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DEMENTIA CAREGIVING BURDEN AND BREAKDOWN

Presented by

Simon Terence O'Donovan

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ABSTRACT

This study was an investigation of the phenomenon of dementia caregiving burden and breakdown in community caregiving situations. 109 carer subjects participated in the study, with 91 current carers – 17 via face-to-face interview and 74 via the internet, and 18 past carers – two via face-to-face interview and 16 via the internet, contributing their experiences of dementia caregiving.

Two new carers' assessment tools were devised to meet more fully the requirements of the 'Carers (Recognition and Services) Act 1995' (DoH, 1995), namely the 'Dementia Caregiving Problems Questionnaire (DCPQ)' and 'Dementia Caregiving Burden Questionnaire (DCBQ)'. These new assessments were tested and demonstrated to be reliable, with Cronbach Alpha scores of 0.7029 and 0.8430 respectively, and are recommended for implementation in clinical practice.

The key predictive risk factors for high caregiving burden in this study were perceived stress; omission of caregiving satisfactions; carer depression; perceived impact on quality of life; perceived helpfulness of community care services; behaviour problems - especially shouting, swearing and screaming, irritability and night disturbance; poor quality carer/dependant relationship; mood problems; perceived helpfulness of informal support; perceived impact of caregiving on dependant emotional well-being and, to a lesser extent, hours spent in caregiving.

The key predictive risk factors for expected relinquishment of home caregiving were DCBQ score; perceived impact on quality of life; perceived stress; carer depression and, to a lesser extent, geographical distance in caregiving; perceived helpfulness of community care services and omission of positive feelings in the carer.

Based on the above risk factors, a new 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)' is proposed for use by community care managers to identify 'at risk' caregiving situations so that service interventions can be targetted more towards carers who are highly burdened in their role, who are at risk of developing psychological health problems or who may be nearing breakdown in their caregiving situation. Thus the effectiveness of service interventions may be maximised and optimal health gain for carers achieved, resulting in improved outcomes for people with dementia.

The DCBRAT and the similarly proposed 'Conceptual Model of Dementia Caregiving, Burden and Breakdown' will need to be further tested in post-doctoral research.

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CHAPTER 1: INTRODUCTION TO THE STUDY

1.1 A personal letter of introduction to the thesis

Dear reader,

As I started writing this thesis, I reminded myself why I had chosen to research the area of dementia caregiving burden and breakdown. What personal and professional experiences had led me to the point where I knew this was an important issue, worthy of further investigation, and what impact on the lives of people caring for those with dementia did I hope my study could have?

As a teenager, I helped care for my grandmother who had suffered memory loss as a result of stroke damage. Perhaps this started my interest in pursuing a career in one of the caring professions? After a short time working in the voluntary sector, I commenced psychiatric nurse training in Cardiff in 1981. After qualifying as an RMN in 1984, I worked for a year in the addictions speciality before requesting a transfer to elderly mentally ill (EMI) services (as they were then termed) based in Whitchurch Hospital, Cardiff.

At an early stage in my career, spanning more than two decades as a specialist nurse within the field of dementia care, I recognised and understood the enormous physical and psychological burden that dementia carers were faced with as their dependants' condition gradually and progressively deteriorated and their caregiving task became increasingly more difficult. Throughout my clinical practice I have often been in the position of offering support to carers who were relinquishing home caregiving and having to resort to a permanent care placement for their relative. The guilt and anger, depression and despair and grief and loss that many experienced during this difficult care transition was only too evident.

I vividly remember one elderly wife carer confiding in me that she felt 'a part of her had died' the day her husband was admitted to long-term care and that if it was not for the fact that she needed to visit him every day to make sure he was allright she 'would have died of a broken heart'. The psychological trauma of being separated from her husband of 50 years, the long-term effects of caregiving burden and the dreadful guilt she felt at having to let her husband enter full-time hospital care resulted in a depressive illness and worsened a serious cardiac condition. This very proud lady had coped for several years with her husband's increasing confusion, wandering and double incontinence without any support from community care services. This was despite the fact that her husband no longer recognised her and had become physically aggressive towards her; that he wandered outdoors most nights and she was exhausted from having her sleep disturbed, and that she had to provide continence care without access to appropriate continence management aids or the help of a tumble dryer or central heating. She had not gained access to services appropriate to meeting her needs, such as the Alzheimer's Society for information and emotional support; day services for short-term breaks from caring and bathing of her husband; the district nursing service for the provision of continence management aids; a social worker for access to welfare benefits to ease the financial burden of caregiving, and a community psychiatric nurse to advise on behaviour management, monitor prescribed medication, and arrange respite breaks from caring. Perhaps most importantly, she did not have access to a health or social services professional who could coordinate service delivery, ensure that she did not slip through the network of support, and monitor her caregiving situation throughout the dementia illness/caregiving trajectory. And yet this lady was in contact with her GP, who had known of her husband's advancing Alzheimer's disease for several years and had been treating her for clinical depression and hypertension. If only he had made an early referral to community EMI services (now MHSOP – mental health services to older people) she would have had timely access to all the above services and care management, including a regular review of her changing needs over time. The crisis that precipitated her husband's emergency admission to permanent care, whereby he assaulted her and she suffered a myocardial infarction, would then perhaps have been prevented and continued home caregiving could have been supported, or a planned and gradual relinquishment of her role could have been facilitated.

Sadly, over the years I have known of many similar situations to the one described above, where carers have been left without any help or support for several years until they are exhausted, demoralised and on the verge of psychological breakdown or physical collapse. One of these carers, who cared for her mother with Alzheimer's disease for seven years before gaining access to support and gave up her job to become a full-time carer at the age of 50, became involved in a joint planning group within Cardiff and expressed the need for there to be a telephone helpline service for carers to contact for information and support, about the illness, services, coping with caring and during a crisis. Working with this carer and others, in 1993 the South Wales Dementia Careline was piloted as part of the researcher's undergraduate research and the service was permanently launched in 1995 with Welsh Office 'Quality Health Strategy' funding to serve the geographical areas covered by the then Gwent Health Commission, South Glamorgan Health Authority, Mid Glamorgan Health Authority and Iechyd Morgannwg. This now ex-carer currently acts as co-ordinator for this service, with support from more than 30 volunteers in manning the telephone helpline and running a drop-in facility and carers support groups.

It is surprising that even now, despite the establishment of memory clinics for the early identification and diagnosis of dementia, the development of specialist multi-agency community MHSOP teams in many areas across the region and the growth in the availability of information on Alzheimer's disease and other forms of dementia in recent years, that organisations such as Dementia Careline still have a large number of contacts with carers whose relatives are suffering with moderate to severe dementia and who, for whatever reason, are not receiving assistance from community care services to support them in their role. They have remained outside of the care system and often have waited until they are desperate before they have gained access to health and social services. This appears to be especially true for those carers whose caregiving situation is not identified at an early stage by their GP and where referral to specialist diagnostic and support services is not forthcoming. The reason for carers failing to access support services remain unclear, but those who have a GP who is well informed about mental health problems in old age and services to this group tend to fare better. Similarly, carers who are more proactive in seeking a diagnosis for their relative and in obtaining assistance also seem to gain earlier access to support. The situation for carers in this respect may have improved somewhat since the recent advent of the anti-dementia drugs donepezil, rivastigmine and galantamine – GPs now have a 'reason' for early referral to organisations such as Cardiff Memory Team, i.e. early diagnosis leads to faster access to drugs which reverse disease symptoms/slow further progression, albeit for a relatively short period. But more work still needs to be done in publicising community mental health services for older people and in training primary care professionals in the early identification and management of dementing illnesses.

Another very real problem that is facing the carers of people with dementia is the increasing prevalence of dementia without a simultaneous level of investment in dementia specific community care services. Whilst dementia prevalence in the UK is predicted to continue to rise steadily over the next 50 years, there is evidence that community care service provision remains under-developed and under-resourced and that there has been a dramatic reduction in the provision of hospital and nursing home long-term care. (The literature supporting these claims is addressed in the next chapter.) Without an urgent and large-scale investment in community dementia care services and in long-term care provision, the situation for dementia carers will continue to deteriorate in forthcoming years, with less access to such vital services as home care support, day care services and respite care. Similarly, a dearth of long-term care provision will result in carers continuing in the caregiving role for longer than is appropriate for their own and their relatives' physical and psychological health. Increased pressures on dementia carers in the community will also lead to an increase in crisis admissions to the limited permanent care which is available and, more importantly, people with dementia receiving poorer quality care as a result of their carers becoming highly stressed and burdened in their role without access to the full range of community care services and future care options which are (or should be) currently available.

Given the current and forecast increased pressures on community dementia care services, it is important to ensure that their limited capacity for intervention is used to its maximum effect. If more relevant carers' assessment tools were in place which examined subjective burden experienced by carers (their perceived stress and the psychological impact of caring) in addition to objective burden (the level of disability of their dependant and the hours input they are providing), which has tended to be the primary focus of carers' assessments (Carers National Association, 1997), then care managers could more effectively target available service inputs to lessen the detrimental physical and psychological impacts of continuous dementia caregiving. Furthermore, if care managers could identify those carers who were most at risk of emotional breakdown or physical collapse in their caregiving situation, then urgent interventions could be more effectively planned to offset crisis admissions to permanent care and continued home caregiving could be better supported.

It should be acknowledged that most care managers are highly skilled in identifying when carers are becoming exhausted, demoralised or depressed in their role and are not coping well with the demands of caregiving, and most respond appropriately to signs of emotional ill-being in carers, who are for the most part recognised as a second 'client' in their own right. But the time available to practitioners for talking in meaningful ways with carers about their level of distress and coping is limited and many carers need a great deal of encouragement to disclose the true depth of their emotional needs. Indeed, some carers may feel ashamed to admit poor coping and feel unable to request increased support. A formalised assessment procedure examining caregiving problems experienced, perceived stress and caregiving burden, available resources and supports, etc. would therefore give care managers a more objective picture of need than might be otherwise be disclosed. In addition, if the key predictors of breakdown in caregiving situations could be identified in such an assessment, care managers could be alerted to the warning signs for risk of breakdown and modify existing care plans and packages of care accordingly.

Additionally, the ways in which carers cope successfully at home and the satisfactions they experience need to be given greater recognition. How some carers cope with a multitude of caregiving problems in the face of little formal and informal support when other carers 'crack' at the onset of particular problems, such as double incontinence, is worthy of further exploration.

There must be a better way to identify the damaging long-term cumulative effects of continuous dementia caregiving and target service inputs to offset breakdown in caregiving situations and avoid subsequent crisis admissions to permanent care. However, prevention of early admission to permanent care must not be the only aim. Such an assessment should also identify those carers who choose not to continue to provide care for their demented dependants at home, and these carers should be helped to relinquish caregiving in a more gradual, planned and humane way at a time that is right for them.

The impact of carer stress and caregiving burden upon the person with dementia also needs to be recognised. It is likely that poor coping, high levels of stress and distress and depression in the carer will have a negative impact on the quality of life of the person cared for. By assessing carer stress, caregiving burden, coping skills and ability and willingness to continue in the caregiving role at regular intervals, and by better targeting service interventions to those carers identified as being most at risk of psychological health problems/breakdown in their caregiving situation, it is likely that the relative well-being of dependants would be promoted and their personhood maintained.

All end of home caregiving decision-making is difficult and emotionally painful for most if not all carers - the daughter carer referred to above described the day that she had to let her mother enter permanent care as being 'worse than the day she had had to have her dog put to sleep'. There must be more that can be done to lessen the trauma involved in this process and improve the physical and psychological outcomes for people with dementia and their carers. My hope for this research is that a further exploration of the experience of dementia caregiving burden and the identification of risk factors for breakdown in caregiving situations, together with the development of appropriate carers' assessment tools, will enable community dementia care practitioners to enhance their practice around assessment and care planning and thus achieve maximum health gain for dementia carers and improved relative well-being for people with dementia.

1.2 Study aims and objectives

This study is an investigation of the phenomenon of dementia caregiving burden and breakdown in community caregiving situations. Specifically, the study aims are:

- To develop and test new carers' assessment tools to meet more fully the requirements of the 'Carers (Recognition and Services) Act 1995'.
- To identify the main risk factors for breakdown in caregiving situations and compare them to previous research.
- To propose a new 'Dementia Caregiving Risk of Breakdown Assessment Tool' for use in clinical practice.
- To propose a 'Conceptual Model of Dementia Caregiving, Burden and Breakdown'.

The objectives for this study are as follows:

- To examine the caregiving problems that carers experience in their role across the dementia illness trajectory;
- To identify the different coping skills and caring/management strategies carers use, which either enhance or reduce their ability to continue in their caring role;
- To identify the main causes of caregiving burden - objective and subjective, in carers of people with dementia in the community;
- To examine the experience of subjective burden across the dementia illness trajectory and the changes in burden over time;
- To identify caregiving satisfactions derived from the caregiving role and the influence these or their absence have on long-term outcomes;
- To examine the impact of dementia caregiving on carers' physical health and psychological well-being over time;
- To identify the main factors which predict carers' ability to continue in their role or the decision to relinquish home caregiving and seek permanent admission of their dependants to long-term care.

It is expected that the study will deepen the understanding by health and social care professionals of the experience of dementia caregiving in the community, the objective and subjective burden suffered by carers and the risk factors implicated in the breakdown of caregiving situations. It is envisaged that a formal 'Dementia Caregiving Breakdown Risk Assessment Tool' will be developed at the conclusion of the study which will enable community care practitioners to undertake more effective risk assessments to help identify carers reaching an emotional breaking point or crisis in caregiving. This could be used in the future to assist care managers in ensuring their interventions become more specifically aimed at meeting the identified psychological support needs of carers as well as those suffering with dementia, i.e. viewing the carer as a 'client' in his or her own right, and thus achieving better targeted service delivery that has a specific aim of preventing emotional and/or physical breakdown in carers and secondary mental illness in this group. Another anticipated outcome (although not to be tested as part of this study) would be more sustained community caregiving situations or more timely facilitated admissions to permanent care where appropriate.

1.3 Introduction to study design

The design for this study was initially longitudinal, following a sample of local carers through one year in their caring role and examining changing needs and outcomes over time, i.e. one year post initial interview. However, the research proved to be more dynamic than initially thought, with new areas of interest being identified during the early stages that required further investigation; problems with research questionnaires being identified and resolved, and new carer sampling techniques becoming available. The research study design therefore changed to be broadly a mixed methods study.

In summary, the following phases to the study were conducted and these will be further explained in the chapter entitled 'Research Methods':

- ➢ Exploration of the literature to refine study aims and objectives and form study hypotheses carried out and research proposal drafted.
- ➢ Study methodology formed with further review of the literature and preliminary research questionnaires designed.
- ➢ Ethical approval submission developed and approval sought.
- ➢ Research questionnaires refined – one for first interview with dementia caregivers caring in the community, and second for follow-up interview one year later (one for carers still caring at home and one for those who had relinquished home caregiving).
- ➢ Research questionnaires piloted on a former carer, now working in services, for relevance, appropriateness and sensitivity of subject matter. Specific repetitions noted and length of interview problematic, hence questionnaire reviewed and shortened.
- ➢ Further 17 interviews conducted, with follow-up interviews being carried out one year on. Both first and second interview phases undertaken simultaneously.

- Due to the withdrawal of subjects (n=3) and dependant/carer deaths (n=4) during the first year of interviews, SWOT analysis undertaken for self-generated proposal to put research questionnaires on-line for a larger international sample of carers to complete in order to: a. support findings of face-to-face interviews, b. further test carers' assessment tools for later inclusion in a proposed dementia caregiving breakdown risk assessment tool, and c. to validate the proposed carers' assessment tools with a larger study sample.
- Two shortened study questionnaires – one for 'current carers' and one for 'past carers' launched on the internet – http://signpostjournal.connect-2.co.uk/dementia.htm
- Web-site available on-line for an international sample of carers to contribute their experiences to the study for approximately one year.
- Questionnaire responses transcribed and qualitative data analysed. SPSS data analysis programme developed and tested for quantitative data analysis.
- Study data analysed and explored against study aims and hypotheses.
- Research findings discussed and recommendations for practice and post-doctoral research made.

1.4 Person-centred care perspective

Whilst this study has a primary focus on the carer's experience and perception, at the heart of the thesis throughout is the person with dementia. The whole ethos of the study is to better recognise and understand the problems that the carers of people with dementia face in their role, the caregiving burden that they suffer and the risk factors implicated in the breakdown of community caregiving situations. This is with the express aims of enhancing the knowledge base and clinical skills of community care practitioners, and providing them with appropriate carers' assessment tools, so that better recognition of at risk caregiving situations can result with a view towards achieving better targeted service interventions that support continued home caregiving or better planned and supported admissions to permanent care. Thus it is hoped that the person with dementia will receive enhanced care from their carer as a result of the care manager ensuring timely and appropriate service interventions and other inputs to reduce carer stress and improve coping. Alternatively, carers will be better supported towards a transition from home to institutional care when this is considered to be in their and their dependants' best interests, perhaps at an earlier stage than might otherwise have been the case. Both would be considered as improved care outcomes for the person with dementia, as well as for their carer.

Chapter 2

BACKGROUND

"Dementia is a cruel disease which robs you of your life and the one you love. Two people suffer as a result of this dreaded illness." (Face carer 5)

CHAPTER 2: BACKGROUND TO THE STUDY

2.1 What is dementia?

Over the centuries the term 'dementia' has meant many things to many people. In language the word 'demented' has commonly been used as a pejorative term to describe 'madness', 'insanity' or 'a loss of control' (Collins English Dictionary, 1992). Indeed, the word 'dementia' comes from the Latin 'dementare', meaning 'madness' or 'to drive mad'.

The medical definition of 'dementia' is quite different, however, with the umbrella term being used to describe a range of organic diseases of the brain of which the primary feature is 'the development of multiple cognitive deficits that include memory impairment' (DSM-IV, 1994).

The World Health Organisation (WHO ICD-10, 1992) has defined dementia as follows:

'Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not usually impaired. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.'

Additionally, the ICD-10 (ps. 29-31) states the following diagnostic criterion for dementia:

- 'A decline in memory, which is most evident in the learning of new information although, in more severe cases, the recall of previously learned information may also be affected.
- A decline in other cognitive abilities characterised by deterioration in judgement and thinking, such as planning and organising, and in the general processing of information.
- Awareness of the environment, i.e. absence of clouding of consciousness.
- A decline in emotional control or motivation, or a change in social behaviour.
- For a confident diagnosis, the symptoms should have been present for at least 6 months.'

However, the following more vivid and perhaps more accessible description is attributed to Professor Tom Arie (cited in Rabago and Bayer, 1998, p. 5):

'Poor ability to think, understand, perhaps to dress, to toilet, to cook, to put oneself to bed, to differentiate between night and day, to want to go to school (aged 80), to want mother, to go naked, to put paraffin on the electric fire.'

2.2 Prevalence of dementia

The Alzheimer's Society estimates that dementia currently affects 750,100 people in the UK. Estimated numbers, using census population statistics for 1996 were: England 634,000, Scotland 60,600, Northern Ireland 14,900 and Wales 40,600.

The prevalence rates for dementia in the UK are: 1 in 1000 for the 40 – 65 age group, 1 in 50 for the 65 – 70 age group, 1 in 20 for the 70 – 80 age group, and 1 in 5 for the 80 years and over group. Whilst dementia is commonly assumed only to affect people in old age - the words 'senile' and 'senility' are still commonly used in language to describe the syndrome, it is important to note that dementia affects some 18,500 younger people in the UK. Indeed, a significant minority of the study cohort are from this group, and the problems and needs experienced by them and their carers may be quite different, as will be explored later in this thesis.

In terms of projected growth, the Alzheimer's Society estimate that by 2010 there will be 840,000 people with dementia in the UK, which is expected to rise to over 1.5 million by the year 2050. Despite this rapid dementia population growth, the Alzheimer's Society argue that to describe the expected situation as 'a demographic timebomb' or 'tidal wave' which the state cannot afford or cater for is misleading and unhelpful, and states its belief that work can be done now with government to ensure a sustainable health care system is developed to meet these increasing needs (Alzheimer's Society, 2001).

Considering the global impact of dementia, Alzheimer's Disease International (ADI) states that there are currently 18 million people with dementia worldwide, and this figure is set to rise to 34 million by the year 2025. Already most people with dementia live in developing countries and in 25 years time over 70% of all people in the world with dementia will be in developing countries. ADI (2001) argues that with these rapidly changing demographics governments urgently need to be planning ahead for the ageing of their populations.

2.3 Cost of dementia

About 6 million people in Britain are carers (DoH, 1999) and it is estimated that they save the government between £33.9 and £39.1 billion each year. These costs are in comparison to British Medical Association estimates that the total cost of institutional care to the state is £7 billion and the cost of all professional care in the community is £3.1 billion. Thus family caregivers currently provide some 77-80% of all the care needed (Nolan et al., 1996).

Extrapolating the above figures, using the 750,100 Alzheimer's Society prevalence figure, one could 'guesstimate' that dementia family caregivers save the government somewhere in the region of £4.2 billion. However, people with dementia do tend to have more complex needs than other groups, for example, it is acknowledged that caring for a person with dementia is more difficult than caring for someone with a static physical disability (Morris et al., 1988), and thus more people with dementia may require institutional care. Wenger (1994) estimated that approximately 43% of people with dementia are cared for within institutional settings and Gordon and Spicker (1997) similarly estimated the level of people with dementia within long-term care at 40%. This means that some 300,000 people with dementia are cared for in permanent care settings and the larger proportion, 450,000 people with dementia, are living in the community supported by informal carers.

There is also growing evidence that the availability of informal carers to provide support is becoming less as the extended family unit is continuing to breakdown, and more older people are now living alone (DoH, 1995). Indeed, the Alzheimer's Society (1994) estimates that there are 154,000 people with dementia living alone, which brings particular difficulties for family carers providing care from a distance for this most vulnerable group. Thus professional care in the community costs may also be higher for people with dementia than for other groups.

Therefore, McNamee et al. (2001) have estimated that for England and Wales the total dementia care cost to social and health agencies lies somewhere between £9.5 billion and £13.5 billion. These figures obviously do not include the financial cost to dementia carers in terms of time lost from work to care, early retirement to take on the role of full-time caregiver and effects on pension, lost earnings from young onset dementia sufferers having to end work early and so on.

2.4 Types of dementia

As stated above, dementia as a syndrome is diverse, embracing many differing pathologies. It is important to describe the range of dementing illnesses which may be present, as many of the different types across the range are suffered by people with dementia in this study. As can be seen in the foregoing, each dementia results in a differing illness trajectory, although there are important commonalities, and thus it is important to detail the factors which may result in a differing caregiving experience for respondents.

The most common type of dementia is Alzheimer's disease, which accounts for about 55% of all cases. Vascular dementia accounts for a further 20% of cases of dementia, dementia with Lewy bodies 15%, fronto-temporal dementia including Pick's disease 5%, and other rarer dementias make up the remaining 5% - these include Huntington's disease, normal pressure hydrocephalus, and secondary dementias, such as dementia in Parkinson's disease, alcohol related dementia, AIDS related dementia and Creutzfeldt-Jakob disease (Alzheimer's Society, 2001). In the following sections of this chapter, and in the appendices for the rarer dementias, each will be discussed in further detail.

2.5 Alzheimer's disease

Alois Alzheimer, a German neurologist, first described 'Alzheimer's Syndrome' and its effects upon a 52-year-old woman, Auguste D, in 1907. For decades the disease was regarded as a 'pre-senile dementia', separate and distinctive from 'senile dementia', that is dementia with onset in old age. However, such a dichotomy is now widely known to be false and artificial, as a dementing illness with a clinical picture of *'progressive impairment over a period of years, the onset and course of which is gradual is, in the main, both clinically and neuropathologically indistinguishable from Alzheimer's disease'* (Stokes and Holden, 1990, p.18). The result is that today most clinicians refer to the onset of Alzheimer's disease in persons under the age of 65 as 'Early onset Alzheimer's disease', and 'Late onset Alzheimer's disease' in persons who develop the illness after the age of 65.

Alzheimer's disease shows a clinical picture of gradual, progressive intellectual and physical impairment over a period of several years. During the course of the disease the chemistry of the brain changes and cells, nerves and transmitters are attacked. At microscopic level, the two most distinctive features of Alzheimer's disease are the presence of neurofibrillary tangles in neurones (made up of tau protein and ubiquitin) and plaques (made up of amyloid protein). Why these changes occur has not yet been established, but there does seem to be a problem with the metabolism of amyloid and tau proteins. How these interrelate and whether they are the cause or the result of underlying disease remains unclear. The disease process attacks and destroys brain neurones, and gradually the brain atrophies, most prominently in the temporal lobes, with changes usually being bilateral and symmetrical.

The neurones which deteriorate in Alzheimer's disease are those which in general use the protein acetylcholine as a neurotransmitter, thus in Alzheimer's disease there is a substantial reduction in the amount of acetylcholine in the brain. This is essential for processing and transferring messages from one part of the brain to another, therefore when there is reduction of it this leads to the impairment seen in the illness (Jackson, 2002 a.).

As the illness gradually and progressively worsens, the symptoms of short-term memory loss, disorientation in time and place, deteriorating ability to carry out complex daily living skills, speech problems such as expressive and receptive dysphasia, deterioration in personality, and various agnosias and apraxias become more obvious and disabling. Over time the person becomes so confused, intellectually impaired, and unable to provide self-care that they are rendered totally dependent on others to meet their needs and maintain their health and safety. It is because Alzheimer's disease affects so many parts of the brain that so many aspects of cognitive functioning are affected.

Although the causes of Alzheimer's disease have yet to be established, various risk factors have been recognised. Of particular importance is research relating to the genetic component of Alzheimer's disease. This is more prominent in families with an early age of onset, but the genetics of later onset Alzheimer's disease are also now better understood.
In 'Early onset Alzheimer's disease' particular genes have been identified. The first of these was on chromosome 21. People with Down's syndrome have an extra chromosome 21 and are known to have a higher risk of developing Alzheimer's disease, and amyloid metabolism abnormalities have also been associated with chromosome 21, thus it was thought that the gene for Alzheimer's disease would be found on this chromosome. However, other genetic abnormalities have been found and these are identified as follows.

About 15 families in the world have a fault on chromosome 21 in a gene called amyloid precursor protein (APP) which affects the production of amyloid. A larger number of families carry a fault on chromosome 14 (presenilin-1) which could be responsible for the majority of early onset cases of 'Familial Alzheimer's disease', sometimes below the age of 40. A smaller group of families, mainly in the US, has a fault on chromosome 1 (presenilin-2). On average half the children of someone with one of these genetic defects inherits it, and probably all those who do develop the disease. Those who do not inherit the genetic fault cannot pass it on, i.e. it does not skip a generation (Alzheimer's Society, 1997).

In 'Late onset Alzheimer's disease' there is a weaker genetic link than with the early onset condition associated with a protein we all have in the blood and brain called apolipoprotein E (ApoE). ApoE has a role in the maintenance and repair of neurones and there are three forms: ApoE 2, 3 and 4. The gene for this substance lies on chromosome 19. ApoE4 is associated with higher risk of Alzheimer's disease. About a quarter of the population inherit one copy of the ApoE4 gene and this increases the risk by up to four times. Two per cent get a 'double dose' of this gene, one from each parent. For these people the risk of Alzheimer's is increased by 16 times. Sixty per cent of the population have a double dose of the ApoE3 gene and are at 'average risk'. About half will develop Alzheimer's by their late 80s. ApoE2 is least associated with Alzheimer's disease, but only one in six people carries it. People who have one ApoE2 gene and one ApoE3 gene, about 11 per cent of the population, have to live into their late 90s before their risk of developing Alzheimer's reaches 50%. One in 200 people inherit two copies of the ApoE2 gene, and their risk of Alzheimer's is very low (Alzheimer's Society, 1997).

There are pros and cons to genetic testing for Alzheimer's disease. For testing are the facts that such knowledge could lead to earlier diagnosis and access to anti-dementia drugs; it helps people plan for the future; and a body of results helps identify new treatments and genetic therapy. Against testing are the facts that the genetic defects cannot at present be repaired and testing raises anxiety without the hope of a cure; a positive test for ApoE4 does not predict you will develop the disease and a negative result doesn't mean you will not; and a positive test has been used discriminatively by insurance companies. However, the Alzheimer's Society advise that if a person has three or more family members with early onset Alzheimer's disease they may want to undergo genetic testing.

Other risk factors for Alzheimer's disease include a history of previous head injury, environmental factors such as ingestion of aluminium or other toxins, viral infections, deficiency of vitamins B12 or folic acid, and thyroid problems, though evidence for these as contributory factors remains rather weak (Jackson, 2002 a.).

2.6 Treatments for Alzheimer's disease

New treatments for Alzheimer's disease have become available in the last few years. Since the mid 1970s it has been recognised that widespread loss of cholinergic function in the cerebral cortex and elsewhere in the brain is characteristic of Alzheimer's disease. The new drugs, donepezil (aricept), rivastigmine (exelon) and galantamine (riminyl), increase the level of brain acetylcholine by blocking the breakdown of this neurotransmitter by inhibiting the responsible cholinesterase enzymes. All three drugs, now approved by the National Institute for Clinical Excellence, delay symptomatic decline in up to 60-70% of patients for an average 6–9 months without serious side effects. There is also evidence that they lead to reductions in behavioural disturbance and improved caregiver burden. A small number of patients improve dramatically. In making its recommendation that the new anti-Alzheimer's drugs should be made available on the NHS at a cost of £42 million per annum, it was recognised that cost savings of around £50 million would be made each year by delaying the entry of people with dementia into permanent care by up to three months (Bayer, 2001).

A range of other potential treatments have received attention over recent years. Most noteable of these are anti-inflammatory drugs, such as nonsteroidal anti-inflammatory drugs or corticosteroids, which appear to decrease the risk of Alzheimer's disease by up to 50% but may be less beneficial in established disease; and anti-oxidant drugs, such as vitamin E or selegiline, which have the potential to slow progression of the disease and delay institutionalisation by up to 200 days. Both of these groups of drugs may help stop the harmful effects of beta amyloid. This is toxic to nerve cells and its accumulation in brains affected by Alzheimer's is thought to set off a 'destructive biochemical cascade of inflammatory and oxygen free radical mediated damage' (Bayer, 2001).

Anti-amyloid approaches to treating Alzheimer's disease are also at the forefront of research and have received intensive media attention over recent years. In December 2000, scientists in Toronto announced that they had developed a potent vaccine for Alzheimer's disease. The vaccine, tested successfully on transgenic mice, was said to block the production of amyloid, clean up brain tissue and prevent the symptoms of Alzheimer's. Early immunisation with beta amyloid resulted in antibodies that prevented the formulation of amyloid deposits. If the same effect can be duplicated in humans it would 'revolutionalise the treatment of Alzheimer's disease' (Bayer, 2001). Clinical trials of the vaccine in human subjects have now commenced and, if successful, could represent real hope for preventative treatment in the not too distant future.

2.7 Phases of Alzheimer's disease and other degenerative dementias

Whilst there is no definitive course of gradual deterioration in Alzheimer's disease and other degenerative dementias, and the pattern and rate of cognitive, behavioural and physical decline varies from person to person, a 'Phase Model', which describes the broad characteristics common to all cases, is generally accepted. The phases of illness, which are perhaps best described in Stokes and Holden (1990), are 'The Forgetfulness Phase' - or minimal to mild dementia, 'The Confusional Phase' - or mild to moderate dementia, and 'The Dementia Phase' - moderate to severe dementia.

In the 'Forgetfulness Phase' the most prominent features are short-term memory problems and time disorientation. Personality change is also an early feature, commented on by carers and relatives. The onset of dementia is typically gradual and insidious, and it may be several months, or even years, before a specialist assessment or diagnosis is sought or given.

In the 'Confusional Phase' deteriorating memory, declining intellectual abilities, profound disorientation in time and place, communication impairment, mood and personality changes and a progressive loss of skills in performing everyday and self-care tasks are characteristic features. Behavioural problems that are difficult for caregivers to manage, such as repetitive questioning, resistance to care, aggression and excessive aimless walking, may peak during this phase.

In the final 'Dementia Phase' there is gross intellectual incapacity in all areas, communication is severely impoverished or absent, personality is submerged by the illness and there is increasing physical frailty, with severe mobility problems, double incontinence and significant weight loss - despite adequate intake. Stokes and Holden (1990, p.20) define the final 'Dementia phase' as *'beginning at the point at which intellectual and self-care abilities would no longer sustain survival if the person were left on their own'.*

Elsewhere, dementia care practitioners have attempted to develop stage models for dementia. The following 'Classification of the stages of dementia' (Cole and Nicholls, 1999) is one where stages are linked to performance scores on the Mini Mental State Examination (Folstein et al., 1975):

STAGE 1 – could score 26 upwards (maximum 30) on MMSE
- Memory slips
- Some forgetfulness
- Person knows there is a problem
- Memory problem causing some distress, resulting in anxiety or depression
- Memory problem not evident to others
- Some loss of concentration and ability to follow instructions

STAGE 2 – could score 20 upwards on MMSE
- Memory problems noticed by nearest relative
- Stage of contacting GP
- Could be diagnosis stage
- Loss of interest
- Requires some help by nearest relative
- Personality intact
- Some cognitive intellectual deterioration
- Able to perform all activities of daily living

STAGE 3 – could score 14 on MMSE
- Confabulation evident
- Periods of becoming lost
- Missing appointments
- Motivation retarded
- Some loss of self-expression
- Some deterioration with answering questions – i.e. inappropriate responses
- Prompting required
- Inability to recall recent events

STAGE 4 – score 7 on MMSE
- Reduced or muddled abilities regarding activities of daily living
- Unable to follow sequence of events
- Unable to follow sequence of eating or preparing food
- Some disorientation – time and place
- Unable to express self

STAGE 5 – MMSE not appropriate
- Unable to perform activities of daily living without assistance
- Disorientation
- Restlessness
- Potential for anger, aggression
- Loss of weight
- Awareness reduced
- Mobility impaired
- Loss of swallowing reflex

STAGE 6
- All care required
- Almost total disintegration of personality
- Requires help with eating and all activities of daily living
- Mobility reduced, difficult, or non-existent
- Final stages of illness
- Cachexia

Alzheimer's Disease International (1999) state the following prevalence of psychiatric symptoms and behavioural disturbances in dementia, all of which cause particular stress and strain on carers and may contribute to the decision to resort to permanent care:

personality change	100%
agitation	over 80%
incontinence (predominantly urinary)	50-60%
depression	25-65%
paranoid ideas	30%
aggression (physical or verbal)	20-30%
wandering	25%
misidentifications	20%
hallucinations (visual and auditory)	15-20%
sexual disinhibition	10%
increased eating	5-10%
screaming	5%
mania	2%

2.8 Vascular dementia

The term 'vascular dementia' in now used instead of 'multi-infarct dementia', as it encompasses dementia arising from any disturbance of blood supply to the brain and recognises that the presence of infarcts is by no means essential for the development of dementia. The condition is thought to be the second most common cause of dementia in the Western world (after Alzheimer's disease), but worldwide it may be the most common cause. The prevalence of pure vascular dementia is relatively low, accounting for 10-20% of cases, but it is now thought that there may be a vascular component in the majority of cases of dementia (Bayer, 2003).

Vascular dementia affects 2-4% of over 65 year olds and 10-15% of 85 year olds. It is more common in men, with a male to female ratio of about 3:1, whereas Alzheimer's disease is slightly more common in women. This may be because of a longer duration of the disease and longer survival in women compared to men (Rabago and Bayer, 1998). It is also more prevalent in people of Afro Caribbean and East Asian origin (Bayer, 2003).

There are several sub-types of vascular dementia, including 'cortical vascular dementia' (associated with large artery, atheromatous or thromboembolic disease); 'strategic infarct dementia' (arising from small, critically located lesions, e.g. in the thalamus, hippocampus or corpus callosum); 'small vessel dementia or subcortical vascular dementia' (caused by multiple subcortical 'lacunes' or deep cerebral infarcts in the basal ganglia, thalamus, brainstem and internal capsule, and 'haemodynamic dementia' (secondary to hypoperfusion associated with cardiac arrest or systemic haemorrhage). Other less common causes of vascular dementia include haemorrhagic dementia, cerebral vasculitis (associated with collagen disorders) and hereditary angiopathies, such as familial amyloid angiopathy and CADASIL – cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (Bayer, 2003).

Genetic factors are less prominent in vascular dementia than in Alzheimer's disease, other than in relation to the generalised risk factors for vascular disease. However, CADASIL is a rare form of vascular dementia that affects younger people, usually with an age of onset in their mid-40s. The gene for this disease has been identified on chromosome 19 (Jackson, 2002 b.).

A stroke increases the risk of developing dementia about nine-fold compared to non-stroke patients (Bayer, 2003). Around 25% of people who have survived stroke develop dementia within 12 months and are between 2 and 10 times more likely to develop dementia than older people who have not had strokes (Shetty, 2003).

Bayer (2003) lists the factors which appear to be important in determining if cerebrovascular disease will cause dementia:

- The total volume of brain tissue which is infarcted. The number of lesions is less important. Extensive white matter lesions appear to make dementia more likely.
- The bilaterality of lesions (perhaps because memory is bilaterally represented).
- The strategic location of the lesions. Often implicated are infarctions in the hippocampus and adjacent limbic structures, or in the corpus callosum and deep frontal white matter.

Vascular dementia is characterised by a more sudden onset than Alzheimer's disease, and progression is usually in a 'stepwise' manner, with periods of plateau followed by sudden decline, caused by further cerebral infarcts. Following infarcts, the individual's level of cognition and functioning deteriorates, often significantly. TIAs - transient ischaemic attacks, are a common feature of vascular dementia. This is where the blood supply to areas of the brain is interrupted for a time as an embolus passes through a blood vessel, leading to a total or partial loss of consciousness, increased confusion and sometimes a hemiplegia. Recovery time is usually a few hours, but can be days. After a TIA, the person may never regain their previous level of functioning and may be noticeably more confused. They have suffered another infarct, i.e. a number of their brain cells have been permanently damaged and will not recover. As these areas of damage build up, the symptoms of dementia become more obvious and disabling, not dissimilar to Alzheimer's disease. However, many vascular dementia sufferers may have died before they reach this stage, often from a more major stroke.

The appearance of symptoms in vascular dementia is more patchy and unpredictable than in Alzheimer's disease, depending on where the damage has occurred. People with vascular dementia tend to have good days and bad days, with more lucid periods. Personality is more likely to remain intact for longer. Emotional lability is a common symptom: the person has little control over their emotions and will cry or laugh inappropriately. Insight into problems and deficits often remains intact for longer, and people suffering from this illness subsequently often suffer from clinical depression, which further challenges their functioning and cognition.

Vascular dementia is caused by disease of the circulatory system and is associated with: high systolic and/or diastolic blood pressure, atrial fibrillation (AF associated with rheumatic heart disease increases risk of stroke 17-fold; non-rheumatic 5-fold), diabetes mellitus (about 15-20% of vascular dementia sufferers are diabetic), high blood cholesterol (raised blood lipids), raised fibrinogen, and smoking (Bayer, 1997). Typically, patients who have an underlying predisposition to vascular disease will be more likely to have a vascular contribution to their dementia (Bayer, 2003).

The main line of medical intervention for vascular dementia is on treating risk factors for generalised vascular disease in order to prevent further cerebral damage. Use of prophylactic low dose aspirin may help prevent further vascular events and slow cognitive decline. Anticoagulation treatment with warfarin is often used in patients with a clear source of emboli, such as those with valvular heart disease or atrial fibrillation. Corticosteroids or immunosuppressant treatment may be indicated in those with active inflammatory arterial disease. Carotid artery surgery may be considered in those with greater than 70% stenosis and relatively mild cognitive deficits. Anticholinesterase drugs such as donepezil, rivastigmine and galantamine are also showing promise in vascular dementia and clinical trials are in progress. There is also some evidence of efficacy of the glutamate receptor antagonist, memantine (Bayer, 2003).

2.9 Dementia with Lewy bodies

Lewy bodies, or 'distinctive intraneuronal inclusions', have been recognised as the pathological hallmark of idiopathic Parkinson's disease since they were first discovered in 1912 by Frederich Lewy, a colleague of Alois Alzheimer. However, unlike Parkinson's disease where Lewy bodies are largely restricted to the substantia nigra, in dementia with

Lewy bodies the intraneuronal inclusions are widely distributed throughout the cortex, commonly but not always associated with the senile plaques typical of Alzheimer's disease (though they are insoluble complexes of proteins totally different to the tangles and plaques of Alzheimer's disease) (Jackson, 2002 b.). The severity of dementia seems to correlate with cortical Lewy body counts (Flattery and Bayer, 1999).

The central feature of dementia with Lewy bodies is progressive cognitive decline amounting to dementia (deficits on tests of attention, fronto-cortical skills and visuospatial ability may be especially significant). In addition, two of the following are required for a probable diagnosis of dementia with Lewy bodies: fluctuating cognition with pronounced variations in level of attention and alertness; recurrent visual hallucinations that are typically well formed and detailed, and spontaneous motor features of Parkinsonism. Additional features supportive of a dementia with Lewy bodies diagnosis are: repeated falls; syncope or transient loss of consciousness; neuroleptic hypersensitivity; systematised delusions, and hallucinations in other modalities (Flattery and Bayer, 1999).

One particularly difficult feature of dementia with Lewy bodies which presents clinical management problems is neuroleptic hypersensitivity, meaning that the very drugs normally used to treat delusions and hallucinations can cause 'malignant neuroleptic syndrome (MNS)' in people with this illness. MNS is a dangerous and life threatening reaction to anti-psychotic medication, characterised by severe and prolonged extrapyramidal reactions, including a dangerously high temperature and exacerbation of confusion. MNS should be regarded as a medical emergency, as it has been associated with a mortality of up to 25% (Flattery and Bayer, 1999).

The management of dementia with Lewy bodies is therefore difficult, with behavioural problems linked to delusions and hallucinations often being hard to keep under control. These, coupled with the frequent falling, loss of consciousness and Parkinsonistic features associated with the disorder bring special challenges for family caregivers. If neuroleptic treatment is considered essential, however, the newer atypical neuroleptics may be better tolerated, though initial reports of the use of respiridone have not been confirmed and only anecdotal reports of the benefits of clozapine and olanzepine are available. The new anticholinesterase drugs, donepezil, rivastigmine and galantamine, may be particularly helpful in dementia with Lewy bodies, despite the fact that they are not yet licensed for treatment of this condition (Flattery and Bayer, 1999).

2.10 Frontotemporal dementia

In 1906 Arnold Pick, a German neurologist, first described the clinical syndrome of progressive personality change associated with bilateral frontal lobe atrophy (CANDID, 1996). 'Pick's disease' and 'Frontal lobe dementia' were until recently thought of as two separate and distinct conditions, but now the term 'Frontotemporal dementia' is now thought to be more appropriate to describe the clinical picture of severe atrophy in the frontal and anterior temporal lobes, which is usually but not always symmetrical (Jackson, 2002 b.). However, it is recognised that Pick's disease can exist as an autosomal dominant genetically inherited condition, known as 'Familial Pick's disease' (CANDID, 1996).

Frontotemporal dementia tends to affect a younger age group than Alzheimer's disease or vascular dementia, with usual age of onset in the 50s or 60s, is more common in women than men and has a stronger genetic component (Bayer and Reban, 1996; Jackson, 2002 b.). Onset is insidious, and the most prominent early symptoms are personality change and dysphasia rather than memory impairment. Mood change, with coarsening of affect, antisocial behaviour and impaired judgement and insight are also common early features. The person may lose their inhibitions and become extrovert or withdrawn. They may talk to strangers, make inappropriate comments in public, be rude or impatient, etc. They sometimes appear selfish, which is caused by a loss of mental flexibility and being unable to see someone else's point of view. The development of routines and obsessional behaviour is also common, e.g. the person may develop compulsory walking routines.

Speech problems are common and range from limited conversational skills and echoing what has just been said to mutism in the more advanced stages of the illness. Overeating and obsessional cravings for sweet foods often leads to weight gain. Excessive alcohol intake may also occur. In the later stages people with this illness may reach out for any available object and compulsively put objects in their mouth (hyperorality). Aggressive behaviour and sexual disinhibition are also common features due to the disinhibition which is characteristic of frontal lobe damage. Difficulties with memory often appear at a later stage, although communication difficulties can make memory problems appear much worse than they actually are.

2.11 Other dementias

Having discussed the four most common types of dementia and demonstrated that the impact of all dementias on family carers, regardless of type, is enormous, information regarding the remaining rarer dementias, which make up 5% of cases, is located in Appendix 5.

2.12 Life expectancy

The life expectancy of the person with dementia, and the rate and pattern of the course of the illness, vary widely from person to person, making it very hard to give a reliable prognosis. However, in community surveys, statistical patterns show that the average interval between detection of dementia and death is about five years. For patients referred to specialist services, the time interval from diagnosis to death is three to four years, and for those entering institutional care the average life expectancy is about two years (Bayer, 1991). It is also generally accepted that deterioration is most rapid in those with young onset dementia, for those in poor physical health, or for those who have more severe symptoms at first presentation, although this may be because the person is further into their dementing illness at the point of identification.

The causes of death in people with dementia would appear to have changed significantly over the last two decades. Before the late 1980s it was not uncommon for the primary cause of death to have been from septicaemia resulting from a sacral pressure sore – indeed this was the primary cause of death for Auguste D way back in 1906! However, with improvements in pressure area care, with new pressure relieving mattresses and cushions becoming available; in continence care, where pads now hold damaging urine away from the skin; in drug treatments, where it is now recognised that the use of sedation should be kept to an absolute minimum; in behaviour management, where physical restraint is now recognised as abusive practice and challenging behaviour is managed by psycho-social approaches; in nutrition, where a wide range of high calorific content food supplements is now available and speech and language therapy advice is sought for swallowing difficulties, and in nursing care, where people with dementia are no longer cared for in bed (unless in the terminal stage of the illness) and are kept active and mobile, it is uncommon for a person with dementia to have a large pressure sore, let alone to die from it.

Today the most common causes of death in people with dementia are aspiration pneumonia and multi-organ failure (Alzheimer's Society, 2001). Because of the above and other improvements in standards of physical and psychological care, people with dementia are now living longer and more, it would appear, are surviving until the terminal stages of their dementing illness. This has brought new challenges for health care professionals, for instance, in relation to end of life decision-making, e.g. when to withdraw artificial feeding, how to ensure effective pain management and how to involve carers in Do Not Resuscitate orders.

2.13 Relevant government legislation and strategy

There have been many acts of parliament and government strategy documents over recent years that have had direct relevance to people with dementia and their carers. A brief overview is provided here to inform the thesis. However, only legislation and strategy relating to the UK is presented, with an acknowledgement that the situation in different areas of the world may be quite different and that both services and entitlements for those dependants and carers living overseas who have contributed to the study are highly varied.

Perhaps the most significant piece of legislation to be passed in recent years that had a direct relevance to people with dementia and their carers was the 'NHS and Community Care Act' (DoH, 1990). This Act brought about some of the biggest changes in the welfare state since the Second World War. Significantly, the Act's first key objective was to promote the development of domiciliary, day and respite care services to enable people to remain in their own homes wherever feasible or possible. The Act also recognised the valuable work that carers undertake and the fact that they provide the majority of community care. And it highlighted that the majority of resources were spent on funding residential and nursing home care; the underpinning philosophy throughout being to promote a shift of resources away from institutional care towards community care. A 'mixed economy of care' was promoted, with local authorities encouraged to purchase a range of community care services from a variety of providers, including the private and voluntary sectors. Perhaps the key requirement in the Act, however, was the duty given to local authorities to carry out assessments for people it believed to be in need of services. Crucially, if the assessment concluded there was a need for certain services, then these had to be provided by the local authority. This helped to overcome, partly at least, the problem of many clients' and carers' needs being overlooked/not assessed and people 'slipping through the net' until precipitant crises brought them to the attention of emergency services.

In 1995 the 'Carers (Recognition and Services) Act' (DoH, 1995) gave carers, for the first time, the right to be consulted about their needs. The Act stated that carers providing 'regular and substantial care' had the right to ask their local authority to undertake an assessment of their ability and willingness to provide and continue providing care when their dependants' needs were being assessed. The results of the carer's assessment are to be taken into account when decisions are made about the type and level of community care services to be provided to the person cared for. What the Act did not provide, however, was the right of carers to be provided with a service as the result of the assessment. It was therefore of limited value. Indeed, in 1997 the Carers National Association produced a report with the title 'Still Battling On', which highlighted that even the limited powers of the Carers Act were largely unimplemented (CNA, 1997). Many local authorities did not have formal assessment procedures and many carers were waiting until they were at breaking point to ask for an assessment of their needs. Even where assessment procedures were in place, they often did not take into account (as guidance recommended) the carer's emotional, mental and physical health, the impact of caregiving tasks undertaken, and the carer's ability to continue to provide care for their dependant.

In 1998 the Prime Minister announced a review of measures to help carers as part of a National Strategy for Carers, entitled 'Caring about Carers'. The objective of the Strategy was to bring together a range of initiatives designed to address carers' concerns and give them increased support. The Strategy highlighted the need for legislation to enable local authorities to provide services directly to carers. This was in recognition that the Carers Act did not give local authorities the power to offer carers services to support them in their caring role.

The Strategy led to the 'Carers and Disabled Children Act 2000' (DoH, 2000), which made four principal changes to the law, with the objective of enabling local authorities to offer new support to carers to help them to maintain their own health and well-being:

1. It gave local authorities the power to supply services direct to carers following assessment. (It enabled local authorities to carry out an assessment in circumstances where the person cared for refuses an assessment for community care services, which is especially helpful in the field of dementia care.)
2. It empowered local authorities to make direct payments to carers for services that meet their needs to empower them to make choices for themselves and to have more control over their lives.
3. It provided for local authority social services to run short-term break voucher schemes, designed to offer flexibility in the timing of carers' breaks and choice in the way services are delivered to persons cared for while their usual carer is taking a break.
4. It also gave local authorities a power to charge carers for the services they receive.

This Act, implemented in Wales via the Welsh Assembly Government Strategy 'Caring About Carers: The Carers Strategy in Wales' (NafW, 2001), appears to have greatly improved the situation for many carers, for example, local implementation has resulted in carers being able to access three free home care hours per week for respite care breaks. This means that for those carers who do not wish to accept a local authority organised care package, perhaps because of a refusal to undergo a social services financial assessment, some limited support is now available. However, carers still need to be knowledgeable about and in touch with the services that can access carer breaks for them, for example the Alzheimer's Society or Crossroads Care, and this means that many may remain unaware of this entitlement.

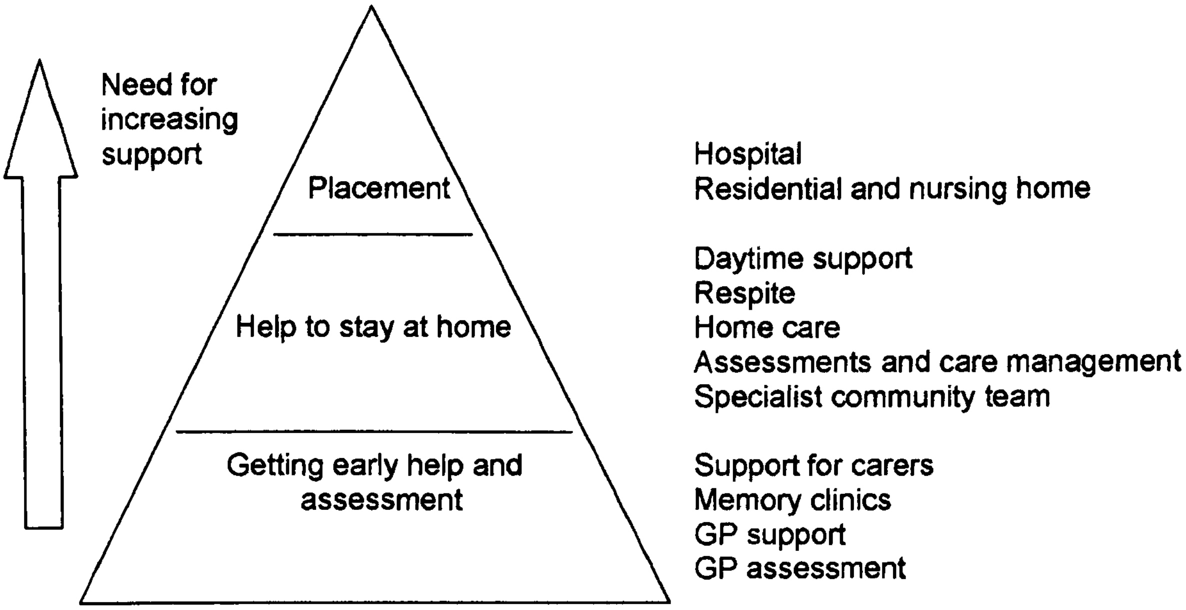
Another significant report recently published that will influence the future shape of services received by people with dementia and their carers is the Audit Commission's 'Forget Me Not' report (2000). This report on mental health services for older people in the UK recommended that:

- GPs and other primary care staff should provide better information, support and advice for users and carers;
- mental health professionals should provide more training and support for GPs and primary care teams;
- service provision should be balanced more in favour of flexible home-based support services;
- health and social services should work more effectively together to make better use of their joint resources;
- and users and carers should be more involved in assessments and care planning decisions.

Following the publication of 'Forget Me Not', the Audit Commission Wales audited mental health services for older people throughout Wales and published its findings in 'Losing Time' (Audit Commission Wales, 2002). This report provided a snapshot of current services, achievements and shortfalls, based on ten multi-agency audits across Wales. The introduction to the report stated that:

'Much needs to be done to ensure that mental health services for older people can deliver the same level and standard of support as those given to other groups of vulnerable people. Agencies need to respond without delay to secure the necessary improvements.' (Audit Commission Wales, 2002, p.3)

An 'integrated care triangle' was proposed within this report, which recognised that people need a range of seamless and integrated support from a variety of services and agencies, and that the focus of care needs to shift further from residential and in-patient services to flexible home-based services which better support people with dementia and their carers.



The main recommendations from 'Losing Time' in relation to people with dementia and their carers were:

- GPs should diagnose dementia as early as possible.
- LHBs should ensure ongoing professional development to improve GPs' ability to detect and manage dementia.
- Specialist mental health services should:
  - promote a greater awareness of their services;
  - provide effective support for primary care;
  - accept referrals from a range of sources, not just GPs;
  - strengthen their support for carers, providing them with assessments of their circumstances, followed by training and guidance.
- Health commissioners should:
  - introduce and fund more memory clinics;
  - ensure NICE guidance on prescribing anti-dementia drugs is implemented.
- Health commissioners, local authorities and health services should work together to:
  - ensure that an adequate and equitable service is provided;
  - review the objectives and delivery of day hospital and day care support;
  - consider how best to provide day services for younger people with dementia, especially in rural areas;
  - develop more flexible emergency and short-term respite care;

- implement a single point for all referrals to ensure a coordinated and prompt multi-agency response;
- ensure there is a process for one integrated health and social care assessment and care management procedure relative to the complexity of an individual's need;
- ensure that home care staff are adequately trained in mental health issues.

'Forget Me Not' and 'Losing Time' are significant documents in that they signal important areas for service development and improvement. The Welsh Assembly Government and Department of Health have acknowledged the Audit Commission's recommendations and work is underway to develop Implementation Plans. It is hoped that necessary milestones will be incorporated into the 'National Service Framework for Health and Social Care for Older People in Wales', due to be developed during 2004. (The NSF for Older People in England was published in 2001 and so does not specifically include the recommendations proposed by the Audit Commission. Nonetheless, a review of the main standards, targets and milestones relating to dementia caregiving follows).

If equitable access to integrated care across primary, secondary and tertiary services could be achieved as recommended by the Audit Commission, this would have a tremendous impact on people with dementia and their carers. Improved GP identification and referral pathways would result in earlier diagnosis; equitable access to early intervention services such as memory clinics would result in improved treatment outcomes; access to specialist care management and community support via multi-professional and multi-agency community mental health for older people teams would result in reduced caregiver burden; increased availability of appropriate day and respite facilities, including dedicated services for younger people with dementia, would result in increased longevity of home caregiving; and an easier pathway to relinquishment of home caregiving to permanent care in appropriate settings would result in reduced risk of breakdown in caregiving situations and crises admissions to permanent care.

As mentioned above, in March 2001 the 'National Service Framework for Older People (England)' (DoH, 2001) was launched with the aim of improving care for older people and rooting out age discrimination. £120m over the next 3 years was announced, to be spent on refurbishing old 'Nightingale wards' and this was on top of the £1.4 bn announced in the 'NHS Plan' (DoH, 2000) to ensure that older people are treated with dignity and privacy, for example, with single sex wards being offered to all older people.

In addition, the National Service Framework proposed:

- New teams and services to enable older people to be treated and cared for at home and prevent unnecessary hospital admissions (including an extra £150m over 3 years on community equipment).
- Better coordination between the NHS and social services, with one stop assessments and individual care plans.
- Rehabilitation service expansion with 5,000 more intermediate care beds and more respite care available for carers.
- Improved coordination to improve care and support for older people with mental health problems and their families.
- An emphasis on earlier diagnosis and fairer access to anti-Alzheimer's drugs.
- An emphasis on health promotion through falls prevention, stroke prevention and treatment and flu immunisation.

And to support this 'transformation' in the standards of care and services offered to older people and their carers:

- An Older Patients' Champion and Patients' Forum in every district.
- A Health Professional given specific responsibility for improving services for older people in every NHS organisation.
- Full information given to patients and families about the options available and wishes respected in decision-making.

Only one NSF Standard specifically applied to older people with mental health problems, and in relation to this the targets, to be achieved by April 2004, were:

- Health Improvement Plans to include the development of an integrated mental health service for older people in each district.
- Primary Care Groups to ensure every GP practice has an agreed protocol to diagnose, treat and care for patients with depression or dementia.
- Health and social care systems to have agreed protocols in place for the care and management of older people with mental health problems.

These targets and milestones have been criticised as being very limited in their scope, and people with dementia and older people with later life mental health problems, a very sizeable combined group in the UK, are felt to require a separate NSF. There are specific concerns about the place of younger people with dementia in the NSF, as they are excluded from both the Mental Health NSF and the Older Peoples' NSF. In Wales it is hoped that the needs of this group, and a more robust representation of health and social care needs of people with dementia/later life mental health problems will be included in the NSF for Health and Social Care of Older People in Wales.

The NHS Plan, mentioned above, published in 2000 was perhaps more directly relevant to people with dementia and their carers in the community, as it included the government's 'Response to the Royal Commission on Long-term Care for the Elderly'. This, of course, has had a major impact on the ways in which people with dementia and their carers access and pay for long-term care. The major announcement was that nursing care in nursing homes would be free under the NHS by October 2001. 'Nursing Care' was defined as including the costs of registered nurse time spent on 'providing, delegating or supervising care in any setting', but did not include 'personal care', including assistance with dressing and bathing, or accommodation costs which were still to be means-tested. Other changes included a delay of 3 months from admission to permanent care before the value of a resident's home is included in the means test to give people time to think about their future; raised capital limits from £16,000-18,000 above which councils will not contribute to the costs of care; and a fairer more consistent approach to charging for home care services.

Despite the announcement initially being greeted as a breakthrough, organisations representing older people branded the government's plans for nursing care as 'unfair, unworkable and a broken promise to the older population' (Alzheimer's Society, 2001). This negative reception was largely because the new system was felt to have introduced a 'postcode lottery', with different arrangements in England, Scotland and Wales. For example, in England older people requiring long-term care qualify for three levels of nursing care funding - £35, £70 and £110 per week, whereas in Wales everyone requiring long-term care will qualify for £90 per week funding for nursing care, and in Scotland the Royal Commission's recommendation to fund personal and nursing care was upheld, with residents in nursing homes funded £90 per week for personal care and £65 per week for nursing care. The Scottish Parliament also made the distinction that all personal care for people living at home will be free.

A coalition of 14 charities and organisations argued that the real cost of nursing care is unlikely to be met by these subsidies and people requiring help with washing, eating and personal care will continue to have to pay for their care from their own savings. The coalition has also stated that the government's new definition of nursing care is completely artificial, arguing that the decision to split nursing from personal care discriminates against those people with long-term illnesses such as Alzheimer's disease. It also warned that the complex assessment and implementation process will lead to confusion, with health and social care professionals ending up spending time on managing intricate funding arrangements rather than providing high quality care for those who need it most.

Until this situation is resolved, the implications for people with dementia and their carers are great. Because of the perceived threat to lifetime savings and assets, including sale of property, many carers are waiting until they are desperate before they accept entry of their relative to permanent care. Many are unaware of their rights in law regarding long-term care funding, and the situation is far from clear for health and social care professionals either. The additional stress caused by unclear charging policies at this most difficult time of decision-making regarding the relinquishment of home caregiving to institutional care may result in carers struggling to continue in their role for far longer than is in their or their relative's best interests and may further carer distress and guilt when permanent care is finally accepted.

An additional and growing problem is that the ramifications of the 'Care Standards Act 2000' (DoH, 2000) has resulted in fewer care home places being available to people with dementia and their carers when entry to permanent care is required/accepted, so people are having to wait for suitable placements to become available and, again, continue for longer in the caregiving role than may be desirable. In addition, many more NHS beds are being 'blocked' by older people waiting for care home placements, and the situation is fast deteriorating, with the number of care home closures accelerating. In 2002, health analysts Laing and Buisson reported the loss of 13,000 nursing and residential home beds in 2001, which was a further drop of around 2% since 2000. Seventy-four thousand long-term care beds have been lost in the care homes sector since 1996 (Laing and Buisson, 2003), and it is believed that this has had a direct effect on bed-blocking with a 13% increase in delayed discharges and a 14% increase in emergency readmissions of patients over the age of 75 in March 2002 (Nursing Times, 2002).

The Care Standards Act 2000 has been roundly blamed for causing this upheaval and chaos in the care homes sector, with independent sector providers closing care homes because they cannot afford to make the environmental and staffing changes necessary to implement government standards, particularly in relation to room size, single room availability and staffing ratios, skill mix and training. Indeed, such was the furore and rate of home closures in 2001 that the government, in a dramatic u-turn, announced in February 2003 that their Care Standards would be urgently reviewed and relaxed, with amended standards coming into effect in June 2003 (BBC News, 2003). However, this climb down, whilst undoubtedly saving some homes from imminent closure, does not resolve the crisis, as another unresolved issue is the low fees paid by local authorities to care homes, which has greatly affected profit margins and made care home provision an unviable business for many firms. Such has been the concern regarding the funding issue, that the Department of Health has recently allocated an additional £300m to local authorities to increase the fees paid to care home owners and, hopefully, the number of care home places available (BBC News, 2003).

Finally, another recent strategic document published by the Welsh Assembly Government in 2001 was 'In Safe Hands: Protection of Vulnerable Adults in Wales' ('No Secrets' in England) (NafW, 2000). Both documents provided guidance for local authorities on how to respond to cases of alleged abuse of vulnerable adults over the age of 18, and required statutory agencies to work collaboratively to develop local policies and procedures to protect vulnerable adults from abuse and inappropriate care. In respect of this thesis, this is relevant both in respect of the fact that highly stressed and burdened carers are more at risk of abusing their demented relative, especially if aggressive behaviour from the dependant is directed at them. 'In Safe Hands' makes it very clear that the response from statutory agencies to abuse from stressed and burned out carers needs to be quite different to that taken with perpetrators who abuse deliberately and systematically.

These documents are also more relevant because the situation for dementia community caregiving has deteriorated over recent years in so much as there are more limited resources to support community care available and there are fewer long-term care beds available, both in the independent and statutory sectors, meaning that pressures on carers are perhaps greater than ever before. Without urgent action to rectify the current crisis of long-term care and increased government funding to increase the availability of specialist community support services for people with dementia to meet the increasing prevalence and therefore health and social care needs of this population, the future looks bleak. This makes this thesis and the resultant carers' assessment tools for use by community care practitioners even more relevant given the current climate, and gives added impetus for its completion.

2.14 The situation for overseas carers

As 57 of the 91 current carer sample and 10 of the past carer sample for this study were caring in countries other than the UK, and 56 of these 67 carers were from the United States of America, attention must be given to the fact that state policy and the level of state support and dementia specific services available greatly differ between countries and continents. For example, in America up until 2001 Medicare did not cover community care and long-term care costs of Alzheimer's disease, and today it still does not cover anti-dementia drug costs, day care charges or the personal care component costs of long-term care. Furthermore, if Medicare insurance runs out whilst the person is still in permanent care the family are required to pay their care costs or recommence home caregiving. The situation for under-privileged families who remain outside of the Medicare system remains grim because although they may qualify for Medicaid support, the choices and quality of care afforded to them will be reduced (www.alzinfo.org 2004).

In 2000, the American Alzheimer's Association strongly urged the US Congress to endorse federal action to incorporate a Family Caregiver Support Program in it's proposed Older Americans Bill. This would fund counselling and support programmes for dementia caregivers, including adult day care and respite care programmes, thus supporting family carers who provide an estimated $196 billion subsidy to the US health care system, more than is spent on formal home health care ($32 billion) and nursing home care ($83 billion) combined, and without whose contribution Medicare and Medicaid would be bankrupt (www.alz.org 2000). The Bill is yet to be enacted and the Alzheimer's Association continues to lobby Congress for increased support to family carers.

Before concluding this section of the thesis, it should be noted that for a small number of carers taking part in this study, the lack of state support for community care and the paucity of dementia specific community care services (a lack of funding support has stifled the development of the full range of services necessary to support home caregiving) may have led to earlier than necessary institutionalisation for many people with dementia. This point will be discussed further later in the thesis.

Chapter 3

REVIEW OF THE LITERATURE

"I am amazed by the ability God has given me to meet the task before me. It has been a privilege of untold proportions." (Internet carer 44)

CHAPTER 3: REVIEW OF THE LITERATURE

3.1 Introduction to the review of the literature

As noted previously, despite the larger response rate from US carers in this study, the focus of this review of the literature is on the UK dementia caregiving phenomenon and the insights and lessons from the literature in relation to this. That is not to say that non-UK articles and texts have been excluded; clearly that is not the case. However, non-UK literature has been reviewed primarily because of it's relevance to the situation of dementia carers in the UK and to this study.

The range and scope of the review was extensive, with articles and text sought from a range of sources, including PubMed, ClinPsych, CINAHL and MedLine electronic search engines. The parameters set for the literature search were English language sources from 1980 – 2000, with an update search being undertaken in 2003 as the final draft of the thesis was written.

The search terms used in the literature search (all linked to 'dementia' or sub-types) were as follows:

Caregiving burden; Dementia caregiving; Burden of care; Dementia care; Relinquishment of care; Institutionalisation risk factors; Permanent care; Caregiving problems; Caregiving demands; Stress of caregiving/caring; Psychological/physical health of carers; Coping skills of carers; Rewards of caregiving/caring; Satisfactions of caregiving/caring; Motivations for caregiving/care; Quality of life of carers; Relationship change between carer/dependant; Community services/formal support for dementia care; Carers Act

Articles were also sourced from reference lists included in papers obtained from the initial literature search.

3.2 Definitions of 'Carer' and facts about carers in the UK

The government definition of 'Carer', which appears in the Carers and Disabled Children Act 2000 (DoH, 2000), is as follows:

'Carers are people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness... The term 'carer' includes people (age 16 and over) who may or may not be a relative and who may or may not be

living with the person for whom they are caring. The Act excludes from the definition of a carer paid care workers and volunteers... The exclusion extends to anyone who is providing personal assistance for payment, either in cash or kind.'

