring less than eight on the Minimental State Examination and so it was decided to exclude this group of people with advanced disease from the main study.

TABLE C: The results of morbidity measures for the pilot study

VARIABLE	TIME 1	TIME 2	STANDARD ERROR		
	(n=16)	(n=12)	OF DIFFERENCE	T	P
	Mean (SD)	Mean(SD)			
Age	76.9 (13.1)				
MMSE	14.4 (6.6)	11.6 (7.3)	1.2	1.7	0.1
SGBRS	20.6 (6.4)	22.8 (7.4)	1.4	-1.7	0.1
PD	5.5 (3.3)	6.6 (2.8)	0.5	-1.9	0.08
AP	9.3 (2.9)	10.0 (3.2)	0.8	-1.0	0.4
CF	2.0 (1.2)	2.3 (1.0)	0.3	-1.7	0.1
SIB	4.1 (2.7)	3.9 (4.4)	1.0	0.3	0.7
DPDS	3.1 (3.0)	2.3 (2.4)			
GHQ	11.4 (8.3)	3.8 (4.4)	2.5	3.3	0.01
DDS	12.3(3.0)				

Key: MMSE Mini mental state examination
SGBRS Stockton geriatric brief rating scale
PD)
AP) subscales of the SGBRS
CF)
SIB)
DPDS Depression score on short care
GHQ General health questionnaire
DDS Dementia score on short care
t test
p probability
SD Standard deviation

PART 2

CHAPTER 2 DESIGN OF THE MAIN STUDY

The study took place in an inner city area of north London and had been granted ethical approval by the local ethical committees.

2.2.1 HYPOTHESIS

The primary hypothesis was that behavioural difficulties in people with dementia identified by carers as particularly distressing can be managed successfully by the implementation of individualised intervention strategies. The primary outcome was a significant improvement in carer mental health as measured by the GHQ. Subsidiary hypotheses were that:

- a. The improvement in carer mental health following intervention would be maintained at follow up (16 +/- 2 weeks later)
- b. The effect of delayed intervention in those people initially allocated to the control group would also lead to a fall in carer GHQ score.

In addition to a change in carer mental health, a further outcome measure was a reduction in those behaviours specified by carers as particularly distressing. In comparison to change in carer mental health changing behaviour is a much less robust outcome measure since recording behaviour is fraught with methodological and technical difficulties (see 2.2.8a). Thus in spite of its clinical importance it takes second place.

2.2.2 POWER CALCULATION

In planning the study, it was necessary to estimate how many dementia sufferers and carers would be required and this would depend on the magnitude of the change in carer GHQ. Given that the mean change in GHQ score in the pilot study was 10 points, a figure of a five point expected change in GHQ score was chosen as this was a conservative estimate of the likely change in GHQ score and yet it seemed clinically significant. The power calculation set a figure of 45 subjects and carers who needed to complete an intervention or a period in the control group to give 80% power in detecting a five point

change in GHQ score at the five percent level ($p < 0.05$)

At the midpoint of the study, a further power calculation was required in order to address subsidiary hypothesis (a). For a five point reduction in GHQ following delayed intervention to be shown to be statistically significant at the 5% level, a minimum of 16 dementia sufferers and carers would need to complete this part of the study.

2.2.3 RECRUITMENT

Since greater numbers of people with dementia and their carers were required in this study than in the pilot study, the recruitment procedure was extended. As well as approaching local day centres for names of elderly people with dementia who might be suitable, carer support groups and local General Practitioners were contacted. Those discharged from hospital old age psychiatry departments were also approached. Dementia sufferers who continued to be under the care of psychiatric services could not be considered for the study since the treatment and support they were receiving might overlap with the interventions introduced as part of the study such that any improvement in carer mental health or behaviour of the dementia sufferer could not be said to be due the intervention study alone. Finally, reports of the study were printed in local newspapers to allow families of people with dementia to make enquiries.

2.2.4 CONSENT

2.2.4a ETHICAL ISSUES

There are important ethical considerations in any intervention trial. Firstly there must be some theoretical basis for considering that the intervention may be of benefit. This criteria was fulfilled by the present study since a wealth of previous work supports the opinion that carers benefit from psychosocial interventions (see 1.5.5) and that behavioural and psychological symptoms of dementia can respond to treatment (see 1.2.4). In addition, a second criteria is that genuine doubt must exist as to whether a particular intervention will prove to be efficacious. Again, the present study fulfilled this requirement since several studies with carers of dementia sufferers involving support, education and advice on the management of behavioural problems had not lead to a significant improvement in carer

mental health (Brodaty et al 1994). This study differed from the work of Brodaty et al 1994 in that care packages were devised and implemented for individual carers and dementia sufferers in the home rather than in a group setting. There was, therefore, reason to test whether this approach might be successful.

A further ethical issue in studies involving people with dementia is that of informed consent. Those in the early stages of a dementing illness may still have the cognitive capacity to give informed consent although this may not be fully informed in that there may be certain aspects of a research project that they are unable to fully grasp. However, other people with an early dementia may be totally unaware that they have a dementing illness and so not see the need to be part of any study. This was partly resolved in this study since the needs of the dementia sufferer and the carer were of equal focus. For those with advanced dementia, consent is possible but informed consent is not and then the only solution is for carers to act as advocates. This was acceptable to the local ethical committee. A further consideration is that the hopes of neither the dementia sufferer or the carer must be raised such that they suffer later disappointment.

2.2.4b CONSENT PROCEDURE USED

As in the pilot study, all those people considered for the study were approached individually and the study explained to them so that it could be discussed fully and any questions answered. Those people with dementia and their carers who wished to take part in the study were asked to give written consent by signing a consent form. Where those with dementia were unable to give consent, carers acted as advocates.

Consent was also sought from the General Practitioners (GP) of both those with dementia and their carers. Each GP was telephoned initially to discuss their patients wish to take part in the study and then again to discuss the elements of any planned intervention. This was clearly essential since the interventions might involve medical, social, or psychological measures that could have implications for their overall care.

2.2.5 INCLUSION CRITERIA FOR THE DEMENTIA SUFFERER

Those people who consented to take part in the study were thought by the referrer to have dementia. This diagnosis needed to be confirmed as discussed in parts 2.2.5a and 2.2.5b below. They also needed to be living with a carer so that any behavioural problems could be assessed. This is discussed in part 2.2.5c.

2.2.5a DIAGNOSING DEMENTIA

There are many ways of making a diagnosis of dementia which are discussed in sections 1-5 below:

1. By history and mental state examination.

This is not satisfactory for research purposes because there can be variability in the opinions of different clinicians so that no comparison with other studies can be made.

2. By the use of questionnaires

There are many questionnaires which have been designed to make assessments of cognitive function quickly. Three such questionnaires are the Mini mental State Examination (MMSE)(see 2.1.1c), the Mental Status Questionnaire (MSQ) (Pfeiffer 1975) and Abbreviated Mental Test (AMT) (Hodkinson 1972) .

THE MINI MENTAL STATE EXAMINATION

This 30 item instrument was used in the pilot study (see 2.1.1c). This is a well validated and reliable instrument but it is a screen for measuring the severity of dementia rather than an accurate scale for diagnosing it. Those with high pre morbid intelligence, may decline in functioning without scoring as having dementia on the MMSE, and those with low levels of educational attainment may score as having dementia when there has been no cognitive decline (Cockerall and Folstein 1988). Furthermore, other psychiatric difficulties such as anxiety and/or depression can lead to low scores in those who are cognitively intact.

THE MENTAL STATUS QUESTIONNAIRE (MSQ)

This is a short memory scale containing ten items (see 1.4.1). It has been widely used and is reported by Wilson and Brass (1973) to be a powerful tool for detecting and quantifying dementia severity having been highly associated with psychiatrists evaluations of the presence and degree of chronic brain syndrome. Being so short, it is quick to administer but may fail to diagnose those with milder disease.

THE ABBREVIATED MENTAL TEST (AMT)

This is also a 10 item confusion scale which has been validated against clinical diagnosis also (Vardon and Blessed 1986). Being so short, it suffers from the same disadvantages as the MSQ discussed above.

3. By the use of operational criteria

Operational Criteria such as ICD 10 and DSM111R are discussed in section 1.1.3. ICD 10 specifies that dementia is a chronic or progressive brain disease affecting multiple higher cortical functions. Although it details that onset must not be sudden and that causes of reversible dementia must be excluded, it does not specify common features of dementia such as memory impairment as a diagnostic criteria. Therefore, what it gains in breadth, it loses in specificity. DSM111R criteria for dementia (1.1.3) are that there must be:

- a. Demonstrable evidence of impairment in short and long term memory.
- b. At least one of:
 - impairment in abstract thinking
 - impaired judgement
 - other disturbance of higher cortical function
- c. The disturbance of a and b significantly interferes with work, social activities or relationships with others
- d. Not occurring exclusively during the course of delirium
- e. Either evidence of a specific organic factor related to the disturbance or the absence of any non organic disorder accounting for the cognitive impairment.

These criteria provide a sensitive measure of cognitive decline when an informant's history is available (as it was in this study) and yet set out specific deficits that must be present for the diagnosis to be made.

4. By semi structured interviews

The Geriatric Mental State (GMS) (see 2.2.8b, 2.2.9) or the Short CARE (see 1.3.1a, 2.2.8a, 2.2.9) are both semi structured interviews. Such instruments allow initially ambiguous responses to be clarified by the interviewer, are known to be valid and reliable and generate diagnoses in a standardised way. They will be discussed in turn below.

THE GERIATRIC MENTAL STATE (GMS)

The GMS was designed for assessment of people aged 65 and over and there is a version designed for community studies (GMS A) (Copeland and Wilson 1989). It has eight subscales covering many dimensions of psychiatric illness (see 2.2.9) and one of these relates to organic brain syndromes. It is able to generate standardised diagnoses from an associated computer algorithm, AGE CAT. There is a severity rating for each subscale: zero, one and two represent no disease or subcaseness, whereas three, four and five indicate disease of increasing severity. In addition, it is valid and reliable having been tested in many validity and reliability studies throughout the world (Henderson et al 1983). However, the number of questions that relate specifically to cognitive impairment are few and therefore it may fail to classify those early in their illness as having a dementia.

THE SHORT CARE

The Short Care (see 1.3.1a, 2.2.8b, 2.2.9) has also been designed for use with people aged 65 years and over living in the community. It contains two subscales for measuring cognitive impairment, the Organic Brain Syndrome Scale (OBS) and the Dementia Diagnostic Scale. The former is a sensitive indicator of cognitive impairment and the latter is used to detect pervasive dementia severe enough for clinical intervention. It also has a subscale for the detection of depression (see 2.2.8b, 2.2.9), but does not include questions on anxiety or psychotic symptoms. Although it can generate a valid and reliable

diagnosis of dementia in a standardised way, it is rather long for the purposes of establishing a diagnosis in order to check whether a given dementia sufferer satisfies inclusion criteria.

5. By Diagnostic Schedules (Cambridge Examination For Mental Disorders In The Elderly)

The Cambridge Examination For Mental Disorders In The Elderly (CAMDEX) (Roth et al 1986) has eight sections: current symptomatology with past history, a cognitive assessment, the interviewers observations, a physical examination, results of laboratory and radiological tests, current medication, additional items of information obtained in the course of the interview and a structured interview with an informant.

The second section assessing cognition is called the CAMCOG. This is a 60 item examination marked out of 107, and contains subscales measuring orientation, language, memory, attention, calculation, praxis, abstract thinking, and perception. The Mini Mental State Examination is included within this assessment although not all its items contribute to the final CAMCOG score.

The CAMDEX has 92% sensitivity and 96% specificity in the diagnosis of four major diagnostic groups; normal, demented, clouded (acutely confused) and depressed. It is clearly a very detailed diagnostic assessment but was too lengthy to use for establishing the diagnosis of dementia as an inclusion criterion.