The Carers National Association (CNA, 2000) definition of 'Carer' is similar and was probably used to inform the above definition:

'A carer is anyone whose life is in some way restricted because of the need to take responsibility for the care of a person who is mentally ill, mentally handicapped, physically disabled, or whose health is impaired by sickness or old age.'

A more apposite definition comes from Mary Culley (1991, p. 45) from the book, 'The Nature of Caring':

'WANTED: Job Title - Carer: An individual required for physically and mentally exhausting work. The job may include heavy lifting and applicants should be capable of working alone for indefinite periods. The successful applicant will be expected to be on call 24 hours a day, seven days a week and will receive holidays if they are lucky or able to pay for someone to replace them. Pay is at a rate below the official poverty line or non-existent. Social status attached to the job is low. Applicants are expected to show evidence of a sense of humour and the patience of a saint. Past experience, training or qualifications are not necessary. No training will be provided for this post.'

The most recent statistics on informal carers in the UK, published in 1998 in the report 'Informal Carers' (CNA, 2000), which was based on figures from the 1995 General Household Survey, indicate that there are about 5.7 million carers in the UK. This means that one in eight people in the UK are carers.

Given that there are more women than men in the adult population, the figures showed that significantly more women provide care than men, with 14% of women providing care and 11% of men. Most commonly people were caring for their parents (6% of adults), while 2% of adults were caring for their spouse. The peak age for becoming a carer was found to be between 45 to 64. 20% of adults in this age group were carers. This compares to 6% of adults aged 16 - 29, 10% aged 30 - 44 and 13% aged 65 or more.

Regarding the nature of caregiving, 60% of carers looked after someone with a physical disability, 7% with a mental disability and 15% with both a physical and mental disability. Although most carers looked after elderly people (71% of those cared for were 65 years or over), older people provided a significant amount of care to others. Of those carers providing care for 20 hours a week or more, 27% were aged 65 years or over.

Although the 1995 figures showed a decline in the overall numbers of carers, the survey found that the numbers of carers providing support for 20 or more hours every week had increased from 1.5 million to 1.7 million. 32% of carers were spending more than 20 hours a week caring and 15% of carers were caring for 50 hours or more. This demonstrated a significant increase in the number of carers providing a substantial amount of care. (In 1990, 23% of carers were spending 20 or more hours a week caring and 11% of carers were caring for 50 hours or more a week.) Where the carer and the dependant lived in the same household, 63% of carers spent 20 or more hours a week caring. 38% of carers living in the same household as the person cared for spent at least 50 hours a week caring.

In terms of the type of care provided, 31% of carers were involved in providing personal care, such as bathing, washing, dressing and toileting; 27% administered medicines to their dependant, and 73% were giving other practical help. When these figures are compared to the 1990 survey, carers have become more involved in providing personal care (22% in 1990) and administering medicines (16% in 1990), whereas slightly fewer carers are providing practical help (79% in 1990).

(Carers National Association, 2000; DSS, 2000)

These statistics are fascinating in themselves, but if one considers that they apply to all adult caregivers across all illness and disability groups, it can be surmised that those caring for a person with dementia will be more commonly living with their dependant (due to the risks posed by people with dementia living alone); providing higher levels of personal care (because of the loss of independent living skills synonymous with dementia); delivering a higher number of care hours per week (because of having to manage mental health as well as physical needs); and that a significant number of carers will themselves be elderly and frail, with their own health needs. The needs of dementia carers and the particular stresses and burdens they face will be the focus of this review of the literature.

3.3 Underpinning theoretical models of dementia caregiving stress and burden

In their 'Transactional Model of Stress', Folkman and Lazarus (1985, p. 152) saw stress as resulting from a transaction between an individual and the environment. The stress process is based on a number of appraisals made by the individual, in which the nature of the demands faced is compared with the perceived ability to cope. Thus stress was defined as:

'A relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person's resources are taxed or exceeded.'

Within this model the existence of certain circumstances in a person's life is not assumed to be stress-provoking. Rather how the individual perceives situations in relation to his or her own resources determines the stress that will be experienced. Therefore, stress is said to occur when there is a mismatch between the nature of the demand and the person's ability to respond.

Nolan et al. (1998) usefully extended this model to embrace stresses, rewards and coping. Thus, a demand or event occurs and a primary appraisal is made. If there is threat, harm or challenge, the individual selects a coping response or resource to deal with the event. If no appropriate response can be made, stress is likely to occur. A reappraisal occurs. If the threat, harm or challenge is met, successful transaction or coping has taken place. If it remains, an alternative strategy may be tried and a repeat appraisal made. If the original demand cannot be successfully dealt with, then negative consequences are likely to arise, including reduced morale, deterioration in physical health and a loss of control.

This model explains why individuals react differently to the same or similar events. Some cope successfully and others do not. It also recognises that certain coping methods are more effective in dealing with certain types of demand. Four main types of coping strategies were described:

1. Preventive action – to ensure that stressful events do not occur, but it is not always possible to predict caregiving events.
2. Direct action – to deal with the stressful event itself, which is most effective for those events amenable to change.
3. Reframing the meaning of events – viewing the event in a different light when it cannot be altered by direct action can be helpful, but depends on the person being well informed and having insight into stressful events.
4. Dealing with the consequences of events – when the above strategies are not effective, e.g. by relaxation techniques.

Nolan et al. (1998, p. 6) stressed that *'it is the subjective interpretation of demands and events that is crucial in understanding stress reactions'.* They stated that objective measures such as dependency indicators can only provide a partial and incomplete picture of a carer's needs, and called for the development of more sensitive assessment approaches.

Coping resources that individuals can draw upon are 'Internal resources' – including personal skills, knowledge of the dependant, life experience, beliefs and values and problem-solving skills, and 'External resources- - including income, housing, informal supports and support from services. Nolan et al. (1998) stated that helping people to develop and use their internal coping resources can be particularly effective as it can increase the carer's sense of control and personal ability. These are linked to feelings of self-esteem and self-confidence, which may add to the carer's quality of life. External coping resources are also seen as being important, but the carer's skills in negotiating how services can best be delivered, for example, may need to be developed.

Perhaps most importantly, Nolan et al. (1998) added the crucial factor of the 'Rewards of Caring' to the stress and coping model. They stated that there is growing evidence that caregiving rewards and satisfactions are prevalent, derive from a number of sources and often co-exist with a range of difficulties. Rewards and satisfactions are associated with:

- improved carer well-being
- an increased commitment to the caregiving relationship
- reduced likelihood of institutionalisation for the dependant
- perception of the dependant as a valued person
- evidence of a good prior relationship with the dependant
- a more positive attitude about the future
- successful coping.

This is crucial, as an absence of satisfaction is likely to be associated with a poorer and more fragile caregiving relationship and may serve as an indicator for increased risk of elder abuse (Archbold et al., 1992). The body of evidence available relating to caregiving relationship and caregiving satisfactions will be explored later in this chapter.

The second theoretical model which underpins this study is Braithwaite's (1990) 'Model of Caregiving Burden'. This model, as the above, was not developed exclusively for dementia caregiving, but both provide a great deal of useful knowledge for this field of practice.

Burden has been a key concept in family caregiving research since the early 1980s (Braithwaite, 1992). George and Gwyther (1986, p. 253) defined caregiver burden as *'the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults'*. This definition was felt to be too broad, however, as it did not distinguish objective from subjective burden, a distinction made as far back as 1966 by Hoenig and Hamilton. Platt (1985, p. 386) clarified this distinction by proposing that objective burden refers to the events and activities associated with negative caregiving experience and subjective burden refers to feelings aroused in caregivers as they fulfilled their caregiving functions. Platt pointed out that objective burden involves *'disruption to family/household life that is potentially verifiable and observable'*, whereas the measurement of subjective burden depends entirely on carers sharing their *'personal feelings'*.

Based on the work of Poulshock and Deimling (1984), Braithwaite (1990) argued that burden should be distinguished from both the impairment of the dependant and the impact of caregiving on the carer. The separate concept of 'impairment' was reserved for the dependant's inability to perform activities of daily living, their cognitive problems or challenging behaviour, and the effects of caregiving upon family life, social life and employment were segregated into the domain of 'impact'. Braithwaite (1990) argued that both concepts are linked strongly with the carer's perception of their situation and need to be considered when assessing caregiving burden. Thus caregiving burden referred to carer distress arising from dealing with the dependant's physical dependence and mental incapacity. Poulshock and Deimling's (1984) work recognised caregiving burden as a subjective phenomenon; what was difficult for one carer need not be difficult for another. Crucially, burden lay in the carer's experience.

Braithwaite (1990) argued that Poulshock and Deimling's (1984) model did not sufficiently take into account carers' feelings about caregiving impact, and that these need to be considered when examining the concept of caregiving burden. This was because previous research had highlighted that personal distress arising from overload and divided loyalties (role conflict) can be just as important as distress arising from the dependant's behaviour (Cantor, 1983; Horowitz, 1985). In both of these studies, adult children carers were found to suffer multiple role strain as parents to their own children, spouses, employees, and carers to elderly parents. Conflicting demands and time constraints resulted in additional burden. Thus, Braithwaite (1990) concluded that Poulshock and Deimling's (1984) definition of caregiving burden should be extended to cover both distress in providing care and distress over the effects of caregiving on one's life, thus her definition was *"distress* *arising from dealing with the dependant's physical dependence and mental incapacity and over the effects of caregiving on one's life".*

Braithwaite (1990) proposed that 'caregiving burden' is very much a subjective phenomenon and that the carer's perception of their situation is the most reliable predictor of the impact of caregiving. Mediating factors were said to include the carer's attitude to caregiving, their preparedness for caregiving, the nature of their social and emotional relationship with the dependant and the availability of formal and informal supports. She suggested that caregiving burden may be at its most acute when caring does not follow its desired path, when it does not make things better, and when it accompanies losses rather than gains in the well-being of the dependant, which makes her 'Model of Caregiving Burden' highly appropriate for the field of dementia care practice.

Three types of variables were considered as being of importance in Braithwaite's (1990) model:

First is the 'Level of demand and workload', which refers to the activities in which carers engage and the responsibilities they accept in order to promote the physical and mental well-being of their dependant. Two aspects of workload are identified: 'Task orientated demands', which are primarily concerned with promoting the dependant's physical well-being; and 'Socio-emotional demands', which are primarily concerned with preserving the dependant's mental health and quality of life.

Second is the 'Availability of personal, social or material resources', which includes 'Problem focused coping strategies', designed to manage the problem and get it under control; 'Emotional focused coping strategies', typified by ignoring the difficult situation and dealing instead with accompanying feelings of distress; 'Personality', where a high self-esteem and a sense of mastery are both linked to successful adaptation; 'Health', where poor physical health has an adverse effect on the carer's capacity to continue caring; and 'Social or material resources', including the availability of informal support from family and friends, formal supports from professionals and financial resources, all of which provide back-up support to the carer.

Third are the 'Five crises of decline' (updated in Braithwaite, 1992), which are:

a. 'Perceiving degeneration' in the dependant focuses attention on death and threatens security and stability. Experiencing the demise of a close and supportive relationship while caregiving undermines belongingness and a sense of being loved.

- Losing a partner who has been depended on for well-being can leave a vacuum for meeting security and physiological needs.

b. 'Unpredictability' in caregiving affects the caregiver's capacity to plan, threatening her sense of order and control. Safety needs for security are at risk of not being met. Self-esteem may suffer if the carer believes she has no control over the course of the dependant's disease.

c. 'Time constraints' threaten basic needs on two fronts – when caregiving is in competition with other commitments and responsibilities, the chances of poor performance as a carer are greater and loss of self-esteem is likely to result; when competing commitments involve friendships and obligations, interpersonal relationships may become strained, jeopardising fulfilment of love and belongingness.

d. 'Interpersonal difficulties' between the carer and dependant are likely to undermine the sense of worth of both, as is a lack of choice in the caregiving role. Resentment and unwillingness to care will prevent carers from developing the confidence and competence they need for high self-esteem. Feeling trapped in the caregiving role and perceiving a lack of control may also threaten safety needs.

Braithwaite (1990) hypothesised that all three predictors of caregiving burden will directly influence the amount of burden that is experienced in caregiving. The expectation, therefore, is that if the level of demand or workload is high, the personal, social and material resources are low and the crises of decline are extreme, the burden of caregiving will be at its greatest.

Braithwaite (1992, p. 19) thus concluded that caring for older people with dementia poses a far greater threat to Maslow's (1962) basic needs * than the normal caregiving activities that women engage in throughout their lives. Subsequently, she redefined caregiving burden as:

'The extent to which the meeting of caregiving demands threatens satisfaction of the caregiver's basic needs of a physiological, safety, social, and self-esteem kind.'

* Maslow's (1962) four basic needs are:

- Physiological needs satisfied through adequate sleep and diet.
- Safety needs refer to the desire for security and order in one's life.
- Love and belongingness needs are fulfilled through group membership and social relationships that are supportive of the self.

- Self-esteem refers to the need to feel worthy, to have self-respect, and to be satisfied with one's own accomplishments.

3.4 The problems that carers of people with dementia face

The support needed to maintain a person with dementia in their own home is immense. Many carers suffer from severe stress and strain as a result of having to provide care 24 hours a day, 7 days a week, often over many years. This endless caring has been referred to as *'The 36 Hour Day'* in an indispensable guide for family carers by Mace and Rabins (1991), first published in 1981. The term emphasises the feelings of stress and strain that many carers recount – that there are never enough hours in the day to do all the work that has to be done and one day tends to merge into the next. Coupled with the fact that dementia carers have to provide constant care and supervision for their dependant is the fact that caregiving problems increase over time and caregiving actually becomes more difficult as problems such as night-time disturbance, aimless wandering, incontinence and aggression are encountered (O'Connor et al., 1990).

A number of studies have suggested that caring for an older person with dementia is more difficult than caring for someone with a static physical disability (Isaacs, 1971; Poulshock and Deimling, 1984; Morris et al., 1988). This could be because the symptoms of dementia have more far reaching consequences on the carer's lifestyle (Horowitz, 1985) and are far more disruptive to the relationship between the carer and dependant (Morris et al., 1988).

Levin et al. (1989), in a groundbreaking study of the problems and needs of carers, explored the multitude of problems that dementia carers faced in their role. They summarised caregiving problems into the following four dimensions:

- 'Practical dimension': most dependants needed regular help with household routines and personal care, such as washing, dressing and feeding. The constant provision of personal care was stressful and most carers would have greatly benefited from increased assistance.
- 'Behavioural dimension': behavioural problems were experienced by all carers to a greater or lesser extent and included 'trying behaviours' – such as repetition, restlessness, clinging or crying, and 'major problems' – including resistiveness, abusive or aggressive behaviour, incontinence and night-time disturbance. Carers generally found these problems more difficult to cope with than practical problems.
- 'Interpersonal dimension': These problems triggered off a wide range of emotions and reactions in carers, the nature of which appeared to be influenced by the

quality of the past relationship with the dependant and the carer's acceptance of the change in their relative.

- 'Social dimension': Most carers had made considerable changes in their lives in order to care for their dependant. The consequences of caring extended to the carer's social life, their ability to continue with employment and their access to emotional support. Most carers continued to care in the face of exclusion from a social life, extreme loneliness and an underlying sadness about the changes in their loved one.

Many studies have attempted to identify which features of dementia caregiving are the most burdensome for carers – Sanford (1975) found that sleep disturbance, faecal incontinence, general immobility and dangerous behaviour were least well tolerated; Hirschfield (1978) and Machin (1980) found that nocturnal wandering, incontinence and the dependant's refusal to wash were the most problematic; Gilleard (1984) found that the need for constant supervision, proneness to falls, incontinence, night-time wandering and the inability of the dependant to engage in meaningful activities on his/her own initiative were perceived as being most problematic by dementia carers; Hayley et al. (1987) found that unpredictable behaviours such as wandering and aggression are particularly stressful as they require continuous monitoring, and Donaldson et al. (1997) found that non-cognitive features, e.g. personality change, and behavioural and psychological symptoms of dementia have a primary role in the genesis of stress.

Morris et al. (1988), in an important review of the literature regarding factors affecting the emotional well-being of dementia carers, summarised the most stressful dementia caregiving problems as being incontinence, over-demanding behaviour, and the need for constant supervision. They also suggested two aspects of caregiving which may be particularly stressful: firstly, the adversive and intolerable behaviour of the person with dementia, including resistive, repetitive or aggressive behaviour, nocturnal wandering etc, and secondly, the 'daily grind' of caregiving in which the carer experiences no respite from the heavy burden of caregiving and has to give constant assistance in personal care tasks, such as washing, dressing and feeding the dependant. Similarly, Gilhooly et al. (1994) identified that 'acts of commission', like urinating in a wardrobe or wandering, are more problematic and therefore stressful for carers than 'acts of omission', such as inability to prepare a meal or take a bath.

A later study by Miyamoto et al. (2002) added to the above findings relating to the care of the 'active' person with dementia and increased stress. They found that the carers of mobile dependants with dementia experienced greater subjective burden than the carers of non-mobile dependants. For the mobile group the main predictors of caregiving burden were wandering, interfering, aggression and repetition, whereas for the non-mobile group repetitive questioning and clinging behaviour were the only predictors of caregiving burden. Miyamoto et al. (2002) recommended that service providers should focus their attention on developing interventions which aim to minimise the impact or avoid the occurrence of these most burdensome behaviours, thereby lessening caregiver burden.

Greene et al. (1982) correlated the degree of behaviour and mood disturbance shown by the dependant with the amount of stress and upset experienced by the carer. They found that whilst the level of cognitive functioning and incapacity to perform self-care tasks had no influence on reported stress levels, the behavioural manifestations of dementia and accompanying mood disturbance were least tolerated by carers. What distressed carers most was the change in their dependant from being an active, able and involved person to one who was apathetic and withdrawn. In addition, the more unstable the mood of the person with dementia, the more negative feelings were experienced by the carer towards their dependant.

Gallicchio et al. (2002) similarly found that behaviour disturbance in the person with dementia, together with poor perceived carer health, was associated with significantly higher odds of high levels of caregiving burden and depression. Female carers in this study suffered more caregiving burden than males, and Gallicchio et al. (2002) suggested that adequate assistance should be given to female carers to ensure that they are not strained beyond what is clinically healthy.

Haley and Pardo (1989) examined the relationship of the severity of dementia to caregiving stress. They proposed that with the progression of dementia whilst cognitive impairment may steadily increase, other stressful behavioural symptoms peak at various stages of the illness. A longitudinal follow-up showed that whilst self-care deficits increased with dementia severity, many distressing behavioural symptoms decreased in later dementia. They concluded that increases and decreases in various dementia patient stressors over time should be considered as factors influencing caregiver coping and that a multi-dimensional assessment of dementia severity and caregiver adjustment is required.

Additionally, Orbell and Gillies (1993) highlighted that early dementia symptoms, although less severe may be more stressful due to uncertainty as to their cause and the changing relationship between the carer and the dependant, particularly in cases when a diagnosis has not yet been given. They agreed that advanced dementia cases may enter a more passive phase where less vigilant caregiver attention is required. Therefore, Orbell and Gillies proposed that the relationship between the duration of illness and carer well-being is 'U-shaped' rather than linear.

Both of these studies build on important research by Gilhooly (1984) which found a significant correlation between the duration of caregiving and the morale and mental health of the carer, but in an opposite direction to that hypothesised. In other words, the longer the carer had been providing care, the higher their morale and the better their mental health. Gilhooly suggested that this finding could be explained in two ways: firstly, the 'survival effect' in relation to mental impairment in the dependant – the carer having survived the worst caregiving problems experienced at an earlier stage in the illness, and secondly, the greater time during which the carer would have an opportunity to learn to cope and adjust – the carer having developed a sense of mastery over caregiving problems.

These findings suggest that in assessing the support needs of dementia carers, it is crucial for professionals, and indeed carer assessment tools, to pay closer attention to behavioural and mood disturbance related problems and their perceived impact on dementia carers, at whatever stage or severity of dementia they are experienced. It is clearly a mistake to focus only on dependency measurement or degree of cognitive impairment as indicators for service intervention, and it is important to reassess needs at intervals throughout the duration of the dementing illness/caregiving trajectory, as stressful caregiving problems will peak and trough at different times for each caregiving situation. If carers could receive maximum assistance from services during the times when the problems they experience and the associated stress are at a peak and be supported through that period, particularly during associated crises, caregiving may become easier and continued home caregiving could be facilitated until a much later stage in the illness or until death of the dependant.

3.5 The physical and psychological health of dementia carers

In 1993, the Alzheimer's Disease Society surveyed 1,303 dementia carers and found that 97% were suffering from emotional difficulty – predominantly stress, and 36% suffered physical discomfort, mainly from backache. In 1994 the Alzheimer's Society issued another report on the health of dementia carers, stating this time that 60% of carers were suffering ill health or nervous problems as a result of caregiving.

In a more detailed study of health impacts on dementia carers, Kielcolt-Glaser et al. (1991) assessed changes in depression, immune function and health in 69 spouse dementia carers, who had been caring for an average of 5 years, and 69 controls. Between intake and follow-up measures 13 months later, carers showed decrements relative to controls on 3 measures of cellular immunity. Dementia carers reported significantly more days of infectious illness, primarily upper respiratory tract infections. The illness episodes were longer and resulted in more physician visits than the episodes for non-caregivers. Carers in this study also had a much greater incidence of depression, with 25% meeting diagnostic criteria at intake and 32% at follow-up, compared with 0% and 6% in controls. Carers who reported lower levels of social support at intake and who were most distressed by behaviour problems showed the greatest and most uniformly negative changes in immune function at follow-up.

As further evidence of ill health, Baumgarten et al. (1992) found that dementia carers reported greater use of prescription medication, pain relievers and heartburn remedies than non-caregivers. Similarly, Grafstrom et al. (1992) found that adult children carers were three times more likely as their age-matched peers to use prescription medications. Haley (1997) stated that dementia carers used more psychotropic medication and suffered with more physical abnormalities, such as elevated blood pressure, high plasma lipid levels and impaired immune function than other carer groups.

Regarding hospitalisation of dementia carers, Moritz et al. (1992) found that the husbands of women with severe cognitive impairment were hospitalised more often than men whose wives had no cognitive impairment. However, the level of cognitive impairment in men was not associated with the hospitalisation of their wives.

In a review of the literature related to dementia caregiving health outcomes, Schulz et al. (1995) concluded that poorer physical health in carers was associated with greater psychological distress (Draper at al, 1992), anxiety (Neundorfer, 1991), depression (Robinson, 1989; Morrissey at el, 1990; Pruchno et al., 1990; Neundorfer, 1991; Hooker et al, 1992; Moritz et al., 1992); and cardiovascular reactivity (Vitaliano et al., 1993). Less social support was an additional carer characteristic that was consistently associated with poorer physical health (Kiecolt-Glaser et al., 1991; Morrisey et al., 1990; Uchino et al., 1992). And higher levels of behavioural disturbance were related to worse health outcomes in two studies, Brodaty and Hadzi-Pavlovic (1991) and Kiecolt-Glaser et al. (1991).

Schulz and Beach (1999) found that carers (though not exclusively of family members with dementia) who report strain associated with caregiving are more likely to die than non-caregiving controls. After 4 years of follow-up, 103 of 392 caregivers (12.6%) had died. After adjusting for sociodemographic factors, prevalent disease and sub-clinical cardiovascular disease, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregiver controls. This vitally important research finding emphasises the need for carers' assessments that determine the degree of perceived caregiving burden and the impacts on physical health, and further highlight the need for services to target their interventions to relieve carers of some of their most stressful experiences.

Regarding psychological health outcomes, clinical depression in dementia carers is a well-researched phenomenon resulting from chronic stress and associated losses experienced over many years duration of caregiving. Estimates for the prevalence of depression in the carers of people with dementia vary from 14% (Morris et al., 1988) to 70% (Terri, 1994) or even 77.8% (Harper et al., 1993), with the main body of work reporting prevalence rates between 30-50% (Williamson and Schulz, 1993; Pagel et al., 1985). In the study by Pagel et al. (1985), 40% of dementia carers were found to be suffering from clinical depression currently and a further 41% reported having been depressed at some stage during the course of their caregiving role. (Outcome measures used in this study were the Becks Depression Inventory, Beck et al., 1974; and Hamilton Depression Rating Scale, Hamilton, 1967.) Thus up to 81% of dementia carers may be at risk of suffering from depressive illness at some stage during their caregiving trajectory, which is a staggeringly high rate given the reduced tolerance and coping ability which may result.

Dura et al. (1990) compared 86 dementia carers with 86 controls for current and lifetime depression, using DSM-III criteria. Dementia carers were significantly more dysphoric than non carers, with 30% having a diagnosable depression compared to just 1% of the control group. Only 2 carers had suffered from depression before the onset of caregiving. Thus, Dura et al. (1990) concluded that the chronic strains of dementia caregiving are linked to the onset of depression in older adults with no prior evidence of psychological vulnerability.

Coope et al. (1995) evaluated psychiatric morbidity in dementia carers using psychiatric interview (a sample of consecutive dementia referrals to old age psychiatry services - 109 in total). 28.4% of carers had a case level depression and 2.75% had a case level of anxiety. A further 11.9% had sub-case levels of depression and 18.3% sub-case levels of anxiety. Thus many dementia carers are at risk of developing depression or anxiety states in addition to those who may already be diagnosed and receiving treatment for these conditions. Coope et al. (1995) also found that first-degree relatives suffered with more depression than friends or more distant relatives, a perhaps not surprising finding, but one that emphasises that primary carers who are co-resident with the person with dementia are more at risk of depression.

Dura et al. (1991) examined anxiety and depressive disorders specifically amongst adult children caring for demented parents. They found that in a sample of 78 adult children carers and 78 control subjects the frequencies of depressive and anxiety disorders did not differ between groups before the onset of caregiving. But during caregiving years 34% of adult children carers met DSM-III criteria, 24% for a depressive disorder and 10% for an anxiety disorder. Only 8% of the control group met criteria for both depression and anxiety. The sample in this study was not exclusively co-resident with the person with dementia – 21/78 were secondary carers, supporting an elderly parent in their role, and 25/78 were supporting their demented parent in a nursing home care setting. Rates did not vary according to gender, co-residence, employment, children or marital status, but less income was associated with more depression. Thus the chronic strains of dementia caregiving were found to be significantly linked to the onset of mental illness in adult children carers, and ending employment to take on the role of dementia caregiver may be a significant risk factor for depression (perhaps linked to diminished socialisation).

Drinka et al. (1987) reviewed 127 patients in geriatric referral clinics who had carers (73% of the patients met DSM-III dementia criteria and 69% depression criteria – 48% had dementia and depression). 117 carers (mean age 70 years, 75% wife caregivers) were assessed by a psychiatrist for depression and 83% met DSM-III criteria for major depression. Quantitative measures of dementia and activities of daily living dependency were not statistically associated with measures of caregiver depression or burden. However, measures of patient depression were significantly correlated with measures of caregiver depression and burden. Drinka et al. (1987) thus concluded that screening for depression should be undertaken in both patients and carers. As the vast majority of depressed carers in this study were not receiving appropriate anti-depressant medication, this study also highlighted that if appropriate treatment and support is given to depressed carers, their ability to cope may be improved and the longevity of caregiving may be increased.

Ballard et al. (1995) examined the aetiology of depression in 109 carers on referral of their dependant to old age psychiatry services. 32 (29.4%) had diagnosable depression using DSM-III criteria, 77 (70.6%) did not. The severity of cognitive impairment in the dependant was found to be significantly associated with depression in carers who lived with the dementia sufferer, and a low level of marital intimacy before the onset of dementia was significantly associated with depression among carers who were marital partners. Older age was significantly associated with depression across all caregiver groups. Thus older spouse carers who have had a poor relationship with their husband/wife before the onset of dementia may be more susceptible to depression and this needs to be considered when undertaking carers' assessments.

Schulz and Williamson (1991) in a 2 year longitudinal study of depression in Alzheimer's carers found female carers reporting high, stable rates of depression throughout the study (which supports previous findings from Fitting et al., 1986, and Zarit et al., 1986, that showed female carers are more susceptible to developing depressive symptoms than males), whereas male carers exhibited significant increases over time. Significant relationships between depression and problem behaviours, negative social support and concern about financial resources were found, and a decline in social support increased depression. Thus Schulz and Williamson (1991) proposed that husband carers whose wives exhibit problem behaviours and who have limited support may be more at risk of depression.

Poulshock and Deimling (1984) highlighted the circular nature of carer stress and depression; depression may lead to less ability to mobilise social support and the resultant social isolation contributes to more depression. Thus those carers who are depressed and isolated in their role may need to be more targeted for service interventions, particularly by way of access to psychological supports, e.g. individual counselling, carers' support groups and telephone helplines (O'Donovan, 1993).

3.6 Risk factors for relinquishment of home caregiving

Despite the tremendous emotional, psychological and social burden of caregiving, most carers derive considerable reward and satisfaction from their role, and most of them express a strong desire to continue supporting their dependant at home for as long as possible and up to their death (Rabowski and Clark, 1985). It is therefore a sad and worrying fact that there is evidence to show that up to one third of all admissions to permanent care are made as a direct result of a breakdown in the caregiving situation, the carer being worn down to the point of total exhaustion or demoralisation, and not as a result of an actual deterioration in their relative's condition (Isaacs, 1971). Levin et al. (1989) found that problems which carers associated with stress, such as incontinence, trying behaviours, lack of normal conversation and social restrictions, affected the likelihood of the dependant's entry into permanent residential care. On initial interview only 13% of their sample would have accepted residential care if it had been offered; 57% would definitely not have accepted it. Despite their willingness to care, 1 in 5 of these carers had allowed their dependant to enter permanent care within one year.

Despite a proliferation of research into dementia caregiving stress over the past two decades, the factors implicated in the breakdown of family care of older people with dementia remain elusive (Lightbody and Gilhooly, 1997). However, there are a growing number of studies which have identified risk factors, and these have been summarised in a review of the literature relating to the relinquishment of home caregiving by Keady (1999) as:

- Role captivity
- Perceived nature and quality of the emotional relationship between the carer and person with dementia
- Carer's use of and access to services
- Carer's age
- Carer's reactions to the exhibited behaviours and ways of managing memory problems
- Persistence of troublesome behaviour, including aggression and incontinence
- Omission of satisfactions from the caregiving relationship
- Availability and contact with friends and satisfaction from such help
- Existence of another dependent relative
- Employment situation of the carer.

Wuest et al. (1994) suggested that making the decision to place a dependant into institutional care may be very painful for dementia carers, thus it is vital that the factors implicated in this decision are better understood. The remainder of this review of the literature will address the risk factors for relinquishment of home caregiving/breakdown in community caregiving situations, as the research relating to the process and outcome of this major decision/care transition is central to this study. If the reasons for planned or unplanned admissions to permanent care could be better understood by health and social care professionals, then service interventions to facilitate continued home caregiving or improve practice around this most difficult care transition could be enhanced, resulting in psychological and physical health gain for carers.

3.7 Carer characteristics – the role of age, gender and kinship

Why and how caregiving responsibility was assumed seems to be important in predicting current levels of caregiver burden, as is planning undertaken before taking on the role of caregiver (Karasik, 1995, in Lightbody and Gilhooly, 1997). Thus those carers who choose to care and have time to prepare psychologically for taking on the role will fare better than those who are thrust into the role unexpectedly through lack of choice. Aneshensel et al. (1995), cited in Zarit and Edwards (1996), found that carers were given little explanation of the meaning and consequences of a dementia diagnosis. They also received virtually no information about caregiving, potential formal resources they might utilise, or legal and financial implications. The one bit of advice they were likely to have been given was that they should consider nursing home placement, an event which for most was many years away. Such poor quality information may be a compounding factor in the experience of caregiving burden.

Both gender and kinship have been found to influence who takes on the caregiving role – there is a traditional expectation that younger females will care for their elderly parents. Horowitz (1985) found that of adult children caregivers, daughters are more likely to be more closely involved in caregiving and therefore experience a higher degree of strain. Jerrom et al. (1993) found that female spouses and adult daughter carers both find caregiving more stressful than their male counterparts. Lightbody and Gilhooly (1997) also stated that female carers experience higher levels of strain than males and that, based on the findings of Kramer and Kipnis (1995), younger carers experience greater burden than older carers. This may be due to the competing demands for time that adult children carers experience; in a study by Levin et al. (1989) 3 in 5 adult children carers combined caregiving with paid employment and other family responsibilities.

Adult daughters provide more care and more difficult care for longer periods of time than other groups (Collopy et al., 1990), both as primary carers and secondary carers supporting their elderly parent in caregiving (McCarthy, 1996). This is often in the face of multiple family and work demands on the time of this group, with more women being in employment, increased economic pressures, fewer children at home, higher divorce rates, delayed marriages and delayed motherhood as significant population profile changes (Cantor, 1983; Brody, 1985). These factors coupled with an expanding elderly population (and thus a greater elderly parental group with dementia) and a simultaneous decline in birth rate resulting in fewer adult children to provide care, has increased the caregiving pressures being placed on this group.

Killeen (1990) similarly found that caregiving stress was more apparent among younger carers who were more likely to have multiple roles and that the dominant coping strategy was to give up personal time, with adverse effects on health perception in this group. Gilhooly (1986) found that the employment situation of the carer was predictive of a decision to relinquish care and Aneshensel et al. (1995) found that the economic situation of carers was a key predictor of breakdown in the caregiving situation. Thus the above assertion that younger carers experience more strain is supported, as adult children carers may have to relinquish work to take on the role of full-time caregiver and may experience considerable financial hardship as a result. This is also true for spouse carers of younger people with dementia in their 40s and 50s. Yee and Schulz (2000) found that female carers, particularly those of younger people with dementia, find it difficult to continue in full-time employment, with the consequence of financial difficulties and potential dependence on welfare benefits.

However, Woods (1999) reminds us that carers are now more likely to be older spouses than adult children and that the majority of siblings that are providing care are close to, or past, retirement age themselves. So perhaps the actual relationship of the carer to the dependant is more important than the age of the carer per se. This seems to be the case, as George and Gwyther (1986) found that the closer the blood/role relationship, the more stressful caregiving becomes. Similarly, Gilhooly (1984) found that the greater the familial distance in terms of blood/role relationship, the better the carer's mental health. This finding is explained in terms of the degree of practical and emotional involvement in caring, i.e. the further the familial distance, the less emotional involvement and caregiving burden there will be.

Amongst spouse carers, wives tend to experience a higher degree of distress and burden (Zarit et al., 1985; Fitting et al., 1986; George and Gwyther, 1986). Zarit et al. (1985) suggested that this may result from males taking a more instrumental and less emotionally involved approach to caregiving, with a tendency to adopt caregiving strategies which distance themselves from everyday problems. They also suggested that formal and informal support may not be as beneficial in alleviating burden for female carers, possibly because they are more reluctant to hand over the caregiving responsibility to others. Services may also perceive that female carers will be better able to cope with caregiving and as a result help is made more readily available to men. Gilhoolhy (1984) similarly found that men tend to use more practical, problem-solving strategies, such as making the most of services on offer, whilst women were more likely to use psychological strategies, such as trying to find explanations for the illness or trying to find something positive in their situation. Where there was no positive side and no explanations were to be found, distress was greater.

It is often assumed that adult children carers will cope better than older spouse carers, as they often have the support of their own husband/wife in caregiving. But Gilhooly (1984) made the important point that many married adult children carers find having to divide their loyalties stressful. This may particularly be the case when caregiving takes place in their demented parent's home rather than their own and time has to be spent away from the partner. In Gilhooly's (1984) study, daughters-in-law gave a great deal of support and help to their husbands, i.e. adult son carers, but sons-in-law, by comparison, gave little help and support and were not true confidantes.

Danis and Silverstone (1981) also drew attention to the stresses involved in providing care to the person with dementia who lives alone, pointing out that in such circumstances, perhaps when an unmarried adult child carer has moved into their dependant's home, or had them move into their home in order to provide more intensive support, there is no-one else to buffer or deflect the play of emotions between the carer and dependant. Thompsell and Lovestone (2002) found that the impact of providing care to a relative with dementia does not lessen with caregiving distance. Carers living distantly from the person with dementia reported similar rates of subjective distress. Their information and support needs equally need to be addressed to those carers living with their dependants, especially if they are the main or 'primary' carer. Gallo (1990) and Spruytte et al. (2001) found that the dependant living alone and the carer providing care from a distance was an important risk factor for institutionalisation of the person with dementia.

However, despite the above research evidence suggesting younger female carers may fare worst in terms of the experience of caregiving burden, the fate of older spouse carers should not be overlooked. This group is the most likely to assume caregiving responsibility (Cohler et al., 1989), and accounts for approximately one third of all informal caregivers (Arber and Ginn, 1991). Older spouse carers may be particularly vulnerable to caregiving burden because of their own diminished capacities associated with normal ageing, worries about the course of the illness, and concerns about transition to widowhood (Groves, 1988). Physical and financial burden are especially high among this group, with many older carers having to manage on a pensioner's wage and being in poor physical health themselves (Cantor, 1983). Indeed, the stress and health risk is so increased in this group that many older spouses die before their dependant, in many cases after having neglected their own health to continue in the caregiving role (Kaplan, 1996). This finding is especially relevant to this study, as during the year between first interview and follow-up one of the carer subjects died.

And yet this group has been found to be the least likely to seek institutional care (Collerick and George,1986). Despite their increased burden, spouse carers are less likely to consider permanent care, perhaps because of stronger ties of love and affection (marriage vows are often quoted) (Gilhooly, 1984), or duty, obligation and resignation (Loos and Bowd, 1997). This is confirmed by Pot et al. (2001), who found that commitment to the caregiving relationship and continuing in role was greater in spouse carers. In this study, people with dementia cared for by non-spouses were more likely to be institutionalised than those cared for by spouses. (Additional predictive risk factors for institutionalisation in this study were non-spouse carers being more extravert and spouse carers perceiving pressure from informal supporters to institutionalise their dependant.)

3.8 Quality of the relationship with the person cared for

Horowitz and Shindleman (1983) found that the closer the past emotional relationship between the carer and dependant, the less strain there is for the carer. They suggested that relatives who maintain positive feelings towards their dementing relative have a greater commitment to caring and a lower level of perceived stress. Gilleard (1985) and Gilhooly (1986) also found that the quality of the pre-morbid relationship impinged on the caregiving situation and that a long and happy marriage may motivate a husband or wife to continue to provide care. However, as Lightbody and Gilhooly (1997) state, there seems to be little basis for assuming that a long relationship will have been a happy one!

A study of wife carers by Motenko (1989) revealed that gratification was associated with greater well-being and frustration with more distress. Wives who perceived continuity in marital closeness since the illness had greater gratification than those who perceived change. Frustrations resulting from disruption of life plans was greatest at the onset of symptoms, but diminished as routines developed, despite the need to provide more care. The meanings of caregiving were more important to well-being than the amount of care provided.

Morris et al. (1988) examined the relationship between marital intimacy, perceived strain and depression in spouse carers of people with dementia. They explored the quality of the marital relationship prior to the onset of illness and also at the time of the study. Carers who experienced less marital intimacy before and during caregiving exhibited higher levels of perceived strain and depression. Those who had high levels of intimacy before the onset of dementia undertook the caregiving role out of affection and a desire to care, rather than out of a sense of obligation or duty. Carers who experienced a greater loss in intimacy had a higher level of depression, but did not show increased perceived strain.

They speculated that a poor pre-morbid relationship makes caregiving more stressful because of a greater difficulty in performing the caregiving role. However, many spouse carers expressed feelings of increased detachment from their spouse as their condition gradually deteriorated.

Hirschfield (1983), Gilhooly (1986) and Spruytte et al. (2001) found that quality of the current emotional relationship with the dependant is more important than the quality of the past relationship with the dependant before the onset of dementia in determining caregiving outcomes. Research by Hischfield (1983) showed that 'mutuality' in the current relationship was a crucial factor in continuing home care versus institutionalisation. Gilhooly (1986) similarly found that the nature of the relationship with the dependant overrode factors such as the mental health of the carer in carers' preference for institutional care. Blood/role relationship was found to be an important variable, as was the quality of the relationship prior to the development of dementia. But current quality was even more important, with many spouse carers, for example, taking their marriage vows quite literally and stating they would continue to provide home care 'until death do us part'. Spruytte et al. (2001) found that a good current relationship between the carer and dependant reduced the risk of nursing home placement, whereas premorbid quality of relationship was not predictive of institutionalisation – preferred or actual.

Many carers report difficulties arising from a change in the relationship with the person cared for, which Marriott (2003) attribute to a perceived 'loss' of the person previously known, caused by the cognitive and personality changes associated with dementia. Williams et al. (1995) similarly found an association between personality change in the dependant and caregiver burden. Orford et al. (1987) found that relationships between people with dementia and carers were characterised by more hostility and less affection than in relationships between carers and people with other mental health problems. Thus the concept of the 'changed person' as well as the changed relationship seems to be important in any analysis of caregiving burden and breakdown.

Wuest et al. (1994) proposed that the changing family relationship arising from the dementing illness results in the person with dementia *'becoming a stranger'*, along a continuum of emotional detachment from intimacy to alienation. Three phases are included in their caregiving dyad: 'dawning' - both parties become gradually aware that the family member is changing; 'holding on' - the carer develops strategies to sustain the relationship and quality of life in the face of increasing losses for both; and 'letting go' - the carer, ultimately estranged from the dependant, relinquishes care. Variables said to effect the experience are: 'commitment' between the family member and carer; 'insidious losses' that result from the disease, particularly failure of recognition; and 'connected' (behaviour that was helpful to the carer) and 'disconnected support' (behaviour that increased the carer's alienation). Wuest et al. (1994) asserted that carers who distance themselves from the dependant are more able to allow others to participate in caregiving, i.e. they were more accepting of services, and those who had emotionally detached from their dependant found the decision to place them in institutional care easier. When reciprocity in the relationship is lost, the carer loses motivation to carry on in their role, particularly if there is a triggering event, such as a violent act towards the carer by the dependant. This model has much to offer, but the assertion that, *'Ultimately, all caregivers detach from the person the victim has become'* (Wuest et al., 1994, p. 439), must be challenged. Undoubtedly, the nature of the emotional attachment changes and there may be some degree of detachment, but deep feelings of love and affection often remain, despite a change in the nature of the relationship, and caring intentions frequently continue, even after home caregiving is relinquished, especially if this transition is made as a result of the carer's physical incapacity to continue in their role.

Many adult children carers use the term 'role reversal' to describe a perception that they themselves have become a parent to their own father or mother in response to their loss of adult competencies as a result of dementia (Brody, 1990). However, in addition to having a perception that they are in a parental role when providing care for their demented relative, many carers also perceive elder care as being equivalent to child care. Albert and Brody (1996) examined this phenomenon, which they termed a *'role violation'*, and reported that 60% of their sample of 426 adult children caregivers strongly agreed that caring for their elderly parent was 'like taking care of a child'; only 12% strongly disagreed with the statement. They asserted that there are real similarities between caring for a child and an infirm elder – both may require help from carers for the satisfaction of certain needs; both may require carers to make decisions on their behalf, and both may require supervision and direction in daily tasks. However, an important difference was highlighted, namely that the older adult is not growing and is not likely to become more independent with time. (Furthermore, carers often express a feeling that the person with dementia is going through a process of unlearning things, or regression, and this can make them feel even more bereft.) In their study, Albert and Brody (1996) found that the best predictors for this phenomenon are the degree of cognitive impairment in the elderly parent, the degree of caregiving burden adult children carers perceive in their role, and the lack of competence in instrumental activities of daily living associated with independent adult living. In addition, those who viewed caregiving as a payback to their parents for their own positive parenting were less likely to infantilise parents who were dementing. It is thus important to consider that this phenomenon may not necessarily be a negative outcome and that for many carers, including spouse carers (this phenomenon is not exclusively experienced by adult children carers), the feelings of love, affection and commitment to caregiving are not dented by the perceived change in the nature of the relationship.

Barnes et al. (1981) discussed the notion of 'anticipatory grief' to describe the losses that carers experience over time as their relative's condition gradually deteriorates. Losses incurred include personality change, loss of sexual partner (for spouse carers), loss of a parent and role reversal (for adult children carers), drastic changes in physical appearance, and the inability of the dependant to communicate with or recognise their relative. Riggans (1992) suggested that as most carers of people with dementia are living with loss and already grieving, the term a 'Living bereavement' was coined to better describe the painful experience of having in many ways lost the person cared for while they are still living. In an important study of grief in Alzheimer's caregiving spouses, Wasow and Coons (1987, p. 21) wrote that, *'Our culture usually does not recognise that caregivers are grieving... during this long, devastating illness'.*

Dempsey and Baago (1998) in their model of 'Latent Grief' highlighted the paradox of dementia – the 'person' or psychosocial self slowly disintegrates or fades, but the body lives on. This view is in direct contradiction to the work of Tom Kitwood (1997, p. 3) who challenged the prevailing view that dementia is *'a death that leaves the body behind'* and argued that *'having dementia does not, in itself, entail a loss of personhood'*, claiming that the fundamental humanity of persons with dementia survives the dementing process, but it holds weight in terms of the perceived grief and loss experienced by carers. As the person's cognitive abilities decline, the carer must absorb more and more responsibility not only for the dependant, but also for the roles he/she previously fulfilled in the relationship (thus embracing the concept of role reversal for spouse carers). Many feelings associated with grief and loss are experienced during this process, primarily anger, guilt, depression, anxiety and helplessness. But carers may not be aware they are grieving and identify their intense emotions as a response to care rather than as a response to loss. The grief is therefore described by Dempsey and Baago (1998) as 'latent', remaining buried away from conscious awareness. They saw latent grief as a major factor in caregiver stress and burnout and believed that an understanding of this process will help to validate the ongoing grief that is part of the carer's experience. Central to this model are three dimensions of loss:

1. Loss of 'person' – with cognitive decline, the person's ability to communicate and interact is impaired and the carer loses a companion, partner, friend, lover, mother, grandmother. With functional decline, gone is the homemaker, gardener, organiser,

etc. The person is no longer able to fulfil the multiple roles he/she previously held in the relationship.

2. Symbolic loss - relates to psychosocial death and the meaning the carer attaches to the ongoing losses as the 'person disappears', such as loss of hopes, dreams and expectations, loss of retirement plans, etc.
3. Loss of self or personal identity in the carer - caregiving involves multiple adaptations for one's own self and a need to assume new roles formerly held by the dependant. There is a need to redefine oneself and make real sense of who one is.

Another loss which could be added to this model is that of loss of the caregiving role which is often perceived after relinquishment of home caregiving. For many years, the carer's life may have been subsumed by their dependant's needs - they may have lost contact with friends or family members, given up work to care and relinquished their own hobbies and interests. If, as above, the person has redefined him/herself as a carer then the loss of this role and valued function is another loss to be mourned – a void which is difficult to fill.

Dempsey and Baago (1998) state that multiple losses within each dimension may be overwhelming for carers. Such grieving has been described elsewhere as 'Ambiguous loss' (Boss, 1991), where the individual is physically present but psychologically absent, and may be viewed as a form of 'Disenfranchised grief' that is not or cannot be openly acknowledged, publicly mourned, or socially supported (Doka and Aber, 1991). In dementia the bonds of attachment are *'severed slowly, incompletely, and ambiguously'* broken, leaving the carer in *'a state of intense anxiety and strong emotional protest'* (Dempsey and Baago, 1998, p. 86).

Shabad (1989) contended that one can perceive and experience psychic loss, despite the physical presence of the person, and that dealing with psychic loss is more difficult than adapting to physical loss. The lack of finality and incompleteness of psychic loss may hamper the individual's adaptation to the grieving process. The process of placing the dependant in institutional care is a further severing of the bonds of attachment which may move the grieving from latency to awareness, as the loss can no longer be denied as the person is no longer physically present. This care transition may thus be incredibly difficult, equivalent to a form of 'quasi-death' (Austrom and Hendrie, 1990).

Loos and Bowd (1997) found that guilt is deepened and emotional well-being is at risk when full-time care is transferred to an institution. And, as Oliver and Bock (1985, p. 28) stated, expressions of guilt are perhaps *'the most debilitating emotions plaguing* *caregivers'*. Finally, the constant role changes throughout the duration of the dementing illness require carers to constantly redefine their shattered sense of self, and the eventual death of their dependant represents the final loss that can be overtly grieved. Thus Dempsey and Baago (1998) make the case for appropriate emotional support to be made available to carers throughout the caregiving trajectory and beyond, including grief counselling while the person with dementia is still living, to allow carers to begin to cope with the ongoing losses they are experiencing.

The length of time involved in caregiving and the stresses associated with the role may curtail preparation for dealing with the death of the person in care. This may in turn result in a more difficult grieving period (Bass and Bowman, 1990). Hubbard (1994) demonstrated that grief occurred during the middle and final stages of dementia caregiving. She found that although carers anticipated the relief that would occur with death, they did not psychologically prepare for the death of the person in care. Walker (1995) found that both the length of caregiving and patient symptoms were related to the severity of grief. A longitudinal study of carer depression after bereavement by Bodner and Kiecolt-Glaser (1994) found that adverse physical and emotional effects of caregiving lasted well beyond the death of the person cared for, and that the many personal sacrifices incurred by carers during their years of caregiving, e.g. the curtailment of significant social and recreational activities and the diminution of the social support network, negatively effected carers' ability to cope. Thus the case could be made for grief counselling and social support for carers also being made available after the death of the person cared for.

3.9 Caregiving satisfactions versus role captivity

As indicated above, the primary responsibility of caring for a person with dementia usually falls upon one family member's shoulders, most often an elderly wife or adult daughter carer (Gilleard, 1984), and this may engender considerable resentment if the carer perceives other family members as being unsupportive to their role (Gilhooly, 1986). Social support has been found to moderate the effects of carer stress (Gallo, 1990), but it appears that it is not the amount of assistance given by family and friends to the caregiving situation, but rather satisfaction with the assistance given that is important (Wethington and Kessler, 1986). The fate of the 'lone carer', who receives no assistance from informal supporters, was also highlighted by Gilhooly (1986), who found that the availability of and contact with friends and satisfaction from such help was predictive of carer preference for institutional care.

'Role captivity' also seems to be an important dementia caregiving phenomenon, reported on by Aneshensel et al. (1993), who found that carers who perceived they were captive in caregiving, i.e. who became unwilling incumbents of the caregiving role through a lack of choices and by default and later found it was an unwanted role, were most at risk of breakdown in their caregiving situation. Similarly, Hirschfield (1983) found that the carer perceiving they are 'tied down' to caregiving, a lack of free time for carers and feelings of resentment, helplessness, hopelessness and guilt were major areas of tension for carers and important variables in predicting institutionalisation.

Almberg et al. (1997) also found that limitation in social life and a lack of positive outlook were important variables in the experience of caregiving burden and burnout. In this study, older wives caring for their husbands, followed by daughters caring for their parents, were more likely to suffer from high levels of burden and were most at risk of burnout. On a similar theme, Annerstedt et al. (2000) found that carers with an impaired sense of self identity, whose own identity had been overtaken by the needs of their dependant and by the caregiving role, were most at risk of breakdown in their caregiving situation. Other key predictors for carers reaching 'breaking point' in this study were the amount of time spent in caregiving each week, the dependant misidentifying the carer, clinical fluctuations in the dependant's condition and nocturnal deterioration.

In both the Hirschfield (1983) and Almberg et al. (1997) studies referred to above, poor physical health in the carer was found to be predictive of institutionalisation/burnout. Physical health outcomes have been explored elsewhere in this chapter, but suffice to say poor health in the carer is a powerful determinant of institutionalisation. Cohen et al. (1993) found that spouses are particularly vulnerable to breakdown in their caregiving situation, because of their advanced age and associated physical frailty. An additional worry for older carers is what would happen to their husband or wife with dementia if they became too ill to provide their care or, worse still, if their dependant outlived them (Marriott, 2003).

Whilst psychological health impacts have been explored elsewhere in this chapter, it is important to recognise that depression in dementia carers is of itself a risk factor for breakdown in caregiving situations (Whitlach et al., 1999) and a major determinant of nursing home placement (Gilleard et al., 1984). Haley et al. (1987) found that dementia carers reported significantly higher levels of depression and negative affect towards their relatives than controls and had lower life satisfaction, significant impairment of their social activities, expressed less satisfaction with their social networks and, again, reported poorer physical health. They also used more prescribed medication and utilised more health care services. Austrom and Hendrie (1992) proposed that the quality of life of dementia carers is invariably affected by caregiving, with 55% reporting physical exhaustion and 75% reporting dissatisfaction with their current state of health. Intervening variables such as the strength of the existing relationship with the dependant and the presence of a social support network were found to be important mediating factors in quality of life impact.

However, it is important to maintain a balanced view of the impact of dementia caregiving and to consider caregiving satisfactions alongside negative physical and psychological health and other quality of life impacts. Nolan et al. (1996) proposed that caregiving satisfactions are prevalent, derive from a number of sources and often co-exist alongside a range of difficulties. McKee et al. (1997) found that many carers in their study (74.5%) reported that they were coping well with the demands of caregiving and found that caregiving satisfactions, such as having an opportunity to repay past kindness, being closer to the person and trying to maintain the dependant's dignity and self-esteem, were important ways of coping.

Cohen et al. (1994) proposed that caregiving satisfactions mitigate against the negative effects of caregiving burden and stress. In their study, enjoyable aspects identified by carers included those related to the relationship with the dependent, e.g. a sense of duty and love, and the desire to see positive outcomes for the dependant, e.g. a sense of mastery and satisfaction with caregiving activities. Positive aspects correlated closely with perceived adequacy of social support, quality of past relationship with dependant and negative carer reactions to behavioural problems. Carer socio-economic situation and dependant gender also emerged as significant correlates and Cohen et al. (1994) proposed that this might be because male carers may have more financial resources at their disposal and female dependants may be more amenable to carer directions and physically easier to manage as they become more impaired. They also suggested that carers with positive personality traits such as extraversion and an ability to view situations as challenging rather than stressful may perceive caregiving as less burdensome and experience more satisfactions.

Orbell and Gillies (1993) found that a lack of satisfaction gained from the caregiving role was the 'single most powerful determinant of carer preference not to continue providing care'. In this study, carers with a preference not to care saw themselves as being unable to satisfactorily meet the needs of their dependant. The most important aspects of care-work satisfaction were self-competence and self-worth gain. Other important variables positively associated with preference to stop caring were age of the dependant, number and frequency of behaviour problems and, surprisingly, the presence of a social support network (the assumption being that friends will be important facilitators of the decision to end home caregiving).

Nolan et al. (1996, p. 103) proposed that caregiving satisfactions may serve as a mechanism to buffer against the inevitable difficulties of caring and act as *'well-springs of hope when all appears despair'*. However, they suggested that there is a particular need to target carers who get no satisfaction from caregiving, as they may be more likely to be near to breaking point. They also suggested, based on the work of Hirschfield (1983) and Archbold et al. (1992), that caregiving situations in which there is 'low mutuality' in the relationship should be 'taken very seriously' in terms of risk for elder abuse.

Research by Kurrle et al. (1992) and Sadler et al. (1995) confirmed the existence of a strong linkage between dementia and elder abuse. Not all people with dementia are abused, however, and as can be seen from the above evidence many carers cope well with the challenges and demands of dementia caregiving. In Sadler's study, the co-existence of dementia with substance misuse or psychiatric illness on the part of the carer or pre-existing family conflict significantly increased the risk of abuse. Dementia in the dependant alone, even coupled with challenging behaviour, was not significantly associated with the risk of the carer abusing the dependant, though carers themselves were more at risk of being abused by the dependant in such situations (Sadler et al., 1995). However, Homer and Gilleard (1990) did find such an association, with abuse perpetrated by carers being more likely as a response to violence or threat of violence towards them by the cared for person. This finding, of the carer abusing in response to being abused, was similarly replicated in an American study by Coyne et al. (1993), who found that 26% of carers who reported having been abused by their dependant also stated that they themselves had been abusive. An additional 4.8% who did not report being abused stated that they had abused.

In a later study by Cooney and Mortimer (1995), using an anonymous questionnaire to carers of people with dementia (33.5% response rate), 55% admitted to perpetrating at least one type of abuse, verbal being the most common. Social isolation and a pre-existing poor relationship with the person cared for were found to be risk factors for verbal abuse and poor relationship for physical abuse. The duration of caregiving was also a significant risk factor, with those caring for the longest being most at risk of becoming abusers.

Quayhagen et al. (1997) found that behavioural deterioration and carer stress enhance the potential for burnout and aggression in families coping with dementia. In this study, abusive behaviour was identified in 33 couples, with 17 carers and 16 dependants as perpetrators. The carer abusers scored higher for depression, anxiety and hostility and were more burnt out from mental, physical and emotional exhaustion. Abusive carers also had poorer physical health, higher situational stress and reported more use of support seeking, escape/avoidance and positive reappraisal coping strategies.

Thus the risk factors for breakdown in caregiving situations that have been discussed in this literature review may be similar to those for the development of abusive caregiving situations. Philp et al. (1997) state that in such cases institutionalisation should be regarded as a positive outcome, especially if it improves the safety and comfort of the person with dementia, reduces carer stress and is achieved at a reasonable cost.

3.10 Caregiving problems predictive of institutionalisation

This section of the literature review is not intended to repeat the previous discussion on research relating to the problems that the carers of people with dementia face, but rather to build on this and examine the research on dementia symptoms specifically in relation to the risk factors for breakdown in caregiving situations/relinquishment of home caregiving.

Severity of dementia and functional dependence seem to be important predictors of institutionalisation – Mittelman et al. (1993) found that dependants' need for assistance with activities of daily living was predictive of nursing home placement; Philp et al. (1997) found that the degree of cognitive impairment as assessed by MMSE score and carers' perceived problems in relation to dependant physical disability were key risk factors; Spruyette et al. (2001) found that the functional level of the dependant was predictive of carer preference for institutionalisation, and Cohen et al. (1993) found that severity of dementia was predictive of actual placement. However, Cohen et al. (1993) stated that whilst severity of dementia was predictive of actual institutionalisation, it was not a significant predictor of carers' decisions to place their dependants in permanent care. They clarified that dependants with advanced dementia in their study were more vulnerable to physical crises which necessitated long-term care placement and that other factors, such as use of services, enjoyment of caregiving, caregiver burden and health, reaction to behaviour and memory problems and presence of troublesome behaviours, were more important predictors of carers' decisions to relinquish home caregiving.

Philp et al. (1997) similarly clarified that whilst their study supported previous research which suggested that severity of cognitive impairment (Pruchno et al., 1990) and problems relating to dependants' physical or behavioural functioning (Branch and Jeffe, 1982;

Chenoweth and Spencer, 1986; Knopman et al., 1988) are important factors predictive of institutionalisation, it was the actual level of physical functioning problems that predicted institutionalisation rather than the perceived impact on the carer, whereas for behavioural problems it was the perceived impact on the carer rather than the actual level of behaviour problems which predicted institutionalisation. Carers' willingness to continue providing care was also identified as a risk factor for institutionalisation in this study.

Looking at specific behavioural problems predictive of institutionalisation, Cohen et al. (1993) found that aggressive behaviour and incontinence were significant risk factors for termination of community care; Hope at al (1998) found that excessive night-time activity, immobility or difficulty in walking and incontinence best predicted institutionalisation within one year (aggression was not predictive of institutionalisation within one year, but was more prevalent within the four months prior to relinquishment of home caregiving), and Annerstedt et al. (2000) found that misidentifications – the dependant failing to recognise their carer, clinical fluctuations (unpredictability) and nocturnal deterioration predicted breakdown in the caregiving situation.

Brodaty et al. (1993) found that dementia severity and the rate of deterioration in the dependant's condition, as well as psychological morbidity in the carer, significantly influenced rates of nursing home admission. They stated that 'how far' the dependant's illness had advanced and 'how fast' it had progressed influenced the outcome of dementia caregiving in respect of relinquishment or continuation of caregiving.

Hope et al. (1998) similarly found that dependants entering institutional care had a significantly longer overall illness duration (9.2 years) than those who died at home (6.8 years). They proposed that this might be because those who died at home had not reached the terminal stage of dementia due to other illnesses of old age, e.g. heart attack, stroke or cancer, and that the carers of those who did reach this advanced dementia stage were overwhelmed by physical factors such as incontinence and immobility needs that required more care than could be provided at home.

Gold et al. (1995) also found that carers cited deterioration in the dependant as the most common reason for ending home caregiving. However, Wimo et al. (1992) found that the level of supervision required by the dependant predicted institutionalisation better than items describing the degree of dementia. Both of these studies also found that exhaustion in the carer was important in predicting relinquishment of home caregiving.

In a study which examined the factors which differentiate family caregivers who place relatives into institutional care (n=284) versus those who continue to provide home care (n=642), Whitlach et al. (1999) found that carers more likely to place were more depressed, caring for relatives with more problem behaviours, e.g. wandering and inappropriate behaviour, and receiving respite assistance. After placement, carers were found to be more burdened and to have declined in physical health, which led Whitlach et al. (1999) to call for services to provide additional psychological support before and after this 'stressful transition in care'.

Similar to those studies cited above, O'Donnell et al. (1992) stated that the best predictors of institutionalisation were paranoia, aggressive behaviour and incontinence in the dependant. However, unlike most of them, O'Donnell et al. (1992) suggested that since troublesome behaviours are potentially treatable aspects of dementia, their management should be a major focus for community care services. With appropriate medical and psychological intervention, these problems could be alleviated, to a greater or lesser extent, and the risk of breakdown in the caregiving situation offset to some degree.

To summarise this section of the review, reference is paid to Haupt and Kurz (1993, p. 745), who suggested that, *'The factors predicting nursing home placement in patients with Alzheimer's disease are complex, including demographic characteristics (older age), level of cognitive and physical functioning (degree of dementia), behavioural abnormalities in daily living (incontinence, aggression and dependant depression), and environmental factors (carers' wishing to leave the care to someone else – motivation in the caregiver to continue in role and the availability of intensive family support to the primary caregiver).'*

3.11 Coping with dementia caregiving

Regarding coping with caregiving, Nolan et al. (1996) summarised the growing consensus in the literature of which coping strategies are the most effective in dementia caregiving as follows:

- Coping may involve direct action (behavioural) or cognitive strategies, or both.
- Problem-solving may not be as useful as some problems are insoluble.
- Individuals who have a range of coping strategies are more likely to cope more effectively. Flexibility is also required so that different approaches can be utilised as appropriate.

- Meanings are particularly important to coping: being able to see things as a challenge rather than as a threat, having a sense of competence and mastery, and perceiving efforts as meaningful are important mediating factors against stress.

The following section of the review looks at some of the research available to support this summary.

Zarit and Edwards (1996) stated that most research on coping (e.g. Lazarus and Folkman, 1984; Pearlin and Skaff, 1995) has identified three broad categories of responses: problem-focused coping strategies, which focus on management of the stressors or situation that gave rise to them; cognitive coping strategies, which are efforts to manage the meaning of the stressful situation, and emotion-focused coping, which involves management of the symptoms of stress. Zarit and Edwards (1996) state that cognitive coping and problem-solving have been found to be related to lower distress and emotion-focused coping to higher distress (Haley et al., 1987; Quayhagen and Quayhagen, 1988; Vitaliano et al., 1991) and that learning to manage stressors more effectively is also helpful (Zarit et al., 1985). However, they also state that ineffective coping can exacerbate behavioural and emotional problems, giving the example of reality confrontation leading to increased agitation in an elderly mother asking to go home to see her deceased parent, whereas validation therapy approaches can lead to a reduction in this problem behaviour.

McKee et al. (1997) stated that because it may not be possible to apply problem-solving to many of the difficulties encountered in dementia caregiving, flexibility in coping style is important. They found that carers appeared to have a dominant 'first-line' method of coping which was used until it was no longer effective, when other, more context-specific 'second-line' coping strategies had to be utilised. Again, this study showed that carers using problem-focused coping scored better on measures of coping than those using emotion-focused strategies. McKee et al. (1997) also suggested that flexibility and ability to adapt may well have an impact upon the capacity to continue in the caregiving role. They proposed that there needs to be a better understanding of how carers adapt their coping behaviours to a changing situation, i.e. in caring for someone with a progressive disease, when at the same time the central problem is not modifiable, as the disease is incurable.

Hooker et al. (1992) found that carers' personality is a potent predictor of perceived stress. High neuroticism and low optimism were significantly related to poor mental and physical health outcomes. In a later study (Hooker et al., 1994), personality factors were examined in relation to coping among spouse carers of people with dementia. In this study, personality traits explained 60% of the variance in emotion-focused coping, 30% of variance in problem-focused coping, and 15% of variance associated with social support coping. Both studies call for personality of the caregiver to be addressed in formulating models of the caregiver/coping process. Pot et al.'s (2001) study highlighted personality features as important in predicting caregiving outcome, with extraversion in non-spouse caregivers increasing the likelihood of institutionalisation. Perhaps this group of carers find the isolation associated with caregiving particularly hard to bear.

Saad et al. (1995) examined the coping strategies used by dementia carers and the impact of these on caregiver depression. They found a depression rate of 25.6% and demonstrated that coping strategies were important mediators of depression in this group. Those carers who used more active intra-psychic coping strategies, e.g. finding meaning and value in caregiving and addressing major themes such as loss and powerlessness, experienced less depression. Feeling at the mercy of circumstances and therefore powerless or helpless was associated with more depression, whereas control and mastery of the situation was associated with less depression. Spending time alone, i.e. away from the dependant, was also found to be important in addressing depression, as it provides opportunities for reflection and undertaking activities that make it easier to cut off from feelings and thoughts. Counselling interventions that offer the opportunity to explore and resolve negative cognitions and emotions, as well as caregiver education around positive coping strategies were also recommended. In this study 10% of carers admitted to using alcohol occasionally or frequently to reduce their distress and, given the association between alcohol use in this group and elder abuse (Brodaty et al., 1994), Saad et al. (1995) proposed that supporting positive coping in carers was an urgent issue for service providers.

Donaldson et al. (1998) proposed three broad ways in which service providers can help reduce caregiving burden and improve coping:

- Altering the symptoms of the illness, using medication and behavioural management approaches.
- Reducing the carer's exposure to these symptoms, using respite care and carer support services.
- Changing the carer's responses to the illness, by means of individual or family therapy for carers.

The next section of this review of the literature examines some of the research evidence around the most beneficial service interventions.

3.12 Benefits and limitations of community care services

To start this section of the literature review, reference needs to be made again to the positive aspects of caring for a person with dementia at home. Keady (1999) states that these can be overlooked in an attempt to provide services to minimise perceived caregiving burden. They are as follows:

- Maintaining a close relationship with a valued person.
- Continuing to express feelings of warmth and comfort.
- Being seen as an 'expert' in providing care.
- Keeping the person out of residential care for as long as possible.

Keady (1999) suggested that community care managers should strive to recognise and maintain these positive dimensions of dementia caregiving when planning service interventions to meet carers' identified needs.

Regarding the literature relating to the benefits and limitations of formal support from community care services, Levin et al. (1989) found that carers bore the brunt of caregiving and experienced considerable stress and burden in their role; that gaps in service provision existed, with many carers slipping through the net, and even when services were available they were not tailored to the needs of carers, e.g. they were only available during office hours. In this study, two thirds of carers received no help whatsoever from services, and a considerable proportion of those receiving support perceived that those services were not relevant to meeting their individual needs. For example, 5 out of 6 carers not in receipt of respite/day care services had never been offered such a break, but were in desperate need of such support. MaloneBeach et al. (1992) confirmed that even though carers generally view community care services as helpful, they often complain that they are not flexible enough or suited to meeting their individual needs.