Fulfilling DSM111R criteria for dementia was made an entry requirement for this study. The reasons for this were that with an informants history available, detecting a history of impairment in both long and short term memory, and impairment in higher cortical functioning which was interfering with work, social life or relationships provided a sensitive measure of change from a previously attained level of functioning. Using DSM111R criteria had the added advantage avoiding the use of a further diagnostic instrument to an already lengthy assessment.

2.2.5b THE SEVERITY OF DEMENTIA

In designing an intervention study, it is important to follow up as many of the initial sample as possible

and this requires minimising the numbers who "drop out". The pilot study, discussed earlier, found that those people who scored less than eight on the MMSE (see above) were often lost to follow up either through death or entering residential care (see 2.1.3). Thus in designing the main study, it was important to assess dementia severity and exclude those who were in the most advanced stages of the disease. Instruments for measuring dementia severity can be divided into those that are semi structured interviews and those that are questionnaires. These are discussed in turn below.

SEMI STRUCTURED INTERVIEWS

- a. The GMS/AGECAT programme (see 2.2.5a, 2.2.8b, 2.2.9)

As discussed earlier, this instrument allocates a severity rating to each subscale including that which measures organic brain disease. The disadvantage of using this as a severity rating is its narrowness, there being only three grades within the caseness range, leading to substantial ceiling and floor effects.

- b. Short CARE (Gurland et al 1984) (see 1.3.1a, 2.2.5a)

As discussed earlier, this contains two subscales measuring cognitive impairment : the organic brain syndrome scale (OBS) and the dementia diagnostic scale (DDS). Thus, this instrument could be used to measure dementia severity, but its length is a disadvantage.

QUESTIONNAIRES

- a. Short Confusion Scales (MSQ and AMT)

These instruments are discussed in 2.2.5a. Neither would be a good measure of dementia severity because, being extremely short, (containing only 10 items), they would give rise to substantial ceiling and floor effects. Thus they would only be able to give a restricted range of dementia severity ratings.

- b. The Mini Mental State Examination (see 2.1.1c, 2.2.5a)

The difficulties with the use of this scale diagnostically have already been described but it is highly satisfactory as a measure of dementia severity. It also has the advantage of having been

used widely in other studies so allowing comparisons to be made. Thus, this instrument was chosen and as suggested in the pilot study, those with scores less than eight were excluded.

2.2.5c LIVING WITH A CARER

It was essential that dementia sufferers recruited into the study were living with a carer as carers were needed to give detailed information regarding behavioural problems in the person they were caring for who might lack insight into their illness and be unable to describe changes in their behaviour. Given that certain behavioural difficulties may relate to personal care or change in sleep pattern, it was important that the carer lived in the same house as the person with dementia rather than simply visited regularly. In addition, carer mental health was itself a focus of the study (see ahead), and as several studies have reported that carers living with a dementia sufferer are more distressed than those living separately (O'Connor et al 1990, Fitting et al 1986, Brodaty and Hadzi-Pavlovic 1990), it was important to take account of this by standardising living arrangements and only including those who lived together.

2.2.6 INCLUSION CRITERIA FOR THE CARER

Change in carer mental health was an outcome measure in this study and thus needed to be assessed using an instrument that was valid, reliable and sensitive to change. In order to allow any improvement in carer mental health to be shown, it was important to only include carers rated as having some psychological morbidity at outset. Given that carers would vary in age, some being under and others over sixty five years, it was also important to either chose different instruments depending on the age of the carer or to use instruments that had been found valid and reliable in people of all ages.

A further consideration in terms of developing a mental health inclusion criterion, was the length of the instrument being used to assess it. Those carers who were recruited into the study clearly required a detailed assessment of their mental health, but at outset, the aim was to screen carers and include only those who were suffering some psychological morbidity.

Possible instruments included those questionnaires specifically designed for carers (see 1.3.1a), semi

structure interviews, depression scales, or screening instruments. These will be discussed in turn.

1. Questionnaires Designed Specifically For Carers

Instruments specifically designed for carers of dementia sufferers such as the Burden Interview, the Strain Scale and the Relatives Stress Scale (see 1.3.1a), are not only designed to measure carer distress; they are all composite measures assessing mood and practical factors such as restrictions imposed on the carers social life and financial stressors. Thus they lack the specificity required for a study that wishes to measure mental health. For this reason, in developing a mental health inclusion criterion for the study, they were not used to screen for carer psychological morbidity.

2. Semi Structured Interviews

Two of the instruments discussed previously in relation to cognitive impairment also have scales that assess mood, namely the Geriatric Mental State (GMS) (Gurland et al 1984) and the Short CARE (Comprehensive Assessment and Referral Evaluation) (Copeland et al 1976). These are discussed further in section 2.2.9 with regard to their suitability for making detailed assessment of carer mental health. Given their length, are not suitable as screening instruments. Also, they are designed only for those aged 65 years and over so alternative instruments would have to have been used for carers under 65 years which would have complicated the recruitment procedure.

3. Depression Scales

There are several instruments for measuring depression such as the Beck Depression Inventory (BDI) (Beck et al 1961), the Hamilton Depression Scale (HDS) (Hamilton 1960), and the Zung Self-Rating Depression Scale (Zung 1965). The BDI and the Zung Depression Scale have been reviewed in 1.3.1a and all three are discussed further in section 2.2.9 in relation to their suitability for making detailed mental health assessments on the carers included in this study. In terms of their use in developing a carer mental health inclusion criterion in this study, they were not chosen because they specifically measure only depression so would not have detected other psychiatric morbidity. Also, the BDI and the Zung Depression Scale are less reliable in older people and many of the carers in this study were aged 65 years and over (see 1.3.1a).

4. Screening Instruments Measuring Psychological Morbidity

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) was designed to rate anxiety and depression without reference to any physical symptoms in order that psychological well being could be assessed in hospital patients. It consists of two seven item scales which make separate ratings of anxiety and depression, rating each on a four point scale. However, the final score is the sum of both of these, and is a measure of caseness rather than being diagnostic. Scores of seven or less indicate non-caseness, scores of 8-10 indicate doubtful caseness and those over 11 indicate definite caseness. It has been found to perform well in identifying psychiatric caseness against the criterion of psychiatric assessment (Wilkinson and Barczak 1988). However, since it was designed specifically for patients with physical illnesses in hospital, it was not appropriate for carers who were living in the community and generally physically healthy.

The General Health Questionnaire (see 1.3.1a) is a screening instrument also gives a measure of psychiatric caseness. It is valid, reliable and sensitive to change (Goldberg 1972, 1978, Goldberg and Huxley 1980). It has versions of varying lengths. The GHQ (28) score out of 28 and this allows it to be sensitive to change. A disadvantage of the instrument is that although it allows assessment of probable psychiatric caseness (score over 4), it does not allow precise diagnoses to be made. However, in terms of setting inclusion criteria for the study, it fulfilled all the requirements.

2.2.7 SUMMARY OF INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria for the dementia sufferer were

1. Having a DSM111-R diagnosis of dementia
2. Living in the community with a carer
3. Having a Mini Mental State score of eight or above

An exclusion criterion for the dementia sufferer was being in current contact with psychiatric services.

The inclusion criterion for the carer was to score as a case on the GHQ.

2.2.8 FURTHER INSTRUMENTS USED IN THE INITIAL ASSESSMENT OF THE DEMENTIA SUFFERER

In order to design an intervention that aimed to reduce specific behavioural problems in a person with dementia a baseline rating had to be made. On initially screening of dementia sufferers and carers to see if they fulfilled the entry criteria, no assessment of behaviour was made since this part of the assessment was very lengthy. However, those who were found not to have any behaviour problems on further assessment had to be excluded.

2.2.8a ASSESSING THE BEHAVIOUR OF THE DEMENTIA SUFFERER

Carer reports of the behaviour problems in a person with dementia will vary in detail and accuracy depending on their powers of observation and their level of distress. A completely impartial behavioural assessment would require an independent observer on a 24 hour basis which was not practical. Also, the presence of such an informant might alter the behaviour of the person with dementia and so lead to an inaccurate assessment of the usual situation. Thus, even allowing for the difficulties of relying on carer reports, it was considered to be the best assessment possible. Therefore all the behavioural assessment scales discussed below involve lists of questions for informants to answer.

In order to elicit behavioural problems in dementia sufferers and to design an intervention that aimed to reduce them, the behavioural assessment needed to fulfil the following requirements. Questions on a very wide range of behaviours were necessary in order to ensure that no areas of behavioural disturbance were missed and to prompt the memory of the informant. The questions about each behaviour needed to be phrased descriptively rather than emotively so that the information collected was as objective and accurate as possible. In addition, the behavioural assessment needed to involve wide frequency rating in order to facilitate measurement of change.

Reports on the behaviour of someone with dementia rely on informant accounts and thus all behavioural rating scales involve lists of questions for informants to answer. There are a number of behavioural rating scales which are reviewed below.

PSYCHOGERIATRIC DEPENDENCY RATING SCALE (Wilkinson and Graham White 1980)

This scale consists of a list of statements regarding a dementia sufferers behaviour which are presented to the informant who then states whether that behaviour is present in the person they are caring for. A drawback of this instrument is that some of these statements are highly subjective and presume a motive on the part of the dementia sufferer, for instance, "interfering", "deliberately disobeys". Thus though ostensibly measuring behavioural disturbance, the scale is also measuring either carer distress or interpretation. For this reason it could not be used in this study.

STOCKTON GERIATRIC BEHAVIOUR RATING SCALE (Meer and Baker 1966).

This includes a wide range of behaviours but there are some important omissions such as wandering behaviour. It has a frequency rating which scores on a three point frequency scale, 0 = never, 1 = occasionally, 2 = frequently. Thus it does not allow a sensitive assessment of frequency to be made or for a change in frequency to be detected (see 2.1.1c). Therefore, it is unlikely to be sufficiently detailed to provide a sensitive measure of behavioural change.

BEHAVE-AD (BEHAVIOURAL PATHOLOGY IN ALZHEIMER'S DISEASE) (Reisberg et al 1987)

This instrument was designed both to measure behavioural symptoms in Alzheimer's Disease and to measure outcome in treatment studies. It has a four point rating scale of severity and covers seven symptomatic categories, paranoid and delusional ideation, hallucinations, activity disturbances, aggressive behaviour, sleep disturbances, affective symptoms and anxiety and phobic disturbance. Disadvantages of this scale are that its has only a four point rating scale, and it uses aggressiveness as a severity indicator for the rating of delusions and hallucinations which can lead to a duplication of recording. It also does not exclude phenomenology related to physical illness and thus risks the inclusion of symptoms caused by delirium.

THE NEUROPSYCHIATRIC INVENTORY (NPI) (Cummings et al 1994)

The NPI was not available when the present study was being designed. It includes detailed sections

designed to detect changes in mood, anxiety and irritability but does not include questions on misidentification, or wandering. It does have the advantage of having both a five point frequency rating and a four point severity rating.

PRESENT BEHAVIOURAL EXAMINATION (Hope and Fairburn 1992)

This is an extremely detailed behavioural assessment scale which incorporates carefully phrased objective questions. For example, the questions on aggression require the interviewer to elicit the exact nature of this (physical, verbal, threatening), possible precipitants such as psychotic experiences, impatience, catastrophic reactions or for no obvious reason, and does not presume any motive on the part of the dementia sufferer or emotion on the part of the carer. The frequency rating is on a seven point scale, and each of these is precisely defined. The domains covered are physical health, mental health, walking, eating, diurnal rhythms, aggressive behaviour, sexual behaviour, incontinence and other individual behavioural abnormalities.