Cohen et al. (1997) found that the carer's perception of the quality of the relief offered by services was more important in terms of the experience of caregiving burden than the frequency and level of services provided. Services which targeted difficulties identified by the carer were perceived as being more beneficial than increasing the level of service provision. Similarly, Bruce and Patterson (2000) found that carers reporting difficulties with health care services had increased levels of stress.

Lightbody and Gilhooly (1997, p. 213) stated that the provision of community care services has not, in general, been found to be related to improved carer well-being or institutionalisation. However, they claim that this might be because the *'care of elderly people has traditionally tended to slot people into a limited number of available services, few of which have had the explicit aim of supporting the informal carer'*. In addition, services have tended to focus on 'acts of omission', e.g. the inability to prepare a meal or bathe, rather than 'acts of commission', e.g. the dependant urinating in a wardrobe or wandering (Gilhooly, 1994), and are not really focused on meeting the carers most difficult or pressing problems. Few services, they claim, have the explicit aim of supporting informal carers.

One service which does have an explicit aim of supporting carers of people with dementia is the Admiral Nursing service, an innovative network of practitioners extending its coverage across the UK and led by The Dementia Relief Trust. Woods et al. (2003) examined the benefits of Admiral Nurses, who work specifically with the carers of people with dementia as clients in their own right, rather than directly with people with dementia. They found that anxiety and insomnia rates were lower for carers receiving support from an Admiral Nurse than those receiving support from traditional services and that, despite some criticism levelled against Admiral Nursing services resulting in poorer outcomes for people with dementia, institutionalisation rates were not increased, which implies that the service improved coping for carers in this group. Woods et al. (2003), taken with the findings of Challis et al. (2002), proposed that specialist mental health services for older people should include an element which is dedicated to the support of dementia carers and that this support should be ongoing, for as long as it is required (importantly, the Admiral Nurse maintains involvement during care transitions and after placement). Admiral Nurses or dedicated Community Psychiatric Nurses were recommended as an effective means of achieving this.

Another important role of the CPN, or Social Worker or Therapist for that matter, is that of Care Manager (the Care Manager co-ordinates service inputs, monitors and supports care workers delivering personal care, provides education and counselling support to the carer, and retains contact for the duration of their role/team involvement). In the Challis et al. (2002) study referred to above, people with dementia and their carers in one community team setting received intensive care management and were compared with those in a similar team which did not provide this service. In the care management team, there were significant improvements in social contact for carers and dependants, a decrease in the stress of carers, combined with a reduction in their input to the care of the client, and significant improvements in overall need reduction, activities of daily living and level of risk among dependants. Despite the increased cost of such intensive and specialist support, Challis et al. (2002) made a strong case for overall cost reduction in the wider implementation of such a service - in an evaluation after one year, 51% of the care management group remained at home compared with only 33% of the control group, i.e. intensive and specialist care management significantly reduced the risk of institutionalisation.

Caregiver training and psychological support, as indicated above, is another important intervention which supports improved coping and outcomes. Cohen et al. (1997) stated that whilst drugs have an important role to play in the management of behaviour disturbance in dementia, training for carers in how to cope with challenging behaviour and manage their stress can be more effective. Miller and Morris (1993) found that carefully designed training programmes achieved long-term benefits in terms of improved coping ability and reduced psychological morbidity amongst carers. Haupt et al. (2000) similarly reported improved coping amongst their carer sample following a 3-month psychoeducative group intervention. In this study, inappropriate coping strategies among carers were modified through education and psychological support, and this in turn resulted in a significant improvement in agitation and anxiety levels in dependants (only 14 families were included in this study, however). In a larger study by Herbert et al. (2003), with a sample of 158 participants (79 subjects; 79 in control group), after fifteen 2-hour weekly sessions focusing on stress appraisal and coping, a 14% decrease in reactions to behavioural problems was noted among carers, together with a significant reduction in behavioural problems among dependants. This was in contrast to the control group, who received the same number of traditional support group sessions, which showed only a 5% decrease in reactions to behaviour problems.

In a large scale study by Mittelman et al. (1993), a reduction in institutionalisation was found after such psychoeducational intervention with carers. In this study, carers receiving individual and family counselling, support group participation and ad hoc consultation had less than half the number of nursing home placements within a year (the intervention programme was ongoing throughout this period) as the control group, who received only routine support. After one year, 35 of the 206 subjects had been placed in institutional care - 11 from the treatment group compared to 24 from the control group). This demonstrates the benefits of education coupled with psychological support, and the cost of organising such programmes is more than offset by reductions in institutional care. This study also highlighted that ongoing rather than time limited support is required.

Many studies also highlight the benefits of respite care. Briggs and Askham (1999, p. 58), in a review of the benefits of respite care – including respite in the home (sitting services), respite outside the home (day care services), temporary/crisis respite intervention or planned rotational respite, stated that the aim of respite care is *'to relieve carers of the burden of caregiving'* (Grasel, 1997) and *'to help delay long-term institutionalisation of the person being cared for'* (Montgomery, 1995; Mountain, 1995). Almberg et al. (1997) also stated that regular periods of respite from the caregiving situation (and social support) may effectively relieve some of the caregivers' experience of burnout.

Respite services are likely to be used differently by adult children carers and spouse carers, with spouse carers being more likely to visit their husband/wife on a daily basis, thereby somewhat defeating the object of the break, whereas adult children carers are more likely to use the break for a holiday (Wright, 1998). There is also evidence that day respite might be used by carers to catch up with care related activities, e.g. shopping, cleaning etc, rather than in having a real break (Berry et al., 1991). Berry et al. (1991) therefore proposed that respite services might be better targeted at adult children carers with dual responsibilities and competing demands, e.g. those involved in family care or who are employed. However, it may be the case that respite care could be made more beneficial for spouse carers with additional home care support to relieve them of their household duties and encouragement from their care manager not to visit their relative whilst in residential/in-patient respite care so that they can have a real break from caregiving.

Unlike the Almberg et al. (1997) study, Lawton et al. (1989) found no effect on carers' mental health and levels of caregiving burden following respite care. But, importantly, satisfaction with respite services was high and respite care was found to sustain people with dementia in the community for longer than controls – an average of 22 days, meaning that such provision may be highly cost effective. Other studies have similarly found a high level of satisfaction with day services, e.g. Levin et al. (1994) found that 92% of carers considered that day care had resulted in an improvement in their own quality of life. Another study by Curran et al. (1996) found that carers reported that their demented relatives' behaviour and mood improved following 3 months day care attendance, perhaps as a result of trained staff giving advice and support on positive behaviour management and the stimulation that day care services provide.

It also needs to be recognised that the use of respite services may in itself be a risk factor predictive of institutionalisation. Levin et al. (1989) found that when carers used respite care at the first interview, there was an increased chance of that person actually being in institutional care by the second interview within one year. Whitlach et al. (1999) similarly found that the use of respite care was a risk factor for relinquishment of home caregiving/institutionalisation, and Hope et al. (1998) found that the use of day care services and time away from the dependant (greater than 16 hours a week) predicted institutionalisation of the dependant. Perhaps the break from 24/7 caregiving afforded by day and respite care provides carers with a view of how life would be if they were relieved of the caregiving role, and entering back into that role, particularly after a longer-term break, becomes a daunting prospect. Similarly, during longer-term respite care the person with dementia's condition may significantly deteriorate, meaning that caregiving post-discharge from the care home/hospital ward may be even more difficult. Hope et al. (1998, p. 688) refer to the receipt of day and respite care services as *'signalling the gradual transition to long-term care'.*

Cunningham and Dick (1995), in a study of the perceived benefits of respite care, concluded that carers need services which are flexible and fit their changing needs and circumstances alongside those of the person they cared for. Similarly, they reported that carers wanted respite services that are properly resourced so that enough services of the right quality and range can be provided. To this end, night respite services out of the home provided by qualified nurses, have been advocated as particularly useful for carers whose sleep is regularly disturbed (Watkins and Redfern, 1997), and twilight day care services (early morning to late evening) have been proposed to benefit working carers, for example, spouse carers of younger people with dementia (O'Donovan, 1999).

The next section examines the process of relinquishment of home caregiving and the impact for carers who place their relatives in permanent care.

3.13 Process and outcomes of institutionalisation

Opit and Pahl (1993) concluded that the key variables in the likelihood of older people being admitted to long-term care were a high degree of dependence, living alone and dementia. This research was quoted in the Royal Commission report on long-term care for the elderly, 'With Respect to Old Age', where it was recongised that *'Dementia at an advanced stage puts co-resident caring under considerable threat'* (HMSO, 1999 p. 62). Furthermore, the common reasons for co-resident caregiving coming to an end were identified as follows:

- Carer's own health problems
- Carer's stress
- Sleep deprivation
- Carer unable to cope with incontinence
- Carer unable to cope physically with caregiving tasks

- Hospitalisation of the cared-for person.

These are felt to be a useful summary for the above discussion relating to predictive risk factors for institutionalisation for the person with dementia, although they apply to older people more generally in this instance. One issue not previously addressed as a risk factor for institutionalisation raised in the Royal Commission document is that of the cared-for person being hospitalised. Wright (1998), cited in the report, found this to be a significant risk factor for both elderly people living alone and those living with a primary carer.

A study by Andrieu et al. (2002) found that 24% of people with dementia had at least one acute hospitalisation (acute medicine not mental health) during one year, and that the variables predictive of acute hospitalisation were poor carer education (about illness management), dependant bathing, toileting and feeding difficulty, history of falls and behaviour disturbance. In this study, the leading causes of hospitalisation were behavioural problems in the dependant (52%), fractures following falls (19%) and breakdown in the caregiver network (11%). Besides medical reasons for admission, caregiver burnout was a considerable factor. Andrieu et al. (2002) recommended that service interventions and caregiver education to reduce the impact of loss of skills in activities of daily living and manage behavioural problems more effectively may reduce acute hospital 'social' admissions for this group and result in a considerable cost saving.

Zarit and Edwards (1996, p.354) stated that *'most families consider placement* (of their dependant in an institution) *at least at some point during their caregiving career'*. However, one of the main reasons for hesitating to place a relative in an institution is the carer perceiving their relative as being too frail to survive the dislocations that accompany institutionalisation (Aneshensel et al., 1993). Indeed, for people with advanced dementia there is a real risk of mortality following placement (Aneshensel, 1993).

However, for those who do decide to relinquish home caregiving and place their relative in an institution, *'placement does not end the caregiving role, but instead represents a restructuring of it'* (Zarit and Edwards, 1996, p 354). For example, Aneshensel et al. (1995) and Duncan and Morgan (1994) found that most carers remained involved in care post-placement, visiting frequently and becoming engaged in some activities of daily living.

As Pot et al. (1997, p. 267) concluded, for some carers placement of their dependant in an institution is *'probably the only adequate way to reduce their psychopathology'* and, regardless of the difficulty of this decision, most experience relief following relinquishment of caregiving. However, for some carers the transition from home care to institutional care is seen as a sign of failure and the welfare of carers at this most painful time has been largely neglected (Dellasega and Nolan, 1997).

One of the key issues influencing decision-making around placement is that of the cost of long-term care, if it is to be provided outside of the NHS (Dellasega and Nolan, 1997). Zarit and Edwards (1996) state that the cost of care is another stressor for the carer post-placement, as nursing home care is rarely covered by insurance (the paper is American, but equally applies to the UK as the state does not cover full care costs). Thus, they state, families *'can experience considerable economic strain'* and spouses of nursing home residents can expect to spend one half or more of their assets on care before state assistance is provided. (In the UK, the person with dementia makes a means-tested contribution to care rather than there being an expectation on the carer to pay for services, though in practice they often make 'top-up' payments in order to obtain a placement of their choosing.)

Institutional placement can also place carers in *'an ambiguous and undefined role'* (Zarit and Edwards (1996, p. 354), described by Rosenthal and Dawson (1991) as 'quasi-widowhood'. Thus many carers continue to experience considerable emotional distress after placement. Zarit and Whitlach (1992) found that despite a decrease in the subjective burden of caregiving – carers felt less overwhelmed, tired and pressured and had more time for activities, emotional well-being did not significantly improve following placement. Carers who were depressed prior to placement often remained depressed after one year following placement. Aneshensel et al. (1995) similarly found that despite the fact that over time the majority of carers' emotional well-being did improve, about a quarter continued to experience significant emotional distress. Zarit and Whitlach (1992) attributed their finding to the stress of making the decision to place the dependant in institutional care, finding a facility that would accept their demented relative and, for some, the stress of having to move their dependant from one care home to another because their needs could not be appropriately met. Dellesega and Nolan (1997) suggested that knowing how to find a suitable care home and concern over what the quality of care might be within the care home are additional concerns for carers.

Zarit and Whitlach (1992, p. 672) proposed that, *'The careers of caregivers do not stop at the institution's door but continue in an altered and still stressful way. Caregivers do not give up their role; they shift their responsibilities'.* However, they also made the point that placement by an uninvolved relative would produce different effects.

3.14 Summary of risk factors for breakdown in caregiving situations

Building on previous analyses of the main predictive factors for institutionalisation of people with dementia undertaken by Lightbody and Gilhooly (1997) and updated by Keady (1999), the following risk factors for breakdown in caregiving situations/institutionalisation have been summarised from the research on dementia caregiving breakdown. The list of research outcomes has been categorised into the following headings: 'carer risk factors' – including caregiving situational factors, and competing demands and nature of relationship; 'objective burden factors' – including dementia symptoms and severity, and the nature and impact of caregiving demands; 'subjective burden factors' – including the emotional and psychological impact of caregiving upon the carer, and psychological health and coping outcomes, and 'access to support factors' – including the availability and impact of community care services, and the availability of informal supports.

Carer risk factors:

- Why and how caregiving responsibility was assumed and planning undertaken for role (Karasik, 1995)
- Carer's age (Gilhooly, 1986); Younger carers experience greater burden (Mittelman, 1993; Kramer and Kipnis, 1995)
- Older wives caring for husbands, followed by daughters caring for parents most at risk of burnout (Almberg et al., 1997)
- Older age in carers (Haupt and Kurz, 1993)
- Associated age and frailty in caregiving spouses (Cohen et al., 1993)
- Spouse carers less likely to seek institutional care (Collerick and George, 1986); Being a non-spouse carer (Pot et al., 2001)
- Non-spouse carers being more extravert in personality (Pot et al., 2001)
- Spouse carers perceiving pressure from informal supporters to institutionalise (Pot et al., 2001)
- Age of dependant (Orbell and Gillies, 1993); Older age in dependant (Haupt and Kurz, 1993)
- Gender of carer – being a female carer (Mittelman, 1993; Jerrom et al., 1993; Lightbody and Gilhooly, 1997; Hope et al., 1998)
- Employment situation of the carer (Gilhooly, 1986); Economic situation of the carer (Aneshensel et al., 1995); Income of carers (Mittelman, 1993)
- Poor carer education (about illness management) (Andrieu et al., 2002)
- Poor carer health (Hirschfield, 1983; Cohen et al., 1993; Almberg et al., 1997)
- Carer's ways of managing memory problems (Keady, 1999)
- Existence of another dependent relative (Gilhooly, 1986)
- Carer living apart from the person with dementia (Spruytte et al., 2001)

Objective burden risk factors:

- Severity of dementia/degree of cognitive impairment (Cohen et al., 1993; Mittelman, 1993; Haupt and Kurz, 1993; Philp et al., 1997); Dependant cognitive functioning (Cohen et al., 1993; Philp et al., 1997); Extent of global cognitive decline (Haupt and Kurz, 1993)
- Severity of dementia and rate of deterioration (Brodaty et al., 1993); Deterioration in the dependant (Gold et al., 1995)
- Overall illness duration (Hope et al., 1998)
- Functional level of the dependant (Spruytte et al., 2001); Dependant's need for assistance with ADLs (Mittelman, 1993); Level of physical functioning in dependant (Haupt and Kurz, 1993; Philp et al., 1997)
- Immobility or difficulty in walking and incontinence (Hope et al., 1998)
- History of falls (Andrieu et al., 2002)
- Dependant bathing, toileting and feeding difficulty (Andrieu et al., 2002)
- Level of supervision required by the dependant (Wimo et al., 1992)
- Clinical fluctuations in symptoms of dementia (unpredictability) (Annerstedt et al., 2000)
- Amount of caregiving time/input each week (Annerstedt et al., 2000)
- Limitation in social life increases likelihood of burnout (Almberg et al., 1997)

- Dependant living alone/caregiving from a distance (Gallo, 1990; Spruytte et al., 2001)
- Persistence of troublesome behaviour, including aggression and incontinence (Cohen et al., 1993); Number and frequency of behaviour problems (Mittelman, 1993; Orbell and Gillies, 1993; Philp et al., 1997); Behaviour disturbance (Andrieu et al., 2002)
- Reaction to behaviour and memory problems (Cohen et al., 1993); Perceived impact of behavioural problems (Philp et al., 1997)
- Acts of commission by dependants (Gilhooly et al., 1994)
- Degree of problem behaviours experienced, especially wandering or inappropriate behaviour (Whitlach et al., 1999)
- Incontinence, aggression and depression in the dependant (Haupt and Kurz, 1993)
- Nocturnal deterioration/disturbance (Annerstedt et al., 2000); Excessive night-time activity (Hope et al., 1998)
- Paranoia, aggressive behaviour and incontinence in the dependant (O'Donnell et al., 1992)
- Misidentification of the carer (Annerstedt et al., 2000)

Subjective burden risk factors:

- Quality of the pre-morbid relationship with the person cared for (Gilleard, 1985; Gilhooly, 1986)
- Quality of the current dependant/carer relationship (Gilhooly, 1986; Spruytte et al., 2001); Low mutuality in the caregiving relationship (Hirschfield, 1983); Carer emotionally detached from dependant (Wuest et al., 1994)
- Level of stress and well-being experienced by carer (Jerrom et al., 1993); Caregiver burden (Cohen et al., 1993)
- Carer's perceived problems in relation to dependant disabilities (Philp et al., 1997)
- Carer's reactions to the exhibited behaviours (Cohen et al., 1993)
- Carer's perceived problems in relation to dependants' physical disabilities (Philp et al., 1997)
- Perceived role captivity (Aneshensel et al., 1993); Lack of time, feeling tied down (Hirschfield, 1983); Feelings of resentment, helplessness and guilt (Hirschfield, 1983)
- Carer's impaired sense of own identity (Annerstedt et al., 2000)
- Lack of satisfaction from the caregiving role (Orbell and Gillies, 1993); Lack of enjoyable aspects to caregiving (Cohen et al., 1993); Lack of positive aspects to caregiving (Cohen et al., 1994)
- Poor perceived self-competence in carer (Orbell and Gillies, 1993)
- Carers with lack of positive outlook on caregiving more vulnerable to burnout (Almberg et al., 1997)
- Depression in carers (Whitlach et al., 1999); Psychological morbidity in carers (Brodaty et al., 1993; Gilleard et al., 1984)
- Exhaustion in the carer (Wimo et al., 1992; Gold et al., 1995)

Access to support:

- Carer's use of and access to services (Cohen et al., 1993)
- Intensive, specialist care management reduces risk of institutionalisation (Challis et al., 2002)
- Structured psycho-educational support to carers reduces risk of institutionalisation (Mittelman et al., 1993)
- Availability of and contact with friends and the satisfaction from such help (Gilhooly, 1986)
- Availability of intensive (informal) family support (Haupt and Kurz, 1993)
- Presence of a social support network (Orbell and Gillies, 1993)
- Caregiving situations in receipt of respite care (Whitlach et al., 1999)
- Being away from the carer (in day/respite services) for more than 16 hours week (Hope et al., 1998)
- Respite services maintain people in the community for longer than controls (22 days) (Lawton et al., 1989)
- Carer's preference for institutional care (Spruytte et al., 2001); Carer's willingness to continue caring (Philp et al., 1997)
- Carer's wish to leave the care to someone else (Haupt and Kurz, 1993)

Table 1.1: Risk factors for breakdown in caregiving situations/institutionalisation

As can be seen from the above list of risk factors, much of the research that has taken place into caregiving breakdown/institutionalisation has focused on specific aspects, such as the nature of the caregiving relationship, the impact of challenging behaviour or the benefits of community services. This study has attempted to take a wider 360^0 exploration of the range of potential risk factors for caregiving burden and breakdown within the dementia caregiving phenomenon. A set of study hypotheses, which are outlined in the following section, have been developed from the review of the literature to outline the main predictions for the study. The success of this approach will be seen in the chapters which follow, where the main study findings will be presented and discussed in relation to previous research and the following study hypotheses will be revisited to determine whether or not they have been supported by research findings. The contribution of this study to the above literature on predictors for breakdown/relinquishment will also be examined.

To finish this chapter, the following section presents a set of study hypotheses, formed out of the review of the literature

3.15 Study hypotheses

With regard to the identification of a set of hypotheses and predictions to be tested via appropriate analyses of the data emanating from the study, these were as follows:

- That the main causes of breakdown in caregiving situations will be more closely associated with higher levels of subjective burden, such as perceived stress associated with direct caregiving problems and perceived impact of caregiving, than objective burden, such as degree of dementia or physical dependency of the dependant.

- That caregiving problems experienced in the behavioural and mood domains will be directly associated with higher levels of subjective burden, and that there will be a peak in subjective burden in the moderate to severe phase of dementia, when the dependant is active and disturbed, and a lessening in subjective burden towards the end of the illness, when the dependant becomes more passive and frail.

- That carers with a poor quality current relationship with their dependant will have a higher degree of subjective burden than those with a good quality relationship, with increased feelings of detachment and role dissatisfaction. Earlier relinquishment of care is expected for non-close caregiving relationships and greater difficulties in relinquishing role are expected in close caregiving relationships.

- That adult children/children-in-law carers with competing demands, such as young children to care for and/or employment responsibilities, will relinquish their caregiving role at an earlier stage than spouse carers. Caring at a distance (i.e. not living with the dependant who lives alone) is also expected to be a predictor of earlier admission to permanent care.

- That sole carers, without informal support from family and friends, will have a higher degree of subjective burden than those with a good informal support network. Those without informal support and who remain outside of the health and social care system, receiving no support from statutory services, are expected to be most at risk of psychological health problems and breakdown in their caregiving situation.

- That those with little or no perceived role satisfaction are expected to experience more subjective burden, be more at risk of psychological health problems and relinquish their caregiving role at an earlier stage. Those with high levels of role satisfaction are expected to experience less subjective burden and be more highly motivated to continue in their caregiving role.

The above predictions were tested by the development and implementation of the following research methods.

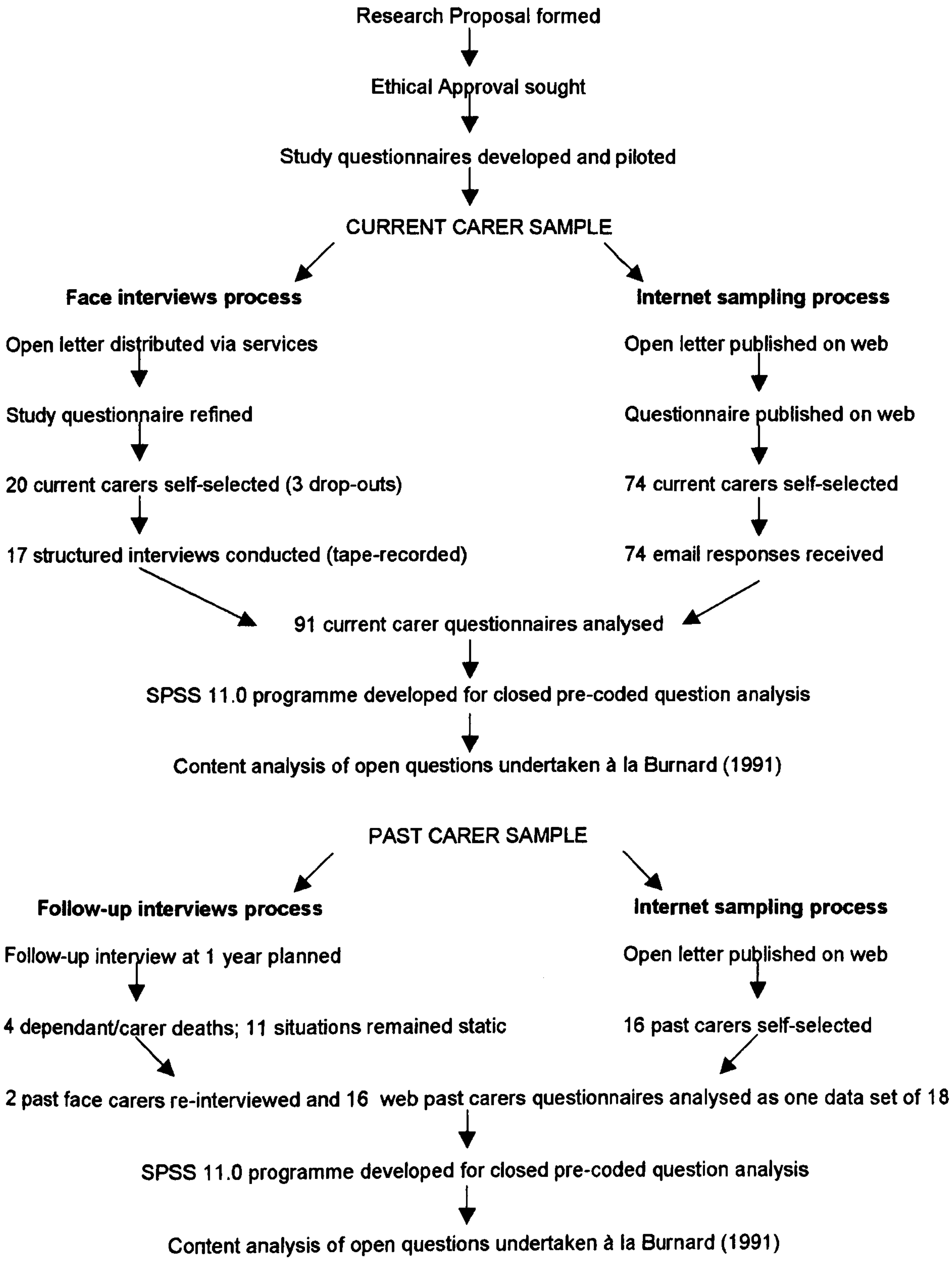
Chapter 4

RESEARCH METHODS

"Completing your questionnaire was like a rock being removed from my shoulders." (Internet carer 59)

4.1 Study design algorithm

The following algorithm provides a visual representation of the various phases of the study design and the major tasks undertaken. This chapter provides detailed information about the research methods developed for the study and discusses their success.



4.2 Introduction

The nature of the research was that of 'field survey', which Clamp and Gough (1999) state is undertaken to study a large and diverse population through appropriate sampling, to discover the incidence, distribution, inter-relationship and behaviour of variables. The study was initially designed as longitudinal, following a sample of local dementia carers through one year in their caring role, i.e. a first interview was to be undertaken at point one with follow-up one year later. However, due to unforeseen problems with the study sample, as outlined below, the study design changed to incorporate an internet-based questionnaire, which attracted a larger, more random international sample. This had the effect of making the study more quantitative than originally intended but also, hopefully, made the research findings more robust. As the research utilised several methods for data collection and the study questionnaires were designed to obtain both qualitative and quantitative data, it should be viewed as a mixed methods study.

4.3 Justification for research methods

Various approaches to researching the phenomenon under investigation, i.e. carers' subjective experience of caring for a person with dementia and the risk factors implicated in breakdown in caregiving situations, were initially explored. These included postal survey of carers known to services/support organisations, telephone survey of carers who had previously contacted Dementia Careline and focus groups of carers accessing Dementia Careline. All three approaches were felt to have some value, but were dismissed for the following reasons:

Postal survey: This approach to research was discounted because the method was felt to be somewhat 'cold', devoid of human contact, i.e. it would not provide the researcher with an opportunity to meet the carer to achieve a 'picture' of their caregiving situation and their emotional responses to questions. Nor would it enable the range of qualitative data required to be adequately recorded, i.e. via tape-recorded interviews. Issues of consent and confidentiality would also need to addressed, e.g. accessing names/addresses of carers known to services/organisations would have serious implications under the Data Protection Act 1998 (Dept. Constitutional Affairs, 1998).

Telephone survey: This approach to research was discounted as it was felt to be contrary to the 'Telephone Helplines Association Guidelines for Good Practice' (THA, 2003), in so much as people calling the Dementia Careline would expect the highest standards of confidentiality. To be called back for research purposes would not only result in a breakdown in the telephone helper/caller relationship, but it could bring the Dementia Careline into disrepute. Carers would also be unlikely to respond favourably to be asked permission to take part in an interview when they had expressly telephoned for information and support. Thus this approach was rejected at an early stage.

Focus groups: The opportunity for arranging focus groups for carers to collectively share their experiences was available to the researcher, but this approach was felt to preclude individual disclosure of very personal or distressing information, e.g. negative feelings or inappropriate caring strategies. The nature of this research was felt to demand a one-to-one approach and thus this approach was rejected in favour of individual carer interviews and, later, internet completed questionnaires.

The main research method employed in this study, therefore, was that of standardised/structured interview, whereby each subject was asked the same questions in exactly the same order. A research questionnaire was prepared for the interview process and the researcher made verbatim notes as the interview progressed. With the carer's permission (see discussion around consent issues below), interviews were also tape-recorded to enable complete transcripts to be made for the purposes of data analysis.

Questionnaires delivered by interview was the selected method for this research because it was felt that as the study focused on the perceived experience of dementia caregiving, this approach would allow for more complete disclosure by subjects. It would also allow the researcher to ask a series of open-ended questions and, through a series of non-verbal and sub-verbal prompts, obtain fuller responses than would otherwise be obtained via written responses to an anonymous, unseen researcher.

Having a nurse researcher working in the field of dementia care present to undertake the interview also meant that a certain level of validation was offered to the carer being interviewed, i.e. with them knowing that the researcher understood their caregiving problems and needs and was non-judgemental. However, care was taken for the interview process not to be sidetracked into a support or counselling intervention, and a degree of objective detachment was required in order to ensure the research data was uncontaminated by the researcher's interference.

Having stated the above benefits of face-to-face interviewing, internet sampling could be viewed as being more 'cold', devoid of non-verbal and sub-verbal prompts, the presence of a knowledgable and understanding interviewer and the opportunity for post-interview follow-on support/referral. This meant that the quality of the information given to potential research subjects had to be very clear and demonstrate the researcher's clinical knowledge and academic standard so that carers felt confident enough to participate. Research subjects, answering postal questionnaires, often feel that this method is less than wholly anonymous and that identifiers may be included on the questionnaire/envelope somewhere. However, as stated below, the internet research sampling method offers almost total anonymity. This was felt again to allow for a maximum level of disclosure and, with many spaces left on the internet questionnaire for in-depth written responses to open-ended questions, perhaps enabled more complete responses than a postal questionnaire would have. There is also something to be said for the facts that many PC users can type faster than they write and that the response is more immediate than having to write on a paper document, place it in a stamped addressed envelope and take it to the post office – there are more steps involved. There is also the chance that the researcher may be on-line as or soon after the questionnaire is returned, so that the subject may feel more urgency in responding than if their questionnaire will not be received for several days and remain unopened for several weeks. Carers engaged in caregiving and unable to leave their dependants alone may also not be physically able to get to a post-box!

4.4 Face-to-face interviews sampling method

The initial local sample of dementia carers for this study was accessed via the South Wales Dementia Careline and local community psychiatric nurses on the four Community Mental Health Services for Older People (MHSOP) Teams in Cardiff and the Vale of Glamorgan. The main reason for working through these services was that researcher was known by practitioners, and this was thought to make access to the study sample easier. However, it has to be acknowledged that this could also have worked against the researcher, i.e. staff in services could have disclosed they they knew me and this could have been offputting to some carers, worried that personal information may be fed back to their care manager or counsellor. A study sample of 20 cases was planned for.

The only inclusion criteria for participation in the study was the dependant having had a formal diagnosis of dementia, by a GP, a local memory clinic, a consultant in old age psychiatry, etc, for more than one year. Participation in the study was entirely voluntary, with carers self-selecting themselves for the study in response to an 'Open Letter to Carers' (see Appendix 1) delivered by community psychiatric nurses to appropriate cases on their caseloads and via carers support groups held at the Dementia Careline Centre in Whitchurch, Cardiff.

Once the carer signed a tear off slip attached to the Open Letter saying they were interested in participating in the study (which were returned to the researcher by CPNs or the Dementia Careline Co-ordinator), telephone contact was made by the researcher, with information about the study being given and appointments made for face-to-face interviews. Carers were explicitly informed that they had the right to withdraw at any stage and reassurance was given about the confidential nature of the study and the fact that service delivery would in no way be effected by their decision to participate or not participate in the study.

4.5 Interview technique

Structured questionnaires were developed to guide the interview (see below) and interviews were tape recorded, with explicit permission of the carer, to enable quantitative and qualitative data analysis. For each carer, an appointment was made with the researcher for approximately one hour for the face-to-face interview to be conducted. During the telephone conversation with the carer at the time of booking, the researcher gave an assurance that information disclosed in interviews would be held in the strictest confidence and that a method was in place to ensure anonymity for subjects. Carers were also informed that they needed to be released from their caregiving responsibilities for the duration of the interview, so that they could talk freely without fear of their dependant being unsafe or becoming distressed. An hours additional respite care was offered to all subjects, but no carer took this up, choosing instead to be interviewed on a day when their dependant was in day hospital or receiving in-patient respite care, or to be interviewed in a room adjacent to their dependant. It should be stressed that the sacrifice of free time by carers to participate in this study was highly valued by the researcher and further demonstrates their altruism, for example, many subjects expressed a desire to help improve the situation for those carers who come after them through their involvement in the study. However, it should also be noted that for several carers who were interviewed when their relative was in an adjacent room, the interview was disrupted by the dependant repeatedly entering the room looking for their spouse/adult child carer, because they had forgotten where they were. This was just one more sign of the incredible stress that carers were under and the patient demeanour they were able to maintain under duress.

Interviewing carers who are, for the most part, highly stressed and burdened in their role is not easy. Many of the carers interviewed were clinically depressed and under great pressure and several became distressed at points during the interview. The researcher would like to emphasise the importance of preparedness for undertaking such difficult interviews and how counselling skills needed to be utilised as a resource in several situations. For example, for carers who disclosed negative feelings such as frustration, anger and guilt, validation and normalisation of feelings was required and some time and space was needed at the end of the interview for the carer to regain their composure before re-entering into the caregiving situation with their dependant again. However, the balance between the roles of nurse as researcher and nurse as counsellor need to be differentiated during such interviews with psychologically vulnerable adults, and the way the researcher did this was to apologise to carers for any distress the line of questioning may be causing them at the time and reassure the carer that there would be time at the end of the interview to talk in-depth about their perceived experiences and needs. On several occasions and for several carers, the interview had to be paused to enable carers to have a break or even a good cry – a cup of tea was often the medium for recomposure. For one or two carers, additional follow-up support was also obviously required and this was accessed by the researcher, with the carer's permission, by him asking the CPN or Dementia Careline co-ordinator to visit/telephone the carer on the next day to check on their emotional well-being (always without revealing the content of interview disclosure, which was held in the strictest confidence).

4.6 Research ethics

In considering research ethics for this study, the ethical principles identified by Gelling (1999), based on the work of Faden and Beauchamp (1986), Garity (1995) and Parahoo (1997), were observed in the study design. These are:

- Beneficence – the requirement to benefit the participant
- Non-maleficence – no harm should come to the participant as a result of taking part in the research
- Fidelity – the building of trust between the researcher and participant. There is an obligation to safeguard participants and their welfare
- Justice – the requirement to be fair to the participant. Their needs should always come before the objectives of the study
- Veracity – the obligation of the researcher to tell the truth about the research, even if it deters potential participants from entering the study
- Confidentiality – within research the confidentiality of information must be respected
- Respect for autonomy – participants must be allowed to make their own decisions about their potential involvement in the research.

The research methods adopted for the study, i.e. the administration of structed questionnaires via face-to-face interviews, were scrutinised by a local Research Ethics Panel and, on the basis of the following assurances, ethical approval was given for the study to proceed:

- Voluntary participation through self-selection – an 'Open Letter' (Appendix 1) with tear-off slip was circulated to carers known to local services by community psychiatric nurses and the Dementia Careline Coordinator. Carers who wished to participate in the study completed the tear-off slip, which gave permission for the researcher to contact them, explain the interview process and make arrangements for the interview.
- Open and full (written) information given about research aims and methods – explicit information was provided to all carers via the above 'Open Letter', and express information was given of the right of all participating carers to withdraw from the study at any time.
- Reassurance of confidentiality and anonymity – in both the 'Open Letter' and at the start of every interview, the researcher stated/re-stated the high level of confidentiality and anonymity with which disclosed information would be treated.
- Formal 'Consent Form' (Appendix 2) to be interviewed and for this to be tape-recorded – a requirement of the Research Ethics Committee was that all carers had the right to refuse to allow their interview to be recorded and that all carers be given reassurance that all tapes would be destroyed after data analysis was completed and that recordings would be used for no other purpose.
- The offer of replacement care to release the carer for interview without reducing their available respite hours – in respect for carers' perceived experience of stress and burden, and dependants' well-being, all carers were offered extra care via day hospital or within the Dementia Careline centre whilst the interview was in progress. All carers were informed that as personal and potentially distressing information was to be discussed, it would be inappropriate for dependants to be present during the interview. No carer took up the offer of extra care, instead choosing to be interviewed whilst their dependant was receiving care in the home or at day hospital, or whilst their dependant was in an adjacent room.
- Offering to access additional support for distressed carers, without breaking confidence of issues/needs disclosed during interview – for carers who were distressed during or following the interview, permission was asked for the researcher to contact their CPN/the Dementia Careline Coordinator to ask for a follow-up contact to ensure their well-being.

- Disclosure of dependant abuse by carers – this was not an issue for the interview carers group, but had it been the researcher would have had a duty of care to the person with dementia to act in their best interests and prevent further harm from coming to them. In such a situation, the subject would have been removed from the research study and advice from the research supervision team and from clinical services managers would have been sought.

The above considerations were felt to meet the four ethical principles for qualitative nursing research outlined by Holloway and Wheeler (1995) - informed consent, the dignity and privacy of research subjects, voluntary participation and protection from harm. Another consideration, based on Holloway and Wheeler's (1995) work was the risk of the nurse as qualitative researcher with recipients of care forming a close and potentially damaging to the research relationship with the participant. In undertaking research with such a vulnerable group who lacked power in their clinical situation, this had to be guarded against, and the researcher took great care to separate out his role as researcher from that of his role as nurse. Therefore, in this research, no subject was previously known to the researcher in his senior nursing role and his clinical identity was withheld from participants – all that carers were told was that the researcher was a nurse working within dementia services.

To conclude this section, reference is made to the Nursing and Midwifery Council 'Code of Professional Conduct' (2002). Several if not all of the key principles for nursing practice are applicable to the nurse as researcher and further support the above ethical principles:
"As a registered nurse, midwife or health visitor, you must: respect the patient or client as an individual; obtain consent before you give any treatment or care; co-operate with others in the team; protect confidential information; maintain your professional knowledge and competence; be trustworthy, and act to identify and minimise the risk to patients and clients."

4.7 Face-to-face interview questionnaire design

The 'Current Caregivers Questionnaire' developed for the first round of interviews comprised the following sections:

Caregiving Situation Details;
including the relationship of the carer to the dependant; the age and sex of the carer and dependant; the diagnosis of the dependant; who gave the diagnosis of dementia; the duration of caregiving, both in terms of the time since the diagnosis was given and the

time before the diagnosis that memory problems were evident; the carer's assessment of the degree of dementia in their dependant; additional illnesses suffered by the dependant; the carer's perception of what it is like to care for a person with dementia; the geographical distance involved in caregiving and the problems this causes; the hours spent in direct caregiving (which included hands-on support and one-to-one supervision) and the impact on the carer's life; the occupational status of the carer; other dependants cared for by the carer; the physical and psychological health of the carer and medications taken; the quality of the previous and current relationship with the dependant; the carer's perception of the changes in the quality of the relationship with their dependant, and the carer's perception of their strengths and weaknesses;

Caregiving Problems Analysis;
including a newly devised 'Dementia Caregiving Problems Questionnaire (DCPQ)' (the development of the DCPQ is discussed in Section 4.8) , assessing the frequency of caregiving problems experienced in the domains of communication problems, confusion problems, behaviour problems, mood problems and self-care/physical problems (see below section on questionnaire development); an assessment of the most stressful/difficult to manage caregiving problems; a review of the coping strategies/caring approaches used to manage caregiving problems; carer disclosure of the most distressing aspects of caring for their demented dependant; a self-analysis of the impact of the caregiving role on emotional and physical well-being, personal relationships/family life and social/work life, and an assessment of the impact of caregiving on the carer's quality of life;

Caregiving Stress and Burden Assessment;
including a newly devised 'Dementia Caregiving Burden Questionnaire (DCBQ)' (the development of the DCBQ is discussed in Section 4.8), assessing the degree of life upset, personal distress, negative feelings and lack of positive feelings experienced by the carer (see below section on questionnaire development), and a self-assessment of perceived overall stress and coping;

Exploration of Available Resources;
including the carer's views of how they could be helped to cope with their current situation and how their stress could be relieved; an analysis of the formal and informal supports received by the carer; the frequency of supports received and their perceived helpfulness; an assessment of unmet service needs; an exploration of the main motivations for continuing in the caregiving role, and expectations for the future.

In addition to the above elements of the questionnaire, the following were also originally incorporated but removed from the study methodology for the following reasons:

- A brief questionnaire was sent to the community psychiatric nurse/Dementia Careline co-ordinator, which sought independent information on the carer's main problems, physical and psychological health, degree of stress/caregiving burden, etc. The completion rate was so poor, mainly due to high caseloads/workload, that this was abandoned at an early stage in the study.
- The CPN/Dementia Careline co-ordinator was also asked to complete a 'Mini-Mental State Examination' (Folstein et al., 1975) for each dependant, to independently verify the degree of dementia in the dependant. This was abandoned for the same reason. It was not possible or feasible for the researcher to take on this additional element as often dependants were not present in the home at the time of interview, and clinical workload precluded additional home visits for this purpose.
- After completion of the face-to-face interview, the carer was asked to complete and return a 'General Health Questionnaire' (Goldberg and Williams, 1988) and a 'Bristol Activities of Daily Living Scale' (Bucks et al., 1996), both of which were intended to be used to validate the newly developed carers' assessment questionnaires. These were again abandoned at an early stage in the study, but this time because of low completion rate by carers, perhaps due to a lack of time, opportunity and inclination to complete them when their dependant was not present. Such questionnaires would, in the main, be completed at a time when the dependant was in day or respite care or had gone to bed, which are valuable times of freedom that the carer may not want to spend in thinking about their psychological health, their dependant's level of dependency or their caregiving situation as a whole.

The above losses are felt not to have affected the study in any great way. They were to be incorporated at an early stage in the study, before the internet sampling method was conceived. Their inclusion for a far larger sample would have resulted in an overwhelming volume of data being amassed, and so it could be seen as fortuitous that they were dropped from the study methodology. The Mini-Mental State Examination (Folstein et al., 1975), however, could have been valuable in supporting carers' assessments of the degree of dementia in their relatives and its loss was unfortunate. That said, it would not have been possible to administer on internet subjects.

The original study questionnaire was piloted on a past dementia carer known to the researcher to test the face validity of the instrument, i.e. in her subjective assessment was the questionnaire relevant, reasonable, unambiguous and clear (Bowling, 1997).

Questions were tested for their relevance, scope and sensitivity and minor refinements were made following this pilot interview, which the test subject found to be very thorough and captured a great deal of her experience. At this stage the main changes made were to the length of the questionnaire, which had taken one and three quarter hours to administer in an interview situation. The 'CAMI: Carer's Assessment of Managing Index' and 'CASI: Carer's Assessment of Satisfaction Index' (Nolan et al., 1998), included in the original questionnaire, were removed due to the length and time of administration and repetition of some questions already included related to coping strategies and caregiving satisfactions.

The revised study questionnaire was then scrutinised by the research supervision team to check it's content validity. This review judged *"the extent to which the content of the instrument appeared logically to examine and comprehensively included, in a balanced way, the full scope of that which it was intended to measure"* (Bowling, 1997, p. 133). The revised questionnaire was subsequently re-tested on the past carer for a final face validity check and was felt to be less arduous to complete and pitched at just about the right content and duration, taking approximately one hour to complete.

The 'Follow-up Interview Questionnaire' was originally devised in two parts, one for 'Current Carers' – those who were still providing care for their dependant one year on, and one for 'Past Carers' – those who had relinquished home caregiving. Due to the methodological problems outlined in the next section and the incorporation of an internet-based sampling technique, follow-up interviews for carers still providing care one year on were not undertaken. Instead, only carers who relinquished care within the year (n=2) were re-interviewed. This was felt to be an appropriate change in methodology, as most caregiving situations were reported to have remained fairly static over the twelve-month period, i.e. dependants' and carers' needs had not changed greatly. As one of the main study aims was to investigate the reasons for relinquishment of home caregiving/breakdown in caregiving situations, data from these two interview carers was analysed with data from the 16 past internet carers' questionnaires as one data set.

The content of the 'Past Caregivers Questionnaire' was as follows:

Caregiving Situation Details;
including the relationship of the carer to the dependant; the age and sex of the carer and dependant; the diagnosis of the dependant; the duration of home caregiving; the carer's assessment of the degree of dementia in their dependant in the month prior to their admission to permanent care; the geographical distance that was involved in home caregiving; the hours previously spent in direct home caregiving and the impact on the

carer's life; the occupational status of the carer when providing home care and after relinquishing home caregiving; the previous quality of the carer's relationship with the dependant prior to relinquishment of home caregiving; the carer's assessment of their physical and emotional health prior to relinquishment of home caregiving and at the time of completing the questionnaire;

Caregiving Problems Analysis;
including retrospective completion of the 'Dementia Caregiving Problems Questionnaire (DCPQ)', assessing the frequency of caregiving problems experienced in the domains of communication problems, confusion problems, behaviour problems, mood problems and self-care/physical problems in the month before relinquishment of home caregiving;

Caregiving Stress and Burden Assessment;
including retrospective completion of the 'Dementia Caregiving Burden Questionnaire (DCBQ)', assessing the degree of life upset, personal distress, negative feelings, and lack of positive feelings experienced in the month prior to relinquishment of home caregiving, and a self-assessment of perceived overall stress and coping prior to relinquishment; and

Exploration of Process and Outcome of Admission to Permanent Care;
including the carer's perceptions of coping prior to relinquishment of home caregiving; an analysis of the formal and informal supports received by the carer prior to relinquishment; categorisation of the main reason for the carer's decision to resort to admission to permanent care; the carer's descriptive outline of what led up to the admission of the dependant into permanent care; who arranged the admission to permanent care; the type of permanent care setting the dependant was admitted to; the carer's degree of satisfaction with the quality of care their dependant receives within the care setting, and their current input to their dependant's care.

4.8 Development of DCPQ and DCBQ

The 'Dementia Caregiving Burden Questionnaire' and the 'Dementia Caregiving Problems Questionnaire' originate from the 'Relatives Stress Scale' and 'Behavioural and Mood Disturbance Scale' devised by Greene et al. (1982). The researcher worked with Crossroads Care Wales in 1997 to develop further Greene et al.'s (1982) tools and pilot them as core carers' assessments for those Crossroads schemes in Wales dealing with older people with dementia (O'Donovan, 1997). The Crossroads Wales study successfully evaluated the revised tools, on a multi-disciplinary basis, and secured their implementation on an all-Wales basis. It also supported the appointment of counsellor posts to Crossroads

Wales EMI care attendant schemes on the evidence of high levels of caregiver burden among Crossroads' existing client-base.

The two carers' assessment tools were further refined for this study, with the changed and additional questions from the original questionnaires mapped out and differentiated below. (The justifications for amended and new items are mapped out in table 4.3 – see page 108.).

Relatives Stress Scale Greene et al 1982 - 15 items	**Caregiving Stress and Burden Questionnaire** O'Donovan 1997 (Crossroads Wales study - 20 items)	**Dementia Caregiving Burden Questionnaire** O'Donovan 2004 (This study - 40 items)
		Life Upset
Do you find it difficult to get away on holiday?	Do you feel that you need a holiday (a long-term break from caring)?	Do you feel that you need a holiday (a long-term break from caring)?
How much has the household routine been upset?		
Do you ever feel that you need a break?	Do you find it difficult to get away for a break for a few hours?	Do you find it difficult to get away for a break for a few hours?
How much has your social life been affected?	How much has your social life been affected by caring?	How much has your social life been affected by caring?
Is your sleep interrupted by...?	Is your sleep disrupted by your dependant?	Is your sleep disrupted by your dependant?
	Do you have family arguments/difficulties associated with your caring situation?	Do you have family arguments/difficulties associated with your caring situation?
Has your standard of living been reduced?	Have your financial circumstances changed or your standard of living been reduced as a result of caring?	Have your financial circumstances changed or your standard of living been reduced as a result of caring?
Are you at all prevented from having visitors?	Do you have difficulty in continuing your relationships, e.g. having visitors or meeting friends, due to your caring commitments?	Do you have difficulty in continuing your relationships, e.g. having visitors or meeting friends, due to your caring commitments?
		Do you find that your caring responsibilities adversely affect other aspects of your life, e.g. your role as a parent/grandparent, your employment/other commitments?
Do you worry about accidents happening to...?	Do you worry about safely leaving your dependant on his or her own?	Do you worry about safely leaving your dependant on his or her own?
		Do you have to undertake caregiving tasks that you feel are beyond your capabilities?
		Personal Distress
Has your own health suffered at all?	Has your own physical health suffered as a result of caring?	Has your own physical health suffered as a result of caring?
Do you ever feel that there will be no end to the problem?	Do you feel there will be no end to your problems?	Do you feel there will be no end to your problems?
Do you ever feel you can no longer cope with the situation?	Do you feel you can no longer cope with your situation?	Do you feel you can no longer cope with your situation?
	Do you feel overwhelmed by your situation?	Do you feel overwhelmed by your situation?
		Do you feel trapped in the caring role?
		Do you feel that you are alone in coping with your caring situation?
	Do you find it distressing that your dependant has changed so much from his or her former self?	Do you find it distressing that your dependant has changed so much from his or her former self?

		Do you have feelings of grief and loss associated with your caring role?
	Do you find yourself becoming tearful or crying?	Do you find yourself becoming tearful or crying?
		Do you feel exhausted and demoralised in your caring role?
		Negative Feelings
Do you ever get depressed by the situation?	Are you depressed about your situation?	Are you depressed about your situation?
	Do you feel like giving up caring?	Do you feel like giving up caring?
Do you ever feel embarrassed by...?	Do you feel embarrassed by your dependant?	Do you feel embarrassed by your dependant?
Do you ever feel frustrated at times with...?	Do you feel frustrated with your dependant?	Do you feel frustrated with your dependant?
Do you ever get cross and angry with...?	Do you get cross and angry with your dependant?	Do you get cross and angry with your dependant?
	Are you resentful about the change in the quality of your own life/missed life opportunities?	Are you resentful about the change in the quality of your own life/missed life opportunities?
		Are you emotionally distant from your dependant?
		Do you view caring for your dependant as being like caring for a child?
		Do you have feelings of guilt associated with your caring role?
		Do you feel helpless and as if things are outside of your control in your situation?
		Positive Feelings
		Do you have a sense of achievement or fulfilment as a result of caring?
		Do you have a sense of purpose and direction in your caring role?
		Do you derive personal satisfaction and reward from your caring role?
		Do you have feelings of positive self-worth/self-esteem arising from caring?
		Do you feel that being a carer has provided an opportunity for personal growth and development?
		Do you feel that caring is a positive way of expressing your love and affection for the person you care for?
		Do you feel that you adopt a positive, problem-solving approach to caring?
		Do you feel that you manage your stress well and overcome it?
		Do you feel that the help you receive from services, family and friends has enabled you to carry on in the caring role?
		Are you feeling hopeful about your future?

	Stress Scale	**Stress Scale**
	Reflecting on your overall care-giving situation, all in all would you say you are: 0 - Coping well/with no stress 1 - Coping fairly well/with a small amount of stress 2 - Just about coping/with a moderate level of stress 3 - Having difficulty coping/with a great deal of stress 4 - Finding it almost impossible to cope/with an extremely high level of stress	Reflecting on your overall care-giving situation, all in all would you say you are: 0 - Coping well/with no stress 1 - Coping fairly well/with a small amount of stress 2 - Just about coping/with a moderate level of stress 3 - Having difficulty coping/with a great deal of stress 4 - Finding it almost impossible to cope/with an extremely high level of stress

Table 4.1: Relatives Stress Scale and DCBQ differentiations mapped out

Behavioural and Mood Disturbance Profile Greene et al 1982 - 34 items	**Caregiving Problems Questionnaire** O'Donovan 1997 (Crossroads Wales study - 40 items)	**Dementia Caregiving Problems Questionnaire** O'Donovan 2004 (This study - 50 items)
		Communication Problems
Does not start and maintain a sensible conversation	Is your dependant able to start and maintain a sensible conversation?	Is your dependant able to start and maintain a sensible conversation?
Does not understand what is said to him/her	Is your dependant able to understand what is said to him/her?	Is your dependant able to understand what is said to him/her?
Does not respond sensibly when spoken to	Is your dependant able to respond sensibly when spoken to?	Is your dependant able to respond sensibly when spoken to?
Goes on and on about certain things	Does your dependant repeat things over and over again?	Does your dependant repeat things over and over again?
Talks all the time	Does your dependant talk all the time?	Does your dependant talk all the time?
Talks nonsense / Wanders off the subject	Does your dependant talk nonsense which you can't understand?	Does your dependant talk nonsense which you can't understand?
		Does your dependant have periods when he/she doesn't speak much at all?
Does not watch or follow TV/Does not read newspapers, magazines, etc	Is your dependant able to read newspapers, magazines, etc., or watch and follow TV?	Is your dependant able to read newspapers, magazines, etc., or watch and follow TV?
Does not take part in family conversations	Is your dependant able to take part in family conversations?	Is your dependant able to take part in family conversations?
Talks aloud to him/herself	Does your dependant talk aloud to him/herself?	Does your dependant talk aloud to him/herself?
		Confusion Problems
Gets mixed up about where he/she is	Does your dependant get mixed up about where he/she is?	Does your dependant get mixed up about where he/she is?
Gets mixed up about day, year etc	Does your dependant get mixed up about the day, date, year?	Does your dependant get mixed up about the day, date, year?
Fails to recognise familiar people	Is your dependant able to recognise familiar people, e.g. family and friends?	Is your dependant able to recognise familiar people, e.g. family and friends?
		Is your dependant able to recognise you and know who you are?
	Does your dependant get mixed up about the time of day/night?	Does your dependant get mixed up about the time of day/night?
		Is your dependant able to hold his/her attention for more than a few minutes?
Seems lost in a world of his/her own	Does your dependant seem lost in a world of his/her own?	Does your dependant seem lost in a world of his/her own?
Wanders outside the house at night	Does your dependant try to get up and dressed/go outdoors during the night?	Does your dependant try to get up and dressed/go outdoors during the night?

Wanders outside the house and gets lost / Gets lost in the house	Does your dependant get lost and can't find his/her way home when outside of the house/do you have to keep them indoors?	Does your dependant get lost and can't find his/her way home when outside of the house/do you have to keep them indoors?
		Does your dependant see or hear things which aren't really there?
		Behaviour Problems
Has to be prevented from wandering outside the house	Does your dependant wander around indoors or outdoors?	Does your dependant wander around indoors or outdoors?
Hoards useless things	Does your dependant tend to collect things and hoard them?	Does your dependant tend to collect things and hoard them?
Becomes angry and threatening	Does your dependant become angry and resistive to care?	Does your dependant become angry and resistive to care?
Endangers him/herself	Does your dependant endanger him/herself by engaging in risky behaviours?	Does your dependant endanger him/herself by engaging in risky behaviours?
Becomes irritable and easily upset	Does your dependant become irritable and easily upset?	Does your dependant become irritable and easily upset?
Accuses people of things	Does your dependant falsely accuse people/you of things?	Does your dependant falsely accuse people/you of things?
	Does your dependant shout/swear/scream at people/you for no obvious reason?	Does your dependant shout/swear/scream at people/you for no obvious reason?
	Does your dependant hit out at you/other people for no obvious reason?	Does your dependant hit out at you/other people for no obvious reason?
		Does your dependant display inappropriate sexual activity/ demands?
	Does your dependant wake you/others during the night?	Does your dependant wake you/others during the night?
		Mood Disturbance Problems
Does not show an interest in news about friends and relations/Sits around doing nothing	Does your dependant show an interest in doing things?	Does your dependant show an interest in doing things?
Appears restless and agitated	Does your dependant appear to be restless and agitated?	Does your dependant appear to be restless and agitated?
Paces up and down wringing his/her hands	Does your dependant pace up and down in a worried or troubled way?	Does your dependant pace up and down in a worried or troubled way?
Cries for no obvious reason	Does your dependant cry/become tearful for no obvious reason?	Does your dependant cry/become tearful for no obvious reason?
Appears unhappy and depressed	Does your dependant appear to be unhappy and depressed?	Does your dependant appear to be unhappy and depressed?
Gets up unusually early in the morning	Does your dependant have difficulty settling to sleep or wake unusually early in the morning?	Does your dependant have difficulty settling to sleep or wake unusually early in the morning?
Mood changes for no apparent reason	Does your dependant's mood change suddenly for no obvious reason?	Does your dependant's mood change suddenly for no obvious reason?
Does not keep him/herself busy doing useful things	Does your dependant isolate him/herself and avoid social contact?	Does your dependant isolate him/herself and avoid social contact?
		Does your dependant never leave your side/shadow you?
Looks frightened and anxious	Does your dependant look frightened and anxious?	Does your dependant look frightened and anxious?
		Self-care/Physical Problems
	Does your dependant have problems in standing/walking - need assistance?	Does your dependant have problems in standing/walking - need assistance?
	Does your dependant have difficulty washing/bathing - need assistance?	Does your dependant have difficulty washing/bathing - need assistance?

	Does your dependant have difficulty dressing/undressing - need assistance?	Does your dependant have difficulty dressing/undressing - need assistance?
	Is your dependant incontinent of urine (may wear pads)?	Is your dependant incontinent of urine during the night (may wear pads)?
		Is your dependant incontinent of urine during the day (may wear pads)?
	Is your dependant incontinent of faeces (day or night)?	Is your dependant incontinent of faeces (day or night)?
	Does your dependant have problems feeding him/herself/ swallowing - need assistance/special diet?	Does your dependant have problems feeding him/herself/ swallowing - need assistance/special diet?
		Is your dependant partly/completely immobile and need lifting?
		Is your dependant prone to having falls/fits/choking attacks?
		Does your dependant suffer with pain/need analgesic medication?
		Additional follow-on Open Questions: What additional problems do you experience in caring for your dependant that are not covered above? Which of these problems are the most stressful/difficult to manage, and why? How well are you coping with and managing these problems? What coping/managing strategies do you use, and how successful are they?

Table 4.2: Behaviour and Mood Disturbance Profile and DCPQ differentiations mapped out

One can see from the first DCBQ table (table 4.1) that 25 new items have been added to Greene et al.'s (1982) original 15-item 'Relatives Stress Scale', and many of the original items have been amended. (Five of the new items were developed and tested in the Crossroads Wales Study by a multi-disciplinary group, and the remaining 20 were developed for this study). The amendments/additions were made on the basis that the original tool did not address several key aspects highlighted in research since its date of publication, and several of the original items needed to be improved in terms of relevance to needs identified by the researcher in his work with dementia carers. It should be acknowledged that the inclusion of new items and the amendment of original items in this questionnaire effectively invalidates the previously validated tool. How the psychometric properties of the 'new' tool were tested and the outcomes of testing will be reported on later in the thesis.

The categorisation of questions into Life Upset, Personal Distress and Negative Feelings headings was already made by Greene et al. (1982), with 5 in each category. However, in the new questionnaire, there are 10 questions in each of these categories and another category, namely (Lack of) Positive Feelings, has been introduced with an additional 10 questions relating to gains and satisfactions or, in the context of scoring, a lack of gains and satisfactions. This addition is crucial, given recent literature relating to the ameliorating effects of satisfactions on carer stress, as cited in the literature review chapter, as well as the fact that the 'Carers Assessment of Satisfactions Index' (Nolan et al., 1998) had to be abandoned at pilot stage due to the length of the questionnaire and time spent in interview.

The inclusion of a 'Stress and Coping Scale' was also introduced to the questionnaire to provide another self-assessment of caregiving burden. This has proved to be extremely helpful in supporting the scores from the associated questionnaire and allowing the community care practitioner to enter into a meaningful dialogue regarding stress and coping as a means of providing increased/enhanced support.

The justifications for new and amended items follows:

Life Upset Questions
Do you feel that you need a holiday (a long-term break from caring)? (Original: Do you find it difficult to get away on holiday?)
The original question was amended to the above because many if not all dementia carers would find it difficult to have a holiday. Somebody would need to take over the full-time responsibility of providing care or institutional respite care would be required. Feeling that one needs a holiday or long-term break from caring puts a different emphasis on this question as many carers feel this need despite the realisation that it is an improbable or even impossible desire. If the carer feels the need for a holiday but it cannot be achieved it is likely to be indicative of high subjective burden. It also highlights the need for access to respite services and is thus valuable for care management practice.
Do you worry about safely leaving your dependant on his or her own? (Original: Do you worry about accidents happening to...?)
The original question was felt to be flawed in that many carers, particularly those providing care for dependants with moderate to severe dementia, would not worry about accidents happening to their dependant because they would not leave them alone unsupervised due to the level of risk present in doing so. Thus for many carers the original question would be marked 'not appropriate'. The new question shifts the emphasis to worrying about safely leaving the dependant alone, which would have relevance to a greater number of carers. If the dependant's needs are such that they cannot be left alone, it is likely to be indicative of high subjective burden. It also highlights the need for access to home care/sitting services and is thus valuable for care management practice.
Do you find it difficult to get away for a break for a few hours? (Original: Do you ever feel that you need a break?)
The original question was felt to be too similar to the first question relating to getting away on holiday, in that some carers would interpret 'break' as meaning a holiday. Changing it to a 'break for a few hours' makes the focus clearer and is indicative of the level of informal support from friends, family, neighbours etc that may be available as a resource to the carer. The absence of breaks is again likely to be indicative of high subjective burden. It also highlights the need for access to home care/sitting services/day care and is thus valuable for care management practice.
How much has your social life been affected by caring? (Original: How much has your social life been affected?)
The only change to this item is the addition of the words 'by caring'. This is a simple clarification and avoids the carer misinterpreting the question and relating it to other aspects of their life. The question was retained as it is felt to have value in determining the effect of caregiving on the carer's own quality of life. The loss of contact with friends and inability to continue with social activities is likely to result in social isolation and diminished access to informal support. Thus it is likely to be indicative of high subjective burden and also indicates the need for befriending services/carers support groups etc and is thus valuable for care management practice.
Is your sleep disrupted by your dependant? (Original: Is your sleep interrupted by....?)

The only change to this item is the amendment of the word 'interrupted' to 'disrupted'. This is a minor change and was made because of the possible interpretation of the word 'interrupted' as being woken for a short time only, whereas 'disrupted' conveys a greater degree of disturbance/impact. The question was retained as it was felt to have value in determining the degree of exhaustion that may be experienced as a result of sleep disturbance/deprivation. Thus it is likely to be indicative of high subjective burden and also indicates the need for night sitting/respite care and is therefore valuable for care management practice.

Do you have family arguments/difficulties associated with your caring situation? (NEW)

This is a new question that was developed for the Crossroads Wales study and has relevance as 25% of carers rated this item as 'frequently/always' in that study. It was felt to be important because of the knowledge that many carers experience difficulties in this area – the children of spouse carers or siblings of adult children carers may not be supportive of the main carer, or the spousal relationship of adult children carers may suffer as a result of the main carer moving in with the dependant/moving them into the marital home to provide care. Whatever the cause, difficulties in the family dynamic are important in that they can reduce the level of informal support available to the primary caregiver and increase tensions within relationships. They are likely to be indicative of high subjective burden and are important to assess in care management practice.

- Ref. Gilleard, 1984 – caregiving usually falls on one person's shoulders and is rarely a shared responsibility.
- Ref. Gilhooly, 1986 – caregiving responsibility may fall to only one member of the family, which often engenders considerable resentment.

Have your financial circumstances changed or your standard of living been reduced as a result of caring? (Original: Has your standard of living been reduced?)

The original question was amended to include 'change in financial circumstances' in addition to 'reduced standard of living', and a clarification 'as a result of caring' was added. These changes were made because a carer's standard of living may not be largely affected even though their financial circumstances may have drastically altered, e.g. the carer who has to take early retirement may have some savings/lump sum to financially support them for a time, but there may be great fears for the future. Making the question more directly related to caregiving, e.g. in purchasing continence aids, laundry costs, new clothing costs etc. is also important for clarification. 'Reduction in standard of living' is important to retain, as this could relate to non-financial impacts, e.g. cleanliness of the home, reduction in room space available (disabled dependant living downstairs), etc. Both are likely to be related to high subjective burden and are important to assess in care management practice. The question could highlight the need for welfare rights and benefits information or financial advice, as well as the need for specialist aids and equipment.

Do you have difficulty in continuing your relationships, e.g. having visitors or meeting friends, due to your caring commitments? (Original: Are you at all prevented from having visitors?)

The original question was amended to the above to broaden it from just having visitors to the home. Being able to leave the home to meet friends is equally, if not more, important. The focus of the question was also changed to emphasise 'continuing relationships', in the knowledge that the time commitment required to fulfil the role of carer can place a strain on relationships with friends, children, spouses and parents. Difficulty in continuing with relationships may result in decreased quality in those relationships and, subsequently, increased social isolation. The support of family and friends to caregiving situations is crucial and without it subjective burden may be greater. Thus this is important to assess in care management practice, and may highlight the need for family intervention work.

Do you find that your caring responsibilities adversely affect other aspects of your life, e.g. your role as a parent/grandparent, your employment/other commitments? (NEW)

This question is new and has been included in the knowledge that competing demands, such as having a child/children to provide care for or being in part or full-time occupation, can increase subjective burden. Role conflict is important to assess in care management practice and may highlight the need for an intensive package of care to support continued role fulfilment in parenting or occupation, or both, or for placement alternatives to be explored.

- Ref. Kramer and Kipnis, 1995 – Younger carers experience greater burden, especially those with a work-role conflict.
- Ref. Skaff and Pearlin, 1992 – Loss of identity may result from 'role engulfment' arising from restriction of activities and social contact.
- Ref. Kaplan, 1996 – Caregiving activities may restructure and take over the life of the caregiver - caregivers decrease their social activities, give up a job, or even relocate to provide care to a parent.

Do you have to undertake caregiving tasks that you feel are beyond your capabilities? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers were coping with caregiving problems that were beyond their physical capabilities, e.g. a wheelchair bound carer having to provide personal care for her dependant resulted in a back injury. In addition, a lack of education/information for carers means that they may not feel skilled in dealing with problems such as aggression or wandering. If caregiving problems cannot be brought under control carers may feel helpless and as if their situation is out of their control. Perceived inability to meet dependant needs is likely to be indicative of high subjective burden and is important to assess in care management practice. Targeted service interventions designed to relieve carers of such caregiving tasks may be protective against breakdown in the caregiving situation.