Since the focus of the present study was to define behavioural problems and reduce them, the PBE was chosen since it was the most detailed instrument available. It fulfilled all the required criteria in that it consisted of questions on a very wide range of behaviours, each item was phrased objectively and it included a wide frequency rating so that change in behaviour could be assessed. Its only drawback was its length (211 items). After completion carers were asked which behavioural difficulties, they found most distressing or hard to manage.

2.2.8b ASSESSING OTHER PSYCHIATRIC SYMPTOMS IN THE DEMENTIA SUFFERER

People with dementia may experience other non cognitive psychiatric symptoms such as depression, delusions, hallucinations, and misidentification syndromes (see 1.2.1). These may lead to behavioural disturbance and therefore it is important that these symptoms are diagnosed and targeted for treatment. Thus in this study, each person with dementia needed to have a thorough psychiatric assessment.

In clinical practice, psychiatric symptoms are elicited by taking a history and a performing a mental state examination. This was not suitable in this instance because in research projects, diagnoses need to

be standardised. It was important that the instrument used covered the range of psychiatric symptoms and preferably allowed diagnosis to be made.

The two types of instrument considered were scales assessing psychiatric symptoms and semi structured interviews. These are reviewed below.

SCALES MEASURING PSYCHIATRIC SYMPTOMS

Scales rating psychiatric symptoms such as the Brief Symptom Inventory (Derogatis and Spencer 1982), and the Short Psychiatric Evaluation Scale (Pfeiffer 1975) (see section 1.3.1a) have been widely used in the measurement of psychiatric symptoms and population norms have been established. However, they are not diagnostic scales and although they have been used on populations over 65 years, they were not designed for use in older people and those who are cognitively impaired.

SEMI STRUCTURED INTERVIEWS

The Short Care (2.2.5a and b) has been specifically designed for use with older people . Although it contains items detecting depression, it does not include questions regarding anxiety or psychotic symptoms.

The Geriatric Mental State (GMS) (Copeland et al 1976), mentioned above (see 2.2.5a and b) has the advantages of having been designed for older people, having a version which was developed for use in the community, and has a computer algorithm (AGECAT) which allows standard diagnoses to be made. It has subscales which cover a wide range of symptom areas; organic brain syndrome schizophrenia and related psychosis, depression, mania, anxiety, obsessional symptoms, phobias and hypochondriasis. A further advantage of the GMS, particularly in assessing psychiatric symptoms in those known to have dementia, is that it allows parallel diagnoses to be made. Thus, if a person has cognitive impairment plus depression, a dual diagnosis can be given in a hierarchical manner. Given these many advantages, it was chosen as the instrument to assess psychiatric symptoms in the dementia sufferers recruited into this study.

2.2.8c ASSESSING THE ASSISTANCE THE DEMENTIA SUFFERER REQUIRED WITH ACTIVITIES OF DAILY LIVING (ADL)

People with dementia experience increasing impairment with activities of daily living (ADL) and assisting with these is often a considerable task for the caregiver. Previous research has produced inconsistent findings as to whether there is an association between such impairment and carer mental health (see 1.4.3). However, since carer mental health was an outcome measure of the present study, it was necessary to measure ADL in case it should be found to be a predictor of outcome, although this was not a primary focus of the study. As the assessment procedure was already lengthy, a short instrument, which was valid, and acceptable to carers was required.

Katz ADL (Katz et al 1963) was chosen. It rates dependency in six areas chosen because they form milestones in the development of self care tasks in children (bathing, dressing, getting to the toilet, continence, feeding, walking) on a seven point scale A-G (Kluger et al). It fulfils the criteria listed above in being brief. It also had the advantage of widespread popularity with clinicians world wide, although it correlates weakly with other mobility scales (Bowling 1991).

2.2.9 INSTRUMENTS USED IN THE FURTHER ASSESSMENT OF THE CARER

As discussed above each carer was screened using the GHQ and excluded if they did not score as cases.

Although GHQ caseness is related to psychiatric caseness it does not give a precise diagnosis. The pilot study only considered whether a general improvement in carer mental health occurred if behavioural difficulties in the dementia sufferer were addressed and therefore the GHQ alone was sufficient. In the main study, one aspect of managing behavioural disturbance in the dementia sufferer was to increase the carer's ability to cope. Therefore, it was important to make a diagnostic assessment of the carer so that any specific mental health needs could be addressed such that their coping capacity was maximised. Secondly, carer mental health was an outcome measure and making a diagnosis was important if a change from caseness to non-caseness was to be demonstrated.

The possible methods of making a specific psychiatric diagnosis on them are reviewed below.

1. Clinical Interview With A Psychiatrist

In clinical practise, the clinical interview involving a full history and mental state examination is the usual way of making a psychiatric diagnosis. Such a method is not suitable in research because the individual assessments of one psychiatrist cannot be standardised and such a method would have precluded any comparison with other studies.

2. Clinical Interview With A Psychiatrist Plus The Use Of Operational Criteria

Operational diagnostic criteria such DSM111R and ICD 10 (see 1.1.3) provide a list of clinical symptoms which must be present for a specified length of time in order for a given diagnosis to be made. Thus, they do provide a standardised method of making a diagnosis once the clinical information has been collected from the patient at interview.

A drawback of using this approach in this study would have been that the clinical information would not have been collected in a standardised way, so the diagnosis would have still been dependent on the rating of an individual psychiatrist.

3. Scales For Measuring Depression

There are many scales which measure depression including the Beck Depression Inventory, the Zung Depression Scale, the Hamilton Depression Scale (Hamilton 1960).

The first two are discussed in detail in section 1.3.1a and are also mentioned in section 2.2.6. Both can be used to diagnose depression and the score also indicates severity so they can be used to measure change. However, both have been criticised for being a less accurate measure of depression in the elderly (see 1.3.1a).

The Hamilton Depression Scale is an observer rating scale which has a structured and an unstructured version. There are 21 items covering depressed mood, feelings of guilt, suicidal ideation, work and activities, insight, retardation, agitation, insomnia, psychic anxiety, somatic anxiety, gastrointestinal

symptoms, general somatic symptoms, loss of libido, menstrual disturbances, hypochondriasis and loss of weight. The ratings are made on either a 3 point (0-2) or a 5 point (0-4) point scale. It cannot be used to establish diagnosis having been designed to measure severity of depression in those in whom a diagnosis had already been made.

Since these scales measure only depression, they do not provide a full diagnostic psychiatric assessment so they were not chosen for the further investigation of the carers mental health in the main study.

4 Semi-Structured Interviews

Semi structured interviews provide a structured and standardised ways of conducting a psychiatric assessment. Examples include the Clinical Interview Schedule, (CIS) (Goldberg et al 1970), the Short CARE (Comprehensive Assessment and Referral Evaluation) (Gurland et al 1984) and the Geriatric Mental State (GMS) (Copeland et al 1976).

The Clinical Interview Schedule (CIS) (Goldberg et al 1970) has been discussed in some detail in section 1.3.1a. It is a screening instrument whose format is that of a semi structured interview. It has been found to have good reliability when used with both lay interviewers and psychiatrists and a revised version now exists (CIS-R) (Lewis et al 1992). The interview asks questions over the time frame of the last seven days covering the following domains: somatic symptoms, fatigue, concentration and forgetfulness, sleep problems, irritability, worry about physical health, depression, depressive ideas, worry, anxiety, phobias, panic, compulsion, obsession, and a screening section for psychotic disorder involving questions regarding elation and ideas of reference. Positive answers to questions in each area are summated to give a total score that is a measure of psychiatric caseness but is not itself diagnostic. The fact that it does not allow a diagnosis to be made is a disadvantage in the context of this study but the breadth of symptoms it assessed for made it an attractive option.

The Short CARE (see 1.3.1a, 2.2.5a and b, 2.2.8b) is a semi structured interview specifically designed for use with older people living in the community. It has diagnostic subscales for assessing both

dementia and depression but no other psychiatric illness.

The Geriatric Mental State (GMS) (see 2.2.5a and b, 2.2.6, 2.2.9) is also a semi structured interview designed for the elderly. As mentioned previously, it covers the range of psychiatric symptoms with sub scales for depression, anxiety, phobia, hypochondriasis, obsessional symptoms, psychosis and organic brain disease. It generates standardised diagnoses from a computer algorithm, AGECAT, (Copeland et al 1986) rating each subscale on a six point scale of severity (0-5).

5. Interviews Specifically Designed For Carers

Many studies which assess mental health of carers use instruments specifically designed for carers such as the Relatives Stress Scale (Green et al 1982), the Strain Scale (Machin 1980) and the Burden Interview (Zarit et al 1980) (see 1.3.1a., 2.2.6) but none of these allow a psychiatric diagnosis to be made. They include items which relate to mood but, as mentioned previously, also include measurement of practical difficulties associated with providing care such as a restriction in social life and financial stress. Thus they are not pure measure of carer mental health. Therefore, they are not suitable scales for measuring carer mental health in this study.

After consideration of all the above methods of assessing the carers mental health, the following instruments were chosen for use in the main study. Since there was no suitable instrument for carers of all ages, it was decided to choose different instruments for performing standardised psychiatric assessments on those under 65, and those 65 years and above. For carers aged 65 years and over, the Geriatric Mental State Examination (GMS) (Copeland et al 1976) was used because of the breadth of symptoms it assesses, and because it allows the generation of standardised diagnosis using a computer algorithm. For those carers under 65, diagnostic information was collected using the revised version of the Clinical Interview Schedule (CIS-R) (Lewis et al.1992) discussed above. Since the CIS-R is not a diagnostic instrument the information collected was used to derive ICD 10 (International Classification of Diseases - edition 10) (WHO 1992) diagnoses. This necessitated the addition a question on diurnal variation in mood, an instruction to the interviewer to note and record agitation or psychomotor retardation and increasing the time frame to include the past two weeks.

Although this seems a complicated way to derive a diagnosis, it was devised because there is no equivalent instrument to the community version of the GMS for this age group. Despite the GMS having been derived from the Present State Examination (PSE) (Wing et al 1974), community versions of the latter have not been developed.

2.2.10 ASSESSMENT OF SOCIAL SUPPORT

The relationship between the social support a carer receives and their mental health is reviewed in 1.3.3. Although the relationship remains uncertain some studies report that social support is associated with better carer mental health (Zarit et al 1980, Morris et al 1989). Therefore, although social support was not an outcome variable in this study, an assessment of social support was important in case it was found to be a predictor of outcome. The information was also helpful in planning appropriate interventions.

For the purposes of this study, which already involved a lengthy assessment interview, a short questionnaire was required which measured social support in an acceptable and reliable way.

Instruments such as the Inventory of Socially Supportive Behaviours (ISSB) (Barrera 1981), the Arizona Social Support Interview Schedule (Barrera 1980,1981), and the Interview Schedule for Social Interaction (Henderson et al 1980) are interviews which are commonly used in research. They are discussed below.

THE INVENTORY OF SOCIALLY SUPPORTIVE BEHAVIOURS (Barrera 1981)

The ISSB consists of 40 items measuring four types of support: emotional, instrumental, information appraisal and socialising. The scale asks interviewees to respond to statements which may or may not relate to real events in their lives. Its validity is doubtful since this was only tested by correlating results with a measure of family relations using 43 student volunteers. Although the relationship was significant, it was not high (0.35) (Barrera 1981). The ISSB is estimated as taking about 10 minutes to complete.

THE ARIZONA SOCIAL SUPPORT INTERVIEW (Barrera 1980,1981)

The Arizona Social Support Interview asks interviewees to identify individuals who provide support in the following areas: private feelings, material aid, advice, positive feedback physical assistance and social participation. Its predictive validity was tested on a sample of 86 pregnant adolescents and although satisfactory in this sample, it is uncertain how valid it would be on a sample of older adult carers. It takes between 15-20 minutes to complete.