- Ref. Braithwaite, 1990 – Due to a lack of choices in care, caregivers are often forced to undertake caregiving tasks which are beyond their capabilities and this can result in physical or psychological health problems.
- Ref. Folkman and Lazarus, 1985 – Stress occurs when there is a perceived mismatch between the nature of the demand and the person's ability to respond.

Personal Distress Questions

Has your own physical health suffered as a result of caring? (Original: Has your own health suffered at all?)

The original question was amended only slightly to clarify that it related to 'physical health' problems only – psychological health problems are addressed elsewhere. It was also amended to clarify the question related to those physical health problems perceived to have resulted from caregiving, rather than those that were pre-existing. Stress related physical health problems such as cardiovascular disease, migraines, asthma, etc, and strain related physical health problems such as back injury, hernia, dislocated shoulder etc, are likely to be related to high subjective burden. They are also indicative of the need for service interventions to relieve the carer of some of the physical demands of caregiving, e.g. double-handed home care support, and thus this question is useful for care management practice.

Do you feel there will be no end to your problems? (Original: Do you ever feel that there will be no end to the problem?)

The original question was slightly amended to the above as several carers in the Crossroads Wales study interpreted the original as meaning dependant death as being 'the end to the problem'. By changing the word 'problem' to 'problems' it was felt the question would be interpreted as relating to problems discussed in the associated 'Dementia Caregiving Problems Questionnaire' as being the most difficult to manage/stressful. The word 'ever' was also dropped from this and several of the questions that follow because it was felt that it could be perceived as relating to thoughts/feelings previously rather than currently experienced. The question was retained as it is likely to be indicative of high subjective burden, as well as carer depression, and thus was felt to be useful for care management practice, e.g. by way of psychological health screening for the carer.

Do you feel you can no longer cope with your situation? (Original: Do you ever feel you can no longer cope with the situation?)

The original question was slightly amended to the above, with the word 'ever' being dropped for the above reason and the words 'your situation' replacing 'the situation'. This change was made as it was felt to be more validating of the carer's situation and reflected greater locus of control. The question was retained as it is likely to be indicative of high subjective burden and is useful to care management practice as it highlights those carers who have poor coping skills. They may particularly benefit from caregiver training and support to improve coping and bring caregiving problems under greater control, e.g. medication management, thus reducing perceived helplessness.

Do you feel overwhelmed by your situation? (NEW)

This is a new question developed for the Crossroads Wales study and has relevance as 28% of carers rated this item as 'frequently/always'. It was felt that the item was important because of the knowledge that many carers feel overwhelmed by their situation. Feeling overwhelmed may be a sign that the carer is reaching emotional breaking point and is likely to be indicative of high subjective burden. It is an important concept to assess in care management practice and could highlight the need for urgent service interventions such as emergency respite care and individual counselling/telephone helpline support.

- Ref. CHSA, 1994 - 40% of carers cited behavioural problems and feeling overwhelmed as reasons for placing relatives in an institution.
- Ref. Coen, 1998 – The major precipitant of long-term institutionalisation is caregiver

overwhelm.

Do you feel trapped in the caring role? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers related feeling 'trapped' in their role. Indeed, one stated that the experience was worse than being 'a prisoner of war'. Feeling entrapped may be a sign that the carer is reaching emotional breaking point and is likely to be indicative of high subjective burden. It is an important concept to assess in care management practice and could highlight the need for service interventions such as at home-based and institutional respite care. It may also indicate the need to explore the carer's willingness to continue in the caregiving role.

- Ref. Aneshensel et al., 1993 – People often become caregivers by default and the role is often unwanted. Being captive in the caregiving role is a risk factor for institutionalisation.
- Ref. Hirschfield, 1983 – Lack of personal time and feeling tied down are risk factors for breakdown in caregiving situations.

Do you feel that you are alone in coping with your caring situation? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers felt alone in coping with their situation. An absence of support from family and friends resulted in less opportunities for breaks from caring and reduced access to emotional support. Feeling alone and unsupported may be indicative of high subjective burden and is important to assess in care management practice. It could highlight the need for access to emotional and social support from befriending services, carers support groups and out of hours telephone helpline support, for example.

- Ref. Gallo, 1990 – Social support has been found to moderate the effects of caregiver stress.
- Ref. Gilhooly, 1996 – The availability of and contact with friends and satisfaction from such help prevents institutionalisation.

Do you find it distressing that your dependant has changed so much from his or her former self? (NEW)

This is a new question that was developed for the Crossroads Wales study and has relevance as 81% of carers rated this item as 'frequently/always'. It was felt that the item was important because of the knowledge that many carers feel distressed by the changes in their relative. The level of distress may be greater if the dependant's personality has drastically changed, if there are behavioural problems present, or the dependant's condition has more rapidly deteriorated, e.g. in young onset dementia. Feeling distressed by the changes in the dependant may be indicative of high subjective burden. It is an important concept to assess in care management practice and could highlight the need for service interventions such as individual counselling /telephone helpline support.

- Ref. Philp et al., 1997 – Severity of dementia and problems relating to dependants' physical or behavioural functioning are important factors predictive of institutionalisation.
- Ref. Brodaty et al., 1993 - Severity of dementia and rate of deterioration are predictors for institutionalisation.

Do you have feelings of grief and loss associated with your caring role? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers disclosed feelings of grief and loss even though their relative was still living. The ongoing deterioration in dementia and the losses incurred over time, e.g. loss of communication, sexual partner, recognition, the person as they once were etc, were a source of distress for many carers. Feeling bereaved but still providing care for the 'changed' person may cause high levels of subjective burden and is thus an important concept to assess in care management practice. It could signal the need for bereavement counselling support.

- Ref. Barnes et al. (1981) - discussed the notion of 'anticipatory grief' to describe the losses that dementia caregivers experience over time as their relative's condition gradually deteriorates.
- Ref. Walker (1995) found that both the length of caregiving and patient symptoms were related to the severity of grief experienced by carers.

Do you find yourself becoming tearful or crying? (NEW)

This is a new question that was developed for the Crossroads Wales study and has relevance as 39% of carers rated this item as 'frequently/always'. It was felt that the item was important because of the knowledge that many carers feel distressed by their situation. Feeling distressed and becoming tearful may be a sign that the carer is reaching emotional breaking point and is likely to be indicative of high subjective burden. It is an important concept to assess in care management practice and could highlight the need for service interventions such as counselling support and/or day/respite care. It could also signal the need for assessment for clinical depression and access to appropriate treatment.

- Ref. Whitlach et al. (1999) - depression in the carer is predictive of breakdown in the caregiving situation.

Do you feel exhausted and demoralised in your caring role? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers disclosed that they felt exhausted and demoralised in their role. Feeling exhausted may diminish the carer's ability to cope with the demands of caregiving and demoralisation may signal the carer is reaching an emotional breaking point. Both are important to assess in care management practice and highlight the need for urgent relief through appropriate breaks from caring and possibly discussions around planned relinquishment of caregiving.

- Ref. Almberg et al. (1997) – Carers who lack a positive outlook on caregiving are more vulnerable to burnout.
- Ref. Gold et al. (1995) – Carers who are exhausted in their role are more at risk of breakdown in their caregiving situation.

Negative feelings

Are you depressed about your situation? (Original: Do you ever get depressed by the situation?)

The original question was slightly amended to the above. The word 'ever' was dropped as the original question could also be interpreted as referring to depression previously rather than currently experienced. 'Are you…' thus clarifies the question relates to here and now feelings. Assessing depression in the carer is important to care management practice and indicates a need for appropriate medical and psychosocial interventions.

Do you feel like giving up caring? (NEW)

This is a new question that was developed for the Crossroads Wales study and has relevance as 30% of carers rated this item as 'frequently/always'. It was felt that the item was an important addition as it resembles the carers' assessment questions recommended in the Carers Act 1995 regarding willingness and ability to continue in the caregiving role. It is a useful indicator for care managers that the carer is considering relinquishment of home caregiving and is a useful basis for entering into a discussion regarding future care intentions. It may also highlight the need for emergency respite care and/or planned admission to a permanent care setting.

- Ref. Spruytte et al. (2001) – Carers' preference for institutional care is predictive of institutionalisation.
- Ref. Philp et al. (1997) – Carers' willingness to continue caring is a predictor for institutionalisation.

Do you feel embarrassed by your dependant? (Original: Do you ever feel embarrassed by your dependant?)

The original question was slightly amended to the above. The word 'ever' was dropped as the original question could also be interpreted as referring to embarrassment previously rather than currently experienced. 'Do you feel…' thus clarifies the question relates to here and now feelings. Embarrassment may significantly effect the carer's social life, if they are unable to leave their dependant at home alone. Assessing embarrassment in the carer is thus important to care management practice and indicates a need for appropriate education and information, and respite services which allow the carer to continue/restart social activities outside the home without the dependant.

Do you feel frustrated with your dependant? ? (Original: Do you ever feel frustrated with your dependant?)

The original question was slightly amended to the above. The word 'ever' was dropped as the original question could also be interpreted as referring to frustration previously rather than currently experienced. 'Do you feel…' thus clarifies the question relates to here and now feelings. Assessing frustration in the carer is important to care management practice and indicates the need for appropriate interventions that relieve the carer of some of their direct caregiving responsibilities. It also signals the need to identify those caregiving problems which are the most frustrating, some of which could be taken over by home care workers, e.g. washing and dressing the dependant may be a significant time of conflict, thus having an impact on reducing subjective burden.

Do you get cross and angry with your dependant? (Original: Do you ever get cross and angry with your dependant?)

The original question was slightly amended to the above. The word 'ever' was dropped as the original question could also be interpreted as referring to feeling cross and angry previously rather than currently. 'Do you get…' thus clarifies the question relates to here and now feelings. Anger is an important indicator that the carer is not coping well with the demands of caregiving and may signal that the caregiving situation is near to breaking point. Assessing anger in the carer is thus important to care management practice and indicates a need for appropriate stress management interventions, respite services and discussion around relinquishment of home caregiving. It could also highlight caregiving situations which are at risk of becoming abusive.

Are you resentful about the change in the quality of your own life/missed life opportunities? (NEW)

This is a new question that was developed for the Crossroads Wales study and has relevance as 33% of carers rated this item as 'frequently/always'. It was felt that the item was important because of the knowledge that many carers feel resentful as a result of their situation. Feeling resentful may be a sign that the carer is reaching emotional breaking point and is likely to be indicative of high subjective burden. It is an important concept to assess in care management practice and could highlight the need for service interventions such as counselling support and/or day/respite care. It could also signal the need for discussion with the carer about relinquishment of home caregiving.

- Ref. Hirschfield (1983) – Feelings of resentment, hopelessness and guilt and predictive of institutionalisation.

Are you emotionally distant from your dependant? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers disclosed that they felt emotionally distant from their dependant. A deterioration in the closeness of the relationship had occurred over time as the dementing illness progressed and was a cause of distress for carers. Caregiving problems such as failure of recognition and loss of mutual communication seemed to influence this perception. Feeling emotionally distant from the dependant may indicate that the carer is suffering high levels of subjective burden and is thus an important concept to assess in care management practice. It could also highlight the need to explore the relinquishment of home caregiving.

- Ref. Wuest et al. (1994) – Family carers struggle on a daily basis with their commitment to the person they knew and their increasing detachment from the stranger that person has become.
- Ref. Hirschfield (1983) - Low mutuality in the caregiving relationship is a risk factor for institutionalisation.

Do you view caring for your dependant as being like caring for a child? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers equated caring for their older parent or spouse to caring for a child or infant. Many also talked of a perceived 'role reversal' in their caregiving situation, i.e. the carer having to take on more of a parental role in caring for their mentally incompetent parent or spouse. This change in the quality of the relationship with the dependant may indicate that the carer is suffering high levels of subjective burden and is thus an important concept to assess in care management practice. It could also highlight the need for service interventions such as counselling interventions around loss and relationship change.

- Ref. Albert and Brody (1996) – Elders' cognitive impairment and perceived burden in caregiving were the strongest predictors of the carer likening elder care to child care.

Do you have feelings of guilt associated with your caring role? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers reported feeling guilty about things said or done, or not said or done. Whilst for some carers this helped drive them to continue to provide care, for others it seemed to be indicative of high levels of subjective burden and is thus an important assessment to make in care management practice. It may also highlight the need for carers to have their role validated by professionals, perhaps via carers support groups or individual counselling interventions, so that their self-expectations and consequently their self-blame are not so high.

- Ref. Woods (1997) – A substantial proportion of carers experience guilt in relation to their caregiving role at some time, particularly when considering permanent care, or even respite care.
- Ref. Hirschfield (1983) - Feelings of resentment, helplessness and guilt are important predictors for institutionalisation.

Do you feel helpless and as if things are outside of your control in your situation? (NEW)

This question is new and arises from observations made in the Crossroads Wales study that several carers disclosed that they felt helpless and as if things were outside of their control. Feeling helpless may diminish coping ability and is important to assess in care management practice as it may indicate high levels of subjective burden. It could highlight the perceived impact of coping strategies used by the carer and indicate the need for caregiver training, especially around managing challenging behaviour and stress.

- Ref. Nolan et al. (1996) - having a sense of competence and mastery, and perceiving efforts as meaningful are important mediating factors against stress.

Positive feelings (ALL NEW)

This set of ten questions are all new and as such are being tested for the first time in this study. Their inclusion is based on research by Nolan et al. (1996), who found that caregiving satisfactions are prevalent, derive from a number of sources and often co-exist alongside a range of difficulties; Cohen et al. (1994), who proposed that caregiving satisfactions mitigate against the negative effects of caregiving burden and stress, and Orbell and Gillies (1993), who found that a lack of caregiving satisfactions was the single most powerful determinant of carer preference not to continue providing care. Equally, Nolan et al. (1996, p. 84) argued that *'the absence of caregiving satisfactions should be taken as an indicator of a fragile and potentially abusive relationship'.* Thus the assessment of caregiving satisfactions is central to this study and should be included in any investigation of caregiving burden and the risk factors for breakdown in caregiving situations/institutionalisation.

Summers et al. (1989), cited in Nolan et al. (1996, p. 103), stated that, *'The identification of positive aspects of a situation – the silver lining effect - may be one of the most powerful cognitive coping strategies of all'.* This is another reason for the inclusion of this category of questions - in most caregiving situations, no matter how difficult, there will be some aspects of satisfaction, and positive feelings need to be explored as part of any carers' assessment. In addition, including this section at the end of a questionnaire examining largely negative impacts and feelings introduces some balance and is helpful in care management practice in helping the carer to focus on the positive aspects of their experience, perhaps for the first time.

The justification for each individual item follows. Sources are Nolan et al. (1996), Nolan et al. (1998), Motenko et al. (1989), Cohen et al. (1994) and Orbell and Gillies (1993).

These items are phrased in the positive, with reversed polarity for scoring, in order that caregiving satisfactions are adequately addressed, rather than a lack of satisfactions, and so that the carer completing the questionnaire perceives some degree of validation of their positive feelings.

Do you have a sense of achievement or fulfilment as a result of caring?

This question was included in recognition that many carers feel a strong sense of achievement or fulfilment from providing positive, person-centred care for their dependant, often against all the odds. Carers often know that the care they are providing is better than that which could be provided in an institution, and this is a source of satisfaction for them. *The reverse polarity question emphasises a greater risk of caregiving burden to those without a sense of achievement or fulfilment from their caregiving role.*

Do you have a sense of purpose and direction in your caring role?

This question was included in recognition that many carers have a strong sense of purpose and direction in their caregiving role. Many carers attach great meaning and value to their role, e.g. many state that a prime aim of their care is to maintain their relative at home and keep them out of an institution; others restate their marriage vows. Many carers take great pride in the fact that they are providing care for their dependant, and this is a source of satisfaction for them. *The reverse polarity question emphasises a greater risk of caregiving burden to those who do not have a sense of purpose or meaning attached to their caregiving role.*

Do you derive personal satisfaction and reward from your caring role?

This question was included in recognition that many carers feel a high level of satisfaction from being in their role and that caregiving is, in many ways, rewarding. Seeing the person happy and contented, well turned out, clean and dry, etc is a great source of satisfaction for carers, particularly if the dependant values their caregiving input. *The reverse polarity question emphasises a greater risk of caregiving burden to those who do not find caregiving satisfying or rewarding.*

Do you have feelings of positive self-worth/self-esteem arising from caring?

This question was included in recognition that many carers have feelings of self-worth and self-esteem arising from caring. As well as coming from positive feedback from their dependant, e.g. through a highly valued 'thank you', this also comes from others outside of the caregiving situation valuing and validating the carer's role and supporting their commitment to caregiving. Perceiving that you are in a valued role is another source of satisfaction for carers. *The reverse polarity question emphasises a greater risk of caregiving burden to those who do not feel their caregiving is a valuable or valued role.*

Do you feel that being a carer has provided an opportunity for personal growth and development?

This question was included in recognition that many carers feel that being in the role of caregiver has provided an opportunity for personal growth and development of their interpersonal, practical and other skills. Many carers state that they have learned much from their experience and are, in many ways, a changed person themselves. After caregiving is over, most would not go back and trade their caregiving role and many feel that the experience has improved them in some way. Perceiving a positive change in oneself can be deeply rewarding. *The reverse polarity question emphasises a greater risk of caregiving burden to those who feel they have not grown and developed as a result of their caregiving experiences.*
Do you feel that caring is a positive way of expressing your love and affection for the person you care for?
This question was included in recognition that many carers feel that caring is a positive way of expressing love and affection. Many carers state they feel they are paying back previous kindnesses, that their relative would do the same if the shoe was on the other foot and that providing personal care is one way of bringing them closer to their dependant. Providing care may also be the best way of valuing and respecting the changed person that their relative now is, and this can be another source of satisfaction. *The reverse polarity question emphasises a greater risk of caregiving burden to those who care out of a sense of duty or obligation rather than love and affection.*
Do you feel that you adopt a positive, problem-solving approach to caring?
This question was included in recognition that many carers feel competent in their role and have achieved a certain degree of mastery over their caregiving situation. Feeling as if one is on top of things and that caregiving problems are manageable rather than overwhelming must be rewarding and a source of satisfaction for carers. This question also emphasises the new skills that carers may have developed in their role and the expert practitioner that many have become in their own right. *The reverse polarity question emphasises a greater risk of caregiving burden to those who do are not good at problem-solving and who feel overwhelmed by the problems which they face.*
Do you feel that you manage your stress well and overcome it?
This question was included in recognition that many carers manage their stress well and have developed strategies to keep it under wraps. This question emphasises the personal qualities which carers may have developed to assist them in their role, such as increased patience and tolerance, but also their level of understanding and awareness of the symptoms/caregiving problems they are dealing with and, ultimately, their knowledge of the dementing illness from which their dependant is suffering. Feeling that you are in control of your situation and having a sense of mastery are additional sources of satisfaction. *The reverse polarity question emphasises a greater risk of caregiving burden to those who do not manage their stress well and are overcome by it.*
Do you feel that the help you receive from services, family and friends has enabled you to carry on in the caring role?
This question was included in recognition that many carers feel that the help that they receive from family and friends and from services has, in many ways, helped them continue in their role. Feeling supported, emotionally or practically, and knowing you are not alone in your situation and that you have additional resources to call upon are useful back ups to the carer. Having access to such supports must be reassuring, especially those which allow the carer to offload their distress and negative feelings. *The reverse polarity question emphasises a greater risk of caregiving burden to those without such supports.*
Are you feeling hopeful about your future?

This question was included in recognition that many carers feel hopeful about their future. They may feel that things are on an even keel and hope that their current situation, and their dependant's level of cognitive and physical functioning, will continue as is for a time, or that things may get easier with additional support or with medication, etc. For those currently coping with a difficult caregiving situation, the hope may be that things will become easier as their dependant's condition further deteriorates, or following their dependant's placement in permanent care or even their death. Hope may be protective against caregiving burden, to some extent. *The reverse polarity question emphasises a greater risk of caregiving burden to those without hope and who may be despairing for their future.*
Stress Scale The Stress Scale is similarly new and its original purpose was to validate 'Dementia Caregiving Burden Questionnaire (DCBQ)', as will be discussed later. Perhaps it's most useful purpose, however, is in entering into a conversation with the carer about their level of stress and how they are coping with their situation, which could lead into a discussion on how both could be improved and which service interventions and other changes could facilitate this.
Reflecting on your overall care-giving situation, all in all would you say you are: *0 - Coping well/with no stress* *1 - Coping fairly well/with a small amount of stress* *2 - Just about coping/with a moderate level of stress* *3 - Having difficulty coping/with a great deal of stress* *4 - Finding it almost impossible to cope/with an extremely high level of stress*

Table 4.3: Justifications for DCBQ items

As can be seen from the above DCPQ table (table 4.2), Greene et al.'s (1982) 34-item 'Behavioural and Mood Disturbance Scale' has also been improved and added to and renamed the 'Dementia Caregiving Problems Questionnaire'. One of the main changes is the categorisation of the now 50 items into the 5 domains of 'Communication', 'Confusion', 'Behaviour', 'Mood Disturbance' and 'Self-care/Physical Problems'. This last category is an important addition, as it provides valuable information about physical dependency and workload for the carer, as well as highlighting problems which may be exceptionally difficult to manage, such as incontinence, falling and pain experience. The changed and additional questions are made on the basis of the researcher's previous research with the Crossroads Wales study referred to above (6 items new to Green et al.'s [1982] 'Behaviour and Mood Disturbance Scale') and his assessment manual, 'Simon's Nursing Assessment for the Care of Older People with Dementia' (O'Donovan, 1994) (an additional 10 new items to the Crossroads revised tool).

The follow-on questions attached to this new questionnaire are perhaps even more important, identifying as they do the most stressful/difficult to manage caregiving problems that the carer has to cope with, as well as the coping strategies and management techniques they use in dealing with these caregiving problems. Again, such information helps the community care practitioner to enter into a meaningful dialogue with the carer regarding caregiving problem management, which could include care education, a change in the package of care to relieve the carer of their most stressful caregiving problems or medication to bring psychotic symptoms or aggression under control.

The following table provides details of the rationale for the changed and new DCPQ questions.

Behavioural and Mood Disturbance Profile	Dementia Caregiving Problems Questionnaire
	Communication Problems
Does not start and maintain a sensible conversation	*Is your dependant able to start and maintain a sensible conversation?*
	There was only a slight change to the language used in this question.
Does not understand what is said to him/her	*Is your dependant able to understand what is said to him/her?*
	There was only a slight change to the language used in this question also.
Does not respond sensibly when spoken to	*Is your dependant able to respond sensibly when spoken to?*
	There was only a slight change to the language used in this question.
Goes on and on about certain things	*Does your dependant repeat things over and over again?*
	The phrasing of this question was improved in order to remove the somewhat negative connotation of 'goes on and on'.
Talks all the time	*Does your dependant talk all the time?*
	This question was slightly changed to improve clarity.
Talks nonsense / Wanders off the subject	*Does your dependant talk nonsense which you can't understand?*
	These two questions were merged into one as it was felt there was a large overlap.
	Does your dependant have periods when he/she doesn't speak much at all?
	This was a new question, included to highlight the distress that is often experienced when there is no verbal communication with the dependant.
Does not watch or follow TV/Does not read newspapers, magazines, etc	*Is your dependant able to read newspapers, magazines, etc., or watch and follow TV?*
	This question was changed to improve clarity.
Does not take part in family conversations	*Is your dependant able to take part in family conversations?*
	As above.
Talks aloud to him/herself	*Does your dependant talk aloud to him/herself?*
	As above.
	Confusion Problems
Gets mixed up about where he/she is	*Does your dependant get mixed up about where he/she is?*
	As above, just a slight change in language for the sake of clarity.
Gets mixed up about day, year etc	*Does your dependant get mixed up about the day, date, year?*
	As above.
Fails to recognise familiar people	*Is your dependant able to recognise familiar people, e.g. family and friends?*
	As above
	Is your dependant able to recognise you and know who you are?
	This was a new question, included in recognition that

	misidentification is very distressing for carers and can result in failed communication, resistiveness etc.
	Does your dependant get mixed up about the time of day/night?
	This was a new question, included because time disorientation can be stressful for carers, particularly if the person is mistaking day for night.
	Is your dependant able to hold his/her attention for more than a few minutes?
	This question is also new, and included because lack of concentration and inattention can make providing care very difficult, e.g. in terms of assisting with ADL tasks.
Seems lost in a world of his/her own	*Does your dependant seem lost in a world of his/her own?*
	There was just a slight readjustment to this question to improve clarity.
Wanders outside the house at night	*Does your dependant try to get up and dressed/go outdoors during the night?*
	This question was changed somewhat so that it could apply to those caring for dependants who may try to get up during the night due to reversed sleep pattern due to day/night disorientation.
Wanders outside the house and gets lost / Gets lost in the house	*Does your dependant get lost and can't find his/her way home when outside of the house/do you have to keep them indoors?*
	These two questions were combined into one as they were felt to overlap. It was designed to highlight place disorientation and the risk to dependants/stress to carers when orientation and road safety skills are impaired.
	Does your dependant see or hear things which aren't really there?
	This question was new and added in the knowledge that hallucinations as psychotic symptoms of dementing illnesses can be very stressful for carers.
	<u>Behaviour Problems</u>
Has to be prevented from wandering outside the house	*Does your dependant wander around indoors or outdoors?*
	This question was changed to focus on the stress of the dependant wandering indoors or outdoors as a behavioural problem to carers.
Hoards useless things	*Does your dependant tend to collect things and hoard them?*
	This question was changed slightly to include 'collecting' and remove 'useless', as to the confused person these actions may be purposeful.
Becomes angry and threatening	*Does your dependant become angry and resistive to care?*
	This question was changed to remove the word 'threatening' as it implied intent. Resistiveness is also a major caregiving problem and was not addressed elsewhere.
Endangers him/herself	*Does your dependant endanger him/herself by engaging in risky behaviours?*
	This question was changed somewhat to improve clarity and link it specifically to the behavioural domain, otherwise it could be interpreted as referring to danger from self-neglect.
Becomes irritable and easily upset	*Does your dependant become irritable and easily upset?*
	There was again just a slight adjustment to this question for clarity.
Accuses people of things	*Does your dependant falsely accuse people/you of things?*
	This question was slightly changed to make it clear that it

	referred to 'false' accusations and that these could be directed at the carer.
	Does your dependant shout/swear/scream at people/you for no obvious reason?
	This was a new question, included in the knowledge that verbal aggression can occur frequently and be a very stressful caregiving problem.
	Does your dependant hit out at you/other people for no obvious reason?
	Again, this was included as it was felt to be an important omission from the previous questionnaire.
	Does your dependant display inappropriate sexual activity/ demands?
	This new question was included in this knowledge that whilst this problem may not commonly be experienced by adult children carers, for spouse carers, perhaps especially those of younger people with dementia, it can be a very distressing problem.
	Does your dependant wake you/others during the night?
	This was also a new question, included because night-time disturbance is frequently experienced by carers and the above questions relating to wandering were not felt to address the carer being woken by noise-making.
	Mood Disturbance Problems
Does not show an interest in news about friends and relations/Sits around doing nothing	*Does your dependant show an interest in doing things?*
	These two questions were felt to be less valuable and merged into the new question above. Disinterest is, again, a stressful problem for the carer trying to stimulate and motivate their dependant.
Appears restless and agitated	*Does your dependant appear to be restless and agitated?*
	There was just a slight change in this question to improve clarity.
Paces up and down wringing his/her hands	*Does your dependant pace up and down in a worried or troubled way?*
	There was just a simple clarification to this question, that pacing may not involve wringing of the hands.
Cries for no obvious reason	*Does your dependant cry/become tearful for no obvious reason?*
	Similarly the change to this question clarified that the person may be tearful but not cry or sob.
Appears unhappy and depressed	*Does your dependant appear to be unhappy and depressed?*
	There was just a simple language change here for improved clarity.
Gets up unusually early in the morning	*Does your dependant have difficulty settling to sleep or wake unusually early in the morning?*
	This question was changed somewhat to highlight difficulty settling to sleep is equally experienced in clinical depression to early morning waking.
Mood changes for no apparent reason	*Does your dependant's mood change suddenly for no obvious reason?*
	There was just a slight change in this question to improve clarity.
Does not keep him/herself busy doing useful things	*Does your dependant isolate him/herself and avoid social contact?*
	This question was changed to link it more to depressive symptomatology and to make it relevant to dependants who may be too impaired to do 'useful things'.
	Does your dependant never leave your side/shadow you?

	This is a new question, included in the knowledge that clinging or shadowing behaviour occurs frequently and can be very stressful for carers.
Looks frightened and anxious	*Does your dependant look frightened and anxious?*
	There was just a slight change in language to this question to improve clarity.
	Self-care/Physical Problems These are a new set of questions which are more physically oriented. They are included to demonstrate the level of physical strain suffered by carers, the physical frailty associated problems they face, and specific caregiving problems which may be beyond their capability to manage without adequate service support and appropriate aids and equipment, e.g. lifting without a hoist, continence care without pads and mattress cover, etc. They are also included in recognition that many carers wish to maintain home caregiving up to the death of their dependant, and that this may necessitate terminal care which meets needs for pain relief, immobility and pressure area care, swallowing problems and choking, etc.
	Does your dependant have problems in standing/walking - need assistance?
	Does your dependant have difficulty washing/bathing - need assistance?
	Does your dependant have difficulty dressing/undressing - need assistance?
	Is your dependant incontinent of urine during the night (may wear pads)?
	Is your dependant incontinent of urine during the day (may wear pads)?
	Is your dependant incontinent of faeces (day or night)?
	Does your dependant have problems feeding him/herself/ swallowing - need assistance/special diet?
	Is your dependant partly/completely immobile and need lifting?
	Is your dependant prone to having falls/fits/choking attacks?
	Does your dependant suffer with pain/need analgesic medication?
	Additional follow-on Open Questions: *What additional problems do you experience in caring for your dependant that are not covered above?* *Which of these problems are the most stressful/difficult to manage, and why?* *How well are you coping with and managing these problems?* *What coping/managing strategies do you use, and how successful are they?*

Table 4.4: Justifications for DCPQ items

As can be seen from the above information, despite being based on previous research by Greene et al. (1982), the 'Dementia Caregiving Burden Questionnaire (DCBQ)' and the 'Dementia Caregiving Problems Questionnaire (DCPQ)' have been changed and improved substantially, to the extent that they can be considered as being new carers' assessment tools. Both tools were tested for reliability in this study, as will be demonstrated later in this thesis, and form the basis of the 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)', which is proposed in the concluding chapter of this thesis.

4.9 Revised research methods

At the end of the first round of interviews it became apparent that there were problems with the sampling method and outcome. Of 20 subjects originally identified for the study, i.e. those who returned the tear off slip on the 'Open Letter to Carers' self-selecting for participation in the study, 3 dropped out before being interviewed in the first round. In addition, of the 17 cases remaining, 4 had to be excluded from the second round of interviews due to dependant or carer death – 3 dependants and 1 carer died during the year interval between first and follow-up interview. In addition, of the remaining sample of 13 subjects, all but two were still providing care and their caregiving situation was reported, by CPNs or the Dementia Careline Co-ordinator, to have remained fairly static. For these reasons, a new sampling method was explored, namely via research questionnaires being published on the internet in order to access an additional study cohort.

A SWOT analysis was undertaken by the researcher, which highlighted the following strengths, weaknesses, opportunities and threats of this new approach:

Strengths:

- Internet-based questionnaires would potentially access a much larger study sample of national /international dementia carers, providing valuable additional study data.
- The newly formed carers' assessment questionnaires would be tested for reliability on a larger sample, thus making them more robust for later inclusion in a 'Dementia Caregiving Breakdown Risk Assessment Tool'.
- Data would be gathered on differences between dementia caregiving in various regions, as well as countries. This would be of secondary interest to the study, but made possible because of this approach.
- Larger numbers would provide increased opportunities to analyse differences between sub-cohorts of carers, e.g. adult children compared with spouse carers, younger dementia carers compared with older sufferer carers, carers living with dependants compared with those caring from a distance.

Weaknesses:

- There may be a danger of attracting bogus carers, who might give misleading responses which would skew study results. This would be hard to police against, but could be overcome by the inclusion of several questions that only genuine carers would be able to answer, e.g. names of medications prescribed for carer and/or dependant, and by requesting carers' e-mail addresses (held confidentially).

- Internet-based questionnaires would be filled in anonymously, so more negative feelings and experiences may be disclosed (which would be an additional strength of this revised methodology). However, this could attract carers seeking emotional support which would not be provided, thus access links to other on-line support sites and telephone helpline numbers would need to be provided.
- The additional study sample obtained may not be fully representative, i.e. only carers with access to a PC could participate. There would be the potential for obtaining a younger sample of middle to upper class carers who may be more computer literate than older carers.

Opportunities:

- The opportunity for going on-line with the study questionnaires was already present with the 'Signpost to Older People and Mental Health Matters' journal web-site being available for additional web-pages to be developed and uploaded, as the researcher hosted and acted as the web-master for this site. Additional pages could also be added free of charge.
- The hit rate for this web-site was high, with over 10,000 visits per annum. The web-site could be advertised with all major search engines and linked with many other mental health/elderly care web-sites. The opportunity for accessing a large sample of dementia carers was therefore great.
- As far as the researcher knew at the time, there were no other similar on-line research questionnaires on dementia caregiving present on the internet. The development of on-line web-based pages for the study would therefore be innovative.

Threats:

- Depending on the volume of responses, time management could become an issue, with the internet questionnaires generating a far larger volume of data sets to analyse. The workload required to create and launch the new web-pages would also be great.
- The potential for additional telephone costs being incurred by carers needed to be considered. As each questionnaire would take about 45 minutes to complete, a large local call rate charge could be incurred, especially if this was done in peak times. A strong suggestion at the start of each questionnaire would therefore be made for carers to download the questionnaire and then complete it off-line, re-starting their web connection after completion so that responses could be sent to the researcher by email.

The SWOT analysis recommended that the threats and weaknesses identified above were overridden by the strengths and opportunities of the proposal. Even if no responses were forthcoming, nothing would have been lost by taking the chance on testing the study tools on-line - the existing interview data would remain unflawed by the change in method. However, amassing another potentially large data set for the study would undoubtedly make findings more conclusive and reliable.

In considering the request to extend the research methods to encompass an internet sampling method, reliability and validity issues were re-explored. As the research questionnaires to be uploaded for 'current' and 'past caregivers' were identical to those delivered via face-to-face interview, reliability and validity considerations were felt to have been previously addressed. Attention was also given to the ethical principles of internet-based research. It was considered that the internet aspect of the study met the ethical principles outlined above through giving full and open information (see Appendix 3 'Open Letter to Dementia Caregivers World-wide'), providing a method which ensured complete anonymity, having a system which promoted self-selection to its highest level and advertising links/providing contacts to additional national and international on-line supports and land-based associations and helplines.

Therefore, the proposal to extend the study to include an internet sampling method not only offered a unique opportunity to build on existing study methods, but also represented an exciting, innovative approach in the field of dementia care research. It was therefore supported by the supervision team with optimism and excitement.

4.10 The literature supporting internet-based research

The use of the internet as a data collection method is very new. In reviewing the available literature on studies which have used the internet for this purpose, papers were found on the internet as a method for data collection on the needs and coping mechanisms of cancer survivors (Fawcett and Buhle, 1995); the experiences of children with serious health problems (Fleiaas, 1998), and the quality of life of patients with ulcerative colitis (Soetikno et al., 1997). No studies were found that used the internet as a research tool with older adults as subjects. However, one study by Czaja and Rubert (2002) did evaluate the use of the internet as part of a telecommunications package available to support dementia caregivers in their role (76 subjects). This study found that the most highly valued resources provided to carers were on-line discussion groups/chat rooms and an on-line resource guide. The authors concluded that new communication technologies such as the internet can help carers meet the challenges of caregiving and improve their quality of life.

So why is the internet so little used as a research tool amongst this group and among older people more generally? One obvious answer, addressed in the SWOT analysis above, is that older people may have less access to the internet and be less knowledgeable about it's use. This was also the conclusion of Morrell et al. (2000) who, in a survey of 550 adults aged 40 years and over, found that the two main reasons for older people not using the internet were lack of access to a computer and lack of knowledge about using the internet. People over the age of 75 were found to have the least interest in using the internet, compared to middle aged (40-59) and young-old people (60-74) who were found to have a similarly high level of interest.

The issues of access and understanding will need to be addressed before internet-based research can gain truly representative sampling in older people as research subjects. However, this study is felt to provide an important demonstration that internet-based research is possible amongst an older study cohort, perhaps especially with those who are housebound. In this study, whilst 38 of the 90 internet respondents were below the age of 50 and the majority of subjects were in their 50s (n=28), 22 were aged over 60 and 7 of these were aged over 70 (1 respondent was in his 80s).

As well as providing new research opportunities, such new technology has also opened up the possibility of innovative on-line support systems becoming available, which are particularly valuable for those isolated from social support or services as a result of their caregiving role. Many voluntary agencies have already established excellent on-line resources for carers, including service directories and resource lists, information leaflets and newsletters and chat rooms and other 'live' supports.

Further research will need to be undertaken to demonstrate the value of such resources in reducing caregiving burden and improving carer well-being. There is also obviously great scope for actually using such support websites as sampling opportunities for this and other research, though the ethics of accessing web visitors seeking information and on-line support as research subjects may require further consideration.

4.11 Questionnaire design for internet sample

It was therefore decided that the following two study questionnaires be put on-line (see Appendix 6):

- 'Current Dementia Caregivers Questionnaire' – for carers still providing care for people with dementia in the community (the only inclusion criteria was that the dependant had received a diagnosis of dementia).

- 'Past Dementia Caregivers Questionnaire' – for carers who had relinquished caregiving at home and whose dependants had been admitted to permanent care (the only inclusion criteria was that entry of the dependant into permanent care had taken place within the last year).

It should be noted that both of the above questionnaires were identical to the study questionnaires used for face-to-face interviews for the first round and one year follow-up with carers who had relinquished home caregiving (the content of questionnaires is outlined above).

To introduce carers to the study and request their participation through completion of the appropriate study questionnaire, an 'Open Letter to Dementia Caregivers World-wide' was launched on-line, linked to the two study questionnaires (see Appendix 3).

The web pages were added to the existing web-site for the Signpost to Older People and Mental Health Matters Journal, managed by the researcher, and publicised in national newsletters for dementia carers, e.g. the Alzheimer's Society Newsletter, Journal of Dementia Care, Signpost Journal, and Caring Matters, as well as on related on-line web links pages, e.g. Alzwell, Dementia Voice, Alzheimer's Society, Eldercare Online, Dementia Services Development Centre Stirling, etc.

The web pages were launched on 1st April 2000 and remained open for internet carer responses until 30th March 2002. During this two year period, 74 Current Caregiver Questionnaires and 16 Past Caregiver Questionnaires were received via email, making a total of 90 web-based responses. This was a far larger additional data set than had originally been expected by the researcher. The response may have been even greater if the research questionnaires had been attached to/published on a larger, better promoted and more easily accessible web-site such as that provided by the national Alzheimer's Society rather than one which has limited resources for advertising, as was the case here.

It should be noted at this stage that the above web pages were developed and launched using Microsoft Frontpage 98. This programme allows for tick boxes and text fields to be created within tables and for subject responses to be emailed to the researcher by the mouse click of a 'Submit' button. Each tick box and text field is coded by the researcher so that emailed responses can be analysed against the original questionnaire, which turned out to be a quite time-consuming method, but one which could not be performed automatically.

4.12 Methods for qualitative and quantitative data analysis

Due to the above changes in study methodology, the approach taken with data analysis also had to change. The main amendments made were as follows:

- The 17 face-to-face interview Current Caregiver Questionnaires were analysed together with the additional 74 internet Current Caregiver Questionnaires received as one data set of 91 subjects.
- The two face-to-face interview Past Caregiver Questionnaires were analysed together with the additional 16 internet Past Caregiver Questionnaires received as one data set of 18 subjects.

Past Caregiver Questionnaires for both face-to-face interviews and internet subjects were subject to a more detailed analysis of the data relating to factors implicated in the breakdown of caregiving situations/the relinquishment of home caregiving. Some additional data on the process and outcome of relinquishment and the characteristics of this study sample is also presented. However, some data from this sample is not presented, e.g. results from the 'Dementia Caregiving Problems Questionnaire' and 'Dementia Caregiving Burden Questionnaire' for this group. The reason for this incomplete presentation of data is that the factors implicated in the decision to relinquish home caregiving, together with an exploration of the phenomenology of dementia caregiving burden, formed the crux of the whole study. For those past carers who contributed their experiences of breakdown/relinquishment, it is likely that this focus would be seen as appropriate and a respectful representation of the most difficult care transition they were faced with. However, it is recognised that there is additional data still available from this sample for further exploration and presentation, and it is planned this will be subject to post-doctoral publication.

Regarding qualitative data analysis, as interviews were structured, with each interview being recorded and transcribed in its entirety and free text being obtained in web-based responses, a method of thematic content analysis was used, based on Burnard's (1991) method. This method was developed from Glaser and Strauss' (1967) 'Grounded Theory Approach' and various works on content analysis by Babbie (1979), Berg (1989), and Fox (1982). The aim of the approach is, *'To produce a detailed and systematic recording of the themes and issues addressed in the interviews and to link the themes and interviews together under a reasonably exhaustive category list'* (Burnard, 1991, p. 462).

In this study, Burnard's (1991) method was slightly adjusted so that it could be applied with both word processed transcripts of interviews and digital html text data contributed by email. Consideration was also given to Moseley et al.'s (1997) cautions regarding the use of computer technology to aid qualitative data analysis, i.e. that the results of lexical searches can only be as good as the commands entered and that care needs to be taken to ensure the true meanings of words and phrases are not lost because of incorrect coding. Thus, in order to ensure that the richness and in depth understanding and meaning of the original context were maintained, the stages of analysis undertaken for qualitative data were as follows:

Stage 1. Interview transcripts and html text data were closely read and preliminary notes were made regarding ideas, general themes and theories which seemed important.

Stage 2. Responses for each open-ended question for qualitative analysis from each data set were transcribed/copied from original questionnaire submissions into new text files (one for each question), which was resaved and labelled. (Original transcripts and html responses were retained uncorrupted separately.)

Stage 3. Responses for each analysis were screened and seemingly irrelevant text was excluded from qualitative data sets.

Stage 4. A visual search for important keywords/text strings was undertaken by the researcher and these were highlighted using the Word XP 'text highlight' tool.

Stage 5. A lexical search of the highlighted keywords/text strings was undertaken using the Word XP 'text find' tool and counts were made. (An example of lexical searching would be to 'text find' *'tir'* which would identify all possible derivations, such as 'tire', 'tired', 'tiredness', 'tiring'.)

Stage 6. Context checks were undertaken by the researcher to ensure keywords were listed and counted appropriately. Care was taken to avoid recording incorrect polarity or meaning, for example *'I am less patient'* against *'He is my patient'*. Moseley et al. (1997) call this lexical followed by semantic analysis.

Stage 7. Keywords/text strings were listed with frequency counts (counted only once for each subject even if used several times within a sentence/phrase). Moseley et al. (1997) call this number of responses versus number of respondents.

Stage 8: Keywords and text strings were collected under sub-headings devised by the researcher when grouping and categorising data.

Stage 9. Sub-headings were grouped under higher order category headings and collapsed into broader categories if necessary.

Stage 10. Final visual checks were made to ensure categories covered all the seemingly important themes in responses by backtracking and reading through original data again.

Stage 11. Original quotations were used to illustrate thematic results.

This method was tested by a member of the research supervision team independently using the same staged approach to analyse several qualitative data sets in order to provide an objective view on the quality and exhaustiveness of the method.

As can be seen above, most of the qualitative data in this study was subject to quantitative analysis through counting the frequency and sequencing of particular words, phrases and concepts in order to establish whether a particular theme or pattern happens a number of times or if it happens in a particular way. This use of quantitative methods in qualitative data analysis is supported by Miles and Huberman (1984, p.49), who advocate the use of numeracy in content analysis, arguing that there is *'a long and well-developed tradition of dealing quantitively with qualitative data'.* Miles and Huberman (1984, p. 41) argue that such linkage between quantative and qualitative data is *'a good idea'*, and propose that qualitative data can *'help by validating, interpreting, clarifying, and illustrating quantitative findings, as well as through strengthening and revising theory'.* Enumeration is therefore accepted as an important part of content analysis, and Miles and Huberman (1984, p. 310) encourage researchers to entertain mixed methods studies, as *'quantitative and qualitative inquiry can support and inform each other'.* This is felt to have been the case for this mixed methods study, where quantification of the qualitative data is viewed as strengthening the process of summarisation and meaningful presentation, rather than as a departure from the qualitative tradition.

With regard to pure quantitative data analysis, all statistical examinations of data presented in this thesis took place using SPSS 11.0 and graphs, charts and other data presented are copied directly from this programme.

All face-to-face interviews questionnaire transcripts (tick box items) and html questionnaire responses (not for qualitative questions) were converted into numerical code for entry into SPSS by the researcher and checked by the research supervisor to ensure coding was accurate and the programme generally was glitch free. A Savfile was created to enable quantitative data analysis.

The main SPSS 11.0 analyses undertaken for quantitative data were:

- Bivariate Correlations procedure to compute Pearson's correlation coefficient and Spearman's rho, with their significance levels. Such correlations measure how variables or rank orders are related. Pearson's correlation coefficient is a measure of linear association. Spearman's rho correlation coefficient is useful to analyse non-linear relationships. (These analyses were undertaken to identify key relationships between data and especially to identify risk factors for caregiving burden and expected relinquishment of home caregiving.)

- Reliability analysis to study the properties of the new carers' assessment scales and the items that make them up. Cronbach's Alpha is a model of internal consistency, based on the average inter-item correlation and Guttman's Split-half splits the scale into two parts and examines the correlation between the parts. (These analyses were undertaken to test reliability of the newly formed carers' assessment tools, namely the 'Dementia Caregiving Problems Questionnaire' and the 'Dementia Caregiving Burden Questionnaire'.)

Chapter 5

RESEARCH FINDINGS

"This IS my life. Mom IS my life. Alzheimer's IS my life.
It's how I think and breathe." (Internet carer 62)

CHAPTER 5: RESEARCH FINDINGS

The intention of this chapter is to present the findings from qualitative and quantitative data analysis, for both current and past caregivers. A brief commentary is provided to highlight key research findings and present initial thoughts on clinical practice implications. A more complete discussion of the main findings in relation to previous research follows in Chapter 6.

CURRENT CAREGIVER SAMPLE

The total current caregiver sample for this study was 91, with 74 submitting internet questionnaires and 17 completing structured questionnaires via face-to-face interviews.

5.1 Country of origin of subjects

Data on the country of origin of subjects are as follows:

Country	Number	Percentage
USA	46	51.1
Wales (17 face-to-face interviews)	19	21.1
England	10	11.1
Canada	5	5.6
Scotland	3	3.3
Malaysia	2	2.2
Northern Ireland	1	1.1
Other countries	4	4.4

Table 5.1: Country of origin of subjects

All but three subjects were from English speaking countries, and the highest response rate was from the USA (n=46 / 51.1%), followed closely by the UK (n=33 / 36.7% when all regions are combined). Although the UK response rate was quite high, the internet response rate for this country was only 21%. The large number of contributions from overseas carers was somewhat unexpected, but very pleasing. The effect of using the internet as a sampling method will be discussed further in Chapter 6. It is also important to note that 17 of the 19 subjects from Wales were interviewed in person by the researcher.

5.2 Relationships of dependants to carers

Data on the relationships of dependants to carers are as follows:

Relationship	Number	Percentage
Mother/mother-in-law	45	50.0
Husband/partner	24	26.7
Wife/partner	11	12.2
Father/father-in-law	4	4.4
Grandparent/grandparent-in-law	3	3.3
Gay partner	1	1.1
Friend	1	1.1
Son	1	1.1

Table 5.2: Relationships of dependants to carers

The majority of subjects were adult children carers (n=49 / 54.4%), followed closely by spouse carers (n=35 / 38.9%). However, 13 of the 17 interviewed subjects were spouse carers and only four were adult children carers, compared with 45 adult children carers in the internet sample and 22 spouse carers. This indicates that the adult children cohort had more access to the internet than older subjects and demonstrates that the caregiver sample obtained for this study is not representative of the community of dementia carers overall. Nonetheless, all carers who participated in the study had an important contribution to make.

5.3 Gender of carers and dependants

71 of the carer subjects were female (78.9%) and 19 were male (21.1%). 58 dependants were female (64.4%) and 32 were male (35.6%). These figures are not surprising and are similar to the national trends in dementia carer and dependant profiles discussed in Chapter 3.

5.4 Age of carers

Data on the age of caregivers are as follows:

Age range	Number	Percentage
21-30	1	1.1
31-40	6	6.7
41-50	29	32.2
51-60	26	28.9
61-70	15	16.7
71-80	11	12.2
81-90	2	2.2

Table 5.3: Age of carers

Face-to-face interview subjects tended towards being an older cohort than internet subjects, with one in their 40s, five in their 50s, two in their 60s, eight in their 70s and one in their 80s. The internet cohort was younger, with one in their 20s, six in their 30s, 28 in their 40s, 21 in their 50s, 13 in their 60s, three in their 70s and one in their 80s. This is not surprising as one would expect a younger cohort to be more computer literate and have easier access to the internet. However, some older carers did contribute their experiences to the study via the internet, demonstrating that web-based on-line carer support associations, chat rooms etc are becoming an important source of additional support to carers, especially to those who are socially isolated.

5.5 Age of dependants

Data on the age of dependants are as follows:

Age range	Number	Percentage
31-40	1	1.1
41-50	2	2.2
51-60	5	5.6
61-70	17	18.9
71-80	36	40.0
81-90	22	24.4
91-100	7	7.8

Table 5.4: Age of dependants

The majority of dependants were older people, as one would expect given the increasing prevalence of dementia with age. Indeed, a large number – 29 (32.2%), were very elderly. However, the carers of a number of younger people (below the age of 60) with dementia (n=8 / 8.9%) took part in the study, and theirs was an important contribution, as it is widely known that services to this 'sub client group' are under-developed, as discussed in Chapter 3.

5.6 Diagnosis of dependants

Data on the diagnosis of dependants are as follows:

Diagnosis	Number	Percentage
Alzheimer's disease	55	60.4
Vascular dementia	9	9.9
Mix Alzheimer's/Vascular	6	6.6
Pick's disease/frontal lobe dementia	4	4.4
Huntington's disease	3	3.3
Parkinson's dementia	2	2.2
Lewy body dementia	2	2.2
Multiple sclerosis dementia	1	1.1
Familial Alzheimer's disease	1	1.1
Vascular dementia + Parkinson's dementia	1	1.1
Dementia + bi-polar illness	1	1.1
Dementia following subarachnoid haemorrhage	1	1.1
Not known/unspecific	3	3.3

Table 5.5: Diagnosis of dependants

The majority of dependants (n=70 / 78.6%) were diagnosed as having the more common forms of dementia - Alzheimer's disease and vascular dementia, or a mix of both.

However, a number of carers participating in the study were caring for dependants with rarer forms of dementia (n=16 / 17.9%). Once again, their contribution is an important one, as the rarer dementias tend to have an atypical presentation and additional caregiving problems are commonly experienced, as discussed in Chapter 2.

5.7 Type of doctor giving the diagnosis of dementia

Data on the type of doctor that gave the diagnosis of dementia are as follows:

Type of doctor	Number	Percentage
Neurologist	24	26.7
GP	18	20.0
Old Age Psychiatrist	13	14.4
Other consultant	10	11.1
Memory Clinic	8	8.9
Combination	8	8.9
Psychiatrist	5	5.6
Not sure	4	4.4

Table 5.6: Type of doctor giving the diagnosis of dementia

Dependants were most commonly diagnosed by a Neurologist (n=24 / 26.7%), with a less prominent role for Old Age Psychiatrists (n=13 / 14.4%) and Memory Clinics (n=8 / 8.9%). Many were diagnosed by a GP (n=18 / 20%), which implies that a specialist, formal assessment and diagnosis had not yet been obtained. As GPs often act as 'gatekeepers' to specialist services, one can assume that many of these carers had not yet gained access to dementia care services in their community. The services received by carers and dependants in this study will be explored later in this chapter. As this sample included dependants from the USA and other countries, one would expect a different diagnostic route profile. Indeed, 11 of the Old Age Psychiatrist diagnoses and five of the Memory Clinic diagnoses were from the UK.

5.8 Time interval since diagnosis/the duration of caregiving

Data on the time interval since diagnosis/the duration of caregiving are as follows:

Time interval	Number	Percentage
Less than one year ago	10	11.1
13 months to 2 years ago	23	25.6
25 months to 3 years ago	15	16.7
37 months to 4 years ago	9	10.0
49 months to 5 years ago	12	13.3
61 months to 6 years ago	3	3.3
More than 6 years ago	18	20.0

Table 5.7: Time interval since diagnosis/the duration of caregiving

A large number of carers had been providing care for their dependants for between 13 months and three years since their diagnosis (n=38 / 42.2%) and ten (11.1%) had been caring for less than a year. However, the majority had been providing care for more than three years (n=42 / 46.7%), and 18 (20%) of these had been providing care for more than six years since their dependant's diagnosis.

The above data may be an under representation of the duration of caregiving. It is widely known that there can be a significant time interval between the person exhibiting memory problems and a diagnosis of dementia being obtained, as discussed in Chapter 3. A number of months, or even years, may need to be added to the time since diagnosis recorded in this study in gaining a true picture of the duration of caregiving. Thus these data suggest that most carers are committed to remaining in the caregiving role and highlights the longevity of their role.

5.9 Carers' assessment of the degree of dementia in their dependants

Data on carers' assessment of the degree of dementia in their dependants were as follows:

Degree of dementia	Number	Percentage
Mild	8	8.9
Moderate	40	44.4
Severe	32	35.6
Very severe	10	11.1

Table 5.8: Carers' assessment of the degree of dementia in their dependants

These data show that the majority of carers were providing care for dependants with moderate to severe dementia (n=72 / 80%), although ten (11.1%) were caring for people with very severe dementia. It should be noted, however, that the above figures are based on carers' perceptions of the degree of dementia in their dependants and are not based on a formal cognitive functioning measure (the Mini-Mental State Examination as an objective measure had to be abandoned for interview subjects for the reasons outlined in Chapter 4 and was not feasible for the internet sample). Nevertheless, with the clinical knowledge that most dementing illnesses progressively deteriorate over time and a correlation coefficient of +0.297 ($p<0.01$) between the variables 'degree of dementia' and 'time interval since diagnosis', carers' perceptions of the degree of dementia in their dependants were shown to be somewhat reliable.

5.10 Additional illnesses/diseases suffered by dependants

Data on additional illnesses/diseases suffered by dependants are as follows:

Additional illness/disease	Number	Percentage
None	42	47.2
Cancer	17	19.1
Heart condition	13	14.6
Non-life threatening physical illness/disease	12	13.5
Stroke damage	10	11.2
Parkinson's disease	4	4.5
Other life threatening physical illness/disease	3	3.4
Other mental health problem	2	2.2

Table 5.9: Additional illnesses/diseases suffered by dependants

In addition to a primary diagnosis of dementia, 47 (52.8%) dependants were suffering from additional illnesses or diseases; 42 (47.2%) were not. It is important to note that 33 (37.1%) dependants suffered from an additional life-threatening illness (Alzheimer's disease and other dementias should be regarded as terminal conditions in their own right), and many suffered additional physical disability as a result of conditions such as stroke (10 / 11.2%) and Parkinson's disease (4 / 4.5%). These data give some idea of the additional challenges to self-care functioning and physical/emotional well-being that dependants experienced and the added caregiving problems and stress/caregiving burden that their carers were faced with.

5.11 What carers said it was like to care for a person with dementia

The first open-ended question in the 'Current Caregivers Questionnaire' (89 of 91 carers responded) asked carers what it was like to care for a person with dementia. The intention of asking such an open question at this point in the questionnaire was to allow carers to ventilate their thoughts and feelings about dementia and being a carer generally, before focusing on particular problems and experiences. For many, this was an opportunity, perhaps the first for some individuals, to share the true depth of their emotions and thinking with a knowledgeable and non-judgemental professional who was there to hear about their needs as separate and distinct from the needs of the dependant. The confidential nature of the questionnaire allowed some carers, especially those answering via the anonymous internet method, to offload some of their most difficult experiences and negative thoughts and feelings.

Summarising these data in a meaningful way is difficult, but emerging themes have been grouped into categories in the table below and begin to demonstrate the real impact of caring for a person with dementia on carers' quality of life. (The method for qualitative data analysis is outlined in Chapter 4.) Following on from this table, some direct quotation is included to illustrate further the range and depth of responses to this question.

Statement Category	Statement	Number
Difficulty and demand (n=69)	Caregiving difficult/hard	25
	Constant/never-ending	7
	Demanding	5
Stress and coping (n=61)	Stressful/stress/stressed	20
	Frustrating	15
	Feel guilt/guilty	7
Grief and loss (n=59)	Caring equated to child/infant care	20
	Loss of/lost person	12
	Distressing watching deterioration/suffering	10
Depression and despair (n=36)	Depressing/depression	10
	Sad/sadness	8
	Heartbreaking/heartwrenching	4
Reward and satisfaction (n=34)	Caregiving rewarding/satisfying	7
	Try and be positive	3
	Made positive choice to care	3
Lost social life and isolation (n=18)	Lonely/alone	4
	Lost freedom/trapped	4
	Not able to work due to care	3
Caregiving problems (n=12)	Lost conversation	3
	Behaviour problems	3
	Sleep disturbance	2
Exhaustion and demoralisation (n=10)	Caregiving tiring/carer tired	7
	Carer subsumed by role	2

Table 5.10 (summary version): Categorisation of emergent themes in response to the open question, 'What is it like to care for a person with dementia/your dependant?' (for complete version see Appendix 4)

The majority of statements about what it is like to care for a person with dementia were negative (231 of 265 / 87.2%). (As with all qualitative data analyses throughout this chapter, themes were only counted once for each caregiving situation.) Whilst it is important to recognise the rewards and satisfactions of caregiving and the ameliorating effects they can have on dementia caregiving stress and burden, it is also important to highlight that the overwhelming description of the perceived experience of carers is negative, especially in response to an open question such as 'What is it like to care for a person with dementia?' that does not explicitly explore the positive aspects of the caregiving experience.

> ***"It is like caring for a totally dependent child who is unlearning everyday skills. The joy in seeing a child grow and learn is missing and replaced by sadness in seeing a loved one slowly lose himself."*** (Internet carer 26)

In the above categorisation of statements, it is important to note that the first three themes - 'difficulty and demand' (n=69), 'stress and coping' (n=61) and 'grief and loss' (n=59), came out a long way ahead of the remaining themes - 'depression and despair' (n=36), 'reward and satisfaction' (n=34), 'lost social life and isolation' (n=18), 'caregiving problems' (n=12) and 'exhaustion and demoralisation' (n=10). These data highlight the enormous task that carers are faced with, and one which continues over many years. The difficulty of their situation and the demands they face; the stress they suffer and the problems they experience in coping, and the feelings of grief and loss they have to bear as their relative's condition deteriorates, together with the impact on their psychological and physical health need to be recognised and validated.

> ***"I feel trapped; certain that for the rest of my life I will be chained to caregiving."*** (Internet carer 70)

5.12 Geographical distance in caregiving relationship

Data on the geographical distance involved in the caregiving relationship are as follows:

Geographical distance in caregiving relationship	Number	Percentage
Living with (same house)	81	90.0
Living nearby (less than 15 mins away)	6	6.7
Living locally (16 mins to an hour away)	1	1.1
Living long distance away (1 hour + away)	2	2.2

Table 5.11: Geographical distance involved in caregiving relationship

The vast majority of carers were living in the same house as their dependants (n=81 / 90%). However, the fact that nine (10%) people with dementia in this sample were living alone is important to highlight, especially given that four dependants living alone were judged by carers to be 'moderately demented', four were 'severely demented' and one was 'very severely demented'. It is likely that over time and with a further deterioration in their cognition, intellectual functioning, self-care abilities and thus safety in their home, that most, if not all, of the people living alone in this sample will, in time, need either to move in with their main carer/have them move into their home to meet their increasing dependency needs, or be admitted to a permanent care setting. This likely outcome is demonstrated by the nine (10%) carers in this sample who had already had to move in to their dependant's home/have them move in with them so that they could provide more intensive care.

To further demonstrate the problems and stress caused by the geographical distance involved in caregiving, the following table summarising responses to the open question 'What problems have been caused due to the geographical distance involved in caregiving?' is provided:

(It is important to note that this question allowed for responses from carers living with their dependants, e.g. for spouse carers who were now sleeping separately from their demented husband or wife due to the onset of incontinence.)

Statement Category	Statement	Number
Adverse change in carers' quality of life (n=74)	Loss/lack of privacy	9
	No time for self	8
	Need for caregiving constant	7
Stress, strain and fatigue (n=41)	Suffer constant stress	9
	Sleep disturbed by dependant	4
	Problems coping with demands of caregiving	4
Negative impact on family, work and finances (n=32)	Disrupted family life	7
	Increased financial burden	6
	Difficulty balancing work with caregiving	5
Problems for carers whose dependents are living alone (n=13)	Fear of dependant safety in own home	4
	Hard to maintain visits to dependant	2
	Have to lead a double life	2
Relationship change (n=9)	Have to sleep separately from dependant	3
	Spend too much time together	2
	Dependant anger towards carer	2
Positive aspects (n=7)	Easier to care living with than separate from dependant	3
	Motivation to keep dependant out of nursing home	3

Table 5.12 (summary version): Categorisation of emergent themes in response to the open question, 'What problems have been caused by the geographical distance involved in caregiving?' (for complete version see Appendix 4)

The above table shows that the majority of the 89 carers who answered this question had to make considerable changes to their own lives during the course of their dependants' illness, regardless of whether they were providing care from a distance or living with their dependant. The largest category - 74 of the 183 statements analysed (40.4%), was related to an adverse change in carers' quality of life.

> ***"There is a need to be ever watchful that she doesn't get into something which could harm her. There are often unpleasant things to clean up. She hides things. Our family is unable to come and go from our home as a family normally would."*** (Internet carer 44)

For many adult children carers, their family life had suffered as a result of taking on the caregiving role, their marriage had suffered, their career had been affected or ended and their quality of life had changed for the worse. As stated above, nine adult children carers had had to move in with their dependant, or have them move in with them. For the nine adult children carers caring from a distance for a relative with dementia living alone, the increased demands, time constraints and emotional difficulties were only too evident.

> ***"There are not enough hours in the day. I lack time to give to my child (mother thinks my daughter is me and I am her own sister). My privacy and time for myself are almost non-existent."*** (Internet carer 6)

For spouse carers there were also important and negative impacts on quality of life, e.g. increased financial burden, inadequate sleep, loss of freedom and limited availability of breaks from caregiving. The impacts of caregiving on quality of life will be further explored in a later section of this chapter.

> ***"I can't leave him because if he tries to stand up from his chair he will wobble and might fall. He needs constant care and supervision. So I just live with this disease and it controls my life."*** (Interview carer 9)

5.13 Hours spent per day/week in direct hands-on caregiving

Data on the number of hours carers spent per day/week in direct hands-on caregiving are as follows:

Hours spent per day/week in direct hands-on caregiving	Number	Percentage
Up to 20 hours per week (part-time caregiving)	5	5.6
21 to 40 hours per week (part to full-time caregiving)	11	12.4
41 to 60 hours per week (more than EC working-time directive)	10	11.2
61 to 84 hours per week (never off duty)	22	24.7
More than 85 hours per week (constant caregiving)	41	46.1

Table 5.13: Hours spent per day/week in direct hands-on caregiving

In response to the question 'How many hours per day/week do you spend in direct hands-on caregiving (the definition included close one-to-one supervision)?', the vast majority of carers were working for considerably more than the EC Working Time Directive of 40 hours per week (n=73 / 82%). Indeed, 22 (24.7%) carers were providing direct care for 61 to 84 hours a week and 41 (46.1%) for more than 85 hours per week (more than 12 hours a day). Although these figures are based on carers' own perceptions of the amount of time they spent in direct hands-on caregiving and close supervision, they are quite staggering in that they represent a massive amount of work undertaken by the sample on behalf of the state (who would have to bear the cost in their absence). It is also important to note that this high level of caregiving input was undertaken in the face of limited or no availability of breaks from caregiving for many carers (as will be demonstrated in a later section of this chapter) and that caregiving input often extended, albeit intermittently, over the 24 hour period, with many dependants needing direct hands-on care and close supervision during night-time as well as day-time hours. This further demonstrates the stark difference between the role of paid, formal carers, who undertake time limited shift-work, with days off and annual leave, and informal carers, whose unpaid caregiving work is unremitting.

An interesting question to ask of the data was to explore whether there was any correlation between the hours spent in caregiving and the degree of dementia in the dependant. One could surmise that the level of caregiving input would increase as the dementing illness progressed. This supposition was partly supported, with a linear correlation of +0.338 ($p<0.01$) being found between these two variables. However, this result does not fully demonstrate how the nature of caregiving changes over time. For example, one would expect a higher level of behaviour management interventions in the 'moderate dementia' cohort of carers and more physical interventions in the 'severe dementia' cohort. This will be further examined in a later section which explores the caregiving problems experienced by carers in this study, but suffice to say at this stage, that caring for a person with dementia generally becomes more difficult and more intensive as the illness progresses.

The following table summarises responses to the open question 'What is the impact of the hours spent in caregiving on your life?'. 89 subjects answered this question.

Statement Category	Statement	Number
Negative impact on quality of life (n=89)	Little/no free personal time Life on hold/no longer have a life Loss of/restricted social life	16 13 9
Caregiving demands (n=84)	Can't leave dependant alone Need for constant caring/supervision Stress/stressful	9 8 6
Impact on employment (n=20)	Given up/can't work due to caregiving Have had to reduce to part-time work due to caregiving Only leave house to go to work	7 3 2
Physical/psychological impact (n=15)	Carer suffers with clinical depression Can't relax Stress headaches	2 2 2
Negative impact on spouse/family (n=13)	Limited time with spouse Limited time with child/children Marital relationship problems	4 4 2
Positive aspects (n=6)	Chose/want to care for dependant	2

Table 5.14 (summary version): Categorisation of emergent themes in response to the open question, 'What is the impact of the hours spent in caregiving on your life?' (for complete version see Appendix 4)

The above table again highlights the enormous, and mostly negative, impact that caring for a person with dementia has on carers' quality of life (89 of the 227 statements /39.2%), especially in relation to their social life, their employment and their relationships. In their statements, carers gave evidence of their caregiving demands to justify the number of hours they had recorded and to highlight the physical and psychological impact of such constant caregiving.

> ***"Terrible really. I'm 76 and I've had no quality of life for years. He can't talk properly, he's incontinent, he has hallucinations and I struggle to get him upstairs to bed because of his mobility problems. Every morning I have to do the laundry and change the bed as it is soaking wet. That's hard."***
> (Interview carer 1)

Much of the direct quotation emphasised the negative impacts of constant caregiving for the many carers who were providing care for their dependants for more than 61 hours per week, a figure well above the EC Working Time Directive of 40 hours.

> ***"I have about two evenings off a week, when carers come in, and two days off when he goes to day hospital. I'm with him all the time otherwise and could never leave him."*** (Interview carer 10)

Several carers spoke movingly of their feeling that their own lives had been subsumed by their dependants' needs and by the caregiving role. The perception that their life was 'on hold' emphasised the sacrifices that most carers have to make to remain in the caregiving role, most of them willingly, as will be evidenced later in this chapter.

> ***"This IS my life now. My friends no longer call, I am unable to pursue a single outside interest. My life, for the present, is consumed by dementia, the same as hers has been."*** (Internet carer 9)

5.14 Occupational status of carers

Data on the occupational status of carers in the study are as follows:

Carers' occupational status	Number	Percentage
In full-time employment	19	21.1
In part-time employment	9	10.0
Given up work to care	29	32.2
Retired early to care	5	5.6
Retired some time ago	21	23.3
Housewife/husband	6	6.7
Unemployed	1	1.1

Table 5.15: Occupational status of carers

The employment status of carers in this sample demonstrates the sacrifices that many had made to take on their role and the competing demands that many were faced with. 28 (31.1%) carers were in full or part-time employment, having to balance a working life with the life of a carer. Having to come home from occupational work to enter into caregiving work was obviously difficult for most if not all of these carers, and the stress and worry of what was happening whilst they were in work was great. 34 (37.8%) carers had relinquished employment to take on the role of full-time carer, emphasising the commitment to caregiving that they had made. It should be noted that for many of those carers who had given up work, taken early retirement or reduced their working hours, the financial impact was great, as will be seen in a later section of this chapter.

In a further exploration of the data on occupational status, it was not surprising to find that there was a correlation between occupational status and hours spent in caregiving of +0.356 ($p<0.01$). However, it was interesting to discover in an analysis of cross tabulations that 21 of the 29 subjects who had given up work to take on the role of full-time carer were providing care for more than 85 hours per week. It was also surprising to find that seven of the nine carers in part-time work were providing care for more than 61 hours in addition to their occupational work and 12 of the 18 carers in full-time work were providing care for more than 41 hours per week. Coming home after a full days work to enter into the caregiving role during the evening and night, as well at weekends, must be extremely detrimental to carers' physical and mental health, especially if home care support services are not available or cannot be afforded during work hours and there is the worry of leaving the dependant at home alone.

5.15 Other dependants cared for by carers

Data on other dependants cared for by carers in this study are as follows:

Other dependants cared for by carers	Number	Percentage
No other dependants	59	65.6
Responsible for the care of a child/children	11	12.2
Responsible for the care of a grandchild/children	4	4.4
Responsible for the care of another elder	9	10.0
Responsible for the care of another person with dementia	1	1.1
Responsible for the care of another elder + child	1	1.1
Responsible for the care of disabled partner + child	1	1.1
Responsible for the care of a disabled child	2	2.2
Responsible for the care of other dependant	2	2.2

Table 5.16: Other dependants cared for by carers

These data demonstrate that for a significant number of carers (n=31 / 34.4%), there were the competing demands of having to provide care for another dependant person in addition to the person with dementia. For 20 (22.2%) carers, care was being provided to a child or children (two of whom were disabled) and for 11 (12.2%) carers care was being provided to another elder (one of whom was a second person with dementia). For two carers, there were the additional demands of caring for another elder plus a child, or a disabled partner plus a child. This finding highlights the complex caregiving situations that exist; it is often the case that there is more than one dependant person requiring care. It might be the case that an older carer has to provide child care for grandchild/children in addition to caring for a spouse with dementia, or that an adult child carer has to provide family care in addition to caring for a parent with dementia, often from a distance. Whatever the circumstances, the additional impact on the carer and perceived burden need to be assessed in care management practice in addition to that relating to the care of the person with dementia.

5.16 Carers' self-assessment of their own physical and mental health

Data on physical and/or mental health problems suffered by carers in this study are as follows:

Physical/mental health problems	Number	Percentage
Generally in good health	40	44.9
Carer has physical disability	2	2.2
Carer is generally frail or infirm	2	2.2
Carer has a non-life-threatening illness or disease	14	15.7
Carer has a life-threatening illness or disease	2	2.2
Carer is receiving treatment for clinical depression	16	18.0
Combination of illness plus disability	2	2.2
Combination of illness plus depression	10	11.2
Combination of illness plus disability plus depression	1	1.1

Table 5.17: Carers' self-assessment of their own physical and mental health

The majority of carers in this study (n=49 / 54.4%) were coping with the demands of caregiving in the face of disability, illness or disease; only 40 (44.9%) thought themselves to be in good health. Those who were in ill-health were mostly coping with non-life threatening conditions (n=20 / 22.5%). However, two (2.2%) were suffering from a life threatening illness or disease and had the additional worry of what would happen to their dependant if they were to become too ill to care for them or even die.

Another significant finding which mirrors other research, is that 27 (30.3%) carers were receiving treatment for clinical depression. This excludes the number who were depressed but not receiving treatment and those who had been treated for clinical depression at some stage during their caregiving role, but were no longer being so treated. The questionnaire required carers to list medications currently received, and these figures are supported by antidepressant medications listed.

It was also interesting to examine the relationship between depression amongst carers and the severity of dementia in their dependants. Two depressed carers were providing care for someone they assessed as having mild dementia, 13 were caring for moderately demented dependants, nine for severely demented dependants and three for very severely demented dependants. This cross tabulation data highlights that depression amongst carers may be more prevalent in the middle phases of the illness trajectory, perhaps when behaviour problems are at their peak and changes in the quality of the relationship between the carer and dependant may be most evident, as will be seen in the next section.

Not surprisingly, clinical depression in carers was associated with higher levels of caregiving burden. 'Dementia Caregiving Burden Questionnaire (DCBQ)' score had a correlation with self-assessed health rating to the extent of +0.420 ($p<0.01$). Similarly, the mean DCBQ score was higher for carers with 'clinical depression' (mean DCBQ 94.3), compared to those who were 'frail and infirm' (mean DCBQ 85.0), those who had a 'non-life threatening illness' (mean DCBQ 76.9), those who had a 'life threatening illness' (mean DCBQ 74.5), and those who assessed themselves as being 'in good health' (mean DCBQ 67.9).

The data on ill-health of carers emphasises the additional challenges to coping with caregiving that most carers were faced with, many with little or no support to relieve them, albeit for a time, of the burden of caregiving. The level of informal and formal support available to carers will be addressed in a later section of this chapter.

5.17 Quality of previous and current relationship between carers and dependants

Data on the quality of the previous and current relationship carers had/have with their dependants are as follows:

Previous quality of relationship	Number	Percent	Current quality of relationship	Number	Percent
Extremely close	46	51.1	Extremely close	26	28.9
Very close	17	18.9	Very close	22	24.4
Reasonably close	20	22.2	Reasonably close	24	26.7
Not very close	5	5.6	Not very close	11	12.2
Distant	2	2.2	Distant	7	7.8

Table 5.18: Quality of previous and current relationship between carers and dependants

These data show that for the majority of carers, there was a deterioration in the quality of their relationship with their dependant since the onset of their illness, with 35 staying at the same point on the closeness scale, 44 deteriorating on the scale to an average of 1.7 points, and 11 improving on the scale to an average of 2.5 points. That is to say, for the majority of those who previously had a close relationship with their relative, there had been a deterioration in the quality of their relationship, and for some this was marked (21 stating a deterioration in the quality of their relationship of 1 point, 18 of 2 points, four of 3 points and one of 4 points). However, it is also important to note that for a minority of carers who had previously had a poor relationship with their dependant, the caregiving relationship had brought them closer together.

To further demonstrate the relationship between the degree of dementia in the dependant and closeness change between the carer and dependant since the onset of their illness, the means of these two variables were compared. This analysis showed that the degree of closeness in the current relationship became less as the degree of dementia increased, with the mean degree of dementia score being 2.36 for the 'very close' relationship rating, 2.42 for 'reasonably close', 2.55 for 'not very close' and 3.00 for 'distant'. However, it should be noted that the mean degree of dementia score for the 'extremely close' rating was 2.50. This is interesting as it supports the above finding which showed that for some carers the degree of closeness to their dependant increased as their dementing illness advanced.

The reasons for relationship changes are many and varied, but in response to an open question asking them to describe how their relationship had changed carers answered as follows:

Statement Category	Statement	Number
Caregiving problems (n=34)	Dependant totally/completely dependent on carer	9
	Carer has had to take charge of everything	8
	Caregiving is stressful	2
Degree of closeness/attachment (n=27)	Still close to dependant	6
	No longer as close to dependant	5
	Have become closer to dependant	4
Relationship breakdown (n=23)	Get angry/lose temper with dependant	4
	No quality in relationship	3
	Feel sorry/pity for dependant	3
Communication breakdown (n=21)	Lack of verbal communication	5
	Dependant can't understand what carer says	4
	Dependant can't respond to carer	3
Coping skills/management strategies (n=20)	Try to remember she is my ...	3
	Try to keep calm/patient	2
	Carer has become a more caring person	2
Relationship change (n=17)	Relationship has not changed	3
	Change in quality of relationship	3
	Relationship has changed for the worse	2
Equivalent to child care (n=16)	Parent now like a child	9
	Spouse now like a child	3
	Like caring for a baby	2
Role change (n=14)	Role reversal/roles reversed	12
Grief and loss (n=12)	Dependant different/changed person	5
	No longer my ...	2
	Feel bereaved	2
Lost partner/spouse (n=10)	No longer have a spousal/marital relationship	5
	Physical/sexual relationship has gone	2
Failure of recognition/ validation (n=10)	Dependant no longer recognises carer	5
	Dependant does not recognise carer's needs	2

Table 5.19 (summary version): Categorisation of emergent themes in response to the open question, 'How has your relationship with your dependant changed since he/she has been ill?' (for complete version see Appendix 4)

One can see from the above data that an important theme emerging from responses to this question was that of role reversal and role change, with 39 (43.8%) of the 89 carers who answered this question using the words 'role', 'reversal/reversed', 'become' and 'changed' (in this context) to describe the shift in their relationship resulting from their parent/spouse/significant other developing a dementing illness. Similarly, 17 (19.1%) carers used the words 'taken over/charge', 'totally/completely dependent', 'do everything' to describe the changes they had had to make in their lives to take on the role of carer and assume the daily tasks that the dependant was responsible for doing before their illness, e.g. dealing with finances having to be taken on by wife carers; doing shopping and cooking having to be taken on by husband carers.

> ***"Hostility has replaced a long, loving relationship. There is a loss of companionship, sharing and caring. I am in charge of everything and more like a parent than a spouse. I no longer have a husband who is concerned about me."*** (Internet carer 5)

Another significant theme emerging from the data was that of the carer equating the care of an older person with dementia to the care of a child or infant, with 23 (25.8%) using the words 'child', 'baby', 'parent' or 'mother/father' (in this context) to describe the significant changes in their dependant resulting from dementia.

Similarly, grief and loss was another significant theme, with 13 carers (14.6%) using the words 'no longer', 'loss'/'lost/losing', 'gone', 'destroyed/damaged' and 'died/death' (in this context) in their responses. However, great sadness was evident in most of the responses to this question.

> ***"We are still close, but there is a lack of communication. Sometimes it gets so lonely when I talk to him and get no response. The role of lover has gone and now I am more in the role of being a nurse. It's like caring for a baby, a different type of attachment."*** (Interview carer 9)

It is also important to highlight that some positive aspects to the changes experienced in the relationship with the relative/significant other as a result of their dementing illness were noted by a large number of carers (30 of 89 / 33.7%). Many of these positive aspects were seen in situations where the previous relationship with the relative/friend was not close and entering into the caregiving role had drawn the carer closer to their dependant and/or the confusion in their dependant had resulted in previous difficulties in the relationship being forgotten.

5.18 Results of 'Dementia Caregiving Problems Questionnaire (DCPQ)'

The frequency of caregiving problems experienced by current carers (completed by 76/91 subjects) was as follows:

DCPQ domain	Dementia caregiving problems	Frequently/Always Combined n= (%)
Communication problems	Repeats things over and over again	46 (60.5%)
	Is (un)able to start and maintain a sensible conversation	41 (53.9%)
	Is (un)able to take part in family conversations	39 (51.3%)
	Is (un)able to read newspapers, magazines, etc., or watch and follow TV	32 (42.1%)
	Has periods when he/she doesn't speak much at all	31 (40.8%)
	Talks aloud to him/herself	22 (29%)
	Talks nonsense I can't understand	22 (28.9%)
	Is (un)able to respond sensibly when spoken to	17 (22.4%)
	Talks all the time	15 (19.7%)
	Is (un)able to understand what is said to him/her	12 (15.8%)
Confusion problems	Gets mixed up about the day, date, year	63 (82.9%)
	Gets mixed up about where he/she is	44 (57.9%)
	Gets mixed up about the time of day/night	42 (56%)
	Is (un)able to hold his/her attention for more than a few minutes	34 (44.8%)
	Seems lost in a world of his/her own	31 (40.8%)
	Gets lost and can't find his/her way home when outside of the house	26 (34.2%)
	Sees/hears things which aren't there	20 (26.3%)
	Is (un)able to recognise familiar people, e.g. family and friends	14 (18.4%)
	Is (un)able to recognise me or know who I am	9 (11.8%)
	Tries to get up and dressed/go outdoors during the night	8 (10.5%)
Behaviour problems	Tends to collect things and hoard them	31 (40.8%)
	Becomes irritable and easily upset	29 (38.2%)
	Becomes angry and resistive to care	23 (30.3%)
	Has to be prevented from wandering outside the house	20 (26.3%)
	Falsely accuses people/me of things	20 (26.3%)
	Wakes me/others during night	18 (23.7%)
	Shouts/swears/screams at people/me for no apparent reason	12 (16%)
	Endangers him/herself by risky behaviours	7 (9.2%)
	Hits out at me/other people	6 (8%)
	Displays inappropriate sexual activity/demands	2 (2.6%)
Mood related problems	Never leaves my side/shadows me	38 (50%)
	(Does not) Shows an interest in doing things	34 (44.7%)
	Appears restless and agitated	33 (43.4%)
	Isolates self and avoids social contact	31 (40.7%)
	Appears unhappy and depressed	26 (34.2%)
	Has difficulty settling to sleep or wakes unusually early in the morning	23 (30.2%)
	Mood changes suddenly for no obvious reason	21 (27.6%)
	Looks frightened and anxious	21 (27.6%)
	Paces up and down wringing his/her hands	18 (23.7%)
	Cries/is tearful for no obvious reason	15 (19.7%)
Self-care problems	Has difficulty washing/bathing - needs assistance	55 (72.4%)
	Has difficulty dressing/undressing - needs assistance	49 (64.4%)
	Has problems in standing/walking - needs assistance	31 (40.8%)
	Incontinent of urine during the night (may wear pads)	29 (38.2%)
	Incontinent of urine during the day (may wear pads)	23 (30.8%)
	Has problems feeding self/swallowing - needs assistance/special diet	23 (30.2%)
	Incontinent of faeces (day or night)	15 (19.8%)
	Partly/completely immobile and needs lifting	13 (17.1%)
	Prone to having falls/fits/choking	11 (14.5%)
	Suffers with pain/needs analgesic medication	11 (14.5%)

Table 5.20: Frequency of dementia caregiving problems experienced by current carers

To provide ease of analysis, the ten highest ranking caregiving problems experienced by carers ('frequently' and 'always' combined) were:

Dementia caregiving problems	DCPQ domain	Combined number	Combined percentage
Gets mixed up about the day, date, year	Confusion	63	82.9%
Has difficulty washing/bathing – needs assistance	Self-care	55	72.4%
Has difficulty dressing/undressing – needs assistance	Self-care	49	64.4%
Repeats things over and over again	Communication	46	60.5%
Gets mixed up about where he/she is	Confusion	44	57.9%
Gets mixed up about the time of day/night	Confusion	42	56%
Is unable to start and maintain a sensible conversation	Communication	41	53.9%
Is unable to take part in family conversations	Communication	39	51.3%
Never leaves my side/shadows me	Mood	38	50%
Is unable to hold his/her attention for more than a few minutes	Confusion	34	44.8%

Table 5.21: Highest ranking dementia caregiving problems experienced by current carers

These data show that the study cohort experienced and were coping with a multitude of caregiving problems across all domains. Time and place disorientation was reported in most dependants, with 63 (82.9%) carers responding that their dependant frequently or always got mixed up about the day, date and year, 44 (57.9%) responding that their dependant frequently or always got mixed up about where he/she was and 42 (56%) responding that their dependant frequently or always got mixed up about the time of day/night. Being unsure of the date or year, not understanding that the place where they are is their home and mixing day and night are memory related problems that may have a significant detrimental effect on the carer and result in high levels of stress. For example, the dependant may be determined to go to school or work from which they have retired, to visit their deceased mother, to return to their childhood home (20 / 26.3% carers frequently or always had to prevent their dependant from wandering outside) or to try getting up and dressing in the middle of the night (18 / 23.7% carers were frequently or always woken during the night by their dependant). Thus commonly experienced confusion related caregiving problems such as these need to be understood in the context of impact on the carer's quality of life, let alone on the dependant's emotional well-being. Additionally, seeing the person you love in distress will be an added source of stress for the carer who is struggling to make their dependant feel safe and contented (26 / 34.2% carers reported that their dependant frequently or always appeared unhappy and depressed and 15 / 19.7% that their dependant frequently or always cried or were tearful for no obvious reason).

Similarly, self-care problems such as washing and bathing difficulty, experienced frequently or always by 55 (72.4%) carers, and dressing and undressing difficulty, experienced frequently or always by 49 (64.4%) carers, need to be explored with the carer in relation to associated difficulties, such as resistiveness to being cared for, experienced frequently or always by 23 (30.3%) carers, and incontinence, experienced frequently or always by 29 (38.2%) carers during the night and 23 (30.2%) during the day. Trying to wash and dress a person with dementia who does not understand your caring motives and fights against you in fear, or who is incontinent just after they have been changed, may result in extreme stress for the carer, whereas if the dependant is more passive and accepting of care these problems may not be so difficult to manage. Again, the carer needs to be asked whether caregiving problems such as these cause high levels of stress and are difficult to manage or whether they can get by without great emotional difficulty. However, carers may find the physical strain associated with such physically demanding caregiving tasks hard to bear, especially if lifting and moving is involved. In either situation, support from home care workers to relieve the carer of these types of caregiving problems can be a great help and enable carers to regain some of their emotional and physical energies to reinvest in other aspects of caregiving.

Three communication problems also featured in the 'Top 10' most frequent caregiving problems. Repeating things over and over again was experienced frequently or always by 46 (50.6%) carers, inability to start and maintain a sensible conversation by 41 (45.1%) carers and inability to participate in family conversations by 39 (42.9%) carers. Problems in understanding language or in producing speech (receptive and expressive dysphasia) are common in dementing illnesses and often result in a breakdown in communication between dependant and carers. This may be exacerbated by memory problems which result in the dependant forgetting what has been said or 'getting stuck in a groove' with a question and repeating it over and over again (perseveration). Such problems can be very difficult to bear and may result in the carer feeling cut off and isolated from the dependant. Over time, the relationship between the carer and dependant can become distant and a role reversal can occur, as described and evidenced above. This may be particularly the case if severe communication problems, such as muteness, in the dependant exist.

Perhaps surprisingly, only one caregiving problem in the 'Behaviour' domain - shadowing the caregiver, which was frequently or always experienced by 38 (50%) carers, and one caregiving problem in the 'Mood' domain - inability to hold attention for more than a few minutes, which was frequently or always experienced by 34 (44.8%) carers, made it into the 'Top 10' most frequently experienced caregiving problems. And yet such problems may cause the most stress and be the most difficult to manage for carers. For example, having your dependant follow you around the house, even to the bathroom in some instances, or their being unable to focus their attention for any time, e.g. when attempting to sit still and eat a meal, can be incredibly stressful and difficult to manage. Over time the carer's ability to cope can be denuded, perhaps resulting in them shouting at or getting angry with the dependant. The carer, in such a high stress situation, can even become abusive towards their dependant, as explored in Chapter 3. This is often associated with high levels of frustration and low levels of tolerance, clinical depression in the carer and using alcohol as a means of coping. In addition, behavioural problems in the dependant are also closely related to carer abuse – the carer may angrily respond to aggression directed at them by the dependant. Although other behaviour and mood related caregiving problems were not reported to frequently or always occur for the study cohort, particular attention should be given to caregiving situations where scores in these domains are even moderately high. Caregiving problems such as physical aggression or violence directed at the carer that occur even infrequently should be a particular cause for concern and trigger urgent service interventions.

The difference between the most frequent caregiving problems experienced and those which are perceived as being the most stressful and difficult to manage is key to this study. Thus an analysis of the most difficult to manage/stressful caregiving problems follows.

5.19 'Dementia Caregiving Problems Questionnaire (DCPQ)' cohort data

Data on results for the cohort of overall scores in the 'Dementia Caregiving Problems Questionnaire (DCPQ)' are as follows:
(It should be noted that 15 of 91 current carers (16.5%) did not complete the DCPQ. All non-completions were from the internet sample and could be attributed either to questionnaire completion fatigue (the DCPQ was a separate and distinct section to the on-line questionnaire) or problems in electronic submission (the DCPQ was the second of four sections which were submitted separately via html 'submit' buttons to the researcher's email address).

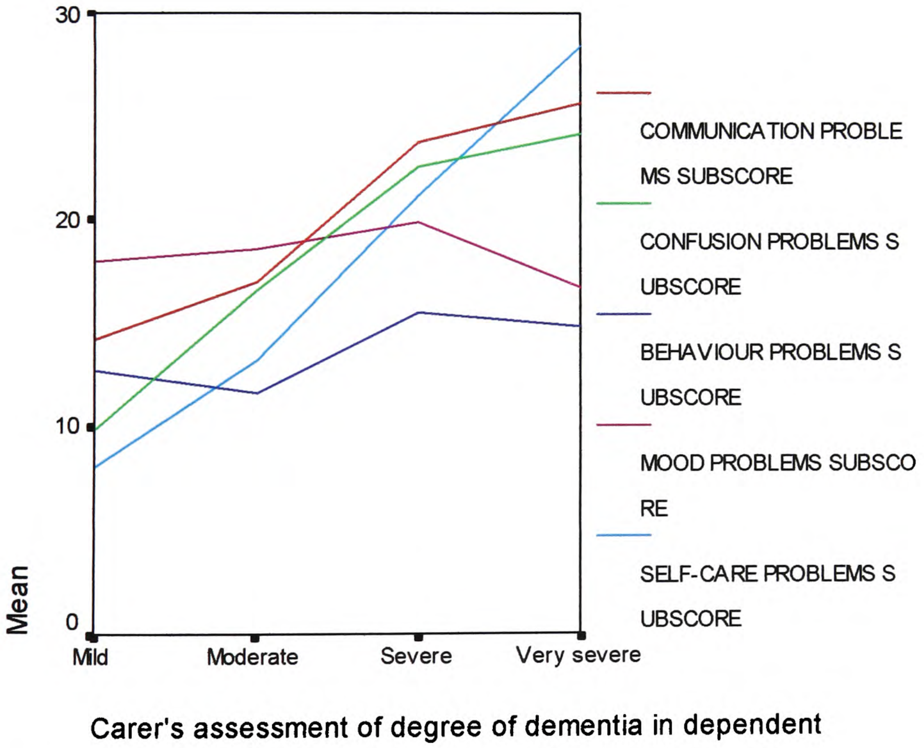
DCPQ domain	DCPQ scores		Number
Communication problems	0 – 10	Minimal to mild caregiving problems experienced	2
	11-20	Mild to moderate caregiving problems experienced	40
	21-30	Moderate to severe caregiving problems experienced	31
	31-40	Severe to extreme caregiving problems experienced	3
Confusion problems	0 – 10	Minimal to mild caregiving problems experienced	9
	11-20	Mild to moderate caregiving problems experienced	35
	21-30	Moderate to severe caregiving problems experienced	26
	31-40	Severe to extreme caregiving problems experienced	5
Behaviour problems	0 – 10	Minimal to mild caregiving problems experienced	37
	11-20	Mild to moderate caregiving problems experienced	27
	21-30	Moderate to severe caregiving problems experienced	8
	31-40	Severe to extreme caregiving problems experienced	3
Mood problems	0 – 10	Minimal to mild caregiving problems experienced	8
	11-20	Mild to moderate caregiving problems experienced	39
	21-30	Moderate to severe caregiving problems experienced	26
	31-40	Severe to extreme caregiving problems experienced	3
Self-care/physical problems	0 – 10	Minimal to mild caregiving problems experienced	21
	11-20	Mild to moderate caregiving problems experienced	25
	21-30	Moderate to severe caregiving problems experienced	21
	31-40	Severe to extreme caregiving problems experienced	9
Overall DCPQ score	0 – 50	Minimal to mild caregiving problems experienced	4
	51-100	Mild to moderate caregiving problems experienced	48
	101 – 150	Moderate to severe caregiving problems experienced	22
	151-200	Severe to extreme caregiving problems experienced	0

Table 5.22: Cohort scores for 'Dementia Caregiving Problems Questionnaire (DCPQ)'

One can see from the above table that three of the 76 (3.5%) current carers who completed the DCPQ three had scores in the 'severe to extreme caregiving problems experienced' category in the 'Communication problems' domain; five (6.6%) had scores in the 'severe to extreme caregiving problems experienced' category in the 'Confusion problems' domain; three (3.5%) had scores in the 'severe to extreme caregiving problems experienced' category in the 'Behaviour problems' domain; three (3.6%) had scores in the 'severe to extreme caregiving problems experienced' category in the Mood problems' domain, and nine (11.8%) had scores in the 'severe to extreme caregiving problems experienced' category in the 'Self-care/Physical problems' domain.

There were no carers with 'Overall DCPQ' scores in the 'severe to extreme' category, which is initially surprising until one considers that due to the changing nature of dementia certain caregiving problems peak at different stages of the illness. For example, mood problems such as clinical depression tend to be experienced at an earlier stage in the illness, while insight is preserved; behaviour problems are more manifest in the middle stages of the illness, when the person is more active and disorientated, and self-care and physical dependency problems are a later feature, when the person becomes less active and more physically frail. However, there were 22 carers (28.9%) with 'Overall DCPQ' scores in the 'moderate to severe' category, and these carers may be those who are particularly vulnerable to breakdown in their caregiving situation.

It was interesting to examine correlations between the 'Degree of dementia', as assessed by the carer, and domain scores from the DCPQ. Positive correlations were found between 'Degree of dementia' and 'Overall DCPQ' score at +0.607 ($p<0.01$); 'Communication' at +0.646 ($p<0.01$), 'Confusion' at +0.561 ($p<0.01$), and 'Self-care/Physical' at +0.585 ($p<0.01$). There was no relationship for 'Behaviour' and 'Mood' domains with 'Degree of dementia'. This is not surprising given that the line graph below clearly demonstrates that 'Self-care/Physical problems', 'Confusion problems' and 'Communication problems' increase incrementally with the 'Degree of dementia', as assessed by the carer, while 'Mood problems' and 'Behaviour problems' follow a different trend. Instead, these caregiving problems show a moderate peak in the 'Severe' stage of dementia, lessening somewhat after this threshold has been passed and the end stage of dementia is reached. These relationships are not surprising, given the clinical picture of increasing cognitive impairment, communication deficits and self-care impairment as dementing illnesses progress and the knowledge that behavioural problems and mood disturbance lessen as persons with dementia move into a more passive and frail 'terminal phase' in their dementing illness.



Graph 5.1: Relationship between degree of dementia and DCPQ domain subscores

The table below adds further support to the above discussion. The implications of these findings in terms of stress, coping and continued home caregiving will be discussed later in this chapter.

Degree of dementia	Communication problems mean score	Confusion problems mean score	Behaviour problems mean score	Mood problems mean score	Self-care problems mean score	Overall DCPQ mean score
Mild	13.6	10.4	12.7	17.3	7.3	62.7
Moderate	16.9	16.6	11.4	18.4	13.6	77.0
Severe	23.7	22.5	15.5	19.8	21.2	102.8
Very severe	25.7	24.1	14.8	16.7	28.4	109.7

Table 5.23: Mean DCPQ scores against degree of dementia

5.20 Caregiving problems and associated stress/caregiving burden

Comparing means for overall 'Dementia Caregiving Burden Questionnaire (DCBQ)' scores (the analysis of which follows) with caregiving problems across all domains in the 'frequently/always' ratings, the results in ranked order were as follows:

DCPQ domain	Dementia caregiving problem	Frequently/ quite a lot - mean DCBQ score	Always/ considerably - mean DCBQ score	Combined frequency - mean DCBQ score
Confusion	Does your dependant try to get up and dressed/go outdoors during the night	n=7 - 91.9	n=1 - 122.0	n=8 - 107.0
Behaviour	Does your dependant display inappropriate sexual activity/demands	n=2 - 99.0	n=0 - 0	n=2 - 99.0
Self-care	Is your dependant prone to having falls/fits/choking attacks	n=7 - 91.0	n=4 - 98.5	n=11 - 94.8
Mood	Does your dependant have difficulty settling to sleep or wake unusually early in the morning	n=13 - 75.6	n=9 - 97.1	n=22 - 93.3
Behaviour	Does your dependant shout/swear/scream at people/you for no obvious reason	n=10 - 98.6	n=1 - 87.0	n=11 - 92.8
Communication	Is your dependant unable to understand what is said to him/her	n=10 - 80.8	n=1 - 101.0	n=11 - 90.9
Behaviour	Does your dependant become irritable and easily upset	n=22 - 84.2	n=6 - 95.2	n=28 - 89.7
Behaviour	Does your dependant become angry and resistive to care	n=16 - 82.7	n=5 - 96.6	n=21 - 89.7
Behaviour	Does your dependant falsely accuse people/you of things	n=12 - 92.5	n=6 - 82.2	n=18 - 88.9
Behaviour	Does your dependant hit out at you/other people for no obvious reason	n=5 - 88.8	n=0 - 0	n=5 - 88.8
Behaviour	Does your dependant wake you/others during the night	n=12 - 75.0	n=6 - 102.2	n=18 - 88.5

Table 5.24: Most burdensome dementia caregiving problems in the 'frequently' and 'always' categories of frequency

(Note: DCBQ range is 0-40 minimal/mild, 41-80 mild/moderate, 81-120 moderate/severe, 121-160 severe/extreme)

The above findings reveal those caregiving problems which carers participating in this study found most burdensome, according to scores obtained from the 'Dementia Caregiving Burden Questionnaire (DCBQ)' in the 'frequently' and 'always' ratings. It is not surprising that dealing with the crises situations of the dependant getting up and dressed and attempting to go outdoors during the night and the dependant falling, fitting or choking rated highly in this analysis of data. Nor is it surprising that the difficult to manage problem behaviours related to inappropriate sexual activity/demands; shouting, swearing or screaming; becoming irritable and easily upset; becoming angry and resistive to care; hitting out at the carer/other people, and being on the receiving end of false accusations feature in the top ten most burdensome problems. However, being unable to understand what is said also rates highly, perhaps because such a breakdown in communication between the carer and dependant has a direct influence on self-care functioning and can add to or even cause other related caregiving problems, for example, resistiveness to care. Two questions relating to night-time problems and loss of sleep for the carer also feature in this analysis, and it is widely known that sleep deprivation and exhaustion has a detrimental effect on carer coping.

However, looking at the most burdensome caregiving problems across the 'rarely, sometimes, frequently, always' range, the top ten most burdensome caregiving problems changes somewhat:

DCPQ domain	Dementia caregiving problem	Frequency of problem	Number / Mean DCBQ score
Confusion	Does your dependant try to get up and dressed/go outdoors during the night?	Always	n=1 – 122.0
Confusion	Does your dependant get mixed up about where he/she is?	Rarely	n=4 – 115.7
Behaviour	Does your dependant wake you/others during the night?	Always	n=4 – 102.2
Communication	Is your dependant unable to understand what is said to him/her?	Always	n=1 – 101.0
Behaviour	Does your dependant display inappropriate sexual activity/demands?	Frequently	n=2 – 99.0
Behaviour	Does your dependant shout/swear/scream at people/you for no obvious reason?	Frequently	n=10 – 98.6
Self-care	Is your dependant prone to having falls/fits/choking attacks?	Always	n=4 – 98.5
Self-care	Is your dependant incontinent of urine during the day?	Frequently	n=3 – 97.7
Mood	Does your dependant have difficulty settling to sleep or wake unusually early in the morning?	Always	n=9 – 97.1
Self-care	Is your dependant partly/completely immobile and needs lifting?	Rarely	n=11 – 97.0

Table 5.25: Most burdensome dementia caregiving problems across the frequency range

The above findings emphasise the importance of recognising that the most frequently experienced caregiving problems are not necessarily those which carers perceive as the most burdensome. For example, managing problems such as place disorientation or having to lift a partly immobile dependant into or out of their chair if they forget how to stand may be perceived as being extremely stressful even though they may occur rarely. The aspect of fear of the 'rare' problem occurring again and the unpredictability associated with dementia caregiving should not go unnoticed. Furthermore, if one considers both of the above lists in terms of carers getting problems under control and having some mastery over their situation, all the caregiving problems listed could be said not only to be difficult to predict, but also they are hard to get under control.

Both sets of findings emphasise once again that a key question in any carers' assessment is to ask not only what caregiving problems are being experienced and their frequency, but also which of these problems, no matter how frequently they are occurring, are perceived by carers as being the most stress provoking/difficult to manage. Reaching a better understanding of the psychosocial impact of caregiving problems upon the carer can help health and social care professionals ensure their interventions are better directed at relieving stress and caregiving burden wherever possible and maximising the impact of their care plan, which of course, should be jointly agreed with the carer. For example, in relation to the above problems the community psychiatric nurse/care manager could advise on reality orientation approaches, sleep management strategies, communication techniques, behaviour management approaches, lifting aids/assistance and other crises management guidelines, thus helping the carer to regain some control over these problems. A medication prescription/review by the dependant's doctor would also be helpful in managing some of the above caregiving problems.

Following on from this discussion, the next set of findings make another important point for consideration: that many caregiving problems show a different trend in DCBQ peak. For instance, several problems show a higher level of caregiving burden in the 'rarely and sometimes' categories and lower DCBQ scores when problem frequency increases to 'frequently or always'. Other caregiving problems show the reverse trend, with caregiving burden peaking in the 'frequently or always' categories. And, importantly, several caregiving problems show a 'U' shaped relationship with DCBQ scores, peaking in the 'sometimes to frequently' categories. These different trends are highlighted in the tables below, and a discussion of the clinical importance of these findings follows:

Dementia caregiving problem	Frequency	Mean DCBQ score
Is your dependant able to start and maintain a sensible conversation?	Frequently	75.0
	Sometimes	77.3
	Rarely	84.3
	Never	74.3
Is your dependant able to respond sensibly when spoken to?	Frequently	73.6
	Sometimes	82.3
	Rarely	82.5
	Never	63.2
Does your dependant repeat things over and over again?	Rarely	71.9
	Sometimes	74.1
	Frequently	79.2
	Always	78.4
Does your dependant talk all the time?	Rarely	78.2
	Sometimes	79.3
	Frequently	86.6
	Always	79.0
Does your dependant have periods when he/she doesn't speak much at all?	Rarely	78.7
	Sometimes	83.3
	Frequently	77.2
	Always	61.8
Does your dependant talk aloud to him/herself?	Rarely	82.0
	Sometimes	85.9
	Frequently	80.6
	Always	69.5
Does your dependant get mixed up about the day, date, year?	Rarely	50.0
	Sometimes	79.6
	Frequently	84.4
	Always	73.3
Does your dependant wander indoors or outdoors?	Rarely	81.8
	Sometimes	85.1
	Frequently	88.6
	Always	79.8
Does your dependant shout/swear/scream at people/you for no obvious reason?	Rarely	80.3
	Sometimes	89.5
	Frequently	98.6
	Always	87.0
Does your dependant show an interest in doing things?	Rarely	69.1
	Sometimes	78.1
	Frequently	89.2
	Always	76.3
Does your dependant pace up and down in a worried or troubled way?	Rarely	84.8
	Sometimes	88.4
	Frequently	76.5
	Always	65.0
Does your dependant's mood change suddenly for no obvious reason?	Rarely	69.8
	Sometimes	80.2
	Frequently	89.6
	Always	77.3
Does your dependant have problems in standing/walking – need assistance?	Rarely	80.1
	Sometimes	83.4
	Frequently	86.4
	Always	75.9
Is your dependant incontinent of urine during the night (may wear pads)?	Rarely	70.6
	Sometimes	90.4
	Frequently	86.7
	Always	77.7
Is your dependant incontinent of urine during the day (may wear pads)?	Rarely	80.1
	Sometimes	92.3
	Frequently	97.7
	Always	73.8

Table 5.26: DCPQ questions with DCBQ mean score peaking in mid range of frequency

(Note: Some questions have reversed polarity, e.g. 'Is your dependant able to start and maintain a sensible conversation?'. All items start with the least and end with the most severe points on the scale.)

The above table shows that 16 caregiving problems across all DCPQ domains had a peak in caregiving burden score in the 'sometimes to frequently' points on the problem frequency scale. The reasons for this finding remain unclear, but this trend may indicate that for the majority of carers, as a level of tolerance builds towards these caregiving problems they become more predictable and thus associated stress and caregiving burden decrease to a more moderate level as problem frequency increases. For example, night-time incontinence may be more difficult to manage when it occurs 'sometimes' or 'frequently' than if it occurs 'always', by which time continence management aids may have been obtained and the carer may be sleeping separately from their dependant. Similarly, pacing up and down may be more difficult to manage when it 'rarely' or 'sometimes' occurs than when it 'frequently' or 'always' occurs, by which time the carer may have become more tolerant to the behaviour and find it less distressing. In addition, other more difficult to manage problems may have taken precedence over these caregiving problems and cause higher levels of stress and caregiving burden.

The following three caregiving problems show a different trend, with the DCBQ score being the highest at the 'rarely' point on the scale and decreasing monotonically with frequency, i.e. being lowest at the 'always' point on the scale. The reasons for this trend are again unclear, but it is likely that the finding demonstrates that for some caregiving problems the onset of the problem causes the most stress for carers and that as it occurs more frequently it becomes easier to manage or has less psychological impact. For example, disorientation around the home and failure of recognition may be very distressing for both the dependant and carer initially and cause many associated difficulties, but may be of less significance as the illness progresses and other problems dominate. Similarly, when the dependant initially develops mobility problems the carer may find having to provide a high level of observation and trying to prevent falls very stressful, whereas when he/she becomes totally chair- or bed-bound the stress is less.

Dementia caregiving problem	Frequency	Mean DCBQ score
Does your dependant get mixed up about where he/she is?	Rarely	115.7
	Sometimes	85.0
	Frequently	72.5
	Always	71.7
Is your dependant able to recognise familiar people, e.g. family and friends?	Frequently	80.3
	Sometimes	78.5
	Rarely	74.9
	Never	71.1
Is your dependant partly/completely immobile and needs lifting?	Rarely	97.0
	Sometimes	84.4
	Frequently	75.5
	Always	65.5

Table 5.27: Dementia caregiving problems with peak in DCBQ mean score in the 'rarely' category of frequency

For some caregiving problems, however, the trend is for caregiving burden scores to increase monotonically with the frequency of the problem. This is most clearly seen to occur in the following four caregiving problems:

Dementia caregiving problem	Frequency	Mean DCGB score
Does your dependant try to get up and dressed/go outdoors during the night?	Rarely	81.8
	Sometimes	82.8
	Frequently	91.9
	Always	122.0
Does your dependant become angry and resistive to care?	Rarely	70.6
	Sometimes	75.0
	Frequently	82.7
	Always	96.9
Does your dependant become irritable and get easily upset?	Rarely	72.0
	Sometimes	79.0
	Frequently	84.2
	Always	95.2
Does your dependant appear to be unhappy and depressed?	Rarely	71.3
	Sometimes	79.7
	Frequently	82.5
	Always	91.7

Table 5.28: Dementia caregiving problems showing exponential increase in caregiving burden with increasing frequency

It may be that the majority of carers simply never become tolerant to these caregiving problems and they never become easier to manage, thus caregiving burden scores build and peak with the highest problem frequency. Dealing with night-time wandering, anger and resistiveness, unpredictable irritability and short-temperedness and dependant depression must be incredibly difficult and stressful for carers and reduce capacity to continue in the caregiving role. Perhaps these problems, together with those identified above as being the most burdensome for carers, should be viewed as being those which health and social care professionals should target for interventions such as caregiver training sessions to improve coping strategies and assist carers to gain more control over them, thus having an impact on reducing stress and caregiving burden. Those most stressful and difficult to manage caregiving problems which the carer could be relieved of by home care workers, for example, washing and dressing the dependant – a time when resistiveness and anger are often experienced, would also be usefully targeted and have maximum benefit for carers, enabling them to continue in the caregiving role for longer than might otherwise be the case if the high stress continued unassisted.

By way of final clarification, the following table lists the caregiving problems which had positive correlations with 'Overall DCBQ' score. The list is somewhat similar to tables 24 and 25, but is more representative as it portrays the most burdensome problems across the frequency range.

Dementia caregiving problem	Correlation with Overall DCBQ score
Shouts/swears/screams at people/me for no apparent reason	+0.452 (p<0.01)
Becomes irritable and easily upset	+0.410 (p<0.01)
Wakes me/others during night	+0.308 (p<0.01)
Has difficulty settling to sleep or wakes unusually early	+0.308 (p<0.01)
Tries to get up and dressed/go outdoors during the night	+0.300 (p<0.05)
Appears to be unhappy and depressed	+0.290 (p<0.05)
Mood changes suddenly for no apparent reason	+0.281 (p<0.05)
Has to be prevented from wandering outside the house	+0.261 (p<0.05)
Endangers self by engaging in risky behaviours	+0.261 (p<0.05)
Prone to having falls/fits/choking	+0.244 (p<0.05)
Hits out at me/other people	+0.245 (p<0.05)
Tends to collect things and hoard them	+0.232 (p<0.05)

Table 5.29: Dementia caregiving problems and correlations with Overall DCBQ score

The above list of most burdensome caregiving problems is relevant in that in terms of risk assessment they may be the most important for the care manager to consider in terms of community care services intervention and care planning. If they occur rarely or sometimes then assessment of perceived impact will be required and appropriate care interventions and service inputs planned; if they occur frequently or always then the risk of high caregiving burden and even breakdown in caregiving situations becomes great and the need for support urgent.

It can be seen from the above list that seven of the 12 most burdensome caregiving problems came from the 'Behaviour problems' domain and three were from the 'Mood problems' domain. In examining correlations between caregiving problem domains and 'Overall DCBQ' scores, the 'Behaviour problems' domain showed a positive correlation of +0.425 (p<0.01) and the 'Mood problems' domain +0.348 (p<0.01). As noted above, caregiving problems experienced in these domains may need to be especially targeted by way of appropriate service interventions and support.

5.21 Results of 'Dementia Caregiving Burden Questionnaire (DCBQ)'

The results of the 'Dementia Caregiving Burden Questionnaire (DCBQ)', completed by 76 subjects, are as follows:

DCBQ domain	Dementia caregiving burden questions	Frequently/Alway Combined n= (%)
Life upset	How much has your social life been affected?	n=66 (86.8%)
	Do you worry about safely leaving your dependant on his/her own?	n=64 (84.2%)
	Do you feel that you need a holiday - a long-term break from caring?	n=46 (60.5%)
	Do you find it difficult to get away for a break for a few hours?	n=44 (57.9%)
	Do you have difficulty in continuing your relationships due to your caring commitments?	n=44 (57.9%)
	Do you find that your caring responsibilities adversely affect other aspects of your life?	n=38 (50%)
	Have your financial circumstances changed or your standard of living been reduced as a result of caring?	n=27 (35.7%)
	Is your sleep disrupted by your dependant?	n=27 (35.5%)
	Do you have family arguments associated with your present situation?	n=14 (18.5%)
	Do you have to undertake caregiving tasks that you feel are beyond your capabilities?	n=11 (14.4%)
Personal distress	Do you find it distressing that your dependant has changed so much from his/her former self?	n=58 (76.3%)
	Do you have feelings of grief and loss associated with your caring role?	n=42 (55.3%)
	Do you feel exhausted and demoralised in your role?	n=32 (42.1%)
	Do you feel there will be no end to your problems?	n=31 (40.8%)
	Do you feel trapped in the caring role?	n=29 (38.2%)
	Do you feel that you are alone in coping with your caring situation?	n=25 (32.9%)
	Do you feel completely overwhelmed by your situation?	n=20 (32.9%)
	Has your physical health suffered as a result of caring?	n=17 (22.4%)
	Do you find yourself becoming tearful or crying?	n=16 (21%)
	Do you feel you can no longer cope with your situation?	n=11 (14.4%)
Negative feelings	Do you view caring for your dependant as being like caring for a child?	n=44 (57.9%)
	Do you feel frustrated with your dependant?	n=27 (35.5%)
	Are you depressed about your situation?	n=25 (32.9%)
	Do you feel helpless and as if things are outside of your control in your situation?	n=23 (30.2%)
	Are you resentful about the change in the quality of your own life/missed life opportunities?	n=16 (21.1%)
	Do you have feelings of guilt associated with your caring role?	n=15 (19.7%)
	Do you feel like giving up caring?	n=12 (15.8%)
	Are you emotionally distant from your dependant?	n=10 (13.2%)
	Do you get cross and angry with your dependant?	n= 5 (6.6%)
	Do you feel embarrassed by your dependant?	n= 4 (5.3%)
(Lack of) caregiving satisfactions (note results for 'rarely/a little' and 'never/not at all')	Do you have feelings of positive self-worth/self-esteem arising from caring?	n=43 (56.6%)
	Are you feeling hopeful about your future?	n=35 (46.7%)
	Do you derive personal satisfaction and reward from your caring role?	n=34 (44.7%)
	Do you feel that being a carer has provided an opportunity for personal growth and development?	n=33 (43.5%)
	Do you have a sense of achievement or fulfillment as a result of caring?	n=29 (38.2%)
	Do you have a sense of purpose and direction in your caring role?	n=23 (30.2%)
	Do you feel the help you receive from services, family and friends has enabled you to carry on caregiving?	n=18 (23.7%)
	Do you feel you manage your stress well and overcome it?	n=18 (23.7%)
	Do you feel that caring is a positive way of expressing your love and affection for the person you care for?	n=16 (21.1%)
	Do you adopt a positive, problem solving approach?	n=12 (15.7%)

Table 5.30: Frequency of responses to DCBQ questions across all domains

To provide ease of analysis, the ten highest ranking DCBQ questions ('frequently' and 'always' combined) were:

DCBQ domain	Dementia caregiving burden questions	Combined Number/%
Life upset	How much has your social life been affected by caring?	66 / 86.8%
Life upset	Do you worry about safely leaving your dependant on his/her own?	64 / 84.2%
Personal distress	Do you find it distressing that your dependant has changed so much from his/her former self?	58 / 76.3%
Life upset	Do you feel that you need a holiday - a long-term break from caring?	46 / 60.5%
Life upset	Do you find it difficult to get away for a break for a few hours?	44 / 57.9%
Negative feelings	Do you view caring for your dependant as being like caring for a child?	44 / 57.9%
Life upset	Do you have difficulty in continuing your relationships due to your caring commitments?	44 / 57.9%
Lack of caregiving satisfactions	Do you have (a lack of) feelings of positive self-worth/self-esteem arising from caring?	43 / 56.6%
Personal distress	Do you have feelings of grief and loss associated with your caring role?	42 / 55.3%
Life upset	Do you find that your caring responsibilities adversely affect other aspects of your life?	38 / 50%

Table 5.31: Highest ranking DCBQ questions

Looking at the above 'Top 10' most frequent responses to the 'Dementia Caregiving Burden Questionnaire (DCBQ)', one can see that the majority of carers had a significant degree of 'Life Upset', with 66 (86.8%) responding that their social life had been considerably or always detrimentally affected by caregiving, 64 (84.2%) frequently or always worrying about safely leaving their dependant alone, 46 (60.5%) frequently or always feeling they needed a holiday or long-term break from caregiving and 44 (57.9%) frequently or always finding it difficult to get away for a break for a few hours. These data, coupled with the findings that 27 (35.5%) carers frequently or always had sleep disturbance and 11 (14.4%) frequently or always undertook caregiving tasks beyond their capabilities, emphasises the enormous commitment that carers had made to providing care for their dependant, often in the face of little or no respite from the constant demands of caregiving.

Looking at these data, one begins to understand the enormity of the role of dementia caregiver and the true nature of caregiving burden in this client group. It is worth reiterating that for most carers their role had lasted for several years, and with little or no day-to-day support from family, friends or services, as will be evidenced later in this chapter. Dementia caregiving had inevitably become more difficult as the dementing illness had progressed and it had accompanied losses rather than gains in the physical and emotional well-being of the dependant.

There was also strong evidence to suggest that many carers in this cohort were having significant emotional problems in coping with the excessive demands of caregiving. Indeed, in response to questions relating to 'Personal Distress' 32 (42.1%) carers admitted to frequently or always feeling exhausted and demoralised in their role, 31 (40.8%) frequently or always felt there would be no end to their problems, 29 (38.2%) frequently or always felt trapped in the caregiving role and 20 (26.3%) frequently or always felt completely overwhelmed by their situation. Another, 25 (32.9%) carers reported frequently or always feeling depressed by their situation and 16 (21%) admitted to frequently or always being tearful and crying. These data support the previous discussion regarding clinical depression in the study cohort.

To further support the previous discussion relating to relationship change, 58 (76.3%) carers frequently or always found it distressing that their dependant had changed so much from their former self, 42 (55.3%) reported frequently or always having feelings of grief and loss and 44 (57.9%) frequently or always equated caring for their older dependant to caring for a child. Perhaps more worryingly, ten (13.2%) carers admitted to frequently or always feeling emotionally distant from their relative and 16 (21.1%) carers did not feel that providing care was a positive way of expressing love and affection for the person cared for. These findings point to significant relationship breakdown between some carers and dependants and are a cause for concern given that many were coping alone in the face of limited breaks and choices for future care.

Responses to several other questions in the 'Negative Feelings' domain are also a cause for concern, with 27 (35.5%) carers stating they frequently or always felt frustrated by their dependant, 23 (30.2%) stating that they frequently or always felt helpless and as if the situation was out of their control, 16 (21.1%) stating that they frequently or always felt resentful about missed life opportunities, 15 (19.7%) stating that they frequently or always felt guilty about their caregiving situation, and five (6.6%) admitting to frequently or always getting cross and angry with their dependant. Indeed, 12 carers (15.8%) stated that they frequently or always felt like giving up caregiving. These responses highlight significant problems in coping with caregiving, especially when viewed in association with responses to '(Lack of) Satisfaction' questions, such as a frequent or always lack of feeling of positive self-worth/self-esteem arising from caregiving reported by 43 (56.6%) carers, a frequent or always lack of feeling hopeful about the future reported by 35 (46.7%) carers, a frequent or always lack of personal satisfaction and reward reported by 34 (44.7%) carers, and a frequent or always lack of a sense of achievement or fulfilment as a result of caregiving reported by 29 (38.2%) carers.

Similarly, the fact that 18 (23.7%) carers frequently or always felt they did not manage their stress well and overcome it and 12 (15.7%) carers frequently or always felt they did not adopt a positive, problem-solving approach to caregiving is concerning, as are the findings that 18 (23.7%) carers frequently or always did not feel that the help they received from services, family and friends enabled them to carry on in the caregiving role and that 25 (32.9%) carers frequently or always felt alone in coping with their caregiving situation.

Particular attention should be given by services to those carers who are coping alone with little or no support and few breaks from caregiving, those who are coping poorly and have a low tolerance threshold, those who are at risk of developing or have developed psychological health problems, and to those who admit to being emotionally detached from their dependant. The risk in this group of carers for breakdown in caregiving situations and crisis unplanned admissions to permanent care, or worse, caregiving situations becoming abusive, is likely to be great. Such carers should be targeted for intensive service interventions, including frequent home care worker support to relieve them of their most stressful caregiving demands, frequent respite breaks from caregiving both in the form of day care and longer-term breaks, and the consideration of facilitated relinquishment of home caregiving. Carers who overtly express a desire to end their caregiving role should be considered a priority for this option.

The 'Dementia Caregiving Burden Questionnaire' designed for this study seems useful in highlighting these concerns and the individual question results and overall domain and questionnaire scores will be of value to care managers in identifying 'at risk' caregiving situations.

By way of clarification, it was useful to examine correlations between the DCBQ and the 'Carers Self-assessed Stress' rating, as an external measure. The results of the strongest positive correlations are as follows:

DCBQ question	Correlation with Carers Stress rating
Do you feel completely overwhelmed by your situation?	+0.724 (p<0.01)
Do you feel you can no longer cope with your situation?	+0.717 (p<0.01)
Do you (not) feel you manage your stress well and overcome it?	+0.710 (p<0.01)
Are you depressed about your situation?	+0.668 (p<0.01)
Do you feel exhausted and demoralised in your role?	+0.666 (p<0.01)
Do you feel there will be no end to your problems?	+0.621 (p<0.01)
Do you feel helpless and as if things are outside of your control?	+0.608 (p<0.01)
Do you adopt a positive, problem solving approach? (reversed)	+0.607 (p<0.01)
Do you feel frustrated with your dependant?	+0.525 (p<0.01)
Do you feel like giving up caring?	+0.511 (p<0.01)
Has your physical health suffered as a result of caring?	+0.506 (p<0.01)
Are you feeling hopeful about your future? (reversed)	+0.500 (p<0.01)
Do you feel trapped in the caregiving role?	+0.488 (p<0.01)
Are you resentful about the change in the quality of your own life/missed life opportunities?	+0.465 (p<0.01)
Do you feel that you are alone in coping with your caregiving situation?	+0.463 (p<0.01)
Do you have to undertake caregiving tasks that you feel are beyond your capabilities?	+0.448 (p<0.01)
Do you view caring for your dependant as being like caring for a child?	+0.418 (p<0.01)

Table 5.32: Correlations between DCBQ questions and 'Carers Stress' rating

(Note: There were 15 other questions with correlations to the level of p<0.01)

These specific questions are those which are most highly associated with high stress and poor coping, and as such may be the most predictive of breakdown in caregiving situations. They, in association with the most burdensome caregiving problems identified above, may be the most valuable for inclusion in a 'Dementia Caregiving Breakdown Risk Assessment' tool, which is proposed in the concluding chapter.

5.22 'Dementia Caregiving Burden Questionnaire (DCBQ)' cohort data

Data on results for the cohort of overall scores in the 'Dementia Caregiving Burden Questionnaire (DCBQ)' are as follows:

(It should be noted that 15 of 91 current carers (16.5%) did not complete the DCBQ (which included the 'Carer Stress Self-assessment' – data on which follows in the next section). All non-completions were from the internet sample and could be attributed either to questionnaire completion fatigue (the DCBQ was a separate and distinct section to the on-line questionnaire) or problems in electronic submission (the DCBQ was the third of four sections which were submitted separately via html 'submit' buttons to the researchers email address).

DCBQ domain	DCBQ scores		Number
Overall DCBQ score	0 – 40	Minimal to mild caregiving burden experienced	7
	41-80	Mild to moderate caregiving burden experienced	34
	81-120	Moderate to severe caregiving burden experienced	31
	121-160	Severe to extreme caregiving burden experienced	4
Life upset	0 – 10	Minimal to mild life upset experienced	3
	11-20	Mild to moderate life upset experienced	22
	21-30	Moderate to severe life upset experienced	38
	31-40	Severe to extreme life upset experienced	13
Personal distress	0 – 10	Minimal to mild personal distress experienced	13
	11-20	Mild to moderate personal distress experienced	22
	21-30	Moderate to severe personal distress experienced	33
	31-40	Severe to extreme personal distress experienced	8
Negative feelings	0 – 10	Minimal to mild negative feelings experienced	21
	11-20	Mild to moderate negative feelings experienced	31
	21-30	Moderate to severe negative feelings experienced	23
	31-40	Severe to extreme negative feelings experienced	1
(Lack of) Positive feelings	0 – 10	Minimal to mild positive feelings experienced	13
	11-20	Mild to moderate positive feelings experienced	30
	21-30	Moderate to severe positive feelings experienced	24
	31-40	Severe to extreme positive feelings experienced	9

Table 5.33: Cohort scores for DCBQ

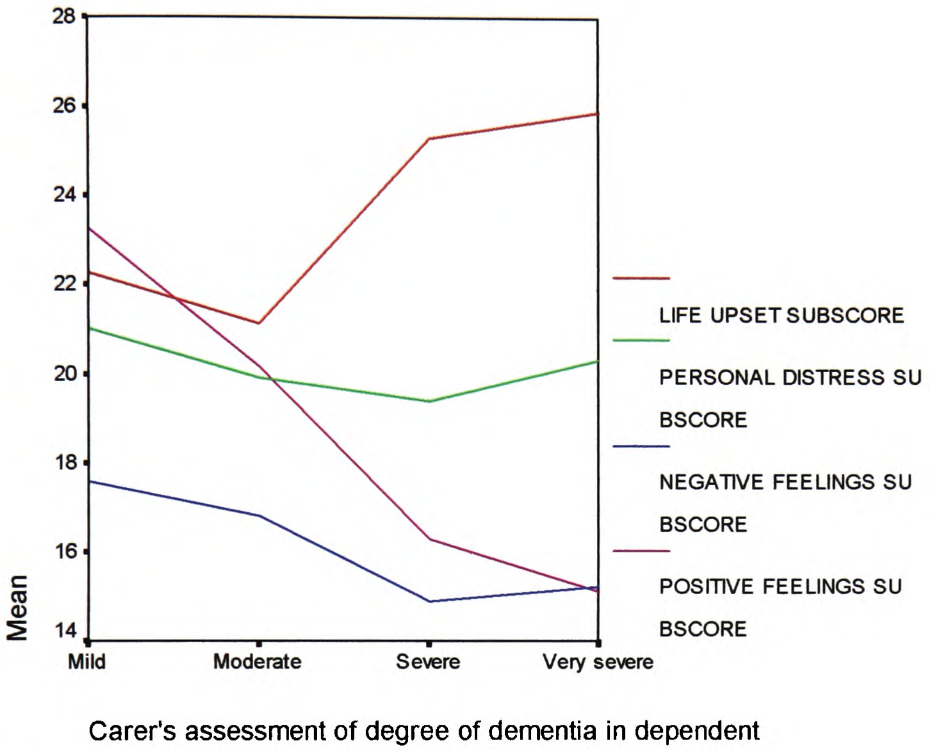
Whilst looking at the 'Overall DCBQ' cohort scores, one can see that there were four carers with scores in the 'severe to extreme' category and 13, eight, one and nine carers with 'severe to extreme' scores in the 'Life upset', 'Personal distress', 'Negative feelings', and '(Lack of) Positive feelings' domain scores respectively.

The lower 'Negative feelings' score could perhaps, in part, be accounted for by the fact that carers find it harder to disclose negative feelings, despite the fact that they are not labelled as such on the questionnaire. Admitting to feelings of frustration, guilt, embarrassment, getting cross and angry with the dependant and feeling like giving up caregiving are not easy to disclose to a stranger, even anonymously. Perhaps they are even not easy to admit to oneself! This is why in future guidance notes for administration of the DCBQ, spaces for comments will be included so that personal insights into the reasons for feelings can be made by carers and observed by care managers.

The following table and graph highlight the differences in 'Dementia Caregiving Burden Questionnaire (DCBQ)' mean domain scores across the trajectory of dementia:

Degree of dementia	Life upset mean score	Personal distress mean score	Negative feelings mean score	(Lack of) Positive feelings mean score	Overall DCBQ mean score
Mild	22.3	21.0	17.6	23.3	84.1
Moderate	21.1	19.9	16.8	20.2	78.0
Severe	25.7	19.9	15.1	16.3	75.8
Very severe	25.9	20.3	15.2	15.1	76.6

Table 5.34: Mean DCBQ scores against degree of dementia



Graph 5.2: Relationship of DCBQ domains with degree of dementia
(Please note that this graph does not begin at point zero)

One can see from the table and graph above that mean 'Life upset' scores peaked in the 'severe' and 'very severe' stages of the illness trajectory. This makes sense, given that the more physically frail person with severe dementia could not be left alone, the carer would inevitably become more socially isolated, getting breaks would become more difficult, perhaps due to the person being too dependent to be appropriate for or travel to day care services, finances would be adversely affected due to continence care and other costs, etc. Indeed, correlations between individual 'Life upset' questions and the 'Degree of dementia' rating were as follows:

'Do you have to undertake caregiving tasks which are beyond your capability?' +0.289 ($p<0.05$)

'Do you have family arguments associated with your caregiving situation?' +0.238 ($p<0.05$)

'Do you worry about safely leaving your dependant at home alone?' +0.233 ($p<0.05$)

These results concur with qualitative data obtained relating to increasing social isolation for the carer as the dementing illness progresses; increased family arguments, often around another family member trying to push the primary carer towards relinquishment of home caregiving; and carers having to work above and beyond their physical capabilities in caring for a person with severe dementia at home, for example, in relation to manual handling issues. These questions may be particularly useful for care managers in decision-making around increasing service interventions to 'at risk' caregiving situations.

The correlation between the overall 'Life upset' domain score and 'Degree of dementia' rating was +0.256 ($p<0.05$).

'Personal distress' scores remained fairly constant across the dementia trajectory, indicating that caring for a person with dementia at whatever stage of the illness results in moderately high levels of distress, grief and loss, exhaustion and demoralisation, etc. There was no relationship between the overall 'Personal distress' domain score or individual personal distress questions and 'Degree of dementia'.

Regarding 'Negative feelings' domain scores, the picture was somewhat different. Scores in this domain peaked in the mild and moderate stages of the illness and fell slightly in the severe and very severe stages. This may be associated with peaks in 'Behaviour' and 'Mood' caregiving problem domains across the dementia trajectory.

Only one 'Negative feelings' question had a correlation (negative) with 'Degree of dementia', and that was:

'Do you have feelings of guilt associated with your caregiving role?' -0.248 ($p<0.05$)

This question may be especially important as it demonstrates a decrease in guilty feelings at things said or done to the dependant as the illness progresses and supports the previous discussions around dementia caregiving becoming less burdensome as the dementia illness trajectory advances to its more advanced stages.

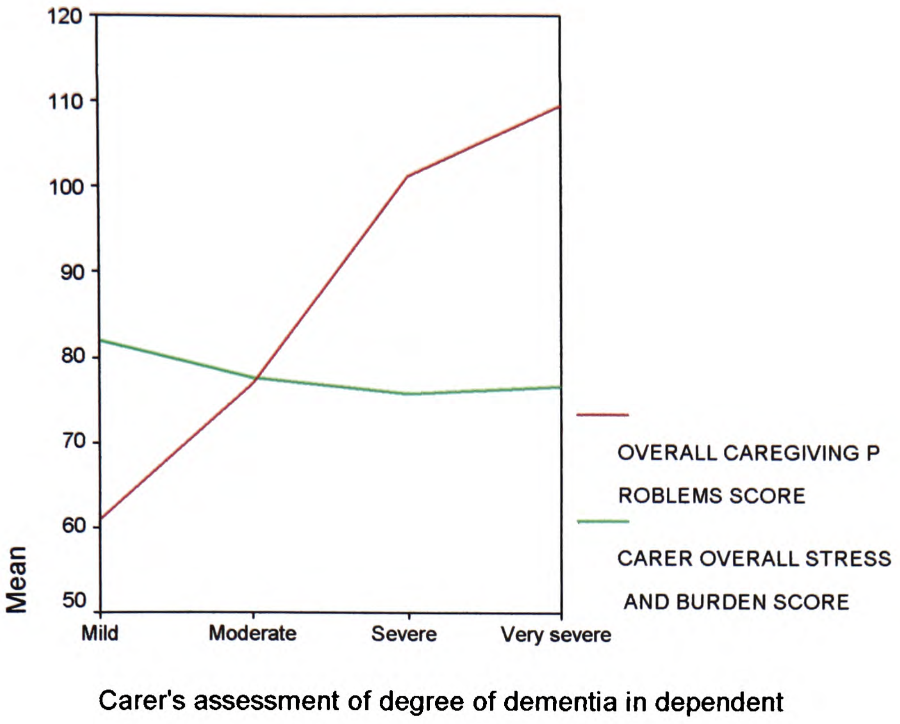
There was no relationship between the overall 'Negative feelings' domain and 'Degree of dementia' rating.

Regarding the '(Lack of) Positive feelings' domain, the picture is very different, with a monotonical decrease in scores across the dementia trajectory, i.e. an increase in positive feelings as the dementing illness advances. Correlations between '(Lack of) Positive feelings' questions and the 'Degree of dementia' rating were as follows:

'Do you derive personal satisfaction and reward from your caregiving role?' -0.354 ($p<0.01$)
'Do you have a sense of achievement or fulfillment as a result of caregiving?' -0.343 ($p<0.01$)
'Do you feel that caring is a positive way of expressing your love and affection for the person you care for?' –0.247 ($p<0.05$)
'Do you feel that you adopt a positive, problem-solving approach to caring?' –0.237 ($p<0.05$)

There was a negative correlation between overall '(Lack of) Positive feelings' domain score and the 'Degree of dementia' rating of -0.301 ($p<0.01$).

Bearing in mind that the '(Lack of) Positive feelings' domain questions are scored with reversed polarity, i.e. a lack of satisfactions, the above negative correlations demonstrate that positive feelings actually increase as the dementing illness advances. This is a crucially important finding as it indicates increasing satisfactions in caregiving and improved coping as the dementing illness progresses. This may be due to a number of factors, such as it becoming easier to care for the person as they become less behaviorally disturbed and more passive and accepting of care; there being less conflict in the relationship as the person becomes more mentally impaired; the carer learning skills, either through trial and error or through receiving information and education, and achieving some mastery over their situation; and perhaps the carer feeling more sympathy for the person with dementia as they become more frail and dependent. Whatever the reason, this finding means that for those currently coping with high levels of behaviour and mood disturbance and experiencing high levels of caregiving burden, particularly in the 'Personal distress' and 'Negative feelings' domains, if service interventions could be increased significantly to provide regular and more flexible breaks from caregiving and if the carer could be relieved of their perceived most stressful and burdensome caregiving problems through targeted home care, improved medication management, etc. until the dementing illness advanced to a more passive stage, then the carer could remain in their role until such time as home caregiving became physically impossible due to physical capability/environmental constraints or the person with dementia died. This might lead to significant health and social services budget savings, e.g. in reducing the need for permanent care beds.



Graph 5.3: Relationship between the DCPQ and DCBQ
(Please note this graph does not begin at point zero)

The above graph demonstrates the relationship between the DCPQ and DCBQ. One can see that whilst the 'Overall DCPQ' score increases monotonically across the dementia trajectory, the 'Overall DCBQ' score remains fairly constant. This is probably because the increase in 'Life upset' domain scores and constancy of 'Personal distress' domain scores are balanced out by the simultaneous decreases in '(Lack of) Positive feelings' domain scores and, to a lesser extent, 'Negative feelings' domain scores.