THE INTERVIEW SCALE FOR SOCIAL INTERACTION (Henderson et al 1980)

This scale comprises 52 questions about the adequacy of people in specific roles: attachment provided by close relationships, social integration provided by membership of a network of persons having shared interests and values, the opportunity for nurturing others, reassurance about personal worth, a sense of reliable alliance, and obtaining help and guidance from informal advisers in times of difficulty. The authors judge the scale to have face validity on the basis of its content, and its construct validity was tested by analysing its outcome in relation to personality assessments made using the Eysenck Personality Inventory (Henderson et al 1980). An inverse relation was found between availability and satisfaction of social support and neuroticism score (-0.18-0.31) and the authors argued that this was explained by neurotic people having difficulty forming relationships. It takes between 30-60 minutes to complete.

The above instruments and various other methods of measuring social support are reviewed by Bowling (1991), who states that there is currently no assessment scale which comprehensively measures the main components of social network and support with acceptable levels of reliability and validity.

None of the above scales were appropriate for use in this study where a quantitative measure of a carers' formal and informal supports was required. Therefore a simple questionnaire was constructed by the author to collect information on the forms of formal support received and how often (home help, meals on wheels, visits from district nurses, day centre attendance, respite in hospital or residential

care) and the amount of informal support given by recording the number of phone calls and visits a carer received per week. The latter was divided into four parts: number of phone calls to or from friends, number of phone calls to or from relatives, number of visits made or received from friends and number of visits made or received from relatives. Each of these was scored on a 6 point scale 0-5, with zero denoting none and five denoting daily contact or more. In addition, the carer was asked to comment on the statement "These days I really don't know who I can rely on for help" and rate how accurately it applied to them on a scale of 0-3 (0 = very true, 1 = pretty true, 2 = not very true, 3 = not at all true). This measure was called "perceived support" and rated on a 4 point scale 0-3.

2.2.11 SUMMARY OF INITIAL ASSESSMENT

2.2.11a SUMMARY OF INITIAL ASSESSMENT

The person with dementia was assessed in the following ways:

1. A diagnosis of dementia was made according to DSM111-R criteria by asking the carer standard questions relating to the operational criteria listed in this diagnostic classification system.
2. Dementia severity rated according to the Mini Mental State Examination.
3. An evaluation of any other psychiatric syndromes was made using the GMS.
4. A behavioural assessment was made from carer reports, using the PBE.
5. Physical dependency was rated using Katz ADL.

The mental health of the carer was assessed using:

1. GHQ as a screening instrument
2. The GMS in those carers under 65
3. The CIS-R with some additional questions in those under 65 such that an ICD-10 diagnosis could be made.
4. The level of informal and formal social support was assessed quantitatively.

Finally carers were asked of all the behavioural difficulties experienced by their relative with dementia, which ones did they find most distressing or hard to deal with.

2.2.11b CONDUCTING THE INITIAL ASSESSMENT

All assessments were completed in the home of the dementia sufferer and their carer. In every case the assessment instruments were administered and/or rated by the author. The GMS, CIS and PBE being semi structured interviews allowed the necessary information to be collected in a conversational and informal manner. All the other scales involved were administered in the same way, for instance, the GHQ can be a self-report questionnaire completed by the interviewee but in this case each question was read out to the carer by the author together with the four possible responses. This was important since some carers would have had difficulty reading the questions and following how to answer. It also continued the informal quality of the assessment process.

2.2.12 PLANNING AN INTERVENTION

Given the range and differing aetiology of behavioural disturbances that may occur in people with dementia (see 1.2.2), and the varying responses of their carers (see 1.3.1b and 1.3.1c), the study was designed on the principle that interventions designed to help them should be planned individually.

In clinical practice, interventions are formulated by a multidisciplinary team such that the training and skills of each member are utilised. In the present study each case was presented to a multidisciplinary team consisting of a consultant psychiatrist for the elderly, a psychologist, and if available, a community psychiatric nurse, a social worker and a pharmacist. All the health workers involved were working in the same community mental health team, and their attendance at these planning meetings depended on their clinical commitments. The team were asked to focus on the behavioural difficulties carers had reported finding most distressing and consider three approaches in designing each intervention:

1. Measures to reduce the frequency and/or duration of problem behaviours (see 2.3.6a) .
2. Measures to reduce carer exposure to problem behaviours (see 2.3.6b)

3. Measures to increase the carer's ability to cope (see 2.3.6c and table 3)

This structure was created in order to aid the development of a broad package of care. For example, an intervention might involve

1. Distraction to reduce a behaviour such as repeated questioning
2. Attending a day centre to both provide further distraction and give the carer some free time
3. Treatment of depression and education about dementia to increase the carers coping ability.

2.2.13 RANDOMISATION INTO INTERVENTION AND CONTROL GROUPS

In order to evaluate the efficacy of the intervention packages on behavioural difficulties and on carer mental health, it was essential that changes in those receiving intervention were compared with a similar group who received no such help over the same time period. Thus, after the intervention packages had been devised, subjects and carers were randomly divided into an intervention group (group A) and a control group (group B) using random permuted blocks. To ensure that every dementia sufferer and carer had the opportunity of receiving an intervention package, those assigned to the control group were offered delayed intervention in phase 2 of the study (see figure 1 at end of chapter).

2.2.14 IMPLEMENTING THE INTERVENTION

The intervention packages were implemented by the author (ACH), in the home of the dementia sufferer and carer. In this way, factors such as the carers inclination to accept help of various kinds and their understanding of dementia could be addressed. In addition, a knowledge of the home environment, for example details such as the ease of access to the lavatory and the lighting, allowed the implementation of the interventions to be tailored to the home environment. Finally, since carers may have difficulty taking their relative with dementia on public transport and given the physical frailty of some of the dementia sufferers and carers, it was more practical for the author to do the travelling.

The person implementing the interventions (ACH) made visits to the house of the dementia sufferer and carer over a 3-4 month period. The frequency and length of the visits was determined by the

content of the intervention and the time needed to implement it. Where interventions were quickly found to be helpful, less time was required, and where interventions were unsuccessful, alternative approaches were tried. If pharmacological measures were used, this required regular assessment to achieve clinical benefit without side effects. Also, in order to be successful, interventions such as encouraging a carer to accept day care, or helping the carer understand that behavioural disturbance was an integral part of a dementing illness, required that the carer trusted ACH and the time taken to establish this was highly variable. Throughout the implementation of the intervention, a diary was kept recording the number of visits, the length of each session and its content.

In situations where a given intervention was unsuccessful or not acceptable to the carer, appropriate changes were made in consultation with the supervising consultant.

2.2.15 FOLLOW UP

The pathways of group A and B through the study is described below as stage one and two. This is represented diagrammatically in figure 1 (see end of chapter).

STAGE 1

Intervention packages were implemented for Group A and Group B acted as a control. After 16 +/- two weeks members of both groups A and B were seen again and the instruments used in the initial assessment were repeated.

STAGE 2

Part of assessing the effectiveness of an intervention, is to examine whether its effects are sustained over time. To measure this, Group A were reassessed on a further occasion 16 +/- two weeks after their initial follow up. The same instruments were used again.

During the same time period, intervention packages derived for group B were implemented. This was to assess the effectiveness of delayed intervention and also for ethical reasons. For lay people not accustomed to thinking in terms of research procedure, being in a control group with no prospect of

Given the numbers of dementia sufferers and carers lost to follow up during the pilot study it was anticipated that this would also happen in the main study. The results analysed are only of those who completed each stage of the study, ie it is a completer's analysis.

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CHAPTER 3 RESULTS OF THE MAIN STUDY

2.3.1 DEMOGRAPHY

THE PARTICIPANTS

88 people were assessed for inclusion in the study of whom 40 were suitable. Of those who were excluded, three subjects were found to be depressed rather than suffering from dementia, seven scored less than eight on the mini mental state examination and four had no behavioural problems. Twenty nine carers were excluded as their GHQ scores did not reach caseness and a further five withdrew consent.

The mean age of dementia sufferers was 81 (range 65-93) 24 were male and 16 female. Their mean mini mental state score on initial assessment was 17 (range 8-28, standard deviation 6). 28 were married, 11 widowed and one had remained single.

THE CARERS

There were 40 carers of whom 29 were female and 11 male. Their mean age was 68 (range 37-89). 28 were spouses (22 wives and six husbands) and 11 looked after parents (five sons and six daughters). One person cared for her aunt.

At initial assessment the mean GHQ score was 11 (range 5-19, standard deviation 4). According to the GMS, 19 carers (48%) were depressed, one suffering from generalised anxiety and another from phobic illness. An additional ten carers (25%) who were under 65 fulfilled criteria for ICD10 depression. Nine (22%) carers were GHQ cases but were not found to have a specific diagnosis according to the GMS in those over 65 years or ICD10 in those under 65.

2.3.2 BEHAVIOURS CARERS FOUND MOST DISTRESSING

Carers reported between one and three difficult behaviours that they found particularly distressing in their relatives and these are given in table 1.

Night disturbance and repeatedly asking the same question were the major difficulty for 14 and 12

carers respectively. The next most common behavioural difficulties were aggression (physical and verbal) and the expression of paranoid ideas, both mentioned by five carers as the most distressing. When it occurred, aggressive behaviour was always regarded as the single greatest problem.

2.3.3 BASELINE MEASURES OF ADL

The Katz ADL scores range from A-G, with A denoting independence in all aspects of self care and G denoting dependence in six basic areas of care (see 2.2.8c). Ten dementia sufferers (25%) were completely independent scoring A. A further 20 (50%) required help in one or two areas of their self care (ie scored B or C). The remaining 10 (25%) scored D or E, needing help in 3-4 aspects of their care. No one scored F or G.

2.3.4 BASELINE MEASURES OF PERCEIVED SUPPORT AND SOCIAL SUPPORT

Baseline scores for the measure of perceived support are as follows (see 2.2.10). Ten carers (25%) rated their perceived support as zero, feeling that there was no-one they could always rely on for help. Seven carers rated their perceived support as 1 or 2 indicating that they felt that in a crisis they could call on a person who might be able to help them. Twenty three carers (57.5%) scored 3, being certain that they would be supported in a crisis.

Baseline score for measures of social support are given in table 2. Amount of contact is given on a six point scale 0-5, with zero denoting no contact and five referring to daily contact and more. Contact by telephone and contact in person are considered separately, with categories for contact with friends and relatives.

Seventeen carers had no contact with friends by telephone and nineteen had no contact with friends in person. Very few people had no contact with any relatives (3 carers had no contact with relatives by phone and 5 had no personal contact). Many carers were in touch with relatives daily or more both by telephone (10) and in person (13).

2.3.5 RANDOMISATION AND GROUP ALLOCATION

22 subjects and carers were allocated to intervention group (A) and eighteen to waiting list control group (B). The sufferer mini mental state score did not differ significantly between them, the mean score being 17 ($p=0.47$) and the range being 8-28 for both groups. Similarly, there was no difference in carer GHQ score, the mean score for the intervention group being 11 (range 6-18) and for the waiting list group being 10 (range 5-19) ($p=0.94$).

Of the 22 subjects and carers allocated to group A, 2 were lost to the study during phase 1; 1 couple moved away and another withdrew consent. For one further subject and carer, the follow up assessment is incomplete and therefore there were 19 carers for whom a GMS rating is available. At the final follow up 14-18 weeks later, 3 subjects had died, 2 had been admitted to residential care and one refused assessment. Therefore 13 subjects and carers completed the final follow up.

18 carers and sufferers were allocated to group B. Five were lost to the study during phase 1; four due to death and one by entering residential care. No further members were lost from this group during their delayed intervention period (phase 2). Therefore there are 13 carers for whom full follow up data is available.