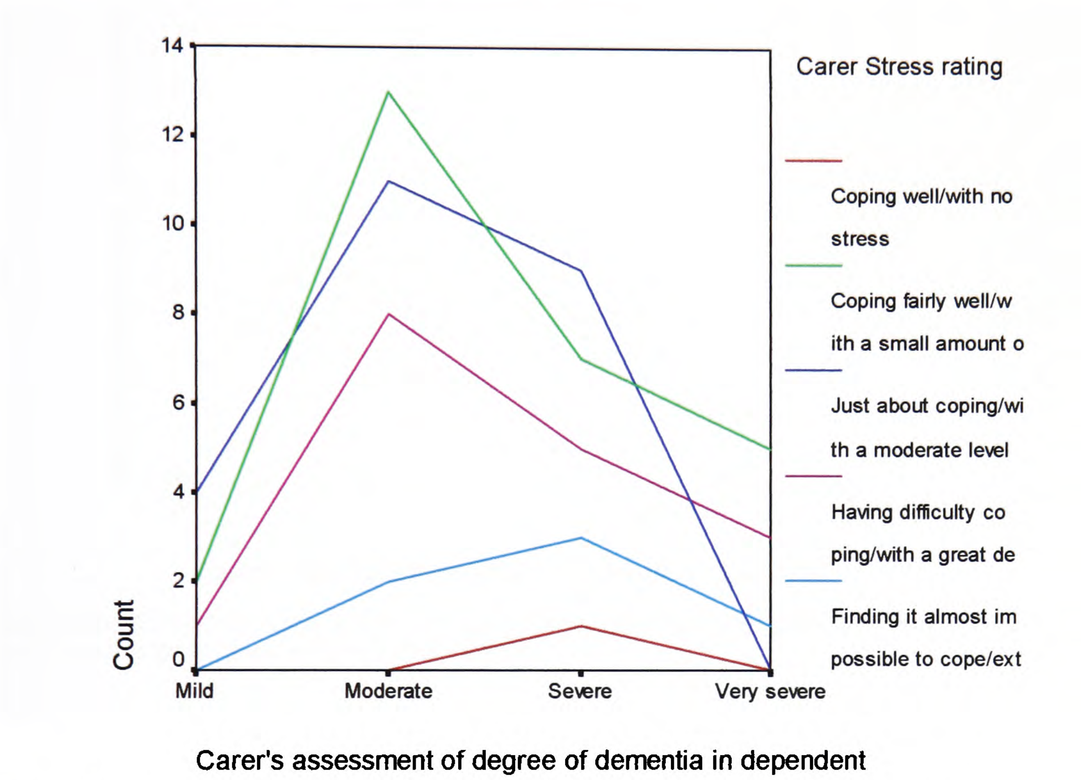
5.23 'Carer Stress Self-assessment' data

Data on the 'Carer Stress Self-assessment Rating' data for the study cohort (completed by 76/91 subjects) are as follows:

Carer Stress Self-assessment Rating	Number	Percent
Coping well/with no stress	1	1.3
Coping fairly well/with a small amount of stress	27	35.5
Just about coping/with a moderate level of stress	24	31.6
Having difficulty coping/with a great deal of stress	18	23.7
Finding it almost impossible to cope/with an extremely high level of stress	6	7.9

Table 5.35: Carer Stress Self-assessment Rating Cohort data

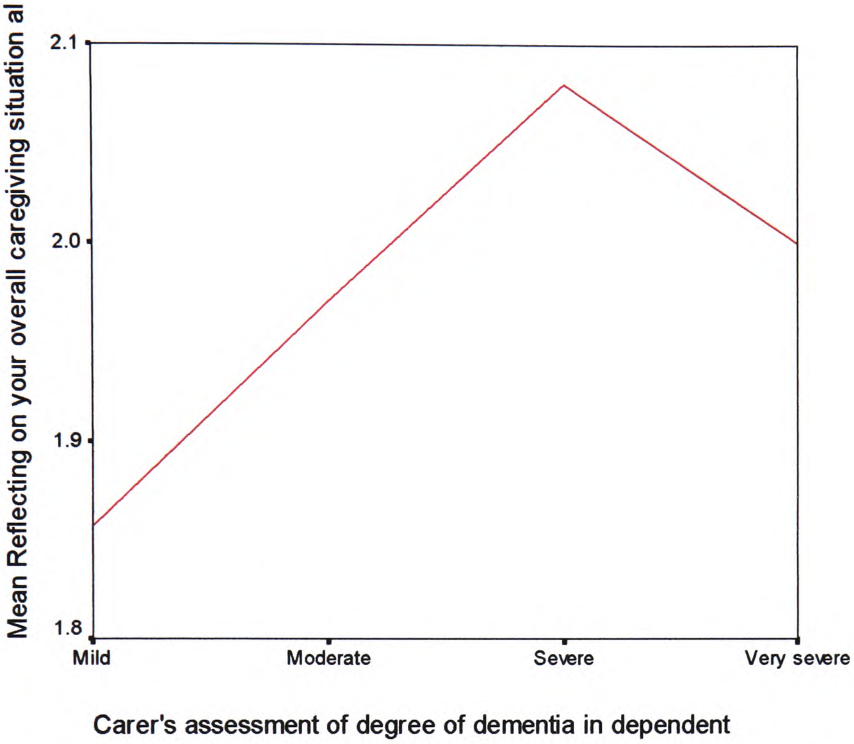
One can see from the above data that the majority of carers were 'Coping fairly well/with a small amount of stress' (27 / 35.5%) or 'Just about coping/with a moderate level of stress' (24 / 31.6%). However, 18 (23.7%) carers were 'Having difficulty coping/with a great deal of stress' and six (7.9%) carers were 'Finding it almost impossible to cope/with an extremely high level of stress'. This 'Carer Stress Self-assessment' item, attached to the DCBQ, appears to be a useful tool in helping carers to consider and identify what degree of stress they are experiencing and their coping ability. This could act as a valuable catalyst for meaningful discussion between the carer and care manager on stress and coping, which are essential to consider when planning service interventions.



Graph 5.4: Relationship of 'Caregiver Stress Self-assessment' scores with degree of dementia

One can see from this graph that there is a peak in the 'moderate' dementia rating for 'Coping fairly well/Small amount of stress', which is not surprising given that there is an expectation that stress increases and coping reduces as dementia becomes more severe. However, there is a similar peak in the 'moderate' dementia rating for 'Just about coping/Moderate level of stress' and 'Having difficulty coping/Great deal of stress', with a reduction in stress/increase in coping as the dementia rating moves towards 'severe' and 'very severe'. Even for the highest point on the stress scale, 'Finding it almost impossible to cope/Extremely high level of stress', there is a peak at the 'severe' dementia point on the scale and a reduction for the 'very severe' dementia rating.

The following graph, which examines the relationship between mean stress/coping scores and severity of dementia ratings demonstrates this more clearly, with an increase in stress/reduction in coping as dementia trajectory moves from ‘mild’ through ‘moderate’ to ‘severe’, where there is a peak and then a reduction towards the ‘very severe’ rating.



Graph 5.5: Relationship of ‘Carer Stress Self-assessment’ mean score with degree of dementia (Please note this graph does not begin at point zero)

These findings support the previous discussion which proposed that dementia caregiving may actually become easier as the illness advances towards its severest stages, with a reduction in stress and improved coping. Thus if the carer could be supported through their peak in stress/poor coping, which occurs for most between the ‘moderate’ and ‘severe’ stages of the illness, then continued home caregiving could be facilitated for many. If carers could receive more intensive service interventions aimed at meeting their specific needs during this most difficult period of caregiving, when behaviour and mood problems are at their peak, then they may be enabled to continue in their caregiving role for several months or years longer, with reduced stress, improved coping and increased caregiving satisfactions.

5.24 Reliability of DCPQ and DCBQ

The DCPQ and DCBQ are the two main research tools devised for this thesis and it is aimed that they will be made available to community care practitioners for implementation in clinical practice after the study is completed. Therefore, it was important to investigate the reliability of the two questionnaires.

The following analysis examines the internal reliability of each of the tools, correlating domain sub scores with each other and the overall scores:

Internal reliability – Dementia Caregiving Problems Questionnaire	Correlation
Communication with Confusion	+0.621**
Communication with Behaviour	+0.467**
Communication with Mood	+0.207
Communication with Self-care/Physical	+0.382**
Communication with Overall DCPQ	+0.773**
Confusion with Behaviour	+0.377**
Confusion with Mood	+0.211
Confusion with Self-care/Physical	+0.439**
Confusion with Overall DCPQ	+0.780**
Behaviour with Mood	+0.484**
Behaviour with Self-care/Physical	+0.002
Behaviour with Overall DCPQ	+0.606**
Mood with Self-care/Physical	-0.003
Mood with Overall DCPQ	+0.466**
Self-care/Physical with Overall DCPQ	+0.649**
Internal reliability – Dementia Caregiving Burden Questionnaire	**Correlation**
	+0.696**
Life upset with Personal distress	+0.503**
Life upset with Negative feelings	+0.265*
Life upset with (Lack of) Positive feelings	+0.724**
Life upset with Overall DCBQ	+0.770**
Personal distress with Negative feelings	+0.574**
Personal distress with (Lack of) Positive feelings	+0.913**
Personal distress with Overall DCBQ	+0.698**
Negative feelings with (Lack of) Positive feelings	+0.888**
Negative feelings with Overall DCBQ	+0.773**
(Lack of) Positive feelings with Overall DCBQ	

Table 5.36: Internal reliability of DCPQ and DCBQ

NB. ** = statistically significant to <0.01 * = statistically significant to <0.05

One can see from this table that there is a high level of correlation between sub-scales within both questionnaires. In respect of the DCPQ, the only sub-scales with no relationship with one another are 'Communication' with 'Mood', 'Confusion' with 'Mood', 'Behaviour' with 'Self-care/Physical', and 'Mood' with 'Self-care/Physical'. These findings are not surprising given the previous discussion concerning the peak of mood and behaviour problems at the moderate and severe stages of dementia and the monotonical increase in communication, confusion and self-care/physical problems throughout the dementia illness trajectory.

In respect of the DCBQ, all sub scales correlate highly with one another except for 'Life upset' with '(Lack of) Positive feelings', where there is a lower correlation. This too might not be that surprising given that 'Life upset' questions focus more on the practical impact of caregiving, whereas all other domains focus on the feelings aroused by caregiving.

The following analysis examines the external reliability of each of the tools, correlating domain sub-scores across both the DCPQ and DCBQ with each other and associated dementia severity and carer self-assessed stress/coping ratings:

External reliability – DCPQ with Carer stress rating	Correlation
Communication with Carer stress	+0.284*
Behaviour with Carer stress	+0.461**
Mood with Carer stress	+0.432**
Overall DCPQ with Carer stress	+0.362**
External reliability – DCBQ with Carer stress rating	Correlation
Life upset with Carer stress	+0.540**
Personal distress with Carer stress	+0.760**
Negative feelings with Carer stress	+0.732**
(Lack of) Positive feelings with Carer stress	+0.606**
Overall DCBQ with Carer stress	+0.790**
External reliability – DCPQ with DCBQ	Correlation
Communication with Life upset	+0.371**
Communication with Personal distress	+0.250*
Confusion with Life upset	+0.292*
Confusion with (Lack of) Positive feelings	- 0.262*
Behaviour with Life upset	+0.442**
Behaviour with Personal distress	+0.361**
Behaviour with Negative feelings	+0.428**
Behaviour with Overall DCBQ	+0.407**
Mood with Life upset	+0.304*
Mood with Personal distress	+0.268*
Mood with Negative feelings	+0.375**
Mood with Overall DCBQ	+0.331**
Self-care/Physical with Life upset	+0.265*
External reliability – DCPQ with Degree of dementia rating	Correlation
Communication with Degree of dementia	+0.666**
Confusion with Degree of dementia	+0.568**
Self-care/Physical with Degree of dementia	+0.572**
Overall DCPQ with Degree of dementia	+0.646**
External reliability – DCBQ with Degree of dementia rating	Correlation
Life upset with Degree of dementia	+0.294*
(Lack of) Positive feelings with Degree of dementia	-0.309**

Table 5.37: External reliability of DCPQ and DCBQ

NB. ** = statistically significant to <0.01 * = statistically significant to <0.05

One can see from this table that there is a high level of correlation between the 'Behaviour' and 'Mood' problem domains of the DCPQ and the 'Carers stress self-assessment' rating. There is also a high level of correlation between the 'Overall DCPQ score' and 'Carer stress' rating, and a lower level of correlation between the 'Communication problems domain and 'Carer stress' rating. This is not surprising given the previous findings and discussion about the most stressful caregiving problems, and indicates that these caregiving problems in particular may need to be a focus for community service interventions with a particular emphasis on problem management/stress reduction.

There is also a high level of correlation between all domains in the DCBQ and the 'Carers stress self-assessment' rating. As the second of these is a single-item self-assessed rating, such a high level of correlation demonstrates external empirical (criterion) validity of the DCBQ as a new carers' assessment tool, indicating that it is highly suitable for implementation in clinical practice.

Regarding correlations between the DCPQ and DCBQ, it can be seen that the highest levels of correlation are between the 'Communication' and 'Life upset' domains, the 'Behaviour' and 'Life upset' domains, the 'Behaviour' and 'Personal distress' domains, the 'Behaviour' and 'Negative feelings' domains, the 'Behaviour' domain and 'Overall DCBQ' score, the 'Mood' and 'Negative feelings' domains, and 'Mood' domain and 'Overall DCBQ' score. In addition, there are lower levels of correlation between the 'Communication' and 'Personal distress' domains, the 'Confusion' and 'Life upset' domains, the 'Behaviour' and 'Life upset' domains, the 'Mood' and 'Life upset' domains, and the 'Self-care/Physical' and 'Life upset' domains.

There are no relationships between the 'Communication' and 'Negative feelings' domains, the 'Communication' and '(Lack of) Positive feelings' domains, the 'Confusion' and 'Personal distress' domains, the 'Confusion' and 'Negative feelings' domains, the 'Behaviour' and '(Lack of) Positive feelings' domains, and the 'Mood' and '(Lack of) Positive feelings' domains.

Perhaps surprisingly, there is also no relationship between the 'Self-care/Physical' problems domain and any of the DCBQ domains, apart from a lower level correlation between the 'Self-care/Physical' problems domain and the 'Life upset' domain. This is very interesting as it demonstrates that these mainly dependency/dementia severity related caregiving problems may be less important than behaviour, mood and communication problems in provoking high levels of caregiving burden.

Similarly, there is a low level of correlation between the 'Confusion' problems domain and the 'Life upset' domain, and a negative correlation between the 'Confusion' domain and '(Lack of) Positive feelings' domain. Again, this is interesting as it indicates that dementia severity is less important in provoking high levels of caregiving burden and that more positive feelings may be experienced as dementia severity increases.

When correlated with the 'Degree of dementia' rating, the DCPQ shows a high level of correlation in the 'Communication', 'Confusion' and 'Self-care/Physical' domains. The overall DCPQ score also correlates with the 'Degree of dementia' rating highly, demonstrating that this newly devised carers' assessment tool, and the above three domains in particular, are highly reliable in measuring caregiving problems experienced as the caregiver journeys along the dementia caregiving trajectory. As previously discussed, the 'Behaviour' and 'Mood' domains peak in the moderate to severe stages of the illness trajectory, so it is not surprising that there is not a linear correlation with dementia severity.

When the DCBQ is correlated with the 'Degree of dementia' rating, only one domain shows a high level of correlation and this is the '(Lack of) Positive feelings' domain, where there is a negative correlation. Again, this supports previous findings and discussions which demonstrate that the satisfactions of caregiving actually increase as the dementing illness becomes more severe and that caregiving may actually become less burdensome and easier to emotionally cope with.

As both the DCPQ and DCBQ comprise of questions which are summed into meaningful sub-scales and overall scores are obtained, the study tools lend themselves to psychometric properties testing. Reproduced below are the Cronbach Alpha coefficients for each index for both carer assessment tools and for the complete questionnaires. Guttman Split Half reliability test results are also included. (76 current carers completed the DCPQ; 76 current carers completed the DCBQ.)

Carer Assessment Tool	Cronbach's Alpha
Dementia Caregiving Problems Questionnaire	.7029
Dementia Caregiving Burden Questionnaire	.8430
Sub-scales	Cronbach's Alpha
DCPQ – Communication	.7359
DCPQ – Confusion	.8017
DCPQ – Behaviour	.8510
DCPQ – Mood	.6738
DCPQ – Self-care/Physical	.8682
DCBQ – Life upset	.8194
DCBQ – Personal distress	.8919
DCBQ – Negative feelings	.8478
DCBQ – (Lack of) Positive feelings	.8585
Carer Assessment Tool	Guttman Split Half
Dementia Caregiving Problems Questionnaire	.6336
Dementia Caregiving Burden Questionnaire	.7581

Table 5.38: Results of reliability tests for the DCPQ and DCBQ

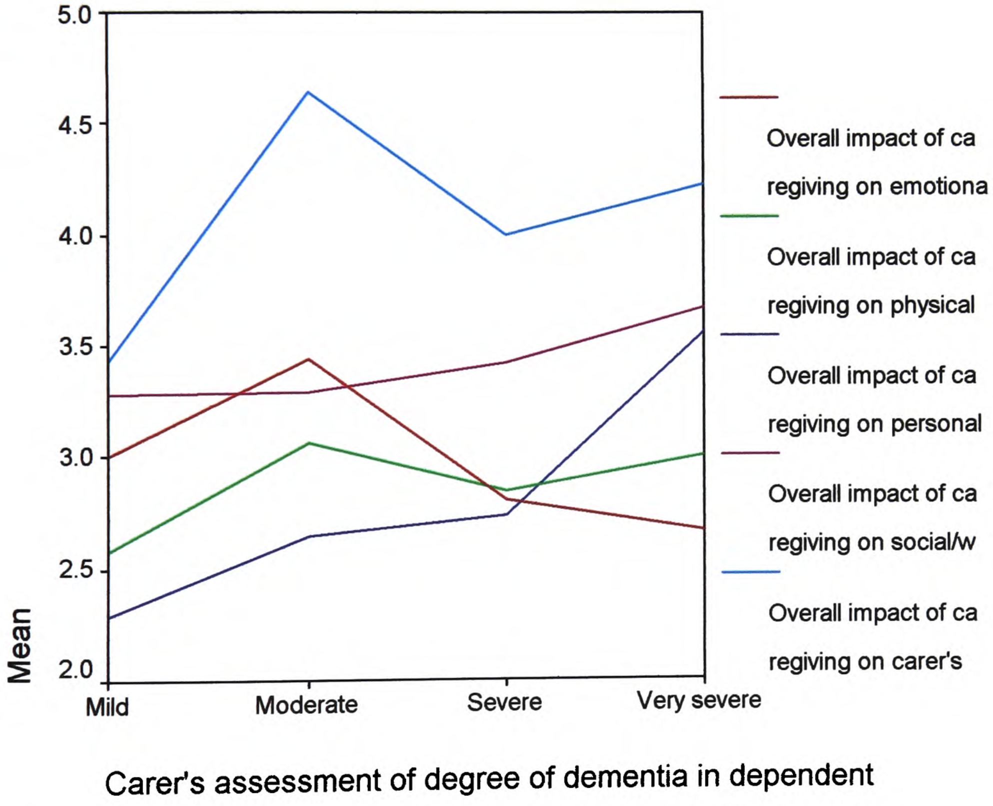
It is convention in psychometric practice to treat a Cronbach Alpha of 0.7 or higher as being adequate to demonstrate reliability. Most of the domains in the table above are above that threshold. The above tests of reliability show that both carers' assessment tools have a high level of internal consistency and can therefore be recommended for implementation in clinical practice. Indeed, since the study commenced and the DCPQ and DCBQ appeared on the internet, many community care practitioners have approached the researcher for preliminary permission to use them in their care management work, which represents further practice-based evidence of their face validity.

5.25 Impact on well-being/quality of life

Data on the perceived impact of caregiving on 'Emotional well-being', 'Physical well-being', 'Personal relationships/Family life', 'Social/Work life' and 'Overall quality of life' for the study cohort are as follows:

Overall impact of caregiving on:	Very positive impact	Positive impact	No real impact	Negative impact	Very negative impact	Extremely negative impact
Emotional well-being	-	7 9.2%	6 7.9%	36 47.4%	27 35.5%	-
Physical well-being	-	2 2.6%	12 15.8%	51 67.1%	11 14.5%	-
Personal relationships/Family life	2 2.6%	8 10.5%	12 15.8%	39 51.3%	15 19.7%	-
Social/Work life	-	1 1.3%	5 6.6%	34 44.7%	36 47.4%	-
Overall quality of life	**2** **2.6%**	**4** **5.3%**	**1** **1.3%**	**43** **56.6%**	**17** **22.4%**	**9** **11.8%**

Table 5.39: Carer well-being/Quality of life rating cohort data



Graph 5.6: Relationship of quality of life ratings to degree of dementia
(Please note this graph does not begin at point zero)

One can see from these data that carers perceived the most negative impact of caregiving as being on their 'Social/Work life (employment)', with a combined total of 70 of the 76 who completed this part of the questionnaire (92.1%) rating the impact in the 'negative/very negative' category. This was closely followed by a combined total of 63

(82.9%) rating the impact on their 'Emotional well-being' as 'negative/very negative', 62 (81.6%) rating the impact on their 'Physical well-being' as 'negative/very negative', and 54 (71%) rating the impact on their 'Personal relationships/Family life' as 'negative/very negative'. It is important to note that for each category there were several 'positive' impact responses, most notably in 'Personal relationships/Family life', where there were eight in the 'positive impact' and two in the 'very positive impact' categories (total 10 / 13.1%).

In terms of the 'Overall quality of life impact' rating, two additional points on the Likert scale were added, namely 'extremely positive' and 'extremely negative' impact ratings. It is important to note that for this rating there were no responses in the 'extremely positive' category and most (69/90.8%) responses were in the negative categories. Particular concern should perhaps be noted for those nine (11.8%) carers who perceived the overall impact of caregiving on their quality of life as being 'extremely negative'. Perhaps they, and their counterparts who rated in the 'very negative' impact category, would be particular candidates for discussions around urgent increases in care packages/respite care in care management meetings if this information was collected in local carers' assessment procedures.

The following table categorises the themes emerging from responses to the open question 'Please describe the impact that caregiving has had on your quality of life.' (71 of the 91 current carer sample responded to this question.)

Statement Category	Statement	Number
Isolation and confinement (n=33)	Can't leave dependant alone/go out Caregiving has restricted life Feel trapped/like a prisoner	14 5 5
Psychological health impact (n=22)	Stress/stressed Lost confidence Suffer from depression	6 3 2
Social life impact (n=21)	No longer have a social life Restricted social life Social life all but gone/practically non existent	9 6 2
Quality of life (n=20)	Have no quality of life Dementia/caregiving changes your whole life Quality of life has suffered	4 3 2
Grief and loss (n=18)	Changes in dependant distressing Distressing to know dementia is a progressive illness Devastated by dementia	4 3 2
Family life impact (n=18)	Little time left for family Caregiving has brought family closer together Family involved in/support caregiving	4 3 3
Impact on friendships (n=14)	Have lost friends as a result of caregiving Contact with friends is restricted Friendships have suffered as a result of caregiving	4 4 2
Physical health impact (n=14)	Physical health has deteriorated as a result of caregiving Caregiving tiring/tired all the time Breathing affected/asthma	5 5 2
Satisfactions of caring (n=13)	Satisfied to know I have done everything I could Relationship with dependant still positive though changed Have learned much through caregiving experience	3 2 2
Motivations for caring (n=11)	Would be devastating to place dependant in care home Want to keep dependant out of care home/at home	3 3
Employment impact (n=9)	Have had to give up work to care Have had to reduce hours worked Work has suffered as a result of caregiving	4 2 2
Holidays (n=9)	Can't go on holiday/weekend breaks due to caregiving	6
Impact on marriage (n=9)	Caregiving has put pressure/stress on marriage Relationship with spouse (non dependant) has suffered	3 2
Financial impact (n=7)	Negative financial impact Reduced income/savings as a result of caregiving	4 2
Religious belief (n=6)	Belief in God Feel blessed by caregiving Caregiving as a mission/ministry	2 2 2

Table 5.40 (summary version): Categorisation of emergent themes in response to the open question 'Please describe the impact that caregiving has had on your quality of life.' (for complete version see Appendix 4)

One can see from these data that the impacts on quality of life in every aspect are great and, for the most part, negative. The most important themes emerging from the qualitative data in respect of this open question were concerning the isolating and confining effects of caregiving (n=33); the negative impact on social life (n=21) and friendships (n=12); the negative impact on family (n=12) and spousal relationships (n=8) (in relation to adult children carers); the negative impact on employment (n=9) and financial state (n=7), and on psychological (n=22) and physical (n=14) health.

> ***"I fear that I am being sucked down a tunnel, that my immune system is suffering, that I am suddenly ageing far more rapidly. I experience fear, loss of confidence and depression in equal measure."*** (Internet carer 70)

However, it should be noted that 45 out of 199 of the recorded themes were positive (22.6%), especially in relation to caregiving satisfactions (n=13) and motivations (n=11);

religious belief (n=6); positive impacts on quality of life (n=6), and positive aspects relating to the support of family (n=6), friends (n=2) and spouse (n=1).

> ***"My life stinks. But I have to say this. When my Mom dies, I'll know that I did what I could. That she stayed home and knew she was loved! THAT is really ALL that matters! ALL THAT MATTERS!!!!!!"*** (Internet carer 62)

Perhaps an important observation to make at this point is that in response to this question 24 of the 71 responses (33.8%) had a mix of negative and positive statements relating to quality of life impacts. The reasons for this are unclear, and obviously each individual highlighted different negative and positive aspects relating to their caregiving situation, but it seems that in reflecting on their own life carers were trying to focus on any positive aspects or outcomes that were evident, such as the support they had received from family or friends, or the fact that their care had kept their spouse or parent out of a care home.

> ***"Things are certainly harder for us as a couple and as a family now. But we have pulled together too. It's upsetting when you think of what is to come though."*** (Interview carer 17)

Nonetheless, the majority of responses to this question were largely negative and the direct quotation highlighted the enormous impact that caring for a person with dementia over many years had had on the lives of carers.

5.26 Correlations between 'Quality of life' ratings and DCPQ and DCBQ

It was interesting to examine correlations between the 'Quality of life' rating scale above and the 'Dementia Caregiving Problems Questionnaire (DCPQ)'. The following table does this, highlighting those caregiving problems that had a significant correlation with self-assessed quality of life ratings in the categories of 'Emotional well-being impact', 'Physical well-being impact', 'Personal relationships/Family life impact', 'Social/Work life impact' and 'Overall quality of life impact'.

DCPQ questions	Emotional well-being	Physical well-being	Personal relationships /Family life	Social /Work life	Quality of life
Is able to start and maintain a sensible conversation	-	-	-	+0.293**	-
Is able to respond sensibly when spoken to	-	-	+0.236*	+0.234*	-
Talks out loud to him/herself	-	-	+0.242*	-	-
Gets mixed up about where he/she is	-0.282*	-	-	-	-
Gets mixed up about the day, date, year	-0.245*	-	-	-	-
Tries to get up and dressed/go outdoors during the night	+0.247*	-	+0.296*	-	-
Becomes angry and resistive to care	-	-	-	+0.312**	-
Endangers him/herself by risky behaviours	-	-	-	+0.250*	-
Becomes irritable and easily upset	-	-	+0.340**	-	-
Shouts/swears/screams at people/me for no apparent reason	+0.240*	-	+0.317**	-	-
Wakes me/others during night	+0.317**	-	-	-	+0.269*
Appears unhappy and depressed	-	-	+0.306**	-	+0.237*
Is incontinent of urine during the night (may wear pads)	-	+0.254*	-	-	-
Is prone to having falls/fits/choking	+0.331**	-	+0.241*	-	-

Table 5.41: Correlations between quality of life ratings and DCPQ questions

NB. ** = statistically significant to <0.01 * = statistically significant to <0.05

This table highlights those caregiving problems which have the greatest correlation with quality of life self-assessment ratings in the 'Emotional well-being impact', 'Physical well-being impact', 'Personal relationships/Family life impact', 'Social/Work life impact' and 'Overall quality of life impact' categories. One can see that 'Becomes irritable and easily upset' had the highest correlation in the 'Personal relationships/Family life impact' category, with a correlation of +0.340 ($p<0.01$), 'Is prone to having falls/fits/choking' had the second highest correlation in the 'Emotional well-being impact' category, with a correlation of +0.331 ($p<0.01$), 'Shouts/swears/screams at people/me for no apparent reason' had the third highest correlation in the 'Personal relationships/Family life impact' category, with a correlation of +0.317 ($p<0.01$), 'Wakes me/others during the night' was joint third in the 'Emotional well-being impact' category, with a correlation of +0.317 ($p<0.01$), 'Becomes angry and resistive to care' had the fourth highest correlation in the 'Social/Work life impact', with a correlation of +0.312 ($p<0.01$), and 'Is able to start and maintain a sensible conversation' had the fifth highest correlation in the 'Social/Work life impact' category, with a correlation of +0.293 ($p<0.01$).

In terms of correlations between caregiving problems and 'Overall quality of life impact', 'Wakes me/others during the night' had a correlation of +0.269 ($p<0.05$) and 'Appears unhappy and depressed' had a correlation of +0.237 ($p<0.05$).

The caregiving problems listed above may thus represent those which have the greatest negative impact on aspects of carers' quality of life. They may be useful to consider for later inclusion in a 'Dementia Caregiving Breakdown Risk Assessment Tool', which is to be developed out of this research.

The next table highlights those 'Dementia Caregiving Burden Questionnaire (DCBQ)' items (amended to reduce table size) that had a significant correlation with self-assessed quality of life ratings in the categories of 'Emotional well-being impact', 'Physical well-being impact', 'Personal relationships/Family life impact', 'Social/Work life impact' and 'Overall quality of life impact'.

DCBQ questions	Emotional well-being	Physical well-being	Personal relationshi s/Family lif	Social /Work life	Quality of life
Do you feel you need a holiday?	-	+0.292*	-	+0.307**	+0.297*
How much has your social life been affected?	-	-	-	+0.358**	-
Is your sleep disrupted?	+0.367**	+0.248*	-	+0.282*	+0.275*
Do you have family arguments/difficulties associated with caring?	-	-	+0.401**	-	-
Do you have difficulty in continuing with relationships?	-	+0.280*	+0.295*	+0.418**	-
Do you find your caring responsibilities adversely affect other aspects of life?	-	-	+0.287*	-	-
Do you have to undertake tasks beyond your capabilities?	+0.303**	+0.268*	+0.239**	-	+0.257**
Has your own physical health suffered as a result of caring?	+0.354**	+0.614**	+0.230*	+0.273*	+0.367**
Do you feel there will be no end to your problems?	+0.449**	+0.396**	-	-	+0.384**
Do you feel you can no longer cope with your situation?	+0.461**	+0.345**	-	-	+0.383**
Do you feel overwhelmed by your situation?	+0.389**	+0.386**	-	-	+0.285*
Do you feel trapped in the caring role?	+0.354**	+0.248*	-	+0.299*	+0.360**
Do you feel that you are alone in coping?	+0.313*	-	+0.409**	-	-
Do you find it distressing that ... has changed so much from his/her former self?	+0.322**	+0.294*	-	-	+0.257*
Do you have feelings of grief and loss associated with caring?	+0.322**	+0.363**	-	-	+0.305**
Do you find yourself becoming tearful or crying?	+0.350**	+0.356**	-	-	-
Do you feel exhausted and demoralised in the caring role?	+0.523**	+0.497**	-	+0.263*	+0.450**
Are you depressed about your situation?	+0.504**	+0.477**	-	-	+0.513**
Do you feel like giving up caring?	+0.400**	+0.337**	-	-	+0.431**
Do you feel embarrassed by ...?	+0.367**	+0.262*	-	-	+0.327**
Do you feel frustrated with ...?	+0.424**	+0.334**	+0.333**	-	+0.282*
Do you get cross and angry with ...?	+0.432**	+0.236*	-	-	+0.325**
Are you resentful about the change in the quality of your life/missed opportunities?	+0.415**	+0.348**	+0.307**	-	+0.359**
Are you emotionally distant from ...?	-	+0.296*	-	-	+0.261*
Do you view caring for ... as being like caring for a child?	-	-	-	-	+0.275*
Do you have feelings of guilt associated with caring?	+0.299*	-	-	-	+0.268*
Do you feel helpless and as if things are outside of your control?	+0.501**	+0.424**	-	+0.249*	+0.398**
Do you have a sense of achievement or fulfilment as a result of caring?	+0.449**	-	-	-	+0.294*
Do you have a sense of purpose and direction in your caring role?	+0.257*	-	-	-	-
Do you derive personal satisfaction and reward from your caring role?	+0.406**	-	-	-	+0.305**
Do you have feelings of positive self-worth/self-esteem arising from caring?	+0.382**	-	-	-	+0.292*
Do you feel caring has provided opportunity for personal growth/development?	+0.306**	-	-	-	-
Do you feel caring is a positive way of expressing love and affection?	+0.235*	-	-	-	-
Do you feel that you adopt a positive, problem-solving approach to caring?	+0.522**	+0.476**	-	-	+0.427**
Do you feel that you manage your stress well and overcome it?	+0.497**	+0.476**	-	-	+0.466**
Are you feeling hopeful about your future?	+0.478**	+0.360**	-	-	+0.357**
Reflecting on your overall care-giving situation, all in all would you say you are:	+0.536**	+0.568**	-	-	+0.514**

Table 5.42: Correlations between quality of life ratings and DCBQ questions

This table highlights those DCBQ questions which have the greatest correlation with quality of life self-assessment ratings in the 'Emotional well-being impact', 'Physical well-being impact', 'Personal relationships/Family life impact', 'Social/Work life impact' and 'Overall quality of life impact' categories. One can see that 'Has your own physical health suffered as a result of caring?' had the highest correlation in the 'Physical well-being impact' category, with a correlation of +0.614 ($p<0.01$); 'Do you feel exhausted and demoralised?' had the second highest correlation in the 'Emotional impact' category, with a correlation of +0.523 ($p<0.01$); 'Do you feel that you adopt a positive, problem-solving approach to caring?' (reverse polarity, i.e. lack of....) had the third highest correlation in the 'Emotional well-being impact' category, with a correlation of +0.522 ($p<0.01$); 'Are you depressed about your situation?' had the fourth highest correlation in the 'Physical well-being impact' category, with a correlation of +0.504 ($p<0.01$), and 'Do you feel helpless and as if things are outside of your control?' had the fifth highest correlation in the 'Emotional well-being impact' category, with a correlation of +0.501 ($p<0.01$). (It is important to note that there were another 44 DCBQ questions with a positive correlation to quality of life category ratings to a value of $p<0.01$.)

In terms of correlations between DCBQ questions and 'Overall quality of life impact', 'Are you depressed about your situation?' had a correlation of +0.513 ($p<0.01$), 'Do you feel you manage your stress well and overcome it?' (reversed polarity, i.e. do not) had a correlation of +0.466 ($p<0.01$), 'Do you feel exhausted and demoralised in your caring role?' had a correlation of +0.450 ($p<0.01$), 'Do you feel like giving up caring?' had a correlation of +0.431 ($p<0.01$), and 'Do you feel you adopt a positive, problem-solving approach to caring?' had a correlation of +0.427 ($p<0.01$). (Another 13 DCBQ questions had a positive correlation to 'Overall quality of life impact' mean rating to a value of $p<0.01$.)

To summarise the above table and discussion, a correlation between DCBQ score and 'Overall Quality of life impact' rating was made. A positive correlation of +0.472 ($p<0.01$) was found.

5.27 Coping strategies used to manage most difficult problems

This section provides an analysis of responses to the open question 'What strategies/approaches do you use to cope with/manage these most stressful/difficult problems?'. Statements were categorised into the following headings, borrowed from Nolan et al. (1998): 'Preventive action', 'Reframing meaning of events/problems', 'Direct action' and 'Dealing with consequences when strategies not effective'. The additional headings of 'Strategies to enhance carer emotional well-being', 'Emotional and/or practical support of others', 'Breaks from caregiving' and 'General comments about coping' were added, as some data fitted into these categories better, and the category 'Direct action' was subdivided into 'Direct action - Strategies to enhance dependant emotional well-being', 'Direct action - Strategies to enhance dependant physical well-being', 'Direct action - Strategies to avoid conflict/distress' and 'Direct action - Strategies to enhance dependant communication' for the purposes of clarity.

71 of 91 current carers answered this question (response rate 73.2%) and 421 statements were made/analysed. Data are as follows:

Statement Category	Statement	Number
Preventive action (n=102)	Reassure dependant everything alright Observe dependant to ensure safety Keep to a daily routine	13 6 5
Strategies to enhance carer emotional well-being (n=69)	Talking to other carers about coping – at group/individually Reading novels/listening to music Prayer/faith	9 8 6
Dealing with consequences when strategies ineffective (n=57)	Try to be patient/patience Just get on with it Ignore behaviour	7 6 5
Reframing meaning of events/problems (n=36)	Remember it's not dependant's fault Accept symptoms as part of the illness Learned to let go/look at loved one beyond illness	6 4 3
Direct action – Strategies to maintain dependant independence (n=29)	Prompt dependant/talk through procedure to retain skills Extra time for self-care/work at dependant's pace Supervision with self-care	7 5 4
Direct action - Strategies to avoid conflict/distress (n=29)	Walk away/leave dependant alone when angry Avoid confrontation/conflict Change the subject	5 5 4
Emotional and/or practical support of others (n=27)	Contact with/help of friends Help of neighbours Children/friends sit with dependant	11 5 3
Direct action -Strategies to enhance dependant emotional well-being (n=26)	Engage dependant in reminiscence/recall Comfort dependant when he/she becomes upset/cries Try to foster dependant's interest in something	5 4 4
Breaks from caregiving (n=15)	Pay carers to have regular breaks Taking time off Going to paid work viewed as a break from caregiving	5 5 4
Direct action -Strategies to enhance dependant physical well-being (n=13)	Have to be forceful/fight to get dependant washed/dressed Try to make dependant as comfortable as possible	4 3 2
Direct action -Strategies to enhance dependant communication (n=12)	Increased physical/tactile contact Use non-verbal communication to back up speech Maintain eye contact	3 3 2
General comments about coping (n=10)	Not coping with aspects of caregiving No coping strategy Gradually learned/learning to cope over time	8 4 3

Table 5.43 (summary version): Categorisation of emergent themes in response to the open question 'What strategies/approaches do you use to cope with/manage these most stressful/difficult problems?' (for complete version see Appendix 4)

The caregiving strategies used showed how skilled the majority of carers had become in providing respectful, person-centred care for their dependant. This is demonstrated by the largest category being 'Direct action' (n=109 - four categories combined), where carers took measures to maintain their dependant's independence (n=29), avoid conflict/distress (n=29), enhance their dependant's emotional well-being (n=26), enhance their dependant's physical well-being (n=13) and enhance their dependant's communication (n=12). The most commonly used strategies in this category were prompting the dependant to maintain their skills (n=7), giving extra time/working at the dependant's pace (n=5), walking away/leaving the dependant alone when angry or distressed (n=5), avoiding confrontation/conflict (n=5) and engaging the dependant in reminiscence/recall (n=5).

> ***"My son has typed us some reminders on his computer which I use so that he will not forget to take his keys out with him, close the door tightly etc. I write things down on a pad, notes about where I am, the day and date and so on. If something works from experience then I follow that as a new coping skill."*** (Interview carer 11)

The dedication and skill of carers was similarly demonstrated in the second largest category, 'Preventive action' (n=102), where carers used techniques to avoid or minimise the likelihood of problems arising in the first place, for example, reassuring the dependant that everything is allright (n=13), observing the dependant to ensure safety (n=6), keeping to a daily routine (n=5) and talking the dependant through caring procedures/actions (n=5).

> ***"Hug her when she is sad and help her vocalise her feelings. Find the things she has lost. Talk to her about the things we have done/places we have gone. I try to help her reminisce by taking her places she will remember."*** (Internet carer 53)

'Strategies to enhance carer emotional well-being' (n=69), was the third largest category, where carers engaged in non-caregiving activities to enhance their own psychological well-being. Such activities included talking to other carers about coping (n=9), reading novels/listening to music (n=8), prayer/faith (n=6) and taking exercise (n=5). All could be said, by enhancing carer well-being, to have an impact on improving carers' coping ability, and this may be especially true of talking to other carers as caregiving strategies will be learned from them as role models.

> ***"Read more on the illness and coping strategies. Join support groups to ventilate my frustrations, share our woes and amusing stories, and know that we are not alone. I am preparing myself for what is ahead."***
> (Internet carer 10)

'Dealing with the consequences when strategies (are) not effective' (n=57), was the fourth largest category, followed by 'Reframing meaning of events/problems' (n=36), 'Emotional and/or practical support of others' (n=27), 'Breaks from caregiving' (n=15) and 'General comments about coping' (n=10).

> ***"The car, I try to avoid. The bathroom, I try to be quick. The reasoning, I don't even try anymore. The fear of her going out, I sleep on the couch and have fitted dead locks on all the doors. I have a sitter while I work. Getting on my meds for depression was a biggy! And I try to keep a sense of humour, try being the operative word!"*** (Internet carer 62)

As demonstrated above, the overwhelming majority of carers used positive coping/caring strategies which appeared to be supportive to their dependant and helpful to their caregiving situation. However, 46 of the 421 statements related to inappropriate caring strategies used, for example, colluding with confusion (n=4), fighting to change the dependant (n=4), shouting at the dependant (n=4), alcohol/smoking (n=3), etc. As commented on above, many carers learn their strategies through trial and error and have limited choices in care. If there are no positive role models, e.g. other carers to learn strategies from, no access to information and literature on the appropriate management of caregiving problems, and limited resources to cope with caregiving problems, then inappropriate caregiving strategies may be used. These may be unhelpful and exacerbate problems or further challenge the dependant's emotional well-being.

In addition, a small number of carers stated that they were unable to cope with aspects of caregiving (n=8 / 11.3%) and four (5.6%) stated that they had no strategies for coping. These carers may be especially at risk of breakdown in their caregiving situation if they feel that the problems they experience are outside of their control.

5.28 Carers' conception of the impact of their caregiving upon their dependants' emotional and physical well-being

Carers were asked to assess the impact that their caregiving had had upon their dependant's emotional and physical well-being. The results are as follows:

Conception of impact of caregiving on well-being	Emotional well-being	Physical well-being
Very positive effect	32 (36%)	41 (46.1%)
Positive effect	22 (24.7%)	35 (39.3%)
It varies	22 (24.7%)	8 (9%)
No real effect	11 (12.4%)	4 (4.5%)
Negative effect	1 (1.1%)	-
Very negative effect	1 (1.1%)	1 (1.1%)

Table 5.44: Carers' conception of the impact of their caregiving upon their dependant's emotional and physical well-being

The overwhelming majority of carers felt that their caregiving had a positive effect on their dependant's physical well-being (n=76 / 85.4%) and on their dependant's emotional well-being (n=54 / 60.7%). This demonstrates that for most carers there was some satisfaction in knowing and/or believing that their caregiving input was making a real difference to their dependant's physical and emotional well-being.

However, 22 (24.7%) carers felt that their caregiving had a variable effect on their dependant's emotional well-being, 11 (12.4%) carers felt it had no real effect and two (2.2%) felt their caregiving had a negative effect on their dependant's emotional well-being. Similarly, eight (9%) carers felt that their caregiving had a variable effect on their dependant's physical well-being, four (4.5%) felt it had no real effect and one (1.1%) felt it had a very negative effect on their dependant's physical well-being. Perceiving that their caregiving has a variable impact or no real impact on their dependant's emotional and/or physical well-being must be a source of distress and despair for carers and increase their caregiving burden.

To support this supposition, it was useful to examine correlations between carers' perceived impact of caregiving on dependant emotional and physical well-being and DCBQ domains. Positive correlations were found between perceived emotional impact of care and 'Negative feelings' (+0.352 p<0.01), perceived emotional impact of care and '(Lack of) Positive feelings' (+0.356 p<0.01), and perceived physical impact of care and 'Negative feelings' (+0.324 p<0.01). There were no relationships between these variables and 'Life upset' or 'Personal distress' DCBQ domains. Regarding 'Overall DCBQ', a positive correlation was found with perceived emotional impact of care at +0.308 (p<0.01), but no relationship was found with perceived physical impact.

These data show that the less positive impact the carer perceives their caregiving is having on their dependant's emotional well-being, the more negative feelings and less positive feelings will be experienced. Similarly, the less positive impact the carers perceives their caregiving is having on their dependant's physical well-being, the more negative feelings will be experienced. Perhaps these findings are not surprising given that if the dependant remains in a state of emotional ill-being despite all the carer's best efforts to provide positive care this will be distressing, depressing and frustrating etc. Similarly, if there are few perceived positive impacts on dependant emotional well-being, caregiving satisfactions will be less. Regarding dependant physical well-being, if the dependant remains physically unwell or frail despite their nutritional, continence, mobility and other physical care inputs they, again, will be more likely to feel negatively about their situation.

Particular clinical concern should be directed towards those three (3.3%) carers who perceived that their caregiving inputs were having a negative impact on their dependant's emotional or physical well-being, i.e. worsening their physical or mental health. They should be a focus for a detailed carers' assessment around their caregiving capability and willingness to continue providing care for their dependant.

5.29 Community care services and informal supports received and their perceived helpfulness

Regarding formal support received from community care services, data are as follows:

Community care services received	Number	Percent
No formal supports received	18	25.7
Helpline/carers group	27	38.6
Home care/sitter (private/statutory)	33	47.1
Home visits by care manager, e.g. CPN, social worker	30	42.9
Day care/day hospital	20	28.6
Respite care	14	20
Other forms of support	5	7.1

Table 5.45: Formal supports received by current carers from community care services

The above table shows that the majority of carers (n=52 / 74%) received a variety of supports from community care services, but it is important to note that of the 70 current carers who responded to this question 18 (26%) were receiving no community care services whatsoever to support them in their caregiving role. (It could also be assumed that several of the 21 carers who did not complete this section of the on-line questionnaire were not in receipt of community care services, perhaps perceiving that the questions relating to services/resources were not relevant to their caregiving situation.)

It is also important to look at the level of support received by those who were in touch with community care services: 11 carers received support from only one service, 20 received support from two services, 12 received support from three services, nine received support from four services and two received support from five services.

Similarly, the frequency of community care service contact for those 52 carers receiving formal support was variable. The data are as follows:

Frequency of input from community care services	Number	Percent
Input once a day	6	8.6
Input twice a day	6	8.6
Input three to six times a week	9	12.9
Input once or twice a week	21	30.0
Input fortnightly	1	1.4
Input monthly	5	7.1
Input bi-monthly	2	2.9
Infrequent input	2	2.9
No services received	18	25.7

Table 5.46: Frequency of input from community care services

One can see from this table that of the 52 carers who received support from community care services, only 12 (17.2%) had once or twice daily assistance, nine (12.6%) had several contacts each week, 21 (30%), the majority, only had assistance once or twice a week, and nine (12.6%) had infrequent assistance.

The level of formal support available to the majority of this sample of carers was thus variable, and it was interesting to examine whether any of those carers receiving little or no formal support were providing care for moderately to severely demented dependants. The following data showed this to be the case.

Frequency of input from community care services	Mild	Moderate	Severe	Very severe
No services	2 (2.9%)	6 (8.6%)	8 (11.4%)	2 (2.9%)
Infrequent assistance	4 (5.7%)	5 (7.1%)	-	1 (1.4%)
Assistance once or twice a week	1 (1.4%)	11 (15.7%)	7 (10%)	2 (2.9%)
Input several times a week	-	5 (7.1%)	3 (4.3%)	1 (1.4%)
Daily assistance	-	5 (7.1%)	4 (5.7%)	3 (4.3%)

Table 5.47: Frequency of input from community care services against degree of dementia

A striking finding is the fact that of the 18 carers receiving no assistance from community care services, 16 (23% of respondents) were providing care for moderately to severely demented dependants, who presumably presented them with challenging behaviour and/or physical frailty needs that were extremely difficult to manage. It is likely that this group, as well as those caring for people with moderate to severe dementia with infrequent assistance (n=6 / 8.6%), were particularly at risk of developing psychological health problems and breakdown in their caregiving situation.

These data highlight that there are an important minority of caregiving situations in the community which, perhaps due to problems with case identification and service accessibility, availability or affordability (see later discussion on services), remain unsupported by way of practical assistance, care management support or breaks from caregiving. Such caregiving situations must be vulnerable to breakdown and demonstrate that there is more work to be done in ensuring a carefully focussed and prioritised service.

For those who were receiving support from community care services, it can be assumed that several had arranged and were paying for these privately (although this distinction was not made in the study questionnaire). The limited amount of formal support available to carers in this sample is important to recognise, but as it included a large number of overseas caregiving situations it would be difficult to extrapolate this finding to being applicable for the UK community care situation generally.

As well as examining data on the level of community care services received by carers, it was also important to explore the perceived helpfulness of services received. Data are as follows:

Perceived helpfulness	Number	Percent
Extremely helpful	30	58.8
Very helpful	9	17.6
Helpful	7	13.7
Unhelpful	1	2.0
Very unhelpful	1	2.0
Extremely unhelpful	3	5.9

Table 5.48: Perceived helpfulness of community care services

It is pleasing to note that the majority of the 51 carers who answered this question (n=46 / 90.1%) perceived that community care services had been helpful to their caregiving situation. However, five (9.9%) perceived services as being unhelpful, and three (5.9%) of these rated services as being 'extremely unhelpful'.

In examining the relationship between data on frequency and perceived helpfulness of community care services, it was interesting to note that there was no correlation between the frequency of services and the 'Overall DCBQ' score. This is likely to be because several carers who were not receiving services may have been at an earlier stage in their caregiving role when fewer or no services were required and caregiving burden was less. However, when one looks at the relationship between perceived helpfulness of community care services and 'Overall DCBQ' score there was a correlation of +0.495 ($p<0.01$). This means that for those carers who were receiving community care services but perceived them as unhelpful to their situation, caregiving burden was higher than for those who perceived them as being helpful. This finding is of crucial importance as it provides evidence that there is a need to improve the quality of community care services that are provided to carers of people with dementia so that they better meet their identified needs.

The next section of this chapter examines qualitative data relating to carers' views of community care services and how they could be improved.

Regarding informal support from family, friends and neighbours, data are as follows:

Informal supports received	Number	Percent
No informal supports	15	21.4
Close family support	19	27.1
Friend/s support	8	11.4
Close family support + friend/s support	7	10.0
Close family support + neighbour/church support	4	5.7
Distant family support + friend/s support	4	5.7
Distant family + friend/s + neighbour/church support	2	2.9
Close family + friend/s + neighbour/church support	2	2.9
Close family + distant family + friend/s + neighbour/church support	2	2.9
Other combinations	7	10.0

Table 5.49: Informal supports received to the caregiving situation

One can see from the above data that the majority of carers in this sample had access to informal support from family, friends, neighbours etc. However, of the 70 carers who responded to this question 15 (21.4%) had no assistance from informal supporters. Coping alone without the support of family and friends must add another dimension of isolation to the caregiving situation, particularly if the quality of the relationship with the dependant has deteriorated.

One can also see from the following table that the frequency of contact with/assistance from informal supporters for a minority of the carers who did have access to this form of support was minimal, with 12 out of 55 carers (21.8%) having contact fortnightly or less.

Frequency of input from informal supporters	Number	Percent
Input daily	15	21.4
Input three to six times a week	7	10.0
Input once or twice a week	21	30.0
Input fortnightly	5	7.1
Input monthly	1	1.4
Infrequent input	6	8.6

Table 5.50: Frequency of input from informal supporters

However, the vast majority of those who did have support from family, friends, neighbours etc found it beneficial, as the following table shows:

Perceived helpfulness of informal supports	Number	Valid Percent
Extremely helpful	26	48.1
Very helpful	17	31.5
Helpful	10	18.5
Unhelpful	1	1.9

Table 5.51: Perceived helpfulness of informal supports

It is vitally important to note that 6 of the 70 carers (8.6%) who responded to this section of the questionnaire received absolutely no assistance to support them in their caregiving role whatsoever, either from community care services or informal supporters. They were coping with their caregiving situation entirely alone – one caring for a dependant with 'moderate dementia' and four for dependants with 'severe dementia'. This group may have been especially at risk of burnout and breakdown in their caregiving situation, particularly if their relative was moderately to severely demented and their behaviour was challenging.

It is also noteworthy that 16 of the 18 carers receiving no community care services and five of those without access to informal support were from the USA; the figures for the UK were one and five respectively. The study sample is too small to draw any firm conclusions from these findings, but it is important to highlight once again the differences between overseas countries and the UK in the state support available to carers in paying for community care and in the range of dementia specific services that are available. It is likely that if there are problems with accessing appropriate forms of formal support, or if those community care services which do exist are perceived as being too costly to purchase care from, then carers may not receive help until much later in the dementia illness trajectory, by which time they will be suffering from the effects of chronic stress and caregiving burden. This equally applies to UK caregiving situations, for example, to those carers and dependants refusing financial assessment for social services funded (or part-funded care packages) due to a perception that the state should provide free care and an unwillingness to disclose assets.

5.30 Suggestions for improving community care services

The next section looks at carers' responses to the open questions 'In what ways have formal support services been helpful or unhelpful?' and 'How do you feel formal support services could improve their support to you and your dependant?' The responses to these two questions were amalgamated into one for analysis as there was a high level of repetition between the two questions, with carers often answering 'ditto' for the second. Data are as follows:

Statement Category	Statement	Number
Service providers (n=37)	Health and Social Services need to work together better No dementia services available Need increased availability of dementia services	6 4 3
Community Psychiatric Nurse (n=31)	CPN arranges changes to services/increased support Can talk to CPN about practical/emotional problems CPN provides ongoing counselling support	6 5 4
Carers Support Group (n=28)	Good for sharing ideas re ways of coping/managing Good place to share/ventilate feelings Good to meet others in similar situations	6 4 3
Home Care/sitting services (n=27)	Need access to a night/day sitting service Home Carer pleasant and talks with dependant Feel dependant is safe with Home Carer	6 3 2
Day Care/Hospital (n=23)	Day care provides some freedom/personal time Day service provides excellent care Dependant refuses to go to day care	5 3 2
Telephone Helpline (n=16)	Provision of information re dementia and services Need access to a telephone helpline service Improved my knowledge and understanding	3 3 2
Respite Care (n=13)	Feel respite care has helped me cope/care for longer Need more respite care Planned respite gives a chance for a family break	6 3 2
Satisfaction with services (n=12)	Support available excellent Very satisfied with services Services help me continue working	5 4 3
Caregiver Training (n=9)	Would benefit from training in dementia care Need training in managing challenging behaviour Need training in activities and stimulation	4 3 2

Table 5.52 (summary version): Categorisation of emergent themes in response to the open questions 'In what ways have formal support services been helpful or unhelpful?' and 'How do you feel formal support services could improve their support to you and your dependant?'. (for complete version see Appendix 4)

It is important to note that only 30 of the 70 carers (42.9%) who completed this section of the questionnaire responded to these questions. This may have been because of questionnaire fatigue - it was towards the end of an extensive questionnaire, or because many carers perceived the question as being irrelevant to them because they were not receiving support from community care services. As 18 carers received no formal supports, the response rate to this question could be viewed as being 30/52 (58%).

Of the 196 separate statements made/strings analysed 123 (62.8%) were positive, relating to some benefit that services had brought to carers. 31 (25.2%) of these statements were positive comments relating to the role of the Community Psychiatric Nurse. This is not surprising, given that 12 of the 17 carers interviewed for the study had their case managed by a CPN. Similarly, 16 of the 123 (13%) positive statements related to the South Wales Dementia Careline and 20 (16.3%) related to Carers Support Groups run by Careline. Again, this is not surprising, given that five of the 17 carers interviewed were involved with this service.

> ***"My CPN has been no end of help to me. I couldn't have gone on much longer without regular respite care either. That helps keep me going, looking forward to my next break and planning what I am going to do with the time off."*** (Interview carer 14)

It is important to note that of the remaining 56 positive comments, 14 (11.4%) related to positive experiences/benefits of day care services, 11 (8.9%) related to home care/sitting services, nine (7.3%) related to respite care and an additional eight (6.5%) statements related to carers' support groups. An additional 12 (9.8%) positive statements made were generic, relating to the perceived overall benefit of services.

> ***"I don't know how I would manage without the support I get from the day hospital. I know he is safe when he is there and this allows me to rest and do things like shopping and cleaning that I can't do when he is at home."*** (Interview carer 6)

The analysis of positive statements highlighted the perceived benefits and importance of services which provided case coordination and management, emotional support and counselling, and practical support and breaks from caregiving.

> ***"The Carers Group has helped by enabling contact with other carers and has been a good place to share experiences and ideas on ways of coping/managing problems. It has been very helpful to be able to talk freely and share your emotions with others who understand."***
> (Interview carer 4)

Of the 73 negative statements made/strings analysed, 14 (19.2%) related to perceived negative impact/unmet need relating to home care/sitting services, nine (12.3%) to day care/day hospital services and four (5.5%) to respite care services. A further nine (12.3%) statements made related to the need for some form of caregiver training in dementia care.

> ***"For services to EXIST, for one thing! For them to be affordable, consistent, dependable, caring, accessible and prepared."***
> (Internet carer 59)

However, the largest category of negative statements made, in fact the largest category overall, was 37 (50.7%) generic negative statements relating to service providers. Carers stated the need for improved collaboration/coordination between health and social services (n=8 / 11%), the need for increased availability of dementia specific services (n=7 / 9.6%), the need for easier access to services (n=5 / 6.8%), and for services to be more affordable (n=5 / 6.8%).

> ***"If you ask hard enough and long enough eventually something happens."*** (Internet carer 20)

5.31 Caregiving satisfactions/motivations for continuing in role

The next section looks at current carers' responses to the open questions 'What are the main satisfactions that you can identify within your caregiving situation?' and 'What are your main motivations for continuing in the caregiving role?' The responses to these two questions were amalgamated into one for analysis as there was a high level of crossover between the two questions, with carers often answering 'ditto' for the second.

Data are as follows:

Statement Category	Statement	Number
Caregiving satisfactions (n=49)	Dependant still happy sometimes Condition stable/dependant still alive due to care provided Have learned skills through caring	9 6 4
Maintain at home/keep out of a care home (n=46)	Desire to keep dependant out of a care home Desire to keep dependant in own home Provide better care than hospital/care home	14 13 5
Love and affection (n=39)	Love/affection as the main motivation to care She/he is my ... Remember love dependant gave	21 9 3
Caregiving motivations (n=29)	Know I am doing the right thing To maintain dependant's quality of life Doing my best for dependant	6 6 4
Commitment to care (n=28)	Want to care for ... Repaying/giving back love/care If situation were reversed dependant would provide care	9 7 3
Duty and obligation (n=23)	It is my duty/obligation Promises made earlier in life No way I could desert/abandon dependant	11 3 2
Future (n=20)	Considering relinquishment of home caregiving/placement Want to carry on/continue caregiving	15 3
Faith (n=15)	Faith/belief in God as a motivation to care Aspects of care a blessing Prayer helps carer to care	8 3 2
Lack of choices (n=12)	No other option/no choice As an only child have to care No-one else to care	6 2 2
Support enables continued caregiving (n=11)	Community care services have enabled continued caregiving I am not alone Family support has enabled continued caregiving	4 3 2
Lack of satisfactions (n=4)	No reward/satisfaction No positive aspects	2 2

Table 5.53 (summary version): Categorisation of emergent themes in response to the open questions 'What are the main satisfactions that you can identify within your caring situation?' and 'What are your main motivations for continuing in the caring role?' (for complete version see Appendix 4)

It is important to note that 67 of the 70 current carers who responded to this section of the questionnaire cited positive gains/satisfactions had from caregiving and/or motivations for continuing in the caregiving role. Of 276 separate statements made/strings analysed, the vast majority (n=262 / 95%) were positive. This is a crucial finding and emphasises that for the majority of caregiving situations there are some positive aspects to be found alongside the stress and burden and grief and loss experienced.

> ***"The fact that I love my wife. It's simple."*** (Interview carer 8)

However, it is also important to recognise that apart from caregiving satisfactions, there were many and varied reasons for carers wishing to continue in role, such as duty and obligation (stated by 23 / 34.3% carers), or wanting to prevent their dependant from entering permanent care (stated by 14 / 20.9% carers) – either because they felt their dependant would be happier in their own home or due to negative perceptions of the standards of care provided in care homes.

> ***"Well, I think that apart from it being a duty, should the situation be reversed I know that she would do now what I am doing for her."***
> (Interview carer 7)

There should also, perhaps, be particular concern for the minority of carers who stated that they experienced no caregiving satisfactions (n=4 / 5.9%) and for those whose only motivation to care was because of a perceived lack of choices and alternatives (n=8 / 11.9%). These carers, and those in the above discussion, may be holding on to the care of their dependant for longer than is appropriate or conducive to their or their dependants' well-being.

> ***"Well, money I suppose. To pay out for a nursing home would be at least £300 a week and I cost nothing. And I don't think he would be happy in a hospital or care home."*** (Interview carer 3)

In summary, concern should be directed towards and attention given to any carers considering relinquishment of caregiving/entry of their dependant to permanent care, for whatever reason. This theme is discussed in detail in the next section of this chapter, but suffice to say for now the 15 (22.4%) carers who expressed they were considering this option appeared, from comments made in response to these questions, to be doing so as a result of exhaustion, demoralisation and incapacity to provide the level of care required rather than because of a change in their dependant's condition.

> ***"Having no other choice at this time. Knowing that at some point it will come to an end. Realising that I have reached the limits of my capability."***
> (Internet carer 24)

5.32 Expectations for the future

Regarding carers' expectations for the future, within one year from interview/questionnaire submission, data are as follows:

Item	Number	Percent
Stay the same/continue as at present	26	38.2
Dependant condition to deteriorate	21	30.9
Death of dependant	6	8.8
Placement of dependant in a care home	15	22.1

Table 5.54: Carer expectations for the future – within one year

One can see from this table that of the 75% (n=68) of current carers who answered this question, 15 (22.1%) expected that their dependant would have entered some form of permanent care within a year from interview/questionnaire submission, i.e. they were considering relinquishment of home caregiving. A further 21 carers (30.9%) expected their dependant's condition to deteriorate and six carers (8.8%) expected that their dependant would have died within the year.

It was very interesting to compare the mean 'Dementia Caregiving Burden Questionnaire' score and 'Carer Self-assessed Stress' rating with the results of this question. (66 of the 68 carers who responded to the question completed the DCBQ.) Data are as follows:

Item	Number	Percent	Mean DCBQ	Mean Stress
Stay the same/continue as at present	26	38.2	63.6	1.52
Dependant condition to deteriorate	21	30.9	77.5	2.24
Death of dependant	6	8.8	77.3	1.83
Placement of dependant in a care home	15	22.1	91.7	2.53

Table 5.55: Mean DCBQ score with Carer expectations for the future

One can see from this table that DCBQ score and carer stress were highest for those 15 carers who were considering relinquishing home caregiving and placing their dependant into a care home, with a mean DCBQ score of 91.7. This is a crucially important finding as it indicates that a high DCBQ score of itself may be predictive of breakdown in the caregiving situation, or at least of expected relinquishment of the home caregiving situation. This was further demonstrated by an analysis of correlations between 'Overall DCBQ' score and 'Carer expectations for the future', which found a positive correlation of +0.415 ($p<0.01$).

It is also interesting to note that expected death of the dependant within a year had a lower mean 'Overall DCBQ' score than expected placement, as did expected deterioration in their condition/increasing difficulty in caregiving. This might be because for those expecting deterioration, their dependant's condition was presently manageable and somewhat less burdensome/stressful, and for those expecting death, their dependant's condition may have been more physically demanding but somewhat less emotionally challenging due to their dependants' illness entering the final terminal dementia phase.

It needs to be re-stated that every caregiving situation needs to be viewed as being unique and the reasons for considering relinquishment of home caregiving will be different in each case. However, in undertaking a carers' assessment the 'Overall DCBQ' score coupled with the response to the question relating to future expectations may be useful indicators that the caregiving situation is at risk of breaking down and that urgent service interventions or planned relinquishment of caregiving may be required.

Thus high 'Overall DCBQ' score – perhaps with a trigger threshold of 90 based on the above evidence, may be a useful prompt for practitioners to enter into discussion with carers around their future care wishes and expectations. Such a prompt may usefully be included in the 'Dementia Caregiving Breakdown Risk Assessment Tool', proposed in chapter 7.

PAST CAREGIVER SAMPLE FINDINGS

5.33 Reasons for relinquishment of home caregiving

The total past carer sample for this study was 18, with two of the local carer sample having relinquished home caregiving during the year between first interview and follow-up interview and 16 past carers submitting internet accessed 'Past Caregiver Questionnaires' via email (10 internet past caregiver subjects were from the USA; five were from the UK and one was from Canada).

Data from 'Past Dementia Caregiver Questionnaires' is presented below, with a focus on the factors implicated in the decision to relinquish home caregiving.

Regarding the duration of home caregiving before relinquishment, two had been caring for less than a year, the majority (n=8) had been caring for between 13 months and three years, two had been caring for between 37 months and five years and six had been caring for six years or more.

Regarding the degree of dementia as perceived by carers prior to dependants' admission to permanent care, one stated that their dependant had 'mild dementia', three had 'moderate dementia', the majority (n=12) stated that their dependant had 'severe dementia', and two had 'very severe dementia'.

Regarding the type of permanent care setting to which the dependant was admitted, the majority of dependants (n=9) were admitted to a private nursing home, five were admitted to a private residential home, two to a local authority run care home, one to a dementia specific assisted living facility and one to a hospital continuing care ward.

Regarding who arranged the admission to permanent care, the majority (n=11) of admissions were arranged by carers themselves, two were arranged by a social worker, two by a community psychiatric nurse, two by another professional and one by a voluntary sector worker. It is important to note that all 11 of the carers who had to make their own arrangements regarding placements were from the USA (n=10) or Canada (n=1). All the remaining seven who had assistance from a variety of professionals (n=6) and the voluntary sector (n=1) were from the UK.

Carers were asked to describe the most stressful/difficult to manage care giving problems in the run up to their dependant's admission to permanent care and to identify one key factor that contributed most to their decision to relinquish home caregiving. Their individual responses to these questions follow. These have not been analysed in detail due to the low number of past carer subjects. However, a commentary will be provided after both tables to highlight common themes.

Carer	Response
1.	My mother was very unhappy at home, which made me unhappy. I became depressed and tearful through lack of sleep – mother was up at all hours. I developed high blood pressure. It was a 24 hour job with no hope of it getting better. I had no time for myself and was unable to work full-time.
2.	Her behaviour deteriorated and she lost the ability to relate to anyone. There was a lot of stress between me and my spouse. I had to resign my job. She became paranoid, thinking everyone was out to get her. Medication made things worse. I had to make all her decisions. She wandered endlessly, which became very difficult to manage and eventually forced placement.
3.	My mother's depression and constant weeping. I was unable to help her feel better. She was so dependent, it was difficult for me to have time to enjoy normal activities. I became socially isolated and some friends and family didn't maintain contact. Incontinence caused the house to smell, which embarrassed me and my mother.
4.	She no longer recognised me and I became more of a parent to her. There was no respite from her agitation. I had to be alert for things being moved inappropriately. She would eat any food (or imagined food) left out. I couldn't communicate with her. It was distressing to lose her personality.
5.	Wandering was very stressful and potentially harmful as we live on a main road. She followed me like a shadow. I could never get a break. Not being recognised was very upsetting, as was being attacked when trying to help her. It was a stark reminder that she was no longer the loving person she used to be. Constant repetition wore me down to screaming point.
6.	I had to be constantly on guard, remembering to go along with his delusions and using humour to prevent his frustration from getting out of control. My husband was up and down all night and I was unable to sleep, which meant I couldn't give him my whole attention as I wasn't rested. I was not able to go out anywhere unless someone stayed with him. In essence, my life was his life.
7.	Providing around the clock care was stressful, but gratifying. I became exhausted as a result of his inability to sleep at night. I had very little time away from the problem and desperately needed respite. His emotional, physical and mental inertia had an enormous impact on me. His vomiting and incontinence decreased his quality of life and curtailed both our social lives. We became isolated. I cried alone and felt I was becoming demented too.
8.	It was confusing and stressful. He was yelling at me and lashing out, which was very painful. His falling and incontinence were difficult to cope with and I wanted to hide my problems from family and friends. I would just grit my teeth and cry. ☹
9.	Even with the help of a paid carer, Mom was not eating, wandered all night and slept much of the day. I work full-time to support myself and Mom lived in a Senior Citizen apartment, so I couldn't move in with her. There was a lot of running back and forth and constant arguing about bathing, dressing, eating etc. There was never a day that wasn't full of Mom or work. There was no time for me at all.
10.	Continually challenging. Family never came to assist.
11.	Mother hated and refused all help.
12.	Anger and aggressive behaviour towards me. Being accused and shouted at. The strain of having to lift her onto and off the toilet. Wandering indoors. Falls.
13.	Money problems, repetition, temper tantrums, outrageous behaviour, sexual connotations.
14.	She woke Daddy throughout the night, so he needed to sleep in the day. That meant I had to keep her occupied. It made me feel like a prisoner. Her mobility deteriorated and she aspirated on her food, so we had to be alert to the risk of falling and choking.
15.	Incontinence, wandering, confusion about time/place, inability to communicate her thoughts/emotions.
16.	Night-time restlessness interrupted my sleep and caused me to remain tense all night. I was always having to change the bedding. There was no time to rest from thinking of all the things that needed doing. I needed to be constantly alert to what she might be doing when she wasn't in view and was always having to think of what she might be needing as she couldn't verbally communicate.
17.	I couldn't manage his behaviour problems. He became resistive and aggressive and no longer recognised me. I felt like a prisoner in my own home. My only release was respite care. The last straw was when he attacked me, holding me up against the wall by my throat. I was afraid of him after that.
18.	His mobility problems worsened and he frequently fell. I often had to get neighbours in to help pick him up off the floor or call 999. He became very resistive and aggressive, lashing out when I changed him. I couldn't rationalise with him at all. I had a very painful knee, which had to be operated on, and he didn't recognise my pain or care about me at all.

Figure 5.1: Responses to the open question, 'What were the most stressful/difficult to manage caregiving problems you were experiencing just prior to your dependent's admission to permanent care?'

Carer	Response
1.	I was unable to rest and couldn't emotionally handle the increasing problems. It was getting very expensive to keep her at home. Her medication costs were $200+ a month. It was cheaper to put her in a home because then the state pay for all medication and other health costs.
2.	Wandering was the main reason for placement. I was getting calls from neighbours all the time. If left alone for five minutes she would wander off. I was unable to rest.
3.	My mother suddenly lost the ability to walk, which made caregiving impossible. Private in-home help is very expensive in the US and insurance seldom covers the cost of home care long-term. There was no way I could manage her needs without help.
4.	I became physically and mentally exhausted. I fell asleep at work and was unable to do my job properly. I suffered a viral infection and only recovered after my wife went into a home. I felt I couldn't cope with any problem at work or home. I was treated for depression. I had coped for 5 years and done all I could. Due to my exhaustion I had to give up.
5.	I found caring for my mother lonely, terrifying and exhausting. I had no help from my doctor or social services. I felt isolated and had no escape. There was nowhere I could go without her wandering after me. She would even come banging on the toilet door! During the last few months I didn't have a night's sleep as I had to keep putting Mum back to bed. I had no life of my own. All I ever did was go to work, come home and look after Mum. The burden became heavier after my father became ill and was no longer able to care for her while I was at work. My family were no support to us.
6.	I tried to avoid arguments, but it didn't help. He knew he had to sit on the toilet, but would refuse to do so. His sleep pattern was reversed and I was unable to sleep. I thought of him as my patient, not my husband. He became very combative and was hurting me. I tried to go on, but my children helped me realise I couldn't. We had used all our assets during the years that he couldn't work – he has young onset familial Alzheimer's.
7.	The lack of adequate and skilled support services and the hopelessness in finding a suitable nursing home placement (for a young man with Down's plus Alzheimer's) pushed me to the edge. Financially, I was at the end of my rope. Without my family's help in the last few months I would have lost my home and become bankrupt.
8.	He fell and couldn't get up or walk at all. I checked us both into an assisted living facility, but by the next day he had to be admitted to a nursing home as he didn't recognise me.
9.	The care worker quit after Mom became angry with her. Things between us had become very adversarial - I seemed to be the enemy. Mom was hospitalised for dehydration and anaemia. I finally had to face the fact that it was beyond our capability to care for her adequately.
10.	I had no help from agencies and health insurance covered no assistance. I couldn't afford help. I had to take leave from work. I was very stressed and distressed. My father had also recently been diagnosed with Alzheimer's. I just couldn't cope.
11.	I couldn't find the help I needed. It was a 24/7 responsibility. I was never at peace and had no life of my own. My mother was gone and I was grieving for her, though she was still alive. I couldn't go on.
12.	Failure to cope with the increasing physical demands of caregiving - even paid carers found severe problems in managing, despite increasing their personnel. I had a worsening medical problem – serious nose bleeds, low blood count and associated lethargy and became too unwell to continue.
13.	She was unable to care for herself when my father died suddenly. I couldn't carry on providing care for her. It was time consuming, aggravating, frustrating and demoralising. She lived a way away and I had to be away from home a lot. There was loss of pay and financial hardship, especially because of the 'phone bill from the endless calls I had to make.
14.	My mother's inability to sleep at night. My father needed to sleep at night. He needed mother out of the house. His health was seriously declining. And I have been disabled for 14 years. His last heart attack necessitated putting her into a home.
15.	The management of incontinence, bathing etc. Cessation of almost all social life. An end to going to the theatre etc. Emotionally and physically drained.
16.	My heart problems were aggravated by the stress I put on myself, wanting to do a good job, and it sapped my strength to continue. I became mentally and physically exhausted.
17.	After he violently attacked me, I knew I couldn't go on. It wasn't in either of our best interests to do so. I called my CPN and he had him admitted as an emergency. But I know he didn't mean it, it was the illness, not him.
18.	I had to go into hospital for surgery on my knee and while he was in respite care I decided that I couldn't have him back home again. I knew I couldn't cope with his aggression and falling any more. And he no longer recognised me, so it didn't seem such a bad thing to do.

Figure 5.2: Responses to the open question, 'Looking back, if you had to identify one care-giving problem or other factor that contributed most to your decision to admit your dependent to permanent care, what would it be?'

The above data shows that the reasons for relinquishment of home caregiving were multi-factorial. One would expect this to be the case with such complex caregiving situations involving two vulnerable adults – the dependant and carer, each with their own set of physical and mental health needs. However, a brief analysis revealed some common key themes:

- Major hassles (n=26): nine carers cited aggression as a key factor; six carers identified wandering as a key problem; four stated that their relative was resistive to care; three cited delusions and false accusations; two cited shouting behaviour, and two repetitive behaviour/conversation.
- Physical demand (n=19): six carers cited continence problems as a key factor; nine stated that their relative had mobility problems or suffered falls, and four cited feeding problems.
- Exhaustion (n=15): eight carers cited sleep disturbance as a key factor; four carers stated that they were exhausted in their caring role, and three carers revealed that they had suffered serious health problems as a result of caring.
- Financial cost of caregiving (n=14): six carers cited the financial cost of continued home caregiving as a key factor; five stated caregiving had had a negative effect on employment/work, and three cited a lack of support from community care services.
- Social life (n=14): four carers cited a lack of breaks from caregiving as a key factor; three carers stated that they felt a prisoner/trapped in the caregiving role; three stated that they were isolated/lonely in their role; two cited a loss of social life, and two cited that they had no life of their own.
- Communication breakdown (n=8): five carers cited a failure of recognition of them by their dependant as a key factor, and three stated that there was an overall failure of communication between them and their dependant.
- Distress (n=8): three carers cited depression in their dependant as a key factor; three stated overall distress at the decline in their dependant, and two stated that their own clinical depression was a key factor.
- Other (n=14): There were many other themes identified that will not be listed here.

The above data again demonstrates the multi-factorial nature of breakdown in caregiving situations/relinquishment of home caregiving. For clarification, a closed question was asked of carers which asked them to categorise the main influence on their decision to resort to admitting their dependant to permanent care. The results were as follows:

Response to question, 'The decision to resort to admitting your dependant to permanent care was...':	Number
Made primarily as a result of a deterioration in your dependent's behaviour	6
As a result of a crisis due to a critical incident in the caregiving situation	5
Made primarily as a result of a deterioration in your dependent's physical state	4
Made primarily as a result of your deteriorating physical state and ability to cope	3
Made primarily as a result of your deteriorating emotional state and ability to cope	3
As a result of an inability to cope financially with the costs of caregiving	3
Made primarily as a result of a deterioration in your dependent's mental state	1

Table 5.56: Data in response to the closed question, 'The decision to resort to admitting your dependant to permanent care was...'.

The above table confirms that for the majority of past carers there was more than one response to this question and no single reason predominated, although for the majority of carers it was the dependant's behaviour rather than their physical condition that proved the last straw.

Six past carers stated that the deterioration in their dependant's behaviour was the main influencing factor on their decision to relinquish home caregiving and admit their dependant to permanent care. Difficulty in managing their dependant's aggression, resistiveness, wandering etc resulted in a breakdown in the caregiving situation, which is an important finding given the previous discussion around these problems peaking in the middle stages of the dementia illness trajectory.

Five carers relinquished home caregiving during a critical incident in caregiving, two of them after being assaulted by their dependant. This highlights the key role of the care manager in facilitating crisis respite care where such problems could be brought under better control and the carer could be given time to consider their future caregiving options.

Four carers relinquished home caregiving because of their dependant's physical state and their inability to manage the physical strain of caregiving. Three of these situations centred around dependants' severe mobility problems (two were following falls where the carer could not get their relative up off the floor). The need for double-handed home care support with access to appropriate equipment to manage intensive physical frailty needs towards the end of the dementing illness is highlighted by these cases.

Three carers stated the main reason for relinquishment was due to the financial burden of caregiving. These cases highlight that it is vitally important that people are made aware of their right to means-tested state support for community care services and that they receive appropriate welfare rights and benefits advice.

Finally, three carers relinquished home caregiving because of a deterioration in their own physical state and ability to cope - two admissions to permanent care were made as a direct result of the carer suffering cardiac problems, which highlights the tremendous physical strain that many carers have to endure in their role. Similarly, three carers relinquished home caregiving primarily because of their own deteriorating emotional state and ability to cope. All three were being treated for clinical depression and were exhausted and demoralised in their caregiving role. The experiences of these six carers highlight the enormous impact that dementia caregiving can have on carers' physical and emotional health and the sad fact that for many a literal physical or psychological breakdown has to occur before permanent care becomes an option.

This chapter of the thesis has, in the main, been a data reporting chapter, presenting key research findings and providing a commentary to highlight salient points, both from a research and practice perspective. The next chapter will discuss these findings in relation to the body of research evidence currently available, in order to demonstrate the originality of this work and the potential contribution of this research to the field of dementia community care practice.

Chapter 6

DISCUSSION OF THE RESEARCH FINDINGS

"It has been disastrous, but I could not just put my father in a home. It would devastate me." (Internet carer 4)

CHAPTER 6: DISCUSSION OF THE RESEARCH FINDINGS

This chapter is intended to highlight the main research findings presented in Chapter 5 and discuss them in relation to previous research. This is in order to demonstrate the potential contribution to clinical practice and to the existing body of research that this study could have. This chapter will be presented under the following headings:

- Discussion of the internet as a research tool
- Discussion of the newly devised carers' assessment tools
- Discussion of the main study findings in relation to previous research
- An analysis of the main risk factors for breakdown of dementia caregiving situations found in this study compared to previous research.

6.1 Discussion of the internet as a research tool

The development of the internet sampling methodology for this study was innovative and had not previously seen in the field of dementia care research, as far as the researcher is aware. Indeed, midway through the study Alzheimer Europe approached the researcher for advice on how to establish an on-line research questionnaire and receive email questionnaire responses.

The internet response rate of 90 subjects (74 current and 16 past carers) over one year of the web-pages being available on-line was not as great as had been hoped for, but it should be stated that the research web-pages were attached to an existing journal web-site. This site has no funding and no dedicated web-master, thus 'hits' relied upon carers visiting the site to access journal pages and linking to the on-line questionnaires, or seeing one of the ten or so web-links that were established with other dementia dedicated web-sites. It is thus likely that future research, perhaps undertaken or supported by one of the major dementia/caregiving organisations, would find this sampling method even more useful and achieve a far larger study sample.

It should be stated that in future research the number of questions/sections in such internet-based questionnaires should be limited to a more manageable number. A reduced number of questions may have resulted in a higher response rate, as well as being easier to analyse. For instance, for several subjects, sections 3 and 4 of the on-line questionnaire were not submitted, either because their modem connection failed due to the length of time it had taken for them to complete the first sections, or because they had grown tired of typing answers to questions or ticking boxes. However, some invaluable data would undoubtedly have been lost if the on-line questionnaires had been reduced. The challenge for all research, of course, is to get the right amount of data from the right amount of questions.

The sampling methods adopted for this research led to a difference between interview and internet cohorts, with an older group of carers being interviewed by the researcher (average age 66.8 years) and a somewhat younger group contributing their experiences via the internet (average age 51.4 years). The internet sampling method also attracted a large number of overseas contributions (n=57 / 77% of 74 subjects, i.e. 17 internet subjects were from the UK), whereas the 17 interview subjects were all from South Wales. Thus the study sample could not be said to be representative of the UK caregiver population overall. However, the findings from this research and the recommendations for clinical practice may be universally relevant, in the same way that the experience of dementia caregiving is universal.

A final comment to make about the internet sampling method is that the anonymous nature of subject questionnaire returns that this method affords may also have allowed carers to give a more complete disclosure of negative feelings and poor coping. In this respect, this sampling method may be very useful for future research into difficult areas of practice, for example in relation to the protection of vulnerable adults from abuse. The methodological difficulties encountered in previous research, e.g. in Coyne et al. (1993) and Cooney and Mortimer (1995), who sent out anonymous questionnaires to carers known to services and whose response rate was only about a third, may thus be overcome.

6.2 Discussion of the newly devised carers' assessment tools

One of the most important outcomes of this study is the development and testing of the 'Dementia Caregiving Problems Questionnaire (DCPQ)' and the 'Dementia Caregiving Burden Questionnaire (DCBQ)'. There has been some serious criticism levelled against those tools which have been developed by Local Authorities to meet the requirements of the 'Carers Recognition and Services Act 1995' (DoH, 1995) because they have tended to focus on dependency of the person cared for and objective burden measures only (Carers National Association, 1997). The above two newly devised carers' assessment tools will not only more adequately meet the requirements of the Carers Act, but will also be useful in clinical practice, giving statutory services community care managers invaluable information about carers' perceived problems, subjective burden and coping strategies, specifically in relation to dementia caregiving situations.

The DCPQ encompasses objective burden measures across 5 domains – communication, confusion, behaviour, mood and self-care/physical. Much of this questionnaire is newly formed and greatly builds on previous work undertaken by Greene et al. (1982), to the extent that it can be considered a newly formed carers' assessment tool (see Chapter 4). The analysis of the difficulty of caregiving problems in addition to their frequency is key to this newly devised questionnaire. Asking which caregiving problems the carer perceives as being the most difficult to manage and what strategies they use to manage those problems, together with the perceived success of those strategies, provides the care manager with vitally important information on the carer's ability to cope with the difficulties they face, the emotional and psychological needs they may have arising from the impact of caregiving, and the inputs which may be required to bring caregiving problems under better control. It also helps to identify those more urgent problems and needs which the carer may have that would benefit from targeted service interventions, such as intensive home care support and flexible day and respite care, to help prevent psychological health problems from developing/worsening and breakdown in caregiving situations/unplanned, crisis admissions to permanent care from occurring.

With a Cronbach's Alpha score of 0.7029 and a Guttman Split Half of 0.6336, the DCPQ can be said to have high internal consistency and can be recommended as reliable for implementation in clinical practice.

The DCBQ encompasses subjective burden measures across 4 domains – life upset, personal distress, negative feelings and (a lack of) positive feelings. Much of this questionnaire is newly formed and builds greatly on previous work undertaken by Greene et al. (1982), to the extent that it can be considered a newly formed carers' assessment tool (see Chapter 4). The DCBQ provides invaluable information to the care manager on the degree of impact of caregiving on aspects of the carer's quality of life and the feelings that caregiving engenders in them. As well as addressing life upset, personal distress and negative feelings, this newly formed questionnaire embraces an assessment of caregiver satisfaction, which is highlighted in the literature as important in having an ameliorating effect on the damaging effects of chronic stress (Keady, 1999). The lack of positive feelings arising from caregiving is actually assessed by the DCBQ, but questions are written in the positive, i.e. each item has a reversed polarity score, thus conveying to the carer that the questionnaire is balanced and validates the positive aspects of their experience.

With a Cronbach's Alpha score of 0.8430 and a Guttman Split Half of 0.7581, the DCBQ can be said to have high internal consistency and can be recommended as reliable for implementation in clinical practice.

Both carers' assessment tools, having been made available on the internet for some time, have been accessed by several community dementia care practitioners and teams in the UK, Australia and USA. As a result, and with permission of the researcher, they are currently being used in clinical practice in more than ten memory clinics and community mental health services for older people teams in these countries, as well as in local services. This evidence of face validity of these tools, together with the above evidence concerning reliability, will enable their extended implementation following post-doctoral publication. Both the DCPQ and DCBQ will form the basis of a new 'Dementia Caregiving Breakdown Risk Assessment Tool', which is proposed as one of the main outcomes of this research in the concluding chapter.

6.3 Discussion of the main study findings in relation to previous research

Several key findings from this study also point to important recommendations for practice, as well as building on previous research. Of particular note are the following:

Commitment to caregiving

- The current carer sample in this study comprised mostly adult children carers (n=49 / 54.4%), followed closely by 35 (38.9%) spouse subjects.
- The majority of carers were providing care for dependants with moderate to severe dementia (n=72 / 80%), and ten (11.1%) were caring for people with very severe dementia.
- The majority had been providing care for more than three years (n=42 / 46.6%), and 18 (20%) of these had been providing care for more than six years since their dependant's diagnosis.
- The overwhelming majority of carers (n=73 / 82%) were providing more care hours (direct hands-on care and one-to-one supervision) than the EC working time directive of 40 hours per week, and 41 of these (46.1%) were providing care for more than 85 hours per week.

These findings demonstrate the tremendous commitment to caregiving that carers in this study made, often in the face of competing demands and with little or no support from community care services, as will be seen later. The high level of workload undertaken on behalf of the state - as it would otherwise have had to provide permanent care, should not be overlooked. (It was estimated that the total cost to health and social services for dementia care in 2001 was between £9.5bn and £13.5bn [McNamee et al., 2001], and this would increase dramatically if informal carers withdrew their support). Carers cannot keep up this amount of workload for long without appropriate forms of support from community care services across the spectrum of informational and educational support, practical assistance at home, breaks from caregiving and counselling interventions from the point of identification/diagnosis up to and beyond the death of the dependant. Without such support to meet their perceived needs and relieve them of their caregiving burden, carers are at significant risk of becoming physically or psychologically ill themselves or relinquishing their role/allowing their dependant to enter permanent care at an earlier stage than would have previously been desired, as will be determined later in this chapter.

Competing demands

- The overwhelming majority of carers were living in the same house as their dependant (n=81 / 90%). However, nine (10%) dependants were living alone, and all of them were judged as being moderately to severely demented.
- A further nine (10%) carers had already moved in with their dependant/had them move in with them so that they could provide more intensive care.
- 28 (31.1%) carers were in full or part-time employment, and 34 (37.8%) had relinquished employment to take on the role of full-time carer.
- 31 (34.4%) were providing care for another dependant person - 11 (12.2%) for another elder, one of which was a second person with dementia.

These competing demands are concerning, given the already near impossible task that carers have already taken on, i.e. caring for a person with a progressive, degenerative brain disease that will ultimately result in death. Most carers had made extreme changes to their lifestyle and the resulting impact on their quality of life, including family relationships and financial status, was great, as will be discussed later in this chapter. The psychological and physical impact of providing care from a distance and worrying about the dependant when they are home alone; trying to sustain full or part-time employment and returning home after paid work to enter into caregiving work, and providing care for a second dependant person must be immense, as seen in the next discussion.

Impact on health

- The majority of carers (n=49 / 54.4%) were coping with the demands of caregiving in the face of disability, illness or disease; only 40 (44.9%) thought themselves to be in good health.
- 20 (22.5%) carers were suffering from non-life threatening conditions and 2 (2.2%) had a life threatening illness or disease.
- 27 (30.3%) carers were receiving treatment for clinical depression, and the majority of depressed carers were caring for a moderately (n=13) to severely demented (n=9) dependant, with there being less depression in the very severely demented (n=3) group.
- Clinical depression in the caregiver was associated with higher levels of caregiving burden (DCBQ correlation with health rating +0.420 $p<0.01$; mean DCBQ score for 'depression' was 94.3, compared to 67.9 'good health', 76.9 'non life threatening illness', 74.5 'life threatening illness', and 85.0 'frail and infirm').

The level of physical illness found in this sample at 54.4% was great, with levels similar to those found by the Alzheimer's Society in 1993, where 36% of carers reported a physical health problem, and in 1994, where 60% reported that they were suffering ill health or nervous problems as a result of caregiving. The impact on psychological health was similarly high, with clinical depression (diagnosed and treated) prevalence at 30% being similar to that reported in studies by Dura et al. (1990) (30% meeting DSM 111 criteria), Ballard et al. (1995) (29.4% diagnosable depression) and Coope et al. (1995), where case level depression was found in 28.4% of carers. However, as depressive illness was confirmed by the prescription of anti-depressant medication in this sample it can be expected that an extra 'sub-case' level would be found similar to the 11.9% identified by Coope et al. (1995), as well as an additional number of carers who were severely clinically depressed but untreated.

Physical and psychological health problems in carers both diminish the ability to cope with the demands of caregiving and serious health problems can result in a breakdown in caregiving situations, as will be discussed later. The health of carers must be assessed in any carers' assessment and the response of GPs in treating diagnosed conditions is vital in supporting continued home caregiving.

It is also important to note that depression in carers may peak in the moderate to severe stages of the dementia trajectory and lessen in the severe to very severe stages. If carers' psychological health problems could be identified at an earlier stage and treated with social and psychological therapies, as well as with medication, then perhaps this would help support continued caregiving until this most difficult phase of the illness had passed. However, easing the burden of caregiving by way of appropriate service interventions must go hand-in-hand with this aspect of mental health care, as will be discussed later.

Relationship change

- For the majority of carers, there was a deterioration in the quality of their relationship with their dependant since the onset of their illness, with 44 deteriorating on the 'closeness' scale to an average of 1.7 points. (35 carers stated there had been no change in the quality of their relationship.)
- The mean degree of closeness in the relationship lessened as the degree of dementia increased, with mean dementia severity scores of 2.36 for 'very close', 2.42 for 'reasonably close', 2.55 for 'not very close' and 3.00 for 'distant'. (For 11 carers with a previously poor relationship with their dependant there was an increase in the quality of their relationship to an average of 2.5 points on the closeness scale.)
- From qualitative data analysis, the most important themes emerging were role reversal (n=39 / 43.8%), equating elder care to child care (n=23 / 25.8%), role change (n=17 / 19.1%) and grief and loss (n=13 / 14.6%).
- On the DCBQ, 58 carers (76.3%) expressed that they frequently or always found it distressing that their dependant had changed so much from their former self; 44 carers (57.9%) frequently or always viewed caring for their older dependant as being like caring for a child; 42 (55.3%) frequently or always had feelings of grief and loss associated with their caregiving role, and ten (13.2%) frequently or always felt distant from their dependant.
- The perceived current quality of the emotional relationship between the carer and dependant was found to be closely associated with the level of caregiving burden experienced, with a correlation with the 'Overall DCBQ' score of +0.407 ($p<0.01$).

These findings support previous research by Williams et al. (1995), who found an association between personality change in the dependant and caregiver burden; Wuest et al. (1994), who proposed that the changing family relationship resulting from the dementing illness results in the person with dementia *'becoming a stranger'*, along a continuum of emotional detachment from intimacy to alienation; Albert and Brody (1996), who reported that 60% of their sample of 426 adult children carers strongly agreed that caring for their elderly parent was 'like taking care of a child', and Morris et al. (1988), who found that carers who experienced less marital intimacy before and during caregiving exhibited higher levels of perceived strain and depression.

The implications for practice of this high degree of relationship change and the strong association with the experience of caregiving burden are great. Perhaps most importantly, the changes in the quality of the relationship and the emotional detachment that are commonly experienced need to be recognised, validated and supported by professionals. Helping carers to understand the changes in their dependant through appropriate counselling interventions and relieving the carer of situations where conflict may be experienced, e.g. during intimate personal care tasks, may maximise the potential for the maintenance of feelings of love and affection despite cognitive decline.

This maintenance of attachment can be seen in the 35 caregiving situations where there was no perceived change in the quality of the relationship with the person cared for. From qualitative data analysis, it seems likely that there was in fact a relationship change for this group of carers, in terms of role change/reversal from a spousal or adult child relationship into more of a parental one; a *role violation* as Albert and Brody (1996) termed it. However, whilst the role relationship changed, the quality of closeness or attachment remained.

Furthermore, for 11 adult children carers the quality of closeness/attachment improved as they entered into the caregiving role and their dependant became more demented. For this group the previous relationship with the person cared for had not been as close, and entering into the caregiving role had drawn them closer to their dependant.

The correlation between the perceived quality of relationship and caregiving burden is an important one, as it supports previous research by Spruytte et al. (2001) which found that a good current relationship between the carer and dependant reduced the risk of nursing home placement. If decreasing quality in the emotional relationship between the carer and person cared for is of such importance and predictive of breakdown in caregiving situations, then perhaps further research into the experiences of the above two groups of carers, or others similar to them, may hold the key to how carers can remain emotionally attached or even draw emotionally closer to their dependant despite their cognitive decline and the increasing caregiving problems experienced.

Frequency of caregiving problems and most burdensome caregiving problems

- The most frequently experienced caregiving problems were time disorientation (n=63 / 82.9%); washing/bathing difficulty (n=55 / 72.4%); dressing/undressing difficulty (n=49 / 64.4%); repetition (n=46 / 60.5%); place disorientation (n=44 / 57.9%); day/night disorientation (n=42 / 56%); verbal communication difficulty (n=41 / 53.9%); family conversation difficulty (n=39 / 51.3%); shadowing (n=38 / 50%), and inattention (n=34 / 44.8%).
- 15 of the 50 caregiving problems showed a non-linear relationship to caregiving burden, with a peak in DCBQ scores in the 'sometimes' or 'frequently' points on the scale, e.g. inability to start and maintain sensible conversation; 3 caregiving problems showed a peak in the 'rarely' point on the scale, e.g. partly/completely immobile/needs lifting; and 4 caregiving problems showed an exponential increase in caregiving burden with increasing frequency across the range, e.g. resistiveness to care.
- The most burdensome caregiving problems across the frequency range (correlations with DCBQ) were 'shouts/swears/screams at people/me for no apparent reason' (+0.452 $p<0.01$); 'becomes irritable and easily upset' (+0.410 $p<0.01$); 'wakes me/others during the night' (+0.308 $p<0.01$); 'has difficulty settling to sleep or wakes unusually early' (+0.308 $p<0.01$); 'tries to get up and dressed/go outdoors during the night' (+0.300 $p<0.05$); 'appears to be unhappy and depressed' (+0.290 $p<0.05$); 'mood changes suddenly for no apparent reason' (+0.281 $p<0.05$); 'has to be prevented from wandering outside the house' (+0.261 $p<0.05$); 'endangers self by engaging in risky behaviours' (+0.261 $p<0.05$); 'prone to having falls/fits/choking' (+0.244 $p<0.05$); 'hits out at me/other people' (+0.245 $p<0.05$), and 'tends to collect things and hoard them' (+0.232 $p<0.05$).

These findings support those from Haley et al. (1987), which showed that unpredictable behaviours such as wandering and aggression are particularly stressful as they require continuous monitoring; Donaldson et al. (1997), who found that non-cognitive features and behavioural and psychological symptoms of dementia have a primary role in the genesis of stress, and Orbell and Gillies (1993), who highlighted that early symptoms, although less severe, may be more stressful due to uncertainty over the cause and the changing relationship between the carer and dependant. They proposed that in advanced dementia the dependant may enter a more passive phase where less vigilant carer attention is required, and concluded that the relationship between illness duration and carer well-being is 'U-shaped' rather than linear. Similarly, Haley and Pardo (1987) found that whilst self-care deficits increase with severity, many distressing behavioural symptoms decrease in late dementia. Therefore the need for a multi-dimensional assessment of dementia severity and carer adjustment is recommended.

This study adds to the above body of evidence, in that the relationship between individual caregiving problems and caregiving burden showed different trends for different problems. For 3 problems – place disorientation, failure of recognition and mobility problems, the highest burden scores were at the 'rarely' point on the scale, with a monotonical decrease in burden with increasing problem frequency. This highlights that some caregiving problems may become easier to manage over time and have less psychological impact, either because of adaptation or because more difficult problems predominate as dementia progresses. 15 caregiving problems – conversational failure, inability to respond sensibly, verbal repetition, overtalkativeness, incommunication, talking to self, time disorientation, wandering, shouting/swearing/screaming, disinterest, pacing, emotional lability, standing/walking difficulty, nocturnal incontinence and daytime incontinence, showed a peak in caregiving burden in the 'sometimes' or 'frequently' points on the frequency scale, with a decrease in burden scores in the 'always' rating. This highlights that for some caregiving problems, as the level of tolerance builds and/or problems become more predictable the psychological impact lessens somewhat, to a more moderate level. And for 4 caregiving problems – night-time wandering, resistiveness, irritability and dependant depression, there was an exponential rise in caregiving burden across the frequency range. For this sample of caregivers, these caregiving problems may be those for which tolerance is never built and they continue to remain unpredictable despite being experienced continually.

Whilst the above findings cannot be extrapolated to dementia carers per se, the above 4 caregiving problems, together with those most burdensome problems (especially shouting/ swearing/screaming; irritability and easy upset; night-time disturbance, and difficulty settling to sleep/waking early), should perhaps be viewed as being those which health and social services care professionals should target for interventions such as caregiver training to help carers gain some mastery over their situation, home care inputs which relieve the carer of some of their most difficult direct caregiving responsibilities and respite care to help remove the carer from the caregiving situation for a time, thereby maximising the potential for the alleviation of caregiving burden.

DCPQ dimensions and relationship with dementia caregiving trajectory and DCBQ

- Positive correlations were found between the 'Communication problems' domain of the DCPQ and 'Dementia severity rating' (+0.646 p<0.01), 'Confusion problems' domain and 'Dementia severity' (+0.561 p<0.01) and 'Self-care/Physical problems' domain and 'Dementia severity' (+0.585 p<0.01). All three domains showed an incremental increase over the dementia caregiving trajectory.

- The 'Mood problems' and 'Behaviour problems' domains showed a non-linear relationship with 'Dementia severity rating', with both domains peaking in the moderate to severe illness stages and lessening in the very severe stage of the dementia trajectory.
- Positive correlations were found between the 'Mood problems' domain and 'Overall DCBQ' score (+0.348 p<0.01) and between the 'Behaviour problems' domain and 'Overall DCBQ' score (+0.425 p<0.01).

These findings support previous research by Donaldson et al. (1997), which found that non-cognitive features of dementia, the presence of psychiatric symptoms and behavioural disturbances have a primary role in the genesis of carer stress; Gilhooly et al. (1994), which found that acts of commission, e.g. wandering, are more problematic and stressful for carers than acts of omission, e.g. inability to wash/bathe, and Greene et al. (1982), which found that negative symptoms such as withdrawal and apathy were more likely to be associated with increased perceived caregiving burden.

The implications of these findings for clinical practice are that behaviour and mood related caregiving problems cause the highest levels of caregiving burden and may have the most negative impact on the psychological well-being of carers. Service interventions such as counselling support, caregiver training, home care support and respite breaks from caregiving may be particularly useful in reducing caregiver burden and enabling continued home caregiving. Similarly, the crucial role of medication management is highlighted, in that together with the above psycho-social interventions targeted (and minimal) sedation, anti-psychotic medication and anti-depressant medication could alleviate behaviour and mood related caregiving problems to a more manageable level. As these problems peak in the moderate to severe phase of the dementia trajectory and tail off in the severe to very severe phase, this means that dementia caregiving may actually become less burdensome/difficult as the illness advances to a stage at which the person becomes more passive and frail.

For those carers who wish to remain in the caregiving role for as long as possible and up to the death of their dependant, the delivery of more intensive service interventions during this most difficult period of caregiving, when mood and behavioural problems and associated caregiving burden are at their peak, may reduce the likelihood of breakdown in the caregiving situation and relinquishment of home caregiving/entry of the dependant to permanent care. The above data highlights the changing nature of the dementing illness over time, the need for regular assessment of perceived need and the importance of frequent adjustments to the community services and treatment care plan. For example, as the dementia illness trajectory progresses towards its final phase more intensive physical support may be required, with double-handed assistance, access to specialist equipment such as hoist and height adjustable bed and sitting services, rather than the out of home breaks from caregiving recommended above for the more active and disturbed phase of the illness. Both types of service provision should be made more available and such an investment could, on the basis of this evidence, reduce the number of permanent care bed days required for this group.

Dementia Caregiving Burden Questionnaire (DCBQ) results and relationship with dementia illness trajectory

- The most frequently experienced 'Life upset' domain questions were concerning negative impact on social life (n=66 / 86%); worry about safely leaving the dependant alone (n=64 / 84.2%), and feeling the need for a long-term break from caring (n=46 / 60.5%). The most frequently experienced 'Personal distress' domain questions were concerning distress at the change in the dependant (n=58 / 76.3%); feelings of grief and loss (n=42 / 55.3%), and feeling exhausted and demoralised (n=32 / 42.1%). The most frequently experienced 'Negative feelings' domain questions were concerning equating elder care to child care (n=44 / 57.9%); frustration with the dependant (n=27 / 35.5%) and feeling depressed (n=25 / 32.9%). The most frequently experienced '(Lack of) Positive feelings' domain questions were concerning lack of feelings of positive self-worth and self-esteem (n=43 / 56.6%); lack of hope for the future (n=35 / 46.7%), and lack of satisfaction and reward (n=34/ 44.7%).
- DCBQ questions with the highest correlations with the 'Carer self-assessed stress' rating were concerning feeling completely overwhelmed by the situation (+0.724 p<0.01); feeling they can no longer cope with the situation (+0.717 p<0.01); feeling they (do not) manage stress well and overcome it (+0.710 p<0.01); feeling depressed about the situation (+0.668 p<0.01); feeling exhausted and demoralised in the caregiving role (+0.666 p<0.01); feeling there will be no end to the problem (+0.621 p<0.01); feeling helpless and as if things are outside of their control (+0.608 p<0.01); (not) feeling that they adopt a positive, problem solving approach (+0.607 p<0.01); feeling frustrated with the dependant (+0.525 p<0.01); feeling like giving up caring (+0.511 p<0.01); feeling their physical health has suffered as a

result of caring (+0.506 p<0.01), and (lack of) feeling hopeful about the future (+0.500 p<0.01).

- Four carers (5.3%) had 'severe to extreme' scores in 'Overall DCBQ' and 13 (17.1%), eight (10.5%), one (1.3%) and nine (11.8%) carers respectively had 'severe to extreme' scores in the 'Life upset', 'Personal distress', 'Negative feelings' and '(Lack of) Positive feelings' domains.
- '(Lack of) Positive feelings' correlated strongly with 'Overall DCBQ' score to a level of +0.764 (p<0.01), meaning that the presence of positive feelings had a negative correlation with 'Overall DCBQ' to the same extent. 13 carers (17.1%) had scores in the 'highly positive to extremely positive' category for positive feelings experienced.
- The correlation between the 'Life upset' domain of the DCBQ and 'Degree of dementia' rating was +0.256 (<0.05). There was no relationship between the 'Personal distress' or 'Negative feelings' DCBQ domains and 'Degree of dementia' rating. However, regarding the '(Lack of) Positive feelings' domain the picture was very different, with a monotonical decrease in scores across the dementia trajectory, i.e. an increase in positive feelings as the dementing illness advanced. There was a negative correlation between the '(Lack of) Positive feelings' domain and 'Degree of dementia' rating of -0.301 (<0.01).

These findings support previous research by Almberg et al. (1997), who found that limitation in social life, poor physical health and a lack of positive outlook were the most important variables in the experience of dementia caregiving burden and burnout; Hirschfield (1983), who proposed that being 'tied down' to caregiving, a lack of free time and feelings of resentment, helplessness, hopelessness and guilt were major areas of tension for dementia carers; Cohen (1994), who suggested that caregiver satisfactions mitigate against the negative effects of burden and stress in caregiving, and Nolan et al. (1996, p103), who proposed that caregiving satisfactions may serve as a mechanism to buffer the inevitable difficulties of caring and act as *'well-springs of hope when all appears despair'*.

It is, of course, important to consider first the above findings relating to the enormous negative impact that dementia caregiving had on this sample of carers. There was strong evidence that the majority of carers in this cohort were having significant emotional problems in coping with the excessive demands of caregiving, that many had developed psychological health problems as a result and that this had reduced their capacity to continue in the caregiving role. Particular concern must be directed towards the four carers with scores in the 'severe to extreme' category for 'Overall DCBQ', who may be most at risk of breakdown in their caregiving situation, especially if they are not in receipt of appropriate forms of support from community care services.

The DCBQ, as a breakdown in caregiving situations risk assessment tool, may also have value as a risk assessment for caregiver abuse. Nolan et al. (1996) stated that there is a particular need to target carers who get no satisfaction from caregiving, as they may be more likely to be near breaking point (Clifford, 1990). This was the case for eight carers (10.5%) in this sample, who had 'severe to extreme' scores in the '(Lack of) Positive feelings' DCBQ domain. Similarly, based on findings from Hirschfield (1983) and Archbold et al. (1992), Nolan et al. (1996) stated that caregiving situations in which there is 'low mutuality' in the caregiving relationship should be 'taken very seriously' in terms of risk for elder abuse. Particular concern should therefore be paid to the ten (13.2%) carers in this study who stated that they frequently or always felt emotionally distant from their dependant; 16 (21.1%) carers who did not feel that providing care was a positive way of expressing love and affection for the person cared for; 29 (38.2%) carers who felt trapped in the caregiving role, and five (6.6%) carers who admitted to getting cross and angry with their dependant. Such caregiving situations, especially if compounded by social isolation and poor premorbid relationship with the dependant (Cooney and Mortimer, 1995), the dependant abusing the carer (Homer and Gilleard, 1990) and the carer abusing drugs or alcohol or having a psychiatric illness (Sadler et al., 1995), should be viewed as 'urgent cases' for access to community care services, especially those that provide breaks from caring, and for consideration for facilitated and supported entry to permanent care. As Philp et al. (1997, p.344) recognised, institutionalisation may be in the best interests of both the person with dementia and the carer in such cases and should be regarded as a positive outcome, especially *'if it improves the safety and comfort of the person with dementia, reduces carer stress and can be achieved at reasonable cost'.*

The presence of a high level of positive feelings for 13 (17.1%) carers in this study should not be overlooked. Whilst the above focus on the negative impact of caregiving is legitimate, a balanced view needs to be taken as caregiving relationships are so complex. Nolan et al. (1998) proposed that caregiving satisfactions are prevalent, derive from a number of sources and often co-exist with a range of difficulties. They called for more research on the rewards of caring, and hopefully this thesis will contribute to the growing body of literature available on this subject.

Of crucial importance was the finding that there was a clear exponential increase in positive feelings across the dementia illness trajectory. The correlation between '(Lack of) Positive feelings' domain and 'Degree of dementia' rating was -0.301 ($p<0.01$). That is to say, the more severely demented the dependant was, the more positive feelings that were experienced. This builds on previous research by Gilhooly (1996), who found a significant negative correlation between the duration of caregiving and the morale and mental health of the carer, i.e. the longer the carer had been providing care, the higher their morale and the better their mental health.

- Particularly strong negative correlations were found between the 'Degree of dementia' rating and the DCBQ questions 'Do you derive personal satisfaction and reward from your caregiving role?' (-0.354 p<0.01) and 'Do you have a sense of achievement or fulfillment as a result of caregiving?' (-0.343 p<0.01) , i.e. both personal satisfaction/reward and sense of achievement/fulfillment increased with dementia severity.

It would appear that the reason for an increase in positive feelings as dementia severity increases is much more than just the 'survival effect' suggested by Gilhooly (1996), but rather a complex interaction of factors such as it becoming easier to care for the person as they become less behaviorally disturbed and more passive and accepting of care; there being less conflict in the relationship as the person becomes more mentally impaired; the carer feeling more sympathy for the person with dementia as they become more frail and dependent and the carer gradually learning skills and achieving some mastery over their situation, as suggested by Gilhooly (1996).

Whatever the reason, the importance of this finding is that for those currently coping with high levels of behaviour and mood disturbance and experiencing high levels of caregiving burden, these will pass with time. If community care managers could be more sensitive to this fact and coordinate increased service interventions to coincide with the most difficult phase in the dementia caregiving trajectory, for example with regular and more flexible respite breaks from caregiving, direct relief of their perceived most stressful caregiving tasks via targeted home care inputs, improved medication management, caregiver training etc, until the dementing illness advanced to a more passive stage, then the carer could remain in their role until such time as home caregiving became physically impossible due to physical capability/environmental constraints or the person with dementia dying. In order to achieve more responsive packages of care, as mentioned above, more frequent assessments of the carer's perceived needs would need to take place and a more flexible and accessible range of community care services would need to be made available within each locality. However, such targeted and adaptable services may lead to a significant reduction in permanent care bed days, thereby achieving some secondary health and social care cost savings in addition to health gain for carers.

The researcher proposes that the newly devised carers' assessment tools measuring objective and subjective burden, namely the 'Dementia Caregiving Problems Questionnaire' and 'Dementia Caregiving Burden Questionnaire', could form the bases of ongoing assessments suggested above as being of vital importance in sustaining continued home caregiving. Furthermore, in practical administration of this tool the researcher has found that carers view both tools as valuable in capturing the perceived reality of their experience. As with Nolan et al.'s (1996, p. 104) 'Carers Assessment of Satisfactions Index', carers in this study appeared to find the focus of the Positive Feelings questions in the DCBQ particularly useful in positively reappraising their situation and, as with the 'CASI', it may have helped them to *'begin to see caring in a different, more positive light'*.

Quality of life impact

- The most negative impact of caregiving was on 'Social/Work life', with 70 carers (92.1%) rating the impact as 'negative/very negative'. This was closely followed by 63 (82.9%) carers rating the impact on their 'Emotional well-being' as 'negative/very negative', 62 (81.6%) rating the impact on 'Physical well-being' as 'negative/very negative', and 54 (71%) rating the impact on 'Personal relationships/Family life' as 'negative/very negative'.
- In terms of 'Overall quality of life impact', 17 (22.4%) carers rated the impact on their quality of life as 'very negative' and nine (11.8%) rated it as 'extremely negative'. (Six carers (7.9%) stated a positive impact on quality of life.)
- The most important themes emerging from qualitative data were concerning the isolating and confining effects of caregiving (n=33); the negative impact on social life (n=21) and friendships (n=12); the negative impact on family (n=12) and spousal relationships (n=8) (in relation to adult children caregivers); the negative impact on employment (n=9) and financial status (n=7), and on psychological (n=22) and physical (n=14) health.
- 45 of 199 themes were positive (22.6%), relating to caregiving satisfactions (n=13) and motivations (n=11); religious belief (n=6); positive impacts on quality of life (n=6), and positive aspects relating to the support of family (n=6) and friends (n=2).
- The correlation between 'Overall quality of life impact' and 'Overall DCBQ' score was +0.472 $p<0.01$.

These findings support previous research by Yee and Schulz (2000), who found that female carers, particularly those of younger people with dementia, find it difficult to continue in full-time employment, with the consequence of financial difficulties and potential dependence on welfare benefits; Terri (1994), who reported that up to 70% of dementia carers suffer with clinical depression; Haley et al. (1997) who stated that dementia carers used more psychotropic medication and suffered with more physical abnormalities such as elevated blood pressure, high plasma lipid levels and impaired immune function, and Austrom and Hendrie (1992), who proposed that whilst the quality of life of the carer is invariably affected by caregiving, with 55% of caregivers reporting physical exhaustion and 75% reporting dissatisfaction with their current state of health, intervening variables such as the strength of the existing relationship with the dependant and the presence of a social support network are mediating factors.

The impacts on employment, emotional well-being, physical health and personal relationships have been discussed elsewhere in this chapter and so will not be re-examined in detail here. Suffice to say, dementia caregiving has major impacts on carers' quality of life as well as upon those of persons cared for. The loss of paid work and the increased financial strain this causes; the onset of clinical depression or cardio-vascular disease and the diminished coping this results in, and the deterioration in family relationships and the isolation this produces as examples of quality of life impacts are all important factors that can increase the likelihood of breakdown in dementia caregiving situations, as will be further discussed later in this chapter. It is therefore vitally important that the impacts on quality of life for each individual carer are examined by community care managers in their carers' assessments and considered when planning care inputs and service interventions.

It is also important to note that 45 of 199 (22.6%) qualitative statements analysed in responses to the open question concerning impact of caregiving on quality of life were positive, and that 24 of the 71 subjects (33.8%) responded with a mix of negative and positive statements. These findings support the above discussion relating to caregiving satisfactions. It is likely that in reflecting on their own quality of life in responding to this question, carers were trying to focus on any positive aspects or outcomes that were evident in their situation, such as the support they had received from family or friends, or the fact that their care had kept their spouse or parent out of a care home. The phrase *'the silver lining effect'* was coined by Summers et al. (1989) (cited in Nolan et al., 1996) to describe the cognitive coping strategy of identifying positive aspects in a largely negative situation successfully used by many carers. It would seem that this struggling to find purpose, meaning and value in an environment of stress, isolation and loss is important as a means of psychologically coping with the adversity of caring for a person with dementia. Not only does this mean that as practitioners we need to maintain a balanced view of dementia caregiving, i.e. that it is *'not all doom and gloom'*, as one carer put it, but also that if, as care professionals, we could help carers to identify positive aspects within their situation then perhaps they would become better psychologically equipped to continue in their role.

Coping strategies used by carers

- 'Preventive action' was the largest category of coping strategies employed by carers (102 statements), followed by 'Strategies to enhance carer emotional well-being' (69 statements), 'Dealing with the consequences when strategies are not effective' (57 statements), 'Reframing meaning of events/problems' (36 statements), 'Direct action – strategies to maintain dependant independence' (29 statements), 'Direct action – strategies to avoid conflict/distress' (29 statements) 'Emotional and/or practical support of others' (27 statements), and 'Direct action – strategies to enhance dependant emotional well-being' (26 statements).
- 13 statements made were related to reassuring the dependant everything is allright; 11 were related to the benefit of contact with/help of friends; nine were related to the benefit of talking with other carers about coping; eight were related to the benefit of personal time in reading novels/listening to music; seven were related to prompting the dependant in order to retain self-care skills; seven were related to trying to be/being patient; six were related to observing the dependant to ensure their safety; six were related to the benefit of prayer and faith; six were related to just getting on with it, and six were related to remembering it is not the dependant's fault.
- 46 of the 421 statements analysed related to inappropriate caring/coping strategies used, such as colluding with confusion (n=4), fighting with the dependant during personal care (n=4), shouting at the dependant (n=4), and using alcohol or smoking as a means of coping (n=3).
- Eight carers (11.3%) stated that they were unable to cope with aspects of caregiving and four (5.6%) stated that they had no strategies for coping.

Nolan et al. (1996) summarised the growing consensus in the literature of which coping strategies are the most effective in dementia caregiving as follows:

- Coping may involve direct action (behavioural) or cognitive strategies, or both.
- Problem-solving may not be as useful as some problems are insoluble.

- Individuals who have a range of coping strategies are more likely to cope more effectively. Flexibility is also required so that different approaches can be utilised as appropriate.
- Meanings are particularly important to coping: being able to see things as a challenge rather than as a threat, having a sense of competence and mastery, and perceiving efforts as meaningful are important mediating factors against stress.

It should be highlighted that all carers in this sample used a range of coping strategies and that the overwhelming majority of these were positive. Carers, for the most part, had become highly skilled in providing respectful, person-centred care for their dependants. Many used recognised therapeutic techniques in responding to their dependants' needs, such as walking away from the dependant and leaving them alone when they are angry (n=5), keeping to a daily routine (n=5), talking through/explaining caring procedures (n=5), engaging the dependant in reminiscence (n=5) etc, and had obviously become 'expert practitioners' in their own right. These strategies could be termed 'direct action' strategies, aimed at preventing the stressful situation from occurring.

The power of information as a coping resource was evident in the nine statements relating to the benefits of talking with other carers as role models, four on the benefits of the internet/chat rooms, three on the benefits of reading about the illness and coping, three on the benefits of talking to a GP and three on the benefits of individual counselling. Such strategies could be termed 'cognitive strategies', as they aim to create a different perception of the stressful situation.

Those strategies used which reframed the meaning of events/problems, such as remembering it is not the dependant's fault (n=6), accepting symptoms as part of the illness (n=4), and looking beyond the illness to the person (n=3), demonstrated the importance of carers 'perceiving (their) efforts as meaningful'. Similarly, 'having a sense of competence and mastery' was evident in responses such as trying to predict/avoid problems (n=5) and gradually learned to cope (n=5).

However, a minority of carers used inappropriate caring strategies to manage their situation (46 of 421 statements analysed). Eight (11.3%) carers stated that they were unable to cope with aspects of caregiving and four (5.6%) carers stated that they had no strategies for coping. The reasons for these data remain unclear, but it is worrying to find that there was a small group of subjects who perceived that they were coping poorly and were ill equipped to provide care for their dependant. Perhaps they were the group who were more likely to be socially isolated, excluded from services and who lacked access to other carers or professionals as role models or information providers. This group of responses show how important it is for any carers' assessment to ask how the carer is managing their caregiving problems and coping with their situation. Only by doing so can inappropriate or ineffective strategies be sensitively highlighted by the community care manager and then addressed via appropriate caregiver education, information and counselling support.

Perceived impact of caregiving

The following data on the perceived impact of caregiving upon dependants' emotional and physical well-being provides further evidence on the perceived coping abilities of carers in this study:

- 32 carers (36%) perceived that their caregiving had had a 'very positive effect' on their dependant's emotional well-being, 22 (24.7%) perceived it had had a 'positive effect' and two (2.2%) perceived it had had a 'negative' or 'very negative' effect; 41 carers (46.1%) perceived that their caregiving had had a 'very positive effect' on their dependant's physical well-being, 35 (39.3%) perceived it had had a 'positive effect' and one (1.1%) perceived it had had a 'very negative' effect.
- Positive correlations were found between 'Perceived impact of care on dependant emotional well-being' and the '(Lack of) Positive feelings' DCBQ domain (+0.356 $p<0.01$), 'Perceived impact of care on dependant emotional well-being' and the 'Negative feelings' domain (+0.352 $p<0.01$), and 'Perceived impact of care on dependant physical well-being' and the 'Negative feelings' domain (+0.324 $p<0.01$). Regarding 'Overall DCBQ' score, a positive correlation was found with 'Perceived impact of care on dependant emotional well-being' at a level of +0.308 ($p<0.01$).

The above data showed that the overwhelming majority of carers felt that their caregiving had a positive effect on their dependant's physical well-being (n=76 / 85.4%) and on their dependant's emotional well-being (n= 54 / 60.7%). This again demonstrates their skilled interventions and commitment to caregiving, and can be viewed as another measure of caregiver satisfaction in so much as the perception that your caregiving is making a real difference to your dependant's emotional and/or physical well-being must in itself be rewarding. These findings accord with those of McKee et al. (1997), who found that most carers in their study (74.5%) reported that they were coping well with the demands of caregiving.

However, concern should be directed towards those 22 (24.7%) carers who felt that their caregiving had a variable effect on their dependant's emotional well-being, the 11 (12.4%) carers who felt it had no real effect and especially towards the two (2.2%) carers who felt their caregiving had a negative effect on their dependant's emotional well-being. Similarly, the eight (9%) carers who felt that their caregiving had a variable effect on their dependant's physical well-being, the four (4.5%) who felt it had no real effect and particularly the one (1.1%) who felt it had a very negative effect on their dependant's physical well-being should be a focus for urgent attention. (It should be noted that such small numbers are not generalisable in research terms, but may have great clinical significance, in that potentially 'at risk' caregiving situations are highlighted by individual responses to these and other questions.)

Perceiving that their caregiving has a variable impact, no real impact or is even detrimental to their dependant's emotional and/or physical well-being must be a source of distress and despair for carers, particularly if they have fully committed themselves to the role and are giving many hours of care a week, have sacrificed many aspects of their life to take on the role of full-time carer and their own physical and psychological health has been negatively effected.

The positive correlations between 'Perceived impact of care on dependant emotional well-being' and the '(Lack of) Positive feelings' DCBQ domain (+0.356 $p<0.01$), 'Perceived impact of care on dependant emotional well-being' and the 'Negative feelings' domain (+0.352 $p<0.01$), and 'Perceived impact of care on dependant physical well-being' and the 'Negative feelings' domain (+0.324 $p<0.01$) confirm that the less positive impact the carer perceives their caregiving is having on their dependant's emotional well-being, the more negative feelings will be experienced and the less positive feelings will be experienced.

These findings may not be surprising given that if the dependant remains in a state of emotional ill-being despite all the carer's best efforts to provide positive person-centred care this will be distressing, depressing and frustrating etc and result in reduced caregiving satisfaction. Suffice to say, if care inputs are not making a difference to the dependant's quality of life then the question must arise, 'Why carry on providing that care?' Perhaps this group should be targeted for urgent carers' assessments around capability and willingness to continue providing care, with a view towards assisted relinquishment of care, especially if service interventions aimed at improving coping fail to improve the perceived caregiving situation.

These findings support previous research by Orbell and Gillies (1993), who found that carers with a preference not to care saw themselves as unable to meet the needs of their dependant. A lack of satisfaction gained from the caregiving role was found to be the 'single most powerful determinant of carer preference not to continue providing care' in this study, which again highlights that responses to the questions relating to perceived impact of caregiving are potentially predictive of breakdown in caregiving situations. Thus poor perception of the impact of caregiving may be a risk factor for relinquishment of home caregiving and should be incorporated into the proposed 'Dementia Caregiving Breakdown Risk Assessment Tool', proposed in Chapter 7 of the thesis.

Services and informal support received

- 18 carers of the 70 who completed this section of the questionnaire (25.7%) received no help whatsoever from community care services in support of their role. They remained outside of the health and social care system, as may some of the 21 other subjects who did not respond, perhaps thinking this section did not apply to them.
- Of the 58 carers who did receive support from community care services, ten (14.3%) had infrequent assistance, 21 (30%) had assistance once or twice a week, nine (12.9%) had help several times each week, and only 12 (17.1%) had daily assistance.
- Of the 18 carers receiving no assistance from community care services, 16 (22.9%) were providing care for moderately to severely demented dependants; six (8.6%) of those receiving infrequent assistance cared for moderately to severely demented dependants.
- 46 of 51 carers (90.1%) perceived services as being helpful to their situation. However, six (11.8%) perceived services as being unhelpful, and three (5.9%) of these rated services as being 'extremely unhelpful'.
- A positive correlation was found between the perceived helpfulness of community care services and overall DCBQ score, to the level of +0.495 ($p<0.01$).

These findings support those of Cohen et al. (1997), who found that the carer's perception of the quality of the relief offered by services was more important in terms of the experience of caregiving burden than the frequency and level of services provided. Services which targeted difficulties identified by the carer were perceived as being more beneficial than actually increasing the level of service provision. Similarly, Bruce and Patterson (2000) found that a significant proportion of carers reported that difficulties with health care agencies contributed to their stress. Nolan et al. (1998) proposed that it is increasingly being recognised that carers are only happy with services if they are convinced that the quality of care offered to their dependant is of an acceptable standard. They refer to Twigg and Atkin's (1994) suggestion that carers often act as *'arbiters of standards'*, which seems particularly relevant in today's culture of social services contracting in home care services from independent sector providers.

The level of community care services received by this cohort of carers was thus minimal, with the majority of caregiving situations receiving little or no formal support. The fact that of the 18 carers receiving no assistance from community care services, 16 (22.9%) were providing care for moderately to severely demented dependants, and a further six (8.6%) in this group received infrequent support from community care services is very concerning. It can be assumed that these carers were coping in the face of challenging behaviour and/or physical frailty needs that were extremely difficult to manage without appropriate forms of support from formal services. It is likely that this group were particularly at risk of developing psychological health problems and breakdown in their caregiving situation.

This finding demonstrates that unsupported caregiving situations DO in fact still exist. People with dementia and their carers and dependants are still slipping through the network of support and remain outside of the health and social care system. It seems that for a minority of carers things may not have changed a great deal from 1987 when Enid Levin and her colleagues reported that many carers were not receiving help from services until it was too late. In this study up to a third of dependants entered permanent care within one year not because of a deterioration in their condition but because of an inability of services to meet their identified needs. This was despite carers' willingness and desire to continue providing care for their dependants for as long as possible and up to their death.

In examining the relationship between data on frequency and perceived helpfulness of community care services, it was interesting to note that there was no correlation between the frequency of services and 'Overall DCBQ' score. This is likely to be because the majority of carers who were not receiving services may have been at an earlier stage in their caregiving role when fewer or no services were required and caregiving burden was less. However, when one looks at the relationship between perceived helpfulness of community care services and 'Overall DCBQ' score there was a correlation of +0.426 ($p<0.01$). For those carers who were in need of community care services and receiving them, but they were perceived as being unhelpful, caregiving burden was higher than for those who perceived services as being helpful.

The above findings are of vital importance as they signal the need for services firstly to be more available and accessible, as recognised in the Audit Commission report 'Forget Me Not' (Audit Commission, 2000), and secondly for them to be of a higher quality, both in terms of the standards of person-centred care provided and in terms of flexibility and reliability.

- 15 (21.4%) carers received no help whatsoever from informal supporters and were coping alone without the support of family or friends. 12 of those 55 carers (17.1%) who did have informal support only had contact fortnightly or less. All but one carer found the informal supports they received to be helpful.

The majority of carers in this sample had access to informal support from family, friends, neighbours etc. However, of the 70 carers who responded to this question 15 (21.4%) had no assistance from informal supporters. Coping alone without the support of family and friends must add another dimension of isolation and aloneness to the caregiving situation, particularly if the quality of the relationship with the dependant has deteriorated. Such carers may be more at risk of developing clinical depression and should be more of a priority for assistance from community care services, especially those that can facilitate continuance of or a restart in social contact through short and longer-term breaks from caregiving, carers' support groups, etc. Such support is crucial, as Gallo (1990) (cited in Marshall, 1997), found that social support moderates the negative effects of caregiver stress, and Gilhooly (1986) found that carers receiving emotional support were more willing to continue in the caregiving role; carers who were dissatisfied with the support received from informal supporters were more likely to express a preference for institutional care.

- Six of the 70 carers (8.6%) who completed this section of the questionnaire received absolutely no assistance to support them in their caregiving role whatsoever, from family, friends or community care services. They were coping with caregiving entirely alone. (One was caring for a dependant with 'mild' dementia, one for a dependant with 'moderate' dementia and four for dependants with 'severe dementia'.)

The above finding is astonishing. It is a sad and worrying fact that six of the 70 carers (8.6%) received absolutely no assistance to support them in their caregiving role whatsoever and were coping with their caregiving situation entirely alone. This group must be especially at risk of breakdown in their caregiving situation as the course of their dependant's progressive dementing illness advances towards a stage at which challenging behaviour will be experienced. The implication for community care services is that more outreach work needs to be undertaken to identify such caregiving situations and provide appropriate and, if necessary, intensive service inputs which alleviate caregiving burden, minimise the risk of crisis, unplanned admission to permanent care and optimise the potential for continued home caregiving, if this is the expressed future care preference of the carer.

- 16 of the 18 carers receiving no community care services and five of those without access to informal support were from the USA; the figures for the UK were one and five respectively.

This difference between study cohorts is important to highlight. Whilst the study sample is too small to draw any firm conclusions from these findings, the different levels of state assistance between countries, and the range and availability of dementia specific community care services in each locality, may be crucial in determining the longevity and quality of continued home caregiving. What is clear is that appropriate service utilisation delays institutionalisation and reduces psychiatric symptomatology among dementia caregivers (Schulz et al., 2002). Without formal and informal support, dementia carers are more likely to experience significant depression, caregiving situations are more susceptible to becoming abusive and crises admissions to care are more likely. These facts are universally relevant.

Suggested service improvements

- Of 196 statements made by 30 carers, 123 (62.8%) were positive, relating to the perceived benefit of the role of the CPN (n=31 / 25.2%) (12 of the 17 carers interviewed had their case managed by a CPN); the South Wales Dementia Careline (n=16 / 13%) and carers support groups run by Dementia Careline (n=20 / 16.3%) (five of the 17 carers interviewed were involved with this service).
- Of the remaining 56 positive comments, 14 (11.4%) related to positive experiences/benefits of day care services, 11 (8.9%) to home care/sitting services, nine (7.3%) to respite care and eight (6.5%) to carers' support groups. An additional 12 (9.8%) positive statements made were generic, relating to perceived overall benefit of services.
- Of the 73 negative statements made, 14 (19.2%) related to perceived negative impact/unmet need relating to home care/sitting services, nine (12.3%) to day care/day hospital services and four (5.5%) to respite care services.

- A further nine (12.3%) statements made related to the need for some form of caregiver training in dementia care.
- The largest category of negative statements made, was 37 (50.7%) generic negative statements relating to service providers, including the need for improved collaboration/coordination between health and social services (n=8 / 11%), the need for increased availability of dementia specific services (n=7 / 9.6%), the need for easier access to services (n=5 / 6.8%), and for services to be more affordable (n=5 / 6.8%).

These findings support the model of caregiver intervention approaches proposed by Donaldson et al. (1998), whereby three broad strategies are recommended: altering the symptoms of the illness by medication and behavioural management approaches – hence the crucial role of the community psychiatric nurse in this study; reducing carers' exposure to symptoms by respite and carer support services – hence the perceived value of day care, home care, respite care and Dementia Careline in this study; and changing the carer's response to the illness by means of individual or family therapy for carers – hence the positive benefit of the CPN as counsellor and DCL carers support groups in this study.

Marriott (2003) recommended an intervention programme for carers comprised of 14 fortnightly sessions focusing on three themes - education/information giving, stress management approaches and coping skills training for difficult caregiving situations. The programme, based on previous work by Marriott (2000), was found to have a positive effect upon stress and depression in carers, as well as reductions in behaviour disturbance and improved activities of daily living skills in dependants. Given the previous discussion on the importance of information as a coping resource for carers in this study and the fact that nine of the 30 carers answering this question called for caregiver training, this type of intervention must be recommended as having an important and powerful place in supporting continued home caregiving. However, the researcher would suggest that a series of time limited interventions has limited value and that ongoing educational and emotional support must be afforded to carers if they are to cope with the changing needs of their dependants and their caregiving situation over time.

Carers' demands for improved service collaboration, increased service availability, easier accessibility and better affordability are easily understood in the context of the paucity of services they were faced with. Their views as service users point to more serious problems and fundamental flaws with service provision and overall state policy regarding community care services that would demand a dedicated doctoral thesis in itself. However, without entering into a lengthy argument concerning the impact of the NHS and social care reforms of the 1990s on people with dementia and their carers, it is important to state that these have *'increased variation in quality and level of (dementia) service provision in the UK'* (Cayton, 1997, p.56). The drive of current state policy, he stated, was *'to reduce the role of the state, to reduce the tax cost, to shift responsibility to the individual or their family'*. Cayton (1997, p.55) called for this to be challenged and for public policy to approach the issues of dementia care with *'positive aims... concerned with quality, universal provision and equality of access to care'*. For this to be achieved, a removal of the health and social care divide, national eligibility criteria and free long-term care for dementia as a terminal illness, were demanded.

Whilst the above recommendations will require major shifts in government policy, there are examples of innovative practice between health and social services working collaboratively that currently help people with dementia and their carers greatly. A 'single management model' for community mental health services to older people has been recommended (Sheard, 1997). In this model, health and social services merge best practice and jointly manage their budgets, staffing and resourcing to achieve an integrated community service for people with dementia and their carers. One key difference between this model and other traditional 'separate' services is intensive care management from a single provider, with health staff such as community psychiatric nurses taking on the care management role to improve case coordination. Additional features are a single referral point for primary care resulting in improved access, greater equity through shared resources and case prioritisation, and collaboration at its highest level with shared team base, case records etc to improve outcomes. The benefits of receiving intensive care management from such joint agency community mental health teams have been examined by Challis et al. (2002). They found that receiving care from such a service resulted in lower levels of caregiving burden for carers and a lower rate of institutionalisation for people with dementia than in the control group, who were supported by traditional services provided by separate NHS and social services teams.

Such joint agency CMHTs for older people exist in the City of Cardiff and Vale of Glamorgan. Their effectiveness has not yet been evaluated, and it should again be highlighted that outcomes for the local face-to-face interview subjects may be different to those of subjects from elsewhere in the UK and overseas. These differences have not been directly explored in this study.

- Of the 276 separate statements made/strings analysed by 67 carers, the vast majority (n=262 / 95%) were positive, highlighting a positive motivation to care or a satisfaction arising from caregiving.
- A small minority of carers stated that they experienced no caregiving satisfactions (n=4 / 5.9%), and eight (11.9%) stated that their only motivation to care was because of a perceived lack of choices and alternatives (n=8 / 11.9%).
- 14 (20.9%) carers stated that their main motivation was to prevent their dependant from entering permanent care, either because they felt their dependant would be happier in their own environment or they held negative views of the standards of care which would be received by their dependant in a care home.
- In response to a closed question on future care expectations, 15 (22.1%) carers expected that they would have relinquished care within one year and their dependant would have entered permanent care.
- A further 26 carers (38.2%) expected that things would stay the same and continue as at present within one year, 21 carers (30.9%) expected their dependant's condition to deteriorate and six carers (8.8%) expected that their dependant would have died within the year.
- The correlation between 'Overall DCBQ' score and 'Future care expectation' was +0.415 ($p<0.01$), meaning that DCBQ score is predictive of expected relinquishment of home caregiving. This is confirmed by a higher mean 'Overall DCBQ' score for the 15 carers considering relinquishing home caregiving and placing their dependant into a care home at 91.7, compared to 63.6 for those expecting things to stay the same, 77.5 for those expecting their dependant's condition to deteriorate and 77.3 for those expecting their dependant to die within one year.

It is important to note that the overwhelming majority of carers who answered this section of the questionnaire experienced caregiving satisfactions and were highly motivated to continue in their caregiving role. This is a crucial finding and emphasises that for the majority of caregiving situations there were some positive aspects to be found alongside the stress and burden and grief and loss experienced. It again demonstrates the importance of assessing caregiving satisfactions in any formal carers' assessment procedure and supports the previous findings and discussion regarding the ameliorating effects of caregiving satisfactions on caregiver burden.