2.3.6 INTERVENTION

An intervention package was implemented for 20 carers during phase 1 and 13 carers during phase 2. Each subject and carer received a mean of 12 visits (range 6-19) lasting an average 58 minutes (range 31-87).

The format of the four intervention programmes is described in 2.2.14 and further details are given below.

2.3.6a INTERVENTIONS AIMED AT REDUCING THE FREQUENCY OF PROBLEM BEHAVIOURS

a) VERBAL AND/OR PHYSICAL AGGRESSION

Low dose neuroleptics were used if either the aggression was associated with psychosis, or the dementia sufferer had "free-floating" irritability. Sulpiride 100 mgs once or twice daily, was well-tolerated and effective. If the outbursts were possibly situational, carers were helped to keep charts recording their occurrence and antecedents so that any precipitants could be avoided or modified.

b) REPEATED QUESTIONING

Many carers are troubled by their relatives tendency to ask the same question again and again. For some dementia sufferers this occurred when they were under-stimulated and the carer was therefore encouraged to involve them in any activity they had previously derived pleasure from, such as housework or watching television. Day centres also helped to provide an occupation.

In other people, the questioning resulted from being unable to remember the answer given. Then the aim of the intervention would be for the carer to find ways of replying with an instruction which led the sufferer to discover the answer in concrete rather than conceptual terms. For example, if the dementia sufferer repeatedly asked if they had enough money, the carer would suggest they went to look in their purse. If they asked the date again and again, the carer would ask them to look at a calendar which had a separate page for each date so that the sufferer would only see one date at a time (as people with dementia can be confused by those which have an entire month on each sheet).

There were some for whom bouts of repeated questioning followed being given information about a forthcoming event. For instance, if they were told about a visit or outing, they would continually ask when it was happening. Carers would then be advised not to tell them about such things in advance. Finally, for some sufferers repeated questioning seemed to be a form

of motor restlessness and it was helped by low dose neuroleptics.

c) NIGHT DISTURBANCE

The interventions suggested would include encouraging daytime activity at home or at a day centre, discouraging sleeps during the day, reducing fluid intake during the evening and, if all else failed, night sedation. Thioridazine was used because of its sedative properties and low profile of other side effects. When this was unsuccessful, chlormethiazole was often effective and well tolerated. Benzodiazepines were generally avoided because of their detrimental effects on cognition, but were used if nothing else was of benefit.

d) URINARY INCONTINENCE

When this occurred, it was intermittent probably reflecting the fact that those with most advanced dementia advanced dementia were excluded from the study. Once urinary tract infection had been excluded, interventions were aimed at encouraging regular toileting, particularly before going out, avoiding evening beverages, and wearing a pad if this was tolerated. For women patients, sanitary towels were more acceptable to them and could contain small leakages.

e) RESTLESSNESS

Where attempts to manage this with distraction techniques in the home, or by providing structured activity at a day centre failed, restlessness responded well to sulpiride (100mg once or twice daily), or thioridazine (10-20mg daily). The doses required to gain clinical effect without side effects were established by regular assessment of the dementia sufferer in the home and discussion with the carer.

f) SEXUAL DISINHIBITION

This was helped by sulpiride (100mg once or twice daily) or thioridazine (10mg once or twice daily). As above, the doses required were established by regular assessment of the dementia sufferer and discussion with the carer.

2.3.6b INTERVENTIONS AIMED AT REDUCING THE CARERS EXPOSURE TO PROBLEM BEHAVIOURS

For each subject and carer all forms of respite were considered and incorporated into the management plan. Referral to day centres, sitting services and for inpatient respite were made, if appropriate and acceptable to the sufferer and carer. Each was intended to reduce the carers' exposure to the behavioural problems. In addition, day centre placement was found to reduce certain behavioural difficulties such as sleep disturbance and restlessness directly by providing a structured daytime activity for the dementia sufferer. Application for attendance allowance and for poll tax or council tax exemption allowed carers to buy the services of private care agencies.

2.3.6c INTERVENTIONS AIMED AT HELPING CARERS COPE WITH PROBLEM BEHAVIOURS

The needs of each carer were considered individually and the care package included measures to increase their ability to cope. Where carers were clinically depressed, the aim was to treat this with antidepressants and psychological support. For some carers, once their depression had been treated, the behaviour difficulties they had found intolerable, ceased to be regarded as a problem. Carers were educated about dementia in order that they could see behavioural difficulties as part of the illness and make plans for the future, thereby feeling more in control. Other strategies to help carers cope included joining the Alzheimer's disease society, attending carer support groups, continuing independent social activities outside the home, time management, and relaxation techniques.

Table 3 lists the interventions used for 6b and 6c and how often they were implemented.

2.3.7 CHANGE IN CARER MENTAL HEALTH

Table 4 shows the change in carer mental health according to GHQ score of the intervention group and control groups during phase 1. The between group difference was examined using a t test and was highly significant. The number of group A carers who were GMS/ICD10 cases fell from 16/19 to 6/19 (McNemars chi squared = 6.75, $P < 0.01$). There was a smaller and statistically non-significant fall in

caseness for group B carers from 8/13 to 4/13.

For those in group B, following delayed intervention, within group analysis shows that although the carer GHQ score fell by a mean of 4 points, this is not statistically significant. (Table 5). There is also no significant change in ICD10/GMS caseness.

Those in group A who initially received intervention, were followed up 16+/-2 weeks later (end of phase 2) and there was no change in their well-being, ie they remained well (Table 6).

2.3.8 CHANGE IN BEHAVIOUR

Tables 7a and b show the changes in the behaviour of those with dementia throughout the study. Table 7a shows the significant improvement in the behaviour of group A compared to group B at the end of Phase 1. Table 7b shows the change in behaviour of those in Group A during phase 2. This does not change significantly ie the improvement in behaviour is maintained. There is no change in the behaviour of those in group B following delayed intervention.

2.3.9 ASSOCIATION BETWEEN CARER MENTAL HEALTH AND BEHAVIOURAL CHANGE

For the initial intervention group A, there was a significant association between change in carer mental health as measured by the GHQ score and improved behaviour (Table 8). However, the association was not apparent when carer mental health was measured in terms of ICD 10/GMS caseness. For the delayed intervention group B neither carer mental health nor behaviour improved, nor was there an association between them.

2.3.10 ANALYSIS OF THE DIARIES RECORDING THE INTERVENTION

The mean number of sessions given to each subject and carer during the intervention programme was 12 (range 6-19) and each session lasted a mean of 58 minutes (range 31-87). The mean amount of of the time spent monitoring and treating carer mental problems expressed as a percentage of the total time input was 24% (range 4-60%). For managing behavioural difficulties, the mean time input was

28% (range 7-59%). A mean of 4% of the time was spent on education about dementia (range 0-14%). Explaining day care and sitting services and encouraging subjects to attend accounted for a mean of 13% of the time (range 3-2%). In total, this accounts for 69% of the time and the remainder of the time was spent in general interaction establishing a therapeutic relationship.

Neither number of visits nor the cumulative length of the intervention was associated with improvement in carer mental health as measured by GHQ (Spearman's Rank Correlation, 0.06, -0.5 respectively). However there was an association between greater length of intervention and continuing behavioural disturbance (Spearman's Correlation = 0.36).

2.3.11 FACTORS ASSOCIATED WITH A FALL IN CARER GHQ

2.3.11a ASPECTS OF THE INTERVENTION AND CARER GHQ

There was no association, as assessed by Spearman's Rank Correlation, between a fall in carer GHQ and either the time input or any one aspect of the intervention package (namely the use of medication, day centre placement or support group attendance). Since education and emotional support were provided to all carers but in a way which was quantitatively and qualitatively different for each one, it is not possible to relate these elements of the intervention to carer GHQ score.

2.3.11b LEVEL OF IMPAIRMENT OF THE DEMENTIA SUFFERER AND CARER GHQ

There was no relationship between the severity of dementia and change in carer GHQ score. ADL score A-G was dichotomised into those who score A and B (basically independent) and those who score C-G (basically dependent) and there was also no association between the degree of ADL impairment and change in carer GHQ for either the initial intervention group A (Fishers Exact Probability $p=0.07$), or the delayed intervention group G (Fishers Exact Probability $p=0.59$)

2.3.11c CARER GENDER AND CARER GHQ

There was no association between the sex of the carer and fall in GHQ score either for those in the initial intervention group A (chi-squared 0.37, $p=0.5$), or for the delayed intervention group B (chi-squared 0.96, $p=0.34$)

2.3.11d SOCIAL SUPPORT AND CARER GHQ

Although the carers' perceived support was not predictive of an improvement in their mental health, there was a significant association between the number of phone calls carers received from friends and a fall in GHQ score (Spearman's correlation = 0.43, $p < 0.05$). In multiple regression analysis (in which time input, MMS, social support and all aspects of the intervention package listed above were entered), it is also only friends' phone calls that is related to an improvement in carer mental health ($p < 0.001$).

2.3.12 FACTORS ASSOCIATED WITH CONTINUING BEHAVIOURAL DISTURBANCE

Considering all factors listed in the previous paragraph, there was an association between continuing behavioural disturbance and fewer visits from relatives (Spearman's correlation = -0.41, $p < 0.05$), more visits from friends (Spearman's correlation = -0.68, $p < 0.05$) and a greater number of hours spent with the carer and sufferer during the intervention (Spearman's correlation = 0.36 $p < 0.05$). The only factor to remain associated with a poor behavioural outcome on multivariate analysis was the greater contact with friends. ($P < 0.01$). There was no association between a failure to improve behaviour and the severity of dementia.

2.2.13 CARER REPORTS OF WHAT ASPECTS OF THE INTERVENTION THEY FOUND MOST HELPFUL

At the end of their intervention period, 31 carers were asked what had helped them most, (Table 9). 11 named 1 aspect of the intervention, 17 gave 2 aspects and 3 carers were unable to be specific (two giving three reasons and one giving four). Carers rated emotional support and change in behaviour as being most helpful.

2.3.14 VIGNETTES OF FOUR INTERVENTIONS WITH DEMENTIA SUFFERERS AND THEIR CARERS IMPLEMENTED DURING THE STUDY

- SUBJECT:** MRS A B (age 76)
CARER: MRS C D (age 45)

RELATIONSHIP Mother and daughter

Mrs A B had a seven year history of memory impairment and at initial assessment scored 23/30 on the Mini mental State Examination. Her daughter had a GHQ score of 6, a CIS score of 17 and had a depressive illness of moderate severity without somatic symptoms according to ICD 10 criteria. They were allocated to the control/waiting list group and during the waiting period, Mrs A B's MMS score fell to 21 and Mrs C D's GHQ score rose to eight.

The behavioural problems that Mrs C D reported having difficulties coping with were:

1. Mrs A B appeared to wait until she very urgently wanted to go to the lavatory before going, and then did not sit on the seat properly such that she wet the floor at least three times daily.
2. Mrs A B would repeatedly ask the same set of questions each morning before leaving for her day centre. These were:
"Am I going anywhere today?"
"Have I got my money?"
"Have I got my keys?"

The intervention package included:

1. Checking for urinary infection and/or glycosuria. Raise lavatory seat. Suggest a rail near the lavatory.
2. To go through morning routine with daughter to see if strategies could be developed which reduced the repetitive questioning.
3. Suggest money and keys were kept by her bed so she always knew where they were. When ready for the day centre, suggest Mrs A B watched the television or played some music so that she had something to occupy her.
4. Look at ways of giving Mrs C D some personal space by other family members sometimes caring for Mrs A B and/or respite in a local residential home so that Mrs C D could have a holiday.
5. Teach Mrs C D relaxation techniques.

RESULT

Mrs C D quickly understood the rationale behind the behavioural techniques. She discovered that if she avoided answering her mother questions directly but suggested that her mother check for herself, then this reduced the questioning. For instance, if Mrs C D answered "do I have enough money" by saying "have a look in your purse and see" rather than simply replying "yes", then the questioning stopped. Using the distraction of television or music also helped. The repetitive questioning ceased to be a problem. It fell from 38 to 10 questions over a weeks recording time. With regard to the difficulties with toileting, these simply resolved. Mrs C Ds GHQ and CIS scores both fell to zero.

- 2. SUBJECT: MRS E F (age 84)**
CARER: MRS G H (age 51)
RELATIONSHIP: Mother and daughter

Mrs E F had lived all her life on a farm in County Donegal and it was only when she was widowed and living alone that her children noticed that she had difficulties with her memory. At initial assessment she had a MMS score of eight. Her daughter scored six on the GHQ, 7 on the CIS (not a case), but fulfilled criteria for having a depressive illness of mild severity without somatic symptoms according to ICD 10.

The behavioural problem which Mrs G H found hardest to deal with was her mother repeatedly asking about old friends long since dead. This usually happened if they were in the kitchen together when Mrs G H was trying to get household chores completed. Episodes could go on for as long as two hours, in which there would be a question every two minutes.

The intervention package included:

1. Expanding the activities of Mrs E F within the home hoping that these would distract her from her questions eg tapes of Irish Music, and knitting.

2. Suggest Mrs E F attend a day centre in order to give Mrs G H some time to herself.
3. Refer Mrs G H to a carers group.

RESULTS

The distraction techniques were not successful as Mrs E F no longer had the capacity to concentrate on anything. However she settled well into a day centre and, on her return, the questioning was less perhaps because she was tired. Then she was tried on sulpiride 100mg bd and the questioning ceased completely without any sedation. Mrs G H's GHQ and CIS scores both fell to zero.

3. **SUBJECT:** **MRS I J**
 CARER: **MR K J**
 RELATIONSHIP: **Husband and wife**

Mrs I J had a three year history of memory impairment and scored 19 on the MMS examination. Her husband scored 5 on the GHQ but did not score as having any specific diagnosis on the GMS.

The behavioural problems which Mr K J found hardest to deal with were:

1. Arguments over housework. She was very slow at any task and he wished to relieve her of chores such as washing up or ironing. This upset her a lot and she would weep and say "leave me alone", or "I've got a headache". The latter was particularly distressing for Mr K J because it upset him to think that his wife was in pain and he worried about what the cause of it might be.
2. Losing things. She would repeatedly lose her purse, her keys and her glasses. She insisted on having these things before going out even though she did not need them.

The intervention package included:

1. He was encouraged to let her do any household chore she could do safely as this was important in order for her to feel useful. Those chores he felt she could not do safely, he was

encouraged to do when she was at her day centre.

2. He was encouraged to keep spare keys, a purse and glasses in a box by the door for going out.
3. Apply for poll tax exemption.

RESULTS

Mrs I J was much happier once allowed to busy herself with housework. Mr K J came to understand that he wasn't protecting her by preventing her do these things. She no longer complained of headaches. Having spare purse, glasses and keys saved him from a regular source of irritation. His GHQ score fell.

4. **SUBJECT:** MR L M
CARER: MRS N M
RELATIONSHIP: Husband and wife

Mr and Mrs were a Hungarian Jewish couple who came to London after the second world war. He was a retired architect who was very aware of his failing intellect. He scored 21 on the MMS examination. Mrs L M had been depressed for many years being preoccupied with the events of the war but her mood had been even worse lately such that she scored 19 on the GHQ at initial assessment and this increased to 22 during the time in the waiting list control group. According to the GMS, she had a diagnosis of depression at severity grade 4.

The behavioural problem that most distressed Mrs L M was her husband's depression. He was enjoying none of his past pleasures, blamed himself for his poor memory and was increasingly easily irritated.

The intervention package planned for them included:

1. To treat Mr N M with an antidepressant, fluoxetine, and reduce his diazepam.
2. To treat Mrs L M with any antidepressant she could tolerate (had a long history of gastric side effects on a range of medications) and reduce her diazepam.
3. Refer to Sobell Day Centre. This was a local Jewish day centre which both Mr and Mrs M

could attend, since it catered for the social and support needs of Jewish people in the area and was not specifically for people with a psychiatric diagnosis.

4. Educate Mrs L M about dementia.

RESULT

Mr N M responded to fluoxetine and his mental state improved such that he ceased to score as a case using the GMS. Mrs L M was unable to tolerate a range of antidepressants all of which were discontinued. Her GHQ fell from 22 to 17 and her rating for depression on the GMS fell from severity level 4 to 3. They both declined to go to the day centre.

PART 2

CHAPTER 4: DISCUSSION OF THE MAIN STUDY

2.4.1 SUMMARY OF RESULTS

The main findings of this study were that implementing individualised packages of care designed to manage those behaviours in people with dementia that carers had specified as troublesome, could successfully:

1. Reduce the frequency or severity of behavioural difficulties as measured by the PBE.
2. Improve carer mental health as measured by change in GHQ score or psychiatric diagnosis (according to the GMS in those aged 65 years or older, or ICD 10 in those who were under 65 years).

2.4.2 ARE THE FINDINGS GENUINE?

In order to be certain that the effect of an intervention is genuine other competing explanations for such a result must be considered and excluded.

Could the positive findings of this study be explained by chance? This is unlikely given that the statistically analysis reported p values of less than .001 for both change in carer GHQ and change in the behaviour of the dementia sufferer in those couples who were allocated to the initial intervention group. The probability of such a result occurring by chance is therefore less than one in a thousand.

Could the findings be explained by an unrealised confounding variable? This possibility should be eliminated by successful randomisation. In this study, control and intervention groups did not differ according to the carers GHQ or the mini mental state examination score of the dementia sufferer (see 2.3.5). Unfortunately data is not available as to the distribution of carer sex between the control and intervention groups. This is a possible confounding variable since research shows female carers to have poorer mental health (see 1.3.2a) and thus if there was a preponderance of females in the control group, this might lead to a greater improvement in the mental health of intervention group carers.

However since there is no association between carer gender and fall in GHQ at follow up (see 2.3.11) and no difference in the initial GHQ of control and intervention group carers overall it is unlikely that carer sex is acting as a confounding variable in this instance.

Thirdly, could some form of bias account for the positive findings of either improved carer mental health or improved behaviour of the dementia sufferer? As explained in 2.2.15 the research assistants completing follow up assessments were blind to group allocation initially but rarely completed a follow up assessment without knowing whether the couple they had just seen had received an intervention package or not. If the research assistants had had a personal inclination for either a positive or negative result, this may have affected the accuracy of their assessment. The effect of this potential source of bias could have been measured and thereby possibly eliminated, if there had been an assessment of whether the blindness had been maintained. For instance, if the research assistants had been asked to guess whether the people they had assessed were intervention control group members, this would have provided a measurement of the extent of blindness. However this was not done.

A further possible source of bias involves differential loss to follow up. If those lost to follow up were those dementia sufferers and carers who were not finding intervention helpful then the absence of their scores might mean that the positive effects of intervention were over estimated. The impact of this source of bias can not be excluded in the findings of the present study. However the total numbers lost from each group either due to death or entering residential care was the same for both group A and group B carers during the study period (it was five) (see 2.3.5).

Finally it is important to acknowledge the possible contribution made by a placebo effect. Placebo controlled trials of medications for the treatment of non cognitive symptoms of dementia report high placebo response rates of 47% (Denay et al 1999) and 35.6% (Street et al 2000). These studies measured change in behaviour using the Behave AD (see 2.2.8a) and the Neuropsychiatric Symptom Inventory (see 2.2.8a) respectively and presumably the researchers administering these scales will not have known whether the person they were assessing was taking the drug they evaluated or a placebo. In the present study behavioural ratings at follow up were made by a research assistant administering

the present behavioural examination (2.2.8a) but collecting information about the dementia sufferer's behaviour from carer reports. Although the research assistants were initially blind to group allocation the carers certainly were not, thus the potential for a false positive result in this instance relates more to the possibility of bias rather than to a possible placebo response.

2.4.3 STATISTICAL ANALYSIS

As explained in 2.2.16 the statistical analysis in this study was based on intention to treat. An alternative method would have been a protocol analysis. This would have involved analysing dementia sufferers and carers only according to what they had received rather than according to the intervention package they were intended to receive. An intention to treat analysis is the more conservative and so will not have over estimated the effect of intervention.

A further feature of the statistical analysis is that it included only those who completed both initial and follow up assessments. A possible alternative would have been to use a "last result carried forward" method such that "drop outs" would be analysed as not having changed according to any of the variables measured. The latter appears more conservative but can produce spurious results if there is a differential in the drop out rate between control and intervention groups.

2.4.4 PSYCHIATRIC MORBIDITY (GHQ CASENESS) IN THE TOTAL SAMPLE ASSESSED FOR INCLUSION IN THIS STUDY

Eighty eight people thought to have dementia were assessed for inclusion in this study, although three were excluded as they had depression and did not fulfil DSM111R criteria for having dementia. Of the 85 carers of dementia sufferers assessed, 29 (34%) were excluded as their GHQ scores did not reach caseness and therefore 66% scored within the caseness range. Those assessed formed a highly selected group of carers since they were recruited from hospital discharge lists, contacting local General Practitioners, day centres, local carers groups, and by self referral following reports of the study in local newspapers. However, the figure of 66% is similar to that found by Gilleard et al (1984), who reported a GHQ caseness rate of 57-73% in another highly selected group of carers whose relatives with dementia sufferers had been referred to a psychiatric day hospital.

As discussed in 1.3.1c, carers of a more representative group of dementia sufferers, not self selected or selected by referral to psychiatric services have much lower rates of psychological morbidity. For instance, Levin et al (1989) and Livingston et al (1996) both report that only about 30 % of carers have a degree of psychological morbidity severe enough to be considered psychiatric cases.

2.4.5 BEHAVIOURS CARERS FOUND MOST DISTRESSING

This study found that night disturbance and repeated questioning were most commonly cited by carers as distressing behaviours. However, where dementia sufferers had aggressive or disinhibited behaviours, these were always the most distressing, more upsetting than either night disturbance and repeated questioning although they occurred less often.

Section 1.2.2 reviews the prevalence of certain forms of behavioural disturbance in dementia. Given that different authors use different terms to describe behaviours which may be similar in nature, the findings of the studies discussed are not easily comparable with those of this study. However, in a sample of dementia sufferers referred to a hospital department, angry outburst occurred in 51%, assaultive behaviours occurred in 21%, and sleep disturbance occurred in 45% (Swearer et al 1988), so their findings differ from the present study where sleep disturbance was reported more commonly than aggressive behaviours. None of the previous literature reports on repeated questioning so no comparisons can be made.

Section 1.4.2 reviews the literature on those behaviours carers find most distressing. Several authors report that behaviours such as losing ones temper, creating clashes, demanding attention, verbal abuse, and embarrassing the caregiver were those that were particularly associated with carer psychological morbidity. These behaviours could all be classed as falling into the category of aggressive and disinhibited behaviours. Thus, the results of the present study are consistent with those of previous work in reporting that aggressiveness in dementia sufferers is particularly distressing for carers.

2.4.6 CARER GENDER AND OUTCOME OF THE INTERVENTIONS IN TERMS OF CARER MENTAL HEALTH

Many studies report an association between female sex and poorer carer mental health (see 1.3.2a). No data is available from this study on any association between carer gender and GHQ score on the sample of eighty eight carers assessed for entry into the study. However, there is data on the outcome of intervention in terms of carer mental health and carer gender and no association is found (see 2.3.11c). Thus neither male or female carers appeared to benefit to a greater or lesser extent from intervention. However, the numbers completing an intervention were small (20 completed an initial intervention and 13 a delayed intervention) and the majority of these were women. It may be that an association would have been found if numbers had been larger.

2.4.7 ADL AND OUTCOME OF THE INTERVENTIONS IN TERMS OF CARER MENTAL HEALTH

Of those 43 dementia sufferers who completed either initial or delayed intervention, only 12 (28%) had low physical dependency needs at outset and all carers were GHQ cases. No association was found between the degree of ADL impairment in the dementia sufferer and the response of the carer to intervention in terms of GHQ caseness (see 2.3.11b). However, it is interesting that none of the carers of dementia sufferers with low dependency needs and nine of those caring for people with high dependency needs became GHQ non-cases following initial intervention.

Perhaps those caring for people with higher dependency needs are easier to help because there is greater scope for them to benefit from simple measures such as the dementia sufferer attending a day centre.

2.4.8 ASSOCIATION BETWEEN SOCIAL SUPPORT, PERCEIVED SUPPORT AND OUTCOME MEASURES

Support from friends as measured by the number of phone calls (but not as measured by visits) was the only factor found to be associated with an improvement in carer well being. In contrast, a poor outcome in terms of behavioural change was associated with more visits from friends and less from relatives

(see 2.3.11d). It seems likely that these contradictory findings are artefactual in this context since only quantitative information regarding social contact was collected. Some of the ostensible "support" may have been experienced as either critical or unhelpful. However, it is possible that the ability to continue social links in spite of the restrictions imposed by caregiving reflects good coping skills. The support of phone calls can be accessed immediately without any prearrangement and having this support may increase a carer's coping potential. Since visits are a less immediate, and less frequent form of contact, this may explain why the same association was not found for them.

In relation to behavioural disturbance, perhaps relatives find it emotionally more difficult to visit behaviourally disturbed people with dementia or may fear they will be expected to provide practical help. The association between behavioural disturbance and more frequent visits from friends may be mediated via concern for the carer.

Perceived support was also found not to be related to carer mental health. This is counterintuitive since one would expect that those carers who felt that there was someone on whom they could always rely on for help would enjoy better mental health. A possible explanation for this is that all the carers recruited into this study were GHQ cases and that in their distressed mental state they felt unsupported. However this is not reflected in the results because many carers were depressed and yet reported feeling highly supported. An alternative explanation is that no association was found because perceived support was measured very crudely by simply asking carers if there was anyone they could always rely on for help and asking them to rate this on a four point scale.

2.4.9 THE EFFECT OF DELAYED INTERVENTION

Despite there being little change in the clinical situation over the waiting period as measured by carer GHQ or the Mini Mental State Score of the person with dementia, delayed intervention failed to produce a statistically significant change in either outcome measure. Although delayed intervention was associated with some improvement in carer mental health, the magnitude of this was not sufficient to reach statistical significance. There was no improvement in the behaviour of the dementia sufferer. Other work has also reported the lack of efficacy of delayed intervention with carers of people with

dementia (Brodaty and Gresham 1989).

Considering carer well being as an outcome measure, perhaps delayed intervention is not effective because, over time, carers lose the capacity to benefit from supportive measures. Accepting help may become another thing to have to make time for so it becomes a burden. An alternative explanation would be that carers were disappointed at being allocated to the control group so were resistant to help.

However, this was not the impression of the author who implemented the interventions. A further explanation is that delayed intervention was found not to be associated with a statistically significant change in carer mental health because of the small numbers who completed this part of the study. In support of this possibility, carer GHQ did fall by four points for the delayed intervention group but in this sample size, this was not sufficient to reach statistical significance.

Considering behavioural change as an outcome measure, it is possible that the failure of delayed intervention to improve behaviour was because such difficulties become more intractable with time. This is not altogether surprising since parallel findings have been reported in other mental illnesses such as schizophrenia (Crow et al 1986). It is also possible that behaviour fails to improve as a result of continuing poor carer mental health. Carers who are depressed may find it harder to implement the steps necessary to reduce problem behaviours. Alternatively, it is also possible that carer mental health fails to improve because of continuing behavioural difficulties.

2.4.10 ASSOCIATION BETWEEN OUTCOME MEASURES AND INDIVIDUAL ELEMENTS OF THE INTERVENTION PACKAGE

The improvement in carer mental health was found not to be significantly associated with any single element of the intervention package nor to the non-specific effect of the amount of time spent with a supportive person.

Behavioural change was also not related to any element of the intervention package but persistent

behavioural disturbance was associated with a greater number of hours spent with the carers during the intervention period. This may be because in cases where behavioural difficulties failed to improve, greater time was spent in further attempts to manage them more successfully.

There are two possible reasons why no association was found between elements of the intervention and the outcome measures:

- a. That the numbers of dementia sufferer and carers receiving each type of intervention were too small for associations to have been detected.

In support of the possibility that certain interventions were particularly effective but were not detected, it was the authors clinical impression that where behavioural difficulties responded quickly to a form of medication, then carer mental health improved more quickly and to a greater extent than in situations where behavioural difficulties required behavioural modification. The latter form of intervention took longer to implement and required the carer to participate with the package whereas the former took effect within days. Perhaps an association between the use of medication and both improvement in behaviour and carer mental health would have been shown if there had been larger numbers.

Two earlier studies have reported that particular interventions can improve carer well being: Gilleard (1987) reported that day care for people with dementia was associated with a reduction in the GHQ score of their carers, and Shibbal Champagne and Lipinska-Stachow (1986) reported that attending a carer support group could reduce carer perceived burden. However neither study had a control group and the outcome measure for the latter was made subjectively from carer reports alone.

- b. No association may have been found between elements of an intervention and outcome because no overall association exists.

Individual carers and dementia sufferers may face different problems and have differing needs such that a single intervention could not be helpful in every case. Perhaps the efficacy of the interventions implemented in this study was due to the fact that they were individually tailored to the needs of the person with dementia and their carer.

Although, it is possible that the study missed the significance of specific interventions because of small numbers and consequent lack of power, these are almost certainly less efficacious than the combined effect of all elements in the intervention package. The findings of this study are supported by the work of Brodaty et al (1994) which concluded that a possible explanation for their intervention package having failed to improve carer well being was that it did not cater for the needs of individual carers. Other studies have failed to show that individually delivered intervention programmes result in an improvement in carer mental health (Toseland et al 1990, Zarit et al 1987), but rather than devise individualised interventions, these studies implemented standard packages of care to carers in the setting of their own homes.

2.4.11 ASSOCIATION BETWEEN IMPROVED CARER MENTAL HEALTH AND IMPROVED BEHAVIOUR

Those people who were assessed for inclusion in the study but who did not fulfil the inclusion criteria of having dementia according to DSM-IV criteria, but who scored as a case on the GHQ, did not have any behavioural assessment. Thus all the dementia sufferers who took part in the study had a behavioural problem. This precludes examination of whether there was an association between behavioural problems and carer mental health at outset.

This study found a positive association between an improvement in carer mental health and an improvement of the behaviour of the person with dementia (see 2.3.9). The direction of any possible causal link remains uncertain. It may be that behavioural problems are an aetiological factor in carer depression and this association is supported by the results of other studies discussed in 1.4.2. Alternatively, carers who are depressed may report more behavioural problems because they have a

lower tolerance to them. However, in this study, the behavioural problems in dementia sufferers were elicited by the use of a detailed structured questionnaire and not from the spontaneous complaints of carers which suggests that the behavioural problems were not simply part of a depressive thought content.

Furthermore, although four carers remained GHQ cases when their relative's behaviour improved, there were no carers who recovered from GHQ caseness when their relatives behaviour remained disturbed. This suggests that carer mental health cannot improve in the presence of the chronic difficulty of having to cope with disturbed behaviour in the dementia sufferer.

2.4.12 CARERS ASSESSMENT OF THE USEFULNESS OF INTERVENTION

When carers were asked what aspect of the intervention had helped them most, the majority (20) cited the emotional support they received (see 2.2.13 and table 8). This is consistent with a previous study (Levin et al 1986).

Only three people rated recovery from depression as of particular benefit even though 15 were treated with antidepressants. This implies that the prescription of medication alone without the other elements of the intervention package may not have been sufficient, because if carers did not perceive them as helping they may not have persisted in taking them. A further possibility is that reporting emotional support as the most useful aspect of the intervention, reflects a non psychiatric way of reporting a recovery from depression, since a carer may experience this as feeling more emotionally supported particularly if they had not interpreted low mood as an illness in the first place.

Other carers rated a change in their relatives behaviour, education or practical help as being of greatest benefit to them. Thus, virtually all elements were considered particularly beneficial by at least some carers, a finding also reported in previous work (Brodaty and Gresham 1989). This indicates the individual nature of carers perceptions and needs.

2.4.13 METHODOLOGICAL LIMITATIONS

The number of people in this study was small because of the stringent inclusion criteria. In spite of small numbers, initial intervention was effective enough to produce clinically and statistically significant change in carer GHQ and the dementia sufferers behaviour. However, there was a smaller and statistically insignificant change in the carer GHQ score of those receiving delayed intervention (a change of 4 points in comparison to 7 points for those receiving initial intervention), but it is possible that this would have reached significance if there had been large enough numbers.

The carers recruited to this study were not a representative sample, being selected only if they were GHQ cases. Outside a research setting, such interventions would not be limited to this group and might be effective in reducing behavioural difficulties in a wider range of people with dementia. However, other work has found that carers of people with a psychiatric illness are reluctant to accept help unless they have an affective disorder themselves (Murray et al 1997). Almost 25% of a sample of carers refused additional help and most of these were GHQ non cases. This, again highlights the individual nature of carer needs and suggests that they accept help when they need it.

Rating change in behaviour was found to be problematic. Each dementia sufferer had between one and three behavioural problems that the intervention package aimed to address. However, at each reassessment point, an overall rating of "improved" or "not improved" had to be made. Thus, if a given dementia sufferer had three problem behaviours, two of which improved and one of which remained unchanged, the overall rating would be improved. The alternative to this would have been to consider each item of behaviour separately and give ratings for individual behaviours rather than for individual people. This was rejected chiefly because it was likely to lead to inaccuracies since those people with more than one behaviour would be "counted" more than once resulting in different people having different degrees of influence on the results. For example a person with two problem behaviours would have twice the influence of someone with one. Also, assessing individual problems separately was thought not to be clinically as meaningful and did not allow for associations with carer mental health to be made. A further issue in the overall behavioural assessment of change was that the people making the rating, although not involved in doing the follow up assessments, were not blind to the cases in

question so were at risk of being biased. This is clearly a weakness in the methodology of this study. Future work would need to address this and use independent workers to make such assessments.

This study found that the improvement in carer mental health and the behaviour of the dementia sufferer which occurred following early intervention, was not related to total time spent with them during the intervention period and thus is unlikely to be due to the non specific effect of spending time with a supportive person. This conclusion is further supported by the fact that improvement is maintained on follow up. However, it could be argued that in order to more rigorously test this, control group members should have received visits of the same frequency and duration as the intervention group but with no input other than general support. Such a study design would have required greater funds.

A limitation of the management strategy described in this study, is that it is likely to be costly since interventions were implemented by a doctor and lasted a mean of 12 hours. However, it may be possible for other health professionals acting as key workers to be equally effective if given medical support. As the aim was to evaluate a clinical approach, carers and dementia sufferers continued to receive active management even when elements of the intervention had reached the limits of their efficacy. Therefore, in clinical practice, less time would have been given, on average, for each dementia sufferer and carer.

In spite of the above, a potential strength of the study is that it mirrors clinical practice. A multi disciplinary assessment of dementia sufferers is made and a multi faceted care plan is devised. Thus the present study might conclude that good clinical practice is effective. However a disadvantage of this approach in a research setting is that it does not allow the effect of individual interventions such as support group attendance or the use of medication to be measured individually. Reviewing previous intervention studies with carers of dementia sufferers (1.5.1-5) most include more than one type of intervention except Toner et al (1987) who analysed on the effects of written educative material regarding dementia and Toseland et al (1990) who considered only group support. So far no consensus exists as to what interventions are helpful either individually or when amalgamated into packages of

care.

Finally, in analysing the results of this study, the author has been frustrated by the information she failed to collect, particularly on those carers and dementia sufferers who were assessed for entry into the study but did not meet inclusion criteria. For instance, it would have added to the scope of this thesis if there had been more data on those carers who were not GHQ cases such as their sex, their social support and the degree of ADL impairment in the person with dementia for whom they were caring.

CHAPTER 5 CONCLUSIONS

2.5.1 IMPLICATIONS FOR CLINICAL PRACTICE

The results of the study show that behavioural difficulties in dementia can be treated effectively. Since changes in behaviour are common in dementia (see 1.2.2) and have a deleterious effect on carer well being (see 1.4.2), this is very relevant to the clinical practice of those working with the elderly in the community.

In order to manage behavioural difficulties, they must first be detected and as a result of this study, a standard questionnaire asking about common behavioural problems in dementia sufferers was added to the assessment form used by a community mental health team for the elderly. This asks about the following behaviours in the dementia sufferer: sleep disturbance, irritable or aggressive behaviour, saying crude or embarrassing things, saying the same thing again and again, seeming miserable and thinking people are against them. A further outcome of this study is that a booklet has been written for carers which gives practical advice on managing certain behavioural difficulties in dementia sufferers. It is called " Because You Care" and was published by the Mental Health Foundation.

This study found that carer mental health can be improved in those who are continuing to care for their relatives with dementia. This may be important in prolonging community care since previous work has shown that where intervention fails to improve carer mental health, this predicts institutionalisation (Gilleard 1987).

In comparing this study with those of other intervention studies (see 1.5.5) which also use carer well being as an outcome measure, the present study is unusual in that it involves individually tailored intervention packages rather than group based intervention programmes. There is no consensus in the literature regarding what interventions are effective but given the individual nature of carers' needs and the wide range of behavioural difficulties in people with dementia, it is likely that individual interventions would be more effective. The same conclusion has been reached by other authors (Brodaty et al 1994)

Finally, this is the second intervention study with carers of dementia sufferers to report that although

early interventions are effective, a delay either dilutes their efficacy or possibly renders them ineffective. This highlights the importance of early referral to psychiatric services.

2.5.2 IMPLICATIONS FOR FUTURE RESEARCH

The importance of this study is that it is the first to evaluate the effectiveness of individually tailored packages of care in the management of both behavioural disturbance in dementia and carer morbidity. However its findings are limited for the reasons described in section 2.4.11.

Before the results of any study can be accepted as accurate they must be replicated. Further studies which enlarge upon the present one are needed, involving greater numbers and a more representative sample of dementia sufferers and their carers. Larger numbers would allow multivariate analysis and so it may be possible to elucidate the most effective elements of the intervention. Follow up studies are required to see if such interventions delay institutionalisation. It would be of interest to see if similar results could be obtained using a key worker model rather than interventions implemented by a doctor which less resembles ordinary clinical practice. Finally, work examining the possibility of preventative interventions with carers which seek to prevent psychiatric morbidity would be valuable.

TABLES

Table 1:

The behavioural disturbances carers found most troublesome in the main study

	Number of carers
Night disturbance	14
Repeated questioning	12
Paranoid outbursts	5
Verbal and physical aggression	5
Fear that the person with dementia might get lost	4
Sexual disinhibition	3
Depressed behaviours	3
Preventing the carer doing housework	1
Groaning	1
Loosing things	1
Contradicting the carer	1

Table 2:

Baseline measures of social support.

Amount of contact with relatives and friends, shown in numbers of carers receiving 0-5 contacts per week

Contact rating per week (0-5)	Contact by telephone with:		Contact in person with:	
	Relatives	Friends	Relatives	Friends
0 (no contact)	3	17	5	19
1	10	9	6	8
2	9	8	9	5
3	2	0	2	3
4	4	4	5	3
5 (daily contact or more)	10	2	13	2

Table 3:

The interventions with carers directed at increasing their ability to cope (the main study)

	Number of carers
Treatment of depression with antidepressants	15
Education about dementia	25
Referral to a support group	15
Time management	4
Relaxation techniques	1
Encouragement to socialise outside the home	25
Providing a break from caring:	
a. Day centre placement	28
b. Sitting services	16
c. Respite	8

Table 4:

Comparison of the change in GHQ score between intervention group A and control group B at the end of phase 1 (the main study)

No.	Initial GHQ	Mean change in GHQ	95% Confidence interval of change	SD of change
Group 20 A	11.5	-6.8	-5.35 to -8.25	3.3
Group 13 B	9.9	-0.9	2.63 to -2.81	5.0

t = 4.1

df 31

p < 0.001

Table 5

GHQ score of group B carers following delayed intervention (phase 2)
(the main study)

Pre-intervention			Post intervention			Mean change in GHQ	Confidence interval of change	SD
n	x	sd	n	x	sd			
13	9	7.3	13	5.1	5.6	-3.9	0.3, -8.1	7.71

t = 1.84

p = 0.091

Table 6

GHQ score of group A carers 14-18 weeks after completing their intervention (phase 2 of the main study)

Post intervention			Follow up			Mean change in GHQ	Confidence interval of change	SD
n	X	Sd	N	X	Sd	-1.5	-3.96, 0.96	4.5
13	5	3.8	13	6.6	6.6			

t = 1.22 p = 0.25

Table 7a

Changes in the behaviour of the person with dementia.

Table 4a - Change in the behaviour of the initial intervention and control groups at the end of phase 1 of the main study

	Behaviour improved	Behaviour not improved
GRP A (intervention)	15	5
GRP B (control)	2	11

$\chi^2 = 8.95$ p, 0.001

Table 7b

Change in the behaviour of the initial intervention group A during phase 2 of the main study.

PHASE 1\PHASE 2	Behaviour improved or improvement in behaviour maintained	Behaviour not improved
Behaviour improved	7	4
Behaviour not improved	1	1

$\chi^2 = 0.8$

Table 8

The association between change in carer GHQ caseness and an improvement in the behaviour of the person with dementia for the main study.

	GHQ case	GHQ non-case
Behaviour improved	4	11
Behaviour not improved	5	0

Fishers exact test $p < 0.01$

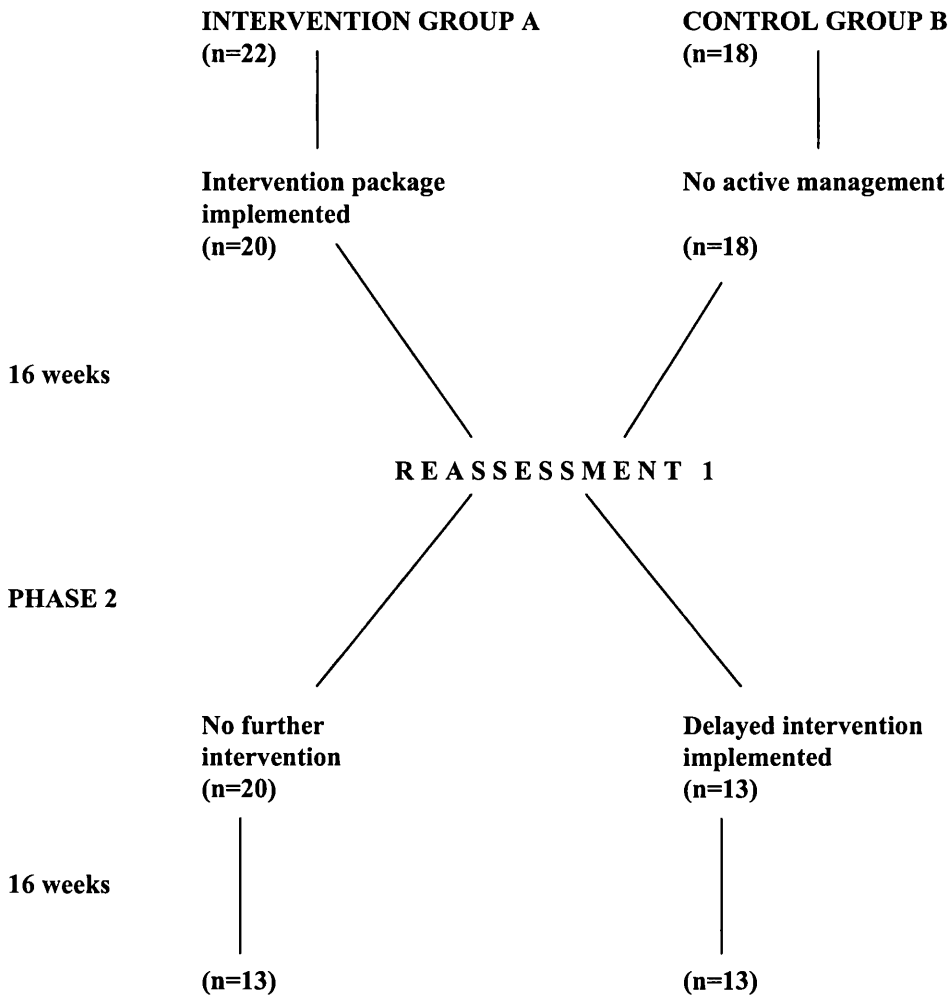
Table 9

The aspects of the interventions carers found most helpful (the main study)

	No. Of carers
Emotional support	20
Change in behaviour	14
Education	9
Practical help	9
Recovery from depression	3
Orthopaedic referral	1

FIGURE 1 Flow diagram of the study design showing group allocation, the time course of the study and patient attrition.

PHASE 1



How long for?
How many times per week?

8. Do you ever get a complete break from caring for N for several days at a time?

NO
YES

Who looks after N then? a. Residential Home
 b. Hospital
 c. Relatives

How often does this happen?
How long for?
When did it last happen?

9. Do you ever go out to see friends?

NO
YES No. of times per week

10. Do you ever go out to see relatives?

NO
YES No. of times per week

11. Do friends ever visit you at home?

NO
YES No. of times per week

12. Do relatives ever visit you at home?

NO
YES No. of times per week

13. Do you keep in touch with friends by telephone ?

NO
YES No. of times per week

14. Do you keep in touch with relatives by telephone?

NO
YES No. of times per week

15. Consider the following statement:

"These days I really don't know who I can count on for help"

Please tick the answer that most applies to you.

- a. Very true (0)
- b. Pretty true (1)
- c. Not very true (2)
- d. Not at all true (3)

APPENDIX 2

PUBLICATIONS ARISING FROM THE RESEARCH

**Hinchliffe A C, Hyman I, Blizzard B, Livingston G (1992)
The Impact on Carers of Behavioural Difficulties in Dementia: A Pilot Study on Management
International Journal of Geriatric Psychiatry 7 8 579-583**

**Hinchliffe A C and Livingston G (1994)
Because You Care - A Guide To Help Carers Cope With Difficult Behaviour In People With
Dementia Published by the Mental Health Foundation**

**Livingston G and Hinchliffe AC (1994)
Treatment of Behavioural Problems in Dementia
Current Medical Literature (Geriatrics) 7 2 35-40**

**Hinchliffe A C, Hyman I, Blizard B, Livingston G (1995)
Behavioural Complication Of Dementia - Can They Be Treated?
International Journal Of Geriatric Psychiatry 10 839-847**

**Hinchliffe A C, Livingston G (1995)
Carers of People with Dementia - Can Their Mental Health Be Improved?
Primary Care Psychiatry 1.**

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