However, there should be particular concern directed towards those carers who experienced no caregiving satisfactions (n=4 / 5.9%) and for those whose only motivation to care was because of a perceived lack of choices and alternatives (n=8 / 11.9%). Orbell and Gillies (1993) found that the single most powerful determinant of carer preference for relinquishment of caregiving was the degree of satisfaction gained from the caregiving role and Almberg et al. (1997) found that carers with a lack of positive outlook on caregiving were more vulnerable to burnout, so this group may be especially at risk of breakdown in their caregiving situation. The risk of such caregiving situations becoming abusive is also likely to be great (Nolan et al., 1996), and thus they should be urgently targeted for intensive service interventions aimed at improving the caregiving experience and carers' assessments to determine willingness and ability to continue providing care. For several of these carers, assisted relinquishment of home caregiving and facilitated entry to permanent care may be in the best interests of both parties.

For the 14 (20.9%) carers whose main motivation in providing care was to prevent their dependant from entering permanent care, there appeared to be several different motivations – carers believing that their dependant would be happier in their own home environment, thinking that their relative's condition would deteriorate if they entered permanent care and perceiving that their dependant would receive substandard care within independent sector care homes. This generally negative view of permanent care settings may well result in greater reluctance of carers to consider relinquishment of home caregiving and may lead to some carers remaining in the caregiving role for longer than is desirable in terms of their own and their dependant's physical and psychological health and well-being.

For those carers considering placement of their dependant in a care home there may also be a lack of choices in homes available and a delay in placement whilst waiting for an appropriate bed to become available due to the large number of independent care homes recently closed in the UK (74,000 permanent care beds lost since 1996 due to independent sector care home closures according to Laing and Buisson, 2003).

The difficulty in finding appropriate care home placements, together with the concern about the quality of care provided in care homes, may be complicating factors in decision-making around this most difficult decision and painful care transition. Thus those carers who are now considering relinquishment of home caregiving/entry of their dependant to permanent care may be at quite a desperate level of need.

Concern should therefore be directed towards and attention given to those carers in this study considering relinquishment of caregiving. 15 carers (22.4%) expected their dependant to enter permanent care within one year. From qualitative data it appeared that this option was being considered because of exhaustion, demoralisation and incapacity to provide the level of care required without appropriate/sufficient service support rather than because of a change in their dependant's condition.

The important messages for service providers arising from these data are firstly, as previously stated, that more needs to be done to help carers continue in the caregiving role for as long as this is feasible or desirable; secondly, that standards of care within the care homes sector must be assured so that carers can feel confident when considering relinquishment of home caregiving that their dependant will receive adequate care; and thirdly, that when it has been decided that relinquishment of home caregiving is in the best interests of all parties this should be professionally facilitated and supported so that this care transition is made less distressing for all concerned and the caregiving relationship can be continued after placement.

Wuest et al. (1994) suggested that making the decision to place a relative into institutional care is very painful and Dellasega and Nolan (1997) highlighted that family carers can feel a profound sense of failure when home caregiving is relinquished, so carers considering making the transition from home care to institutional care must be supported through this process, preferably by a community care manager who is known and trusted and plays a key role in arranging and facilitating the permanent care placement. Aftercare for carers who relinquish home caregiving is also required, as Aneshensel et al. (1995) found that whilst most carers' psychological stress reduced after their dependants' institutionalisation, for a minority there were poor emotional outcomes.

The above discussion points are supported by the finding that caregiving burden was higher for those considering relinquishment of care within one year (mean DCBQ 91.7) than for those expecting to remain in the caregiving role (mean DCBQ 63.6 'stay the same'; 77.5 'deteriorate') and even those who expected their dependant to die within the year (mean DCBQ 77.3). This finding makes sense when one considers that for those carers whose dependant's condition remains somewhat stable there may be a greater sense of predictability of and mastery over caregiving problems; for those who expect deterioration in their dependant's condition and increasing difficulty in caregiving their dependant's level of need/severity of dementia may presently be at a more manageable stage, and for those expecting death of their dependant caregiving may be more physically demanding but less psychologically challenging. There is also the satisfaction for this group that they have survived in the caregiving role beyond the most difficult and challenging period and have been able to provide one-to-one person-centred care up to the 'terminal' phase of their loved one's illness.

The Royal Commission on Long Term Care (HMSO, 1999, p.65) recognised that, *'It is likely to be particularly difficult to maintain a dementia sufferer in a co-resident caring situation and the cost to the person providing such care may be very high.'* However, it also referred to Levin et al.'s (1989) study which found that 35% of people with dementia died at home and that this was at the express wish of their carers. The Royal Commission (HMSO, 1999, p.62) acknowledged that, *'Even dementia sufferers can be cared for successfully (up to their death) at home'*, and recommended that where this is possible and desirable it should be facilitated.

Thus there may be some professional mileage in the notion that in severe dementia caregiving situations in the community, the carer should become the focus of care management as the primary client. The proven benefits of the Admiral Nursing Service (Woods et al., 2003), which is directed towards supporting the carers of people with dementia rather than people with dementia as clients, support this view. If state policy is to be directed towards enabling continued home caregiving and reducing the dependence on long-term care provision, such carer directed services must be urgently developed in all areas.

The above finding of a correlation between 'Overall DCBQ' score and 'Expectation for the future' is also crucially important as it demonstrates that the 'Dementia Caregiving Burden Questionnaire' may be of itself predictive of breakdown in the caregiving situation, or at least of expectation of relinquishment of home caregiving. Thus this, together with the question on future expectations are worthy of inclusion in the proposed 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)', the development of which will be discussed in the next chapter. Similarly, high 'Overall DCBQ' score may be a useful trigger for the care manager to enter into discussion with the carer about their future care wishes/expectations. A threshold of a score of 90 or more on this assessment should highlight those caregiving situations which are most at risk of breakdown/those carers who are considering relinquishment of home caregiving, and as such may be useful as a prompt for inclusion in the proposed DCBRAT.

Past caregiver findings (n=18)

- Regarding the past caregiver sample (n=18), eight carers had been providing care for between 13 months and three years and six carers had been carers for more than six years prior to relinquishment of home caregiving; the majority of carers (n=12) stated that their dependant had 'severe dementia' at the time they were admitted to permanent care; the majority of dependants (n=9) were admitted to a private nursing home, and the majority (n=11) of admissions to permanent care were arranged by carers themselves.
- The reasons for relinquishment of home caregiving were multi-factorial, with 26 qualitative statements made/strings analysed referring to 'Major hassles', including aggression (n=9) and wandering (n=6); 19 referring to 'Physical demand', including mobility problems/falls (n=9) and incontinence (n=6); 15 referring to 'Exhaustion', including sleep disturbance (n=8) and exhaustion (n=4); 14 referring to the 'Financial cost of caregiving', including financial impact (n=6) and effect on employment/work (n=5); 14 referring to 'Social life', including lack of breaks (n=4) and perceived role entrapment (n=3); eight referring to 'Communication breakdown', including failure of recognition (n=5) and communication failure (n=3), and eight referring to 'Distress', including depression in the dependant (n=3) and decline in the dependant (n=3).
- For six carers, the deterioration in their dependant's behaviour was the main influencing factor in their decision to admit their dependant to permanent care; five carers relinquished home caregiving during a critical incident in caregiving; four carers relinquished home caregiving because of their dependant's physical state/their inability to manage the physical strain of caregiving; three carers relinquished home caregiving due to the financial burden of caregiving; three carers relinquished home caregiving because of a deterioration in the carer's physical state/ability to cope, and three carers relinquished home caregiving/sought permanent care for their dependant primarily because of their own deteriorating emotional state and ability to cope.

The majority of past carers had been providing care for their dependants for several years through the progression of their dementing illness to a severe stage, and most needed 24 hour nursing care within their new care environment. This demonstrates the tremendous commitment that these carers had made to providing care for their relative for as long as possible in their home environment, and the skills that most had developed in providing person-centred care for their dependant who had now entered a formal care setting where a whole staff team provided that care.

As stated previously, the decision to relinquish home caregiving and seek a permanent care placement is probably one of the most difficult and distressing for a carer. Professional assistance in supporting this decision should be viewed as an essential, core requirement of service provision and is vitally important, not only to ensure appropriate placement and care for the person with dementia, but also to support the carer through the psychological aftermath of relinquishment.

For the majority of past carers (n=6) the deterioration in their dependant's behaviour was the main influencing factor on their decision to resort to permanent care. Their inability to manage their dependant's aggression, resistiveness, wandering etc resulted in them relinquishing home caregiving, which is an important finding given the previous discussion around behaviour and mood related problems and associated caregiving burden peaking in the middle stages of the dementia trajectory and caregiving satisfactions increasing and caregiving burden lessening towards the end stages of the illness.

Several carers (n=5) relinquished home caregiving during a critical incident in caregiving, two of them after being violently assaulted by their dependant. The need for intensive service support at such times should not be under-estimated, both in terms of providing emotional and practical support to the carer and facilitating urgent access to permanent care, or preferably crisis respite care where such problems may be brought under some control and the carer could be given time to consider their future caregiving options.

Several carers (n=4) relinquished home caregiving because of their dependant's physical state and their inability to manage the physical strain of caregiving. For three carers these problems centred around the carer's incapacity to manage their dependant's severe mobility problems, especially around responding to falls. The need for increased service support to manage intensive physical frailty needs towards the end of the dementing illness is highlighted by these cases, for example with the need for hoist and double-handed home care visits.

A further three carers stated the main reason for relinquishment of home caregiving was due to the financial burden of caregiving. This issue is discussed above, but it is important to note that it is vitally important that people are made aware of their right to means-tested state support for community care services and that they receive appropriate welfare rights and benefits advice.

Three carers relinquished home caregiving because of a deterioration in the carer's physical state and ability to cope - two admissions to permanent care were made as a direct result of the carer suffering cardiac problems, which may have been attributed in part to the tremendous physical strain which many carers have to endure. Similarly, three carers relinquished home caregiving/sought permanent care primarily because of their own deteriorating emotional state and ability to cope. All three were being treated for clinical depression and were exhausted and demoralised in their caregiving role. The experiences of these six carers highlight the enormous impact that dementia caregiving can have on carers' physical and emotional health and the sad fact that for many a literal physical or psychological breakdown has to occur before permanent care becomes an option. Health screening for dementia carers is thus vital in ensuring early treatment for diagnosed conditions, and early service interventions could play an important role in lessening the likelihood of detrimental psychological and physical health impacts and in supporting continued home caregiving.

Due to the small past carer sample in this study, it is not realistic to extrapolate these findings across the whole dementia caregiver population. However, it is important to recognise that for the majority of the above caregiving situations, the early delivery of an appropriate level of community care service interventions across the range of psychological, physical and social supports, including access to emergency respite care, counselling support, intensive home care support, home based respite care/night sitting etc, may have been sufficient to offset the need for admission to permanent care, particularly for those who relinquished home caregiving during a crisis. This would then provide more time for decision-making regarding future care options and continued home caregiving could be supported or future planned relinquishment facilitated. Both outcomes would result in less psychological trauma to the carer and potential cost savings in terms of permanent care bed days.

6.4 Risk factors for breakdown in caregiving situations/relinquishment of home caregiving revisited

As one of the main aims for this study was to investigate the main risk factors for breakdown in caregiving situations/relinquishment of home caregiving and to propose a 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)' for implementation in clinical practice, it was important, by way of a final analysis, to examine previously discussed study findings against the variable regarding 'Future expectation for caregiving within one year' – scale 'stay same', 'deteriorate', 'dependant death' and 'relinquishment/placement' (68 carers / 74.7% responded to this question).

The following list of risk factors for caregiving burden/expected relinquishment of caregiving was identified from this analysis and is worthy of consideration for inclusion in the DCBRAT, a draft of which can be found in the following chapter:

DCBQ score was found to be predictive of the caregiver expecting to relinquish home caregiving within one year (correlation +0.415 p<0.01)

Geographical distance in caregiving was predictive of expected relinquishment of caregiving (correlation +0.309 p<0.05)

Hours spent in caregiving was predictive of high caregiving burden (DCBQ correlation +0.277 p<0.05)

Poor current quality of relationship with dependant was predictive of high levels of caregiving burden (DCBQ correlation +0.407 p<0.01)

Clinical depression in the caregiver was predictive of high levels of caregiving burden (DCBQ correlation +0.420 p<0.01) and expected relinquishment of caregiving (correlation DCBQ question 'Are you depressed?' with expected relinquishment of caregiving +0.339 p<0.01)

Behaviour problems (BP) were predictive of high levels of caregiving burden (BP domain correlation with DCBQ +0.425 p<0.01)

Mood problems (MP) were predictive of high levels of caregiving burden (MP domain correlation with DCBQ +0.348 p<0.01)

Specific caregiving problems predictive of high levels of caregiving burden were shouting/swearing/screaming (DCBQ correlation +0.452 p<0.01), becomes irritable and easily upset (+0.419 p<0.01), wakes me/others during night (+0.308 p<0.01), difficulty getting to sleep/early waking (+0.308 p<0.01), night-time wandering (+0.300 p<0.05), appears unhappy/depressed (+0.290 p<0.05), mood changeable (+0.281 p<0.05), has to be prevented from wandering (+0.261 p<0.05), endangers self (+0.261 p<0.05), hitting out (+0.245 p<0.05), choking/fits/falls (+0.244 p<0.05) and collects and hoards (+0.232 p<0.05). Caregiving problems predictive of expected relinquishment of caregiving were becomes irritable and easily upset (correlation +0.275 p<0.05) and gets mixed up about the time of day and night (correlation +0.249 p<0.05).

Specific DCBQ questions predictive of expected relinquishment of caregiving were: feel exhausted and demoralised (correlation +0.416 p<0.01), feel can no longer cope (+0.401 p<0.01), feel need a holiday (+0.398 p<0.01), feel do not manage stress well/overcome it (+0.395 p<0.01), feel caregiving beyond capabilities (+0.395 p<0.01), physical health suffered (+0.390 p<0.01), feel depressed (+0.339 p<0.01), feel overwhelmed (+0.336 p<0.01), feelings of grief and loss (+0.331 p<0.01), adverse effect on quality of life (+0.324 p<0.01), feel guilty (+0.282 p<0.05), distressed at changes in dependant (+0.271 p<0.05), difficulty continuing relationships (+0.278 p<0.05), affected social life (+0.263 p<0.05), feel trapped (+0.263 p<0.05), feel like giving up (+0.259 p<0.05), feel alone in caregiving (+0.256 p<0.05), feel helpless (+0.253 p<0.05), feel no end to problems (+0.242 p<0.05) and feel (lack of) achievement from caregiving (+0.242 p<0.05)

Quality of life rating was predictive of high caregiving burden (DCBQ correlation +0.472 p<0.01) and expected relinquishment of caregiving (correlation +0.393 p<0.01). Impact on quality of life – emotional well-being was predictive of high DCBQ score (correlation +0.576 p<0.01), Impact on quality of life – physical well-being was predictive of high DCBQ score (+0.507 p<0.01), Impact on quality of life – social life/employment was predictive of high DCBQ score (+0.278 p<0.05), Impact on quality of life – personal relationships/family life was predictive of high DCBQ score (+0.236 p<0.05).

Self-assessed carer stress rating was predictive of high caregiving burden (DCBQ correlation +0.776 p<0.01) and expected relinquishment of caregiving (correlation +0.357 p<0.01)

Perceived impact of caregiving on dependant emotional well-being rating was predictive of high caregiving burden (DCBQ correlation +0.308 p<0.01)

Perceived helpfulness of community care services rating was predictive of high caregiving burden (DCBQ correlation +0.459 p<0.01) and expected relinquishment of caregiving (correlation +0.302 p<0.05)

Perceived helpfulness of informal support rating was predictive of high caregiving burden (DCBQ correlation +0.340 p<0.05)

Omission of positive feelings was predictive of high caregiving burden (DCBQ correlation +0.764 p<0.01) and expected relinquishment of caregiving (correlation +0.251 p<0.05)

Table 6.1: Risk factors for caregiving burden/expected relinquishment of caregiving from this study

Chapter 7

CONCLUSIONS

"I am determined to be a survivor and to have an active and happy life when all this is over. There will be an end to it!" (Internet carer 5)

CHAPTER 7: CONCLUSIONS

This final chapter of the thesis aims to synthesise the main study findings and:

- Discuss these in relation to the original study aims and hypotheses – have they been achieved/supported?
- Propose a 'Dementia Caregiving Breakdown Risk Assessment Tool' for implementation in clinical practice.
- Propose a 'Conceptual Model of Caregiving Burden and Breakdown' to inform clinical practice.
- Address the limitations of the study.
- Suggest recommendations for post-doctoral research.
- Present some final personal observations and conclusions.

7.1 Study aims and hypotheses revisited

This section of the chapter revisits the original study aims and hypotheses outlined in the introductory chapter and discusses to what degree they have been achieved/supported and whether any additional unexpected outcomes have resulted.

The aims for the study were as follows:

- *To identify the main risk factors for breakdown in caregiving situations and compare them to previous research.*
- *To develop and test new carers' assessment tools more fully to meet the requirements of the 'Carers (Recognition and Services) Act 1995'.*
- *To propose a new 'Dementia Caregiving Breakdown Risk Assessment Tool' for use in clinical practice.*
- *To propose a 'Conceptual Model of Dementia Caregiving, Burden and Breakdown'.*

The above study aims have all been met. The newly devised carers' assessment tools, namely the 'Dementia Caregiving Problems Questionnaire (DCPQ)' and 'Dementia Caregiving Burden Questionnaire (DCBQ)', have been found to be reliable and somewhat valid. They can be recommended for implementation in clinical practice. Indeed, several teams have already implemented them and given positive feedback.

The main risk factors for breakdown of caregiving situations have been determined for this study sample and compared to previous research – see below. Some methodological problems have been identified, but in the main these findings can be proposed to be a valuable contribution to the growing body of evidence on dementia caregiving burden and breakdown.

Based on the study questionnaire, newly devised DCPQ and DCBQ assessment tools and study findings on risk factors for breakdown, a new 'Dementia Caregiving Breakdown Risk Assessment Tool (DCRBAT)' has been proposed for implementation in clinical practice. Further post-doctoral research will be required to evaluate the benefits of this assessment for people with dementia, their carers and community care practitioners. Similarly, a 'Conceptual Model of Dementia Caregiving, Burden and Breakdown' has been proposed, but this too needs to be tested further for its relevance to practice.

The main hypotheses for the study were as follows. Findings in support of each are detailed:

1. That the main causes of breakdown in caregiving situations will be more closely associated with high levels of subjective burden, such as perceived stress associated with direct caregiving problems and perceived impact of caregiving, than objective burden, such as degree of dementia or physical dependency of the dependant. Clinical depression in the carer will be especially associated with relinquishment of home caregiving.

This hypothesis was supported by the following findings: a positive correlation between DCBQ score and expected relinquishment of home caregiving (+0.415 $p<0.01$); between carer stress/coping rating and expected relinquishment of home caregiving (+0.357 $p<0.01$); between clinical depression in carers and DCBQ score (correlation +0.420 $p<0.01$); between feeling depressed (DCBQ question) and expected relinquishment of caregiving (correlation +0.339 $p<0.01$); between quality of life rating and expected relinquishment of home caregiving (+0.393 $p<0.01$), and between perceived impact of caregiving upon dependant emotional well-being and DCBQ score (+0.308 $p<0.01$).

As expected, there was no relationship between objective burden ratings, e.g. DCPQ domains, degree of dementia or hours spent in caregiving, and expected relinquishment of caregiving (although there was a correlation of +0.256 ($p<0.05$) between the DCBQ Life upset domain and degree of dementia and a correlation of +0.277 ($p<0.05$) between the DCBQ and hours spent in caregiving). However, there was evidence from past caregiver findings that several caregiving situations broke down primarily due to physical strain/inability to care, which is demonstrated in the positive correlation between expected relinquishment of caregiving and the DCBQ questions regarding feeling exhausted and demoralised (correlation +0.416 p<0.01), feeling caregiving is beyond capabilities (correlation +0.395 p<0.01) and feeling physical health has suffered (correlation +0.390 p<0.01).

2. That caregiving problems experienced in the behavioural and mood domains will be directly associated with higher levels of subjective burden, and that caregiving problems in the confusion and self-care/physical domains will increase across the dementia illness trajectory. It is also expected that there will be a peak in subjective burden in the moderate to severe phase of dementia, when the dependant is active and disturbed, and a lessening in subjective burden towards the end of the illness, when the dependant becomes more passive and frail.

This hypothesis was supported by the following findings: positive correlations between the DCPQ Behaviour problems domain and DCBQ (+0.425 p<0.01), the DCPQ Mood problems domain and DCBQ (+0.348 p<0.01), the DCPQ Confusion problems domain and degree of dementia rating (+0.568 p<0.01), the DCPQ Self-care/Physical problems domain and degree of dementia rating (+0.572 p<0.01), and between the DCPQ Self-care/Physical problems domain and hours spent in caregiving rating (+0.367 p<0.01).

A non-linear relationship was found between Behaviour problems and dementia severity rating (mean BP score 12.7 for 'mild, 11.4 'moderate', 15.5 'severe' and 14.8 'very severe') and between Mood problems and dementia severity rating (mean MP score 17.3 for 'mild, 18.4 'moderate', 19.8 'severe' and 16.7 'very severe'), i.e. both domain scores peaked in the 'severe' rating and decreased in the 'very severe' rating. However, there was no obvious peak in DCBQ scores in the moderate to severe phase of dementia as expected. Instead, DCBQ score remained fairly constant throughout the dementia trajectory, with higher scores in the 'mild' and 'moderate' dementia ratings (mean DCBQ 84.1 'mild', 78.0 'moderate', 75.8 'severe' and 76.6. 'very severe'). An unexpected finding was that Positive feelings scores, i.e. caregiving satisfactions, actually significantly improved as dementia severity increased (mean PF 23.3 'mild', 20.2 'moderate', 16.3 'severe', 15.1 'very severe'), which has important implications for practice as discussed previously.

3. That carers with a poor quality current relationship with their dependant will have a higher degree of subjective burden than those with a good quality relationship, with increased feelings of detachment and role dissatisfaction. Earlier relinquishment of care is expected for non-close caregiving relationships and greater difficulties in relinquishing role are expected in close caregiving relationships.

This hypothesis was partly supported by the following study findings: a positive correlation between quality of current relationship rating and DCBQ score (+0.407 p<0.01) and a positive correlation between the following DCBQ questions and current quality of relationship rating – feeling distant to dependant (+0.691 p<0.01), feeling like giving up caring (+0.497 p<0.01), not feeling that caring is a way of expressing love/affection (+0.440 p<0.01), lack of personal satisfaction/reward (+0.385 p<0.01), feeling resentful (+0.373 p<0.01), feeling embarrassed (+0.370 p<0.01), not feeling stress is managed well and overcome (+0.354 p<0.01), feeling frustrated (+0.338 p<0.01), and feeling trapped (+0.313 p<0.01).

Further research will be needed to determine outcomes regarding earlier relinquishment of care for non-close relationships and physical and psychological health outcomes for carers with close relationships who relinquish care.

4. That adult children/children-in-law carers with competing demands, such as young children to care for and/or employment responsibilities, will relinquish their caregiving role at an earlier stage than spouse carers. Caring at a distance (i.e. not living with the dependant who lives alone) is also expected to be a predictor of earlier admission to permanent care.

This hypothesis was supported by the following findings: positive correlations between the DCBQ question caregiving adversely effects other aspects of life and expected relinquishment of caregiving (+0.324 p<0.01), between quality of life rating and expected relinquishment of caregiving (+0.393 p<0.01), between younger age and DCBQ Life upset domain (+0.335 p<0.01), between the DCBQ question caregiving adversely effects other aspects of life and age (+0.445 p<0.01), and between geographical distance in caregiving and expected relinquishment of caregiving (+0.309 p<0.05).

5. That sole carers without informal support from family and friends will have a higher degree of subjective burden than those with a good informal support network. Those without informal support and who remain outside of the health and social care system, receiving no support from statutory services, are expected to be most at risk of psychological health problems and breakdown in their caregiving situation.

This hypothesis was partly supported by the following study findings: a positive correlation between the DCBQ question (lack of) help from services/family/friends enables continued caregiving and frequency of formal support (+0.444 p<0.01), between (lack of) help from services/family/friends enables continued caregiving and frequency of informal support

(+0.404 p<0.01), and between the DCBQ question feel alone in caregiving and frequency of informal support (+0.315 p<0.01). There was also a positive correlation between clinical depression in carers and frequency of support from community care services, albeit at a lower level (negative correlation –0.286 p<0.05, i.e. the more services received, the less depressed the carer).

Perceived helpfulness of community care services and informal supports seemed to be more important than frequency of supports, however, with positive correlations between DCBQ score and perceived helpfulness of community care services (+0.459 p<0.01), between DCBQ Life upset domain and perceived helpfulness of community care services (+0.444 p<0.01), between perceived helpfulness of community care services and expected relinquishment of caregiving (+0.302 p<0.01) and between DCBQ and perceived helpfulness of informal supports (+0.340 p<0.05).

Similarly, there were positive correlations between a low perceived helpfulness of community care services and the DCBQ questions have to undertake caregiving tasks beyond capabilities (+0.528 p<0.01), feel overwhelmed (+0.512 p<0.01), feel trapped (+0.460 p<0.01), feel resentful (+0.440 p<0.01), feel can no longer cope (+0.413 p<0.01) and find it difficult to get a break (+0.358 p<0.01). There were also positive correlations between a low perceived helpfulness of informal supports and the DCBQ questions find it difficult to get a break (+0.441 p<0.01) and feel trapped (+0.372 p<0.01).

There was no relationship between caregiving situations without support and caregiving burden, however, perhaps because several of these carers were at a stage where such support was not required. However, individual cases certainly were in urgent need of support and not receiving assistance from community care services or family/friends and were almost certainly at risk of breakdown in their caregiving situation/psychological ill health. The researcher would recommend that despite a lower level of evidence, a lack of formal and informal support should be included in the proposed risk assessment tool as factors predictive of breakdown/relinquishment, particularly in caregiving situations where there is a moderately to severely demented dependant.

6. That those with little or no perceived role satisfaction are expected to have high levels of subjective burden, be more at risk of psychological health problems, and relinquish their caregiving role at an earlier stage. Those with high levels of role satisfaction are expected to experience less subjective burden and be more highly motivated to continue in their caregiving role.

This hypothesis was supported by the following findings: a positive correlation between the (lack of) positive feelings domain of the DCBQ and carer depression (+0.359 p<0.01), between the (lack of) positive feelings domain of the DCBQ and expected relinquishment of care (+0.251 p<0.05), between (lack of) positive feelings and quality of life rating (+0.387 p<0.01), and positive correlations between the (lack of) positive feelings domain and DCBQ questions feeling helpless (+0.566 p<0.01), feeling depressed (+0.552 p<0.01), feeling trapped (+0.525 p<0.01), feeling can no longer cope (+0.514 p<0.01), feeling exhausted (+0.507 p<0.01), feeling overwhelmed (+0.502 p<0.01) and feeling like giving up caregiving (+0.445 p<0.01).

As discussed above, caregiving satisfactions increased with dementia severity, meaning that if the carer can be helped, with appropriate support and service interventions, to survive the most difficult 'active' phase of their illness into the more 'frail' advanced dementia phase then caregiving may become more satisfying and less burdensome, meaning that many admissions to permanent care could be prevented. This is a crucial but unexpected finding, worthy of further investigation.

7.2 Development of proposed 'Dementia Caregiving Breakdown Risk Assessment Tool'

The key risk factors for high levels of caregiving burden and expected relinquishment of home caregiving/breakdown in caregiving situations identified in Chapter 6, together with the formal questions required in the 'Carers (Recognition and Services) Act 1995' regarding carers' ability and willingness to continue providing care, form the basis of questions recommended for inclusion in a 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)'. This has been drafted below and is recommended for implementation in clinical practice. It should be noted that the questions relating to the risk factors identified in this study are allocated points which, together with the DCPQ and DCBQ scores – both of these new carers' assessment tools are included in their entirety as they have proven reliability and validity, form the 'Risk of breakdown score'.

The following guidance notes have been drafted for care managers to support them in their implementation of this tool in clinical practice:

- ➢ The DCBRAT should be administered at least annually by the care manager as dementia caregiving problems/needs change over time. Using professional judgement, the assessment should be made sooner if the caregiving situation has changed significantly.

- Ideally, the DCBRAT should be administered via a face-to-face interview, with the care manager giving sufficient time to enable a more complete disclosure and providing appropriate psychological support as required. However, the DCPQ and DCBQ may be left with the carer prior to assessment for self-completion, if adequate care is taken in briefing and debriefing the carer.
- Wherever possible, verbatim notes should be made by the completing care manager on the DCBRAT to illustrate the ratings made with carer comments relating to caregiving impact. (Additional space will be included at a later date to enable direct quotation to be recorded on the assessment, and to make the DCPQ and DCBQ more user-friendly for self-completion.)
- The completion of the DCBRAT and summation of the risk assessment score should be undertaken by the care manager, but the scoring system and outcome may be shared with the carer and used as the basis for discussion around future care planning where appropriate.

These recommendations for implementation are made on the basis of experience gained in this study of interviewing carers, particularly in relation to the psychological support which is often required when distressing experiences and feelings are shared by carers, perhaps for the first time. They will need to be amended/added to following post-doctoral piloting of the DCBRAT – see later section.

(Note that justifications for scored elements of the DCBRAT are included alongside items in red ink. Correlation scores with DCBQ = Dementia Caregiving Burden Questionnaire; EROC = Expected relinquishment of care and QOL = Quality of life are used as the main justifications.)

Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)

Simon O'Donovan, 2004

Assessor details:
Referrer details:
Date of assessment:

Carer details *(note details)*
Name of carer:
Age of carer:
Address/contact details of carer:
GP/contact details:

Dependant details *(note details)*
Name of dependant:
Date of birth/age of dependant:
Address of dependant:
Dementia diagnosis:
MMSE score: __ / 30
Date of dementia diagnosis/duration of caregiving:
Physical diagnoses:

Carer's health status *(note responses)*
Physical health/frailty of carer ([1]add 10 points for severe ill health/physical frailty):
Psychological health of carer ([2]add 10 points for clinical depression):
Disability/capability issues: [1]DCBQ with QOL Physical well-being impact 0.507 ($p<0.01$)
Medications taken by carer *(list)*: [2]DCBQ 0.420 ($p<0.01$); EROC 0.339 ($p<0.01$)

Competing demands *(note responses)*
Hours per week spent in caregiving (hands-on/supervision) ([1] add 5 points for 60 hours +):
Employment situation of carer ([2] add 5 points for working carer):
Geographical distance in caregiving ([3] add 5 points if living separately): [1] DCBQ 0.277 ($p<0.05$)
Family situation: [2] DCBQ with QOL Social life/Work impact +0.278 ($p<0.05$)
Other dependants: [3] EROC 0.309 ($p<0.05$)

Quality of current relationship with dependant *(note responses)*
Extremely close
Very close
Reasonably close
Not very close (add 5 points)
Distant (add 10 points) DCBQ +0.308 ($p<0.01$)

Support available to caregiving situation *(list and note perceived unmet support needs)*
Informal supports received [1] DCBQ +0.340 ($p<0.05$)
    Informal supporters [2] DCBQ +0.459 ($p<0.01$); EROC +0.302 ($p<0.05$)
    Frequency of informal support
    Perceived helpfulness of informal support ([1] add 5 points for unhelpful/or 'no support')
Community care services received
    Services received
    Frequency of services
    Perceived helpfulness of services ([2] add 10 points for unhelpful/or 'no services')

Perceived impact of caregiving *(note perceptions)*
Perceived impact on dependant's physical well-being
    Very positive impact
    Positive impact
    Variable impact
    Negative impact
    Very negative impact
Perceived impact on dependant's emotional well-being
    Very positive impact
    Positive impact
    Variable impact
    Negative impact (add 5 points)
    Very negative impact (add 10 points) DCBQ +0.308 ($p<0.01$)

Perceived impact of caregiving on carer's quality of life *(note perceptions)*
    Very positive impact
    Positive impact
    Variable impact
    Negative impact (add 5 points)
    Very negative impact (add 10 points) DCBQ +0.472 ($p<0.01$); EROC +0.393 ($p<0.01$)

Carers Act questions *(note responses)*
Are you willing to continue in the caregiving role?
Are you able to continue in the caregiving role?
What unmet needs do you have as a carer?

Dementia Caregiving Problems Questionnaire (DCPQ) (scale – 0 never, 1 rarely, 2 sometimes, 3 frequently, 4 always, except items marked * which have reversed polarity) *(add direct quotation)*

Which of the following **'Communication Problems'** does your dependent have?

Is your dependant able to start and maintain a sensible conversation? *
Is your dependant able to understand what is said to him/her? *
Is your dependant able to respond sensibly when spoken to? *
Does your dependant repeat things over and over again?
Does your dependant talk all the time?
Does your dependant talk nonsense that you can't understand?
Does your dependant have periods when he/she doesn't speak much at all?
Is your dependant able to read newspapers, magazines, etc., or watch and follow TV? *
Is your dependant able to take part in family conversations? *
Does your dependant talk aloud to him/herself? **ComP sub total __**

Which of the following **'Confusion Problems'** does your dependant have?

Does your dependant get mixed up about where he/she is?
Does your dependant get mixed up about the day, date, year?
Is your dependant able to recognise familiar people, e.g. family and friends? *
Is your dependant able to recognise you and know who you are? *
Does your dependant get mixed up about the time of day/night?
Is your dependant able to hold his/her attention for more than a few minutes? *
Does your dependant seem lost in a world of his/her own?
Does your dependant try to get up and dressed/go outdoors during the night?
Does your dependant get lost and can't find his/her way home when outside of the house/ do you have to keep them indoors?
Does your dependant see or hear things that aren't really there? **ConP sub total __**

Which of the following **'Behaviour Problems'** does your dependant have?

Does your dependant wander around indoors or outdoors?
Does your dependant tend to collect things and hoard them?
Does your dependant become angry and resistive to care?
Does your dependant endanger him/herself by engaging in risky behaviours?
Does your dependant become irritable and easily upset?
Does your dependant falsely accuse people/you of things?
Does your dependant shout/swear /scream at people/you for no obvious reason?
Does your dependant hit out at you/other people for no obvious reason?
Does your dependant display inappropriate sexual activity/demands?
Does your dependant wake you/others during the night? **BP sub total __**

Which of the following **'Mood Problems'** did your dependant have?

Does your dependant show an interest in doing things? *
Does your dependant appear to be restless and agitated?
Does your dependant pace up and down in a worried or troubled way?
Does your dependant cry/become tearful for no obvious reason?
Does your dependant appear to be unhappy and depressed?
Does your dependant have difficulty settling to sleep/wake unusually early in the morning?
Does your dependant's mood change suddenly for no obvious reason?
Does your dependant isolate him/herself and avoid social contact?
Does your dependant never leave your side/shadow you?
Does your dependant look frightened and anxious? **MP sub total __**

Which of the following **'Self-care/Physical Problems'** does your dependant have?

Does your dependant have problems in standing/walking - need assistance?
Does your dependant have difficulty washing/bathing - need assistance?
Does your dependant have difficulty dressing/undressing - need assistance?
Is your dependant incontinent of urine during the night (may wear pads)?
Is your dependant incontinent of urine during the day (may wear pads)?
Is your dependant incontinent of faeces (day or night)?
Does your dependant have problems feeding him/herself/swallowing?
Is your dependant partly/completely immobile and does he/she need lifting?
Is your dependant prone to having falls/fits/choking attacks?
Does your dependant suffer with pain/need analgesic medication? **SC/P sub total __**

DCPQ Cronbach Alpha 0.7029; DCPQ Guttman Split Half 0.6336
Behaviour domain with DCBQ +0.425 (p<0.01); Mood domain with DCBQ +0.348 (p<0.01)

Coping questions *(note responses)*
What additional problems do you experience in caring for your dependant that are not covered above?
Which of these problems are the most stressful/difficult to manage, and why?
What coping/management strategies do you use, and how successful are they?

Carer coping/stress rating *(discuss with carer)* DCBQ +0.776 (p<0.01); EROC +0.357 (p<0.01)
0 - Coping well/no stress, 5 - Coping fairly well/low stress, 10 - Just about coping/moderate stress, 15 - Having difficulty coping/high stress, 20 - Almost impossible to cope/severe stress

Dementia Caregiving Burden Questionnaire (DCBQ) (scale – 0 never, 1 rarely, 2 sometimes, 3 frequently, 4 always, except items marked * which have reversed polarity) *(add direct quotation)*

Life upset questions

Do you feel you need a holiday (a long-term break from caring)?
Do you worry about safely leaving your dependant on his/her own?
Do you find it difficult to get away for a break for a few hours?
How much has your social life been affected by caring?
Is your sleep disrupted by your dependant?
Do you have family arguments/difficulties associated with your caring situation?
Have your financial circumstances changed/your standard of living reduced as a result of caring?
Do you have difficulty in continuing your relationships, e.g. having visitors/meeting friends,

due to your caring commitments?
Do you find that your caring responsibilities adversely affect other aspects of your life, e.g. your role as a parent/grandparent, your employment?
Do you have to undertake caregiving tasks that are beyond your capabilities? **LU sub total __**

Personal distress questions

Has your own physical health suffered as a result of caring?
Do you feel there will be no end to your problems?
Do you feel you can no longer cope with your situation?
Do you feel overwhelmed by your situation?
Do you feel trapped in the caring role?
Do you feel that you are alone in coping with your caring situation?
Do you find it distressing that your dependant has changed so much from his/her former self?
Do you have feelings of grief and loss associated with your caring role?
Do you find yourself becoming tearful or crying?
Do you feel exhausted and demoralised in your caring role? **PD sub total __**

Negative feelings questions

Are you depressed about your situation?
Do you feel like giving up caring?
Do you feel embarrassed by your dependant?
Do you feel frustrated with your dependant?
Do you get cross and angry with your dependant?
Are you resentful about the change in the quality of your own life/missed life opportunities?
Are you emotionally distant from your dependant?
Do you view caring for your dependant as being like caring for a child?
Do you have feelings of guilt associated with your caring role?
Do you feel helpless and as if things are outside of your control? **NF sub total __**

Positive feelings questions

Do you have a sense of achievement or fulfillment as a result of caring? *
Do you have a sense of purpose and direction in your caring role? *
Do you derive personal satisfaction and reward from your caring role? *
Do you have feelings of positive self-worth/self-esteem arising from caring? *
Do you feel that being a carer has provided an opportunity for personal growth and development? *
Do you feel that caring is a positive way of expressing your love and affection for your dependant? *
Do you feel that you adopt a positive, problem-solving approach to caring? *
Do you feel that you manage your stress well and overcome it? *
Do you feel that the help you receive from services and family/friends has enabled you to carry on caring? *
Are you feeling hopeful about your future? * **PF sub total __**

DCBQ Cronbach Alpha 0.8430; DCBQ Guttman Split Half 0.7581
DCBQ with EROC +0.415 ($p<0.01$); (Lack of) Positive feelings domain with EROC +0.251 ($p<0.05$)

Future expectation within one year *(discuss with carer)* DCBQ +0.415 ($p<0.01$)
0 - Things stay the same, 10 – Things get worse, 15 – Dependant death, 20 – Placement of dependant

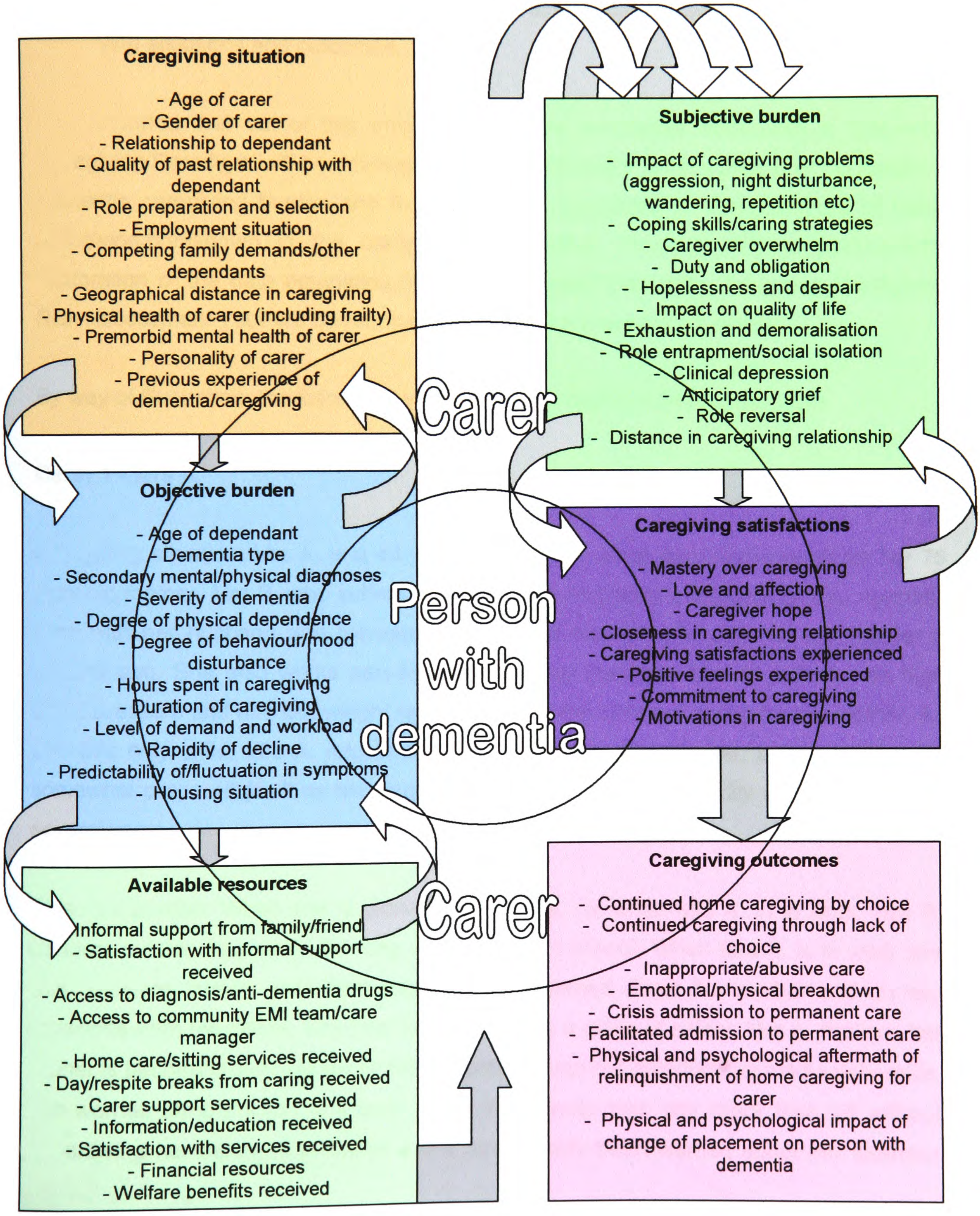
DCPQ score: __ /200
(0-50 = Minimal caregiving problems; 51-100 = Moderate caregiving problems; 101-150 = Severe caregiving problems; 151-200 = Extreme caregiving problems)

DCBQ score: __ /160 *(* a score of 90+ should prompt discussion around future care needs and wishes)*
(0–40 = Minimal caregiving burden; 41–80 = Moderate caregiving burden; 81–120 = Severe caregiving burden; 121–160 = Extreme caregiving burden)

Breakdown Risk Assessment Score: __ /480
(0-120 – Minimal risk of breakdown, 121-240 – Moderate risk of breakdown, 241-360 – Severe risk of breakdown, 361-480 – Extreme risk of breakdown)

7.3 Proposed 'Conceptual Model of Dementia Caregiving Burden and Breakdown'

The following proposed draft conceptual model has been developed out of an analysis of findings from this study, previous research findings and an extensive review of the literature. It is proposed to inform clinical practice and further illustrate the main findings from this study. However, as it remains untested it should be viewed as hypothetical, pending further post-doctoral exploration.



The arrows in the above diagrammatical illustration are intended to represent the inter-relationships between caregiving situational factors, objective burden and available resources and their combined effect upon the experience of subjective burden. Subjective burden is ameliorated, to a greater or lesser extent, by caregiving satisfactions experienced and this combined subjective experience will largely determine caregiving outcomes. The person with dementia remains at the centre of the model and the carer is the person holding the dementia caregiving situation together – the keystone, so to speak, without whose support the dependant would enter permanent care. Such a conceptual framework is intended to help explain the differences between different dementia caregiving situations and outcomes.

It is intended that out of this empirically derived conceptual framework a 'Dementia Caregiving Paradigm' will be developed to aid practitioners' understanding of the nature of dementia caregiving burden and the risk factors implicated in relinquishment of home caregiving/breakdown in the caregiving relationship. However, further post-doctoral exploration of the data emanating from the proposed 'Dementia Caregiving Breakdown Risk Assessment Tool' will be required to inform future research directions.

By way of illustration, the following two case studies highlight these differences:

Carer 1 - Mrs A.

Caregiving situation: Mrs A. is a 46 year old daughter carer providing support for her 75 year old mother, Mrs B, who suffers with moderate Alzheimer's disease. Mrs A. normally lives with her husband and teenage children, but moved in to care for her mother 8 months ago. She also works part-time as an office manager. Mrs A. suffers with high blood pressure and has lost weight recently, due to the stress of caring for her mother. As Mrs B.'s only child, Mrs A. reluctantly took on the role of caregiver, although she was somewhat prepared for it as her mother's condition has been steadily deteriorating over several years.

Objective burden: When she is alone in the house, i.e. when Mrs A. in in work, Mrs B. wanders outside frequently, thinking she is going to school. When Mrs A. is in work she often receives 'phone calls from neighbours concerned about her mother and on two occasions from the police, who had taken Mrs B. to a place of safety. Mrs A. realises her mother is becoming increasingly at risk at home, due to her deteriorating road safety skills. She worries terribly when she is in work, but cannot take any more time off without jeopardising her career any further – she has already been warned about her sickness rate. Mrs B. also wakes her daughter frequently during the night, asking her to take her to her deceased mother's house (she thinks her daughter is an aunt).

Available resources: Mrs A.'s children sit with her mother when they can, but there are several hours each week when there is no-one to supervise Mrs B. and Mr A. cannot help during the day due to his own work commitments, which require him to commute some distance from the family home. Mrs A. has recently attempted to access support via her mother's GP, but only Memory Clinic involvement has been forthcoming to date. Mrs A. is currently in touch with the Alzheimer's Society to see if any sitting service is available in her area.

Subjective burden: Mrs A. feels exhausted and overwhelmed in her current situation. She fears that she will soon have to give up work to care for her mother full-time. Her social life is non-existent and outside of work she has no contact with friends, who don't understand the full extent of her problems. Mrs A. feels that her own marriage is suffering as a result of her caregiving responsibilities and it is several weeks since she stayed at home with her husband and family for a weekend (when her mother was taken to hospital following a fall in the street). Mrs A. is deeply distressed by the changes in her mother, especially her failure of recognition, and feels she is probably a little depressed herself.

Caregiving satifactions: Mrs A. is deeply committed to remaining in the caregiving role. She loves her mother deeply and feels a debt of gratitude to her as her sole parent (she brought her up single-handedly). There are significant moments of clarity which Mrs A. feels make continued caregiving worthwhile, and while Mrs A. still communicates love and affection to her daughter, albeit at a different level, she refuses to consider relinquishing home caregiving.

Caregiving outcome: Mrs A. experiences considerable caregiving burden, but she wishes to remain in the caregiving role for as long as she is able, though this may require her to relinquish paid work in the near future.

Carer 2 - Mr P.

Caregiving situation: Mr P. has been caring for his wife with moderate Alzheimer's disease for more than 5 years. She is a younger person with dementia, aged 56, and he is now 63 years old. Mr P. took early retirement to care, which has caused him some considerable financial hardship, especially as his wife also had to finish work early as a result of her dementing illness. Caregiving came out of the blue for Mr P. and he felt ill-prepared for the caring role, but his 2 daughters have helped greatly and he feels he has adjusted well under the circumstances.

Objective burden: Mrs P.'s Alzheimer's disease has rapidly advanced, which is often the case for younger sufferers. Her presentation has also been more challenging and it has been commonplace for Mr P. to be on the receiving end of verbal and physical assaults. Mrs P. is especially resistive to care and fights against being washed and dressed. She is also reluctant to be fed, which is especially concerning for Mr P., as his wife has lost several stones in weight since the onset of her illness. Just recently, Mrs P. has begun to be incontinent, both of urine and faeces, which has forced them to sleep separately for the first time.

Available resources: Mr P. receives support from a community mental health team. A CPN calls monthly for support and to monitor the situation and home carers call in the morning and evening to help get his wife up and put her to bed. Mr P. has to help them, as his wife's hands have to be held during all personal care interventions due to her resistiveness. Mr P. also avails himself of a carers' support group for husband carers, which he finds especially helpful as it enables continued social contact. Indeed, the group often meets in a local pub - a sitter is provided to enable Mr P. to attend. Mr P.'s daughters sit with their mother several afternoons a month, so that their father can get out and do the shopping and generally have a break. Mr P. has full access to benefits, but as a younger carer they are insufficient to pay for extra care, as he is not yet of pensionable age.

Subjective burden: Mr P. feels that he has managed his wife's challenging behaviour well. He has heavily invested in providing her care at home, to the detriment of his social life and employment, and feels he would be at a loss without her at home to care for. Mr P. talks of his wife, as she was, being dead to him in many ways. He cares deeply about the changed person that she now is, but his feelings for her have changed. He says that he has days when he gets very low, but he is able to busy himself and not dwell on things too much. One great fear that Mr P. has is how he will cope if his wife becomes more frequently incontinent, as this is something he could not cope with without extra support.

Caregiving satisfactions: Mr P. has a strong sense of mastery over his caregiving situation and wishes to care for his wife up to her death at home. However, he feels that he will need extra care to do so, especially with regard to his wife's continence care and her physical frailty needs – she now needs considerable help to stand and be helped from bed to chair etc. Without a full care package, including day and night continence care, Mr P.

worries that his wife may have to be admitted to a nursing home. He says that he will fight against this for as long as he can, and hopes that extra care will be funded on an ongoing basis.

Caregiving outcomes: Mr P. feels only moderately burdened and wishes to remain in the caregiving role. However, he will need intensive support from community care services in order to do so.

These case studies again demonstrate that each caregiving situation is unique and support Braithwaite's (1990) assertion that caregiving burden is very much a subjective phenomenon and that the carer's perception of their situation is the most reliable predictor of the impact of caregiving.

7.4 Limitations of the study

The researcher acknowledges that this study has several limitations and would like to explore these at this stage in the thesis before proceeding to make propositions for post-doctoral research.

A significant problem was the shift in methodology midway through the study, following carer drop-out and dependant/carer deaths in the face-to-face interview sample, to embrace an internet questionnaire which attracted a larger study cohort and overseas subjects. In many ways this proved to be a strength of the study, for example in relation to testing the reliability of the new carers' assessment tools, but it did significantly alter the whole ethos of the study from a purely qualitative piece of research to a mixed methods study. Also, the experience of services of overseas carers was inevitably different to that of the UK carer sample, making this aspect of the study findings in particular less generalisable to a UK population. However, the researcher would strongly argue that other aspects of the study findings were not affected by the participation of an overseas cohort of carers, as the experience of dementia caregiving is universal, as are the burden experienced and the risks for breakdown, as evidenced in the study findings.

The relatively small study sample also makes it difficult to extrapolate the findings from this study and generalise them across the dementia caregiver population per se. Instead, the researcher would view this study as being exploratory and contributing further evidence to the body of literature regarding dementia caregiving burden and breakdown. Further post-doctoral research will be required to push the boundaries of this study forward and extend it to one which conclusively demonstrates the factors implicated in the experience of caregiving burden and breakdown of caregiving situations/relinquishment of home caregiving.

The abandonment of the Mini-mental State Examination test (Folstein et al., 1975), dropped because of failure to administer by assisting practitioners and the impossibility of administering it upon the dependants of internet subjects, was also unfortunate as it's absence meant that an assessment of dementia severity rating by the carer was purely subjective and dependant on their understanding of the dementia illness trajectory. With hindsight, the rating scale used could have been supported by examples of dementia symptoms that could be expected at each point on the scale to achieve a more reliable carer assessment. Similarly, the abandonment of the General Health Questionnaire (Goldberg and Williams, 1988), dropped because of failure to administer by assisting practitioners and withdrawal from the internet questionnaire because of the already overly large volume of on-line questions, was unfortunate because data on 'psychiatric caseness' in carers in support of the self-assessed carer health rating was lost. However, this was partly overcome by requesting drug prescription information from carers as supporting evidence for clinical depression in carers.

The point made above regarding the large volume of questions presented on-line for carers to complete is also considered as another limitation of the study. The fact that a higher response rate for internet subjects (n=74) was received for the earlier sections of the on-line study questionnaire – 'caregiving situation' (n=73), 'caregiving problems' (n=59) and 'caregiving burden' (n=59), as opposed to the last section - 'caregiving resources' (n=34), may have been indicative of carer fatigue in completion of the questionnaire or a failed modem connection after so long spent on-line completing the questionnaire (estimated time in completion was 45 minutes). This would need to be addressed in future research using this data sampling/collection method.

7.5 Recommendations for post-doctoral research

The 'Dementia Caregiving Breakdown Risk Assessment Tool (DCBRAT)' is recommended for piloting in clinical practice and a detailed evaluation should follow, perhaps via face validity tests, to determine if community care practitioners perceive it as being useful in highlighting 'at risk' caregiving situations and supporting their decision-making regarding individual care planning and community care management.

More in-depth research should follow to investigate whether the DCBRAT makes a real difference in adjusting service interventions to the 'at risk' group of carers and in outcomes for people with dementia and their carers, i.e. more sustained home caregiving situations and fewer unplanned crisis admissions to permanent care.

Additionally, such post-doctoral research, perhaps administering the DCBRAT on a larger sample of dementia carers on a quarterly basis, would enable an analysis of risk factors prior to placement of people with dementia in permanent care and, together with a post placement interview/questionnaire with the carer, could prove the assessment tool as valid and reliable in predicting relinquishment of home caregiving.

The proposed 'Conceptual model of dementia caregiving burden and breakdown' is obviously very tentative and will require further elaboration and testing to demonstrate its authenticity.

7.6 Personal observations

To conclude this thesis, the researcher would like to reflect on this research and make some personal observations based on the interviews and email interactions with carers.

The lessons learned from carers who have contributed their experiences to the study have been incredibly useful and are worthy of sharing with others in this field of practice. They are as follows:

- That the majority of carers make enormous sacrifices to take on the role of carer and the quality of their own life is often greatly effected. *The lesson for service providers is that their contribution to care needs to be more recognised and highly valued. Service interventions aimed at enabling carers to continue with aspects of their social life, employment etc are supportive of continued home caregiving and need to be further developed.*

- That many carers on identification have been coping for several months or years without a formal diagnosis or support from family or friends or community care services. *Service providers need to do more to reach out to caregiving situations and take positive action to ensure that people with dementia and their carers receive timely and appropriate forms of support. The skills of carers, often learnt through trial and error, need to be further validated and supported by service providers.*

- That all carers cope with a multitude of different caregiving problems across all dimensions and most cope with these problems in a positive, person-centred way. *Service providers need to recognise carers' coping skills and support them in their role, providing appropriate information and support throughout and beyond the dementia caregiving trajectory. Caregiving skills training for carers has a very important place in the range of carer support services currently on offer and needs to be made more widely available.*

- That many carers experience considerable satisfaction in their role, are highly committed to caregiving and wish to care for their dependant up to their death. *Service providers need to focus more on the satisfactions of caregiving and determine satisfactions and motivations as part of their carer assessment procedures. At home 'terminal dementia care' services need to be further developed to provide an alternative option to nursing home or hospital care.*

- That most carers experience high levels of caregiving burden in their role, many in the face of challenging behaviour and/or physical frailty problems, and have limited or no access to home care support workers, in home or out of home breaks from caregiving and appropriate aids and equipment. *Service providers need formally to assess the subjective impact of caregiving problems on the carer and take positive action to relieve caregiving burden by delivery of appropriate community services care packages that relieve them of their most stressful caregiving tasks and provide them with regular opportunities for time away from the caregiving situation. Service commissioners need to ensure that a flexible range of home care, day care and respite services are available equitably in each locality.*

- That each situation is unique and needs to be viewed as such – each carer has different caregiving satisfactions, caregiving problems/needs, perceived caregiving burden, and service requirements. *Services providers need to be more sensitive to this fact and focus more on tackling problems which are perceived by the carer as being those which are the most stressful/difficult to manage.*

- That dependants' and subsequently carers' needs change over time as the course of the illness progresses, often suddenly and dramatically. *Service providers should be more aware of changing dependant/carer needs over time across the dementia trajectory and need to ensure that community care plans are regularly reviewed and that care managers are allocated to the caregiving situation for the duration of the dementing illness.*

- That a significant number of carers are not fairing well (including some known to services), are burnt out, depressed, exhausted and demoralised in their role. *Service providers need to ensure that such carers are identified and offered appropriate support. Service commissioners need to make available in each area services such as out of hours telephone helpline, night sitting support and emergency respite care.*

- That whilst most carers wish for continued home caregiving to be facilitated by improved service inputs, it must also be recognised that some do not wish to continue in the caregiving role or feel unable to. *Carers' assessments need to identify such carers and service providers need to offer appropriate support in facilitating permanent care placements. Support should also be offered to the carer after placement so that guilt and distressed is normalised and validated.*

- That there are some carers who have not chosen to be in the role of caregiver, are unwilling or ill equipped to remain in that role and engage in inappropriate or abusive care practices as a means of coping. *Service providers need to be skilled in identifying such caregiving situations and respond urgently under local protection of vulnerable adult guidelines to ensure vulnerable adults are protected from harm.*

7.7 Final conclusions

This study adds greatly to the existing body of research on dementia caregiving burden and breakdown, but also provides dementia community care managers with new carers' assessment tools for implementation in clinical practice. Thus the research has remained clinically grounded and focused on practice development, as well as theoretical development.

The DCPQ and DCBQ as new carers' assessment tools are now available for implementation in clinical practice and have demonstrated reliability in identifying carers who are coping poorly with the demands of caregiving and who need additional support or assisted relinquishment. They also help meet the requirements of the Carers (Recognition and Services) Act (DoH, 1995) and address several of the criticisms levelled against local authorities in their development of formal carers' assessment procedures. The fact that many teams across the UK and further afield are now using these assessments in practice further emphasises their face validity.

The proposed DCBRAT, which incorporates the above tools in their entirety and encompasses other identified key carers' assessment questions, whilst requiring further testing, is also offered for implementation in practice and, it is expected, will further assist community care practitioners in their quest to provide targeted support to caregiving situations at risk of breaking down. Further post-doctoral research will be undertaken to ensure the further development and implementation of this risk assessment tool.

Similarly, the proposed conceptual model is at an early stage in development and will need to be more rigourously researched and tested. However, it has already had some value in nurse education concerning dementia caregiving burden and breakdown and, together with the DCBRAT, has been perceived as being useful in hypothetical case study analyses and care planning.

Perhaps most importantly, the study findings will further develop dementia community care practitioners' understanding of the subjective experience of dementia caregiving, and the problems and needs of carers. The findings concerning caregiving satisfactions and risk factors for breakdown in caregiving situations will be especially important in informing care management practice. It is anticipated that this new information, together with the above carers' assessment tools, will enhance community care services' response to caregiving situations and improve outcomes for carers and dependants alike.

The new finding from this research regarding caregiving satisfactions increasing with dementia severity is unique and, if replicated in other research, could have major implications for dementia community care practice. By more effective targeting of service interventions to those carers most burdened and at risk of psychological health problems or breakdown in their caregiving situation, which has been shown to peak in the middle to severe stage of the dementia trajectory, more carers could be enabled to continue in role until their dependant's illness progressed to a more passive and frail stage when caregiving is less psychologically burdensome. With developments in community care services to enable more 'terminal phase' dementia care at home, i.e. with double-handed care packages and all necessary physical aids and equipment, more carers could continue providing care for their dependants up to their death at home, which is the desired end outcome of caregiving for most. The cost saving from off-setting the need for permanent care in this way would be likely to be great, allowing for further investment into community care services. However, quality, access and affordability issues would need to be addressed before this became a realistic transformation in dementia care provision. The range and flexibility in the pattern of services available would also need to be improved for this to become a reality, for example with acess to weekend and twilight day care, emergency respite care, night sitting services, etc. in every area.

As has been previously stated, whilst the above would be a desirable outcome for many carers, it would not be for a significant minority. Many carers have not chosen and do not wish to continue in the caregiving role. Not all carers have had positive relationships with their parents or spouses in the past, before the onset of dementia, and many do not wish to abandon aspects of their life to become a full-time carer. There will still need to be the availability of high quality permanent care provision for these caregiving situations and, for many, an earlier relinquishment of caregiving than is currently the case may be in the best interests of both carers and dependants. Earlier facilitated relinquishment, following assessment that this is the most appropriate service response, may have the effect of offsetting crises admissions to care and help prevent vulnerable adult abuse.

The innovative aspects of the research methods utilised in this study are also to be highlighted as important study outcomes. The innovative internet sampling and data collection method developed for this study in particular could prove extremely beneficial for future caregving research across client groups and may be especially relevant for studies investigating difficult issues such as vulnerable adult abuse, child protection, self-harm/suicide prevention, etc. where subject anonymity is important. The electronic qualatative data analysis method used in this study would also appear to be somewhat innovative and is to be recommended for replication in other studies with a large qualitative element, replacing the arduous paper analyses/reanalyses and elaborate filing systems of more traditional methods.

Having had time for reflection on this seven year research programme, and by way of final concluding thoughts for the thesis, the researcher would propose that the study has provided tremendous opportunities for personal growth and professional development. Not only has the study developed his research skills and enhanced writing and presentation abilities, but it has also enhanced his clinical expertise, especially in relation to counselling interventions. The part-time M.Phil/Ph.D route has undoubtedly assisted the researcher in career pathway progression towards Consultant Nurse status and has enhanced his clinical credibility and professional standing within his employing Trust. It should be recommended, therefore, to other potential Ph.D students considering this study route. One note of caution, however, would be that there is a need for endurance and commitment to undertake such long-term research, which makes it all the more important for the subject matter to be clinically relevant and grounded in practice. Having a clear motivation to improve clients' and/or carers' quality of life or health experience in some way is the key to ensuring successful completion, and knowing that your research could help deprived and vulnerable members of society is the best driving force. My sincere hope is that this thesis, in some small way, will make a real difference to the future lives of carers and clients affected by *'this dreadful illness'*.

The researcher would like to conclude this thesis by offering heartfelt thanks to those carers who have participated in the study and contributed their experiences towards the development of carers' assessment tools, which are aimed at improving the situation for those who follow in their footsteps by enabling health and social care services practitioners to better identify and respond to their perceived needs.

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Appendix 1

OPEN LETTER TO CARERS

AN OPEN LETTER TO CARERS OF COMMUNITY MHSOP TEAMS

Thursday, 10 February 2000

Simon O'Donovan
Nursing Practice Development Advisor
c/o The Service Development Team
(MHSOP)
Royal Hamadryad Hospital
Hamadryad Road
The Docks
Cardiff
CF1 6UQ
Telephone: 01222 494952
Fax: 01222 496431
E-mail: sodonovan@msn.com

Dear Carer

I am a Senior Nurse working with Cardiff and District Community NHS Trust, currently studying for my Doctorate in Nursing. My research study focuses on the main difficulties that carers have in caring for a loved one with dementia and the way that stress and caregiving burden changes over time.

I am writing this letter to all carers served by Community MHSOP (Mental Health Services for Older People) Teams in Cardiff to ask if you would be willing to participate in the study. This would involve the completion of a short questionnaire sent to your home address (takes about 15 minutes), an initial interview with you - taking approximately one and a half hours, and an assessment of your dependant's degree of confusion (takes about 30 minutes).

After this initial interview I would be in touch with you again one year after initial interview to see how things are changing for you and your dependant over time, to see how you are coping and to find out how services are responding to your changing needs. These interviews would take place either at the Dementia Careline Centre in Whitchurch, Cardiff, or in your own home, according to your preference.

Our hope is that the results of this study will help to improve methods of assessment and support for carers of people with dementia in the community, and generally raise awareness of the service needs of carers to managers and policy makers in the statutory services responsible for delivering services to people like yourself

If you do decide to participate in the study you can write your details on the tear off slip overleaf and send them to the above address, or you can leave this with your Care manager. I will then be in touch with you within a couple of days of receiving your details to make an appointment for an interview and send you the short questionnaire mentioned above. If required, I will also try and make arrangements for the care of your dependant while the interview is going on so that you can relax knowing they are being looked after.

At any stage in the study you can decide to drop out: there is no long-term commitment. Knowing how hard it is for carers to find the time to do anything outside their role, I will understand if you decide not to take part.

Thank you for your time and attention. If you want to ask any questions about the study, please do not hesitate to contact me on the telephone number above.

Yours sincerely

Simon O'Donovan
Nursing Practice Development Advisor
Cardiff Community Healthcare NHS Trust

✂---

I would like to participate in the research study which looks at carers' stress and burden over time and agree:

- to complete a short questionnaire which will be sent to my home
- to be interviewed on two occasions - on first meeting the researcher, and one year after the first interview
- for my dependant to be assessed by the researcher, using an accepted interview schedule, to determine their level of confusion.

MY NAME IS: ....

MY ADDRESS IS: ....

....

....

....

MY TELEPHONE NUMBER IS: ....

SIGNED: ....

DATE: ....

Appendix 2

CONSENT FORM

MHSOP DIRECTORATE
Cardiff Community Healthcare
Royal Hamadryad Hospital
Hamadryad Road
The Docks
CARDIFF CF1 6UQ
Tel: 01222 494952
General Manager: Mrs. Christine Dyer, MBE

SCHOOL OF NURSING
University of Glamorgan
Glyn Taf Campus
Pontypridd
Mid Glamorgan
CF37 1DL
Tel: 01443 480480
Head of School: Professor Donna Mead

Consent Form

FOR PARTICIPATION IN THE CARERS' RESEARCH STUDY

We would be grateful if you could read and complete the following short Consent Form. Thank you for your help in this matter.

I, ______________________________ *(block capitals please)*

agree that I have been formally asked for my written consent to participate in the research study being conducted by Simon O'Donovan into 'The Experience of Care-giving Stress and Burden in the Carers of People with Dementia'.

I agree that I am willing to participate in the study (being interviewed on two separate occasions - initial interview and follow-up at one year), and give permission for my relative's degree of memory impairment to be assessed, on the understanding that:

- *all information given or obtained will be treated in the strictest confidence;*
- *there is in place a method which ensures that I cannot be identified from data held by the researcher;*
- *I can withdraw from the study at any time simply by telephoning the researcher.*

I also give permission for my interview to be tape recorded for the purposes of the study, on condition that recordings will not be used for any other purpose and that they will be destroyed once the research is completed.

Signed: ______________________________

Witnessed: ______________________________

Date: ______________________________

Appendix 3

OPEN LETTER TO DEMENTIA CAREGIVERS WORLDWIDE

An Open Letter

To Dementia Caregivers Worldwide

14th April 2000

Dear Caregiver

Firstly, thank you for taking the time to visit this web-site.

My name is Simon O'Donovan and I am a senior psychiatric nurse specialising in dementia care and working for Cardiff and Vale NHS Trust, Wales, UK. I am currently studying for my Doctorate in Nursing at the University of Glamorgan in Mid Glamorgan, and my thesis is an investigation of the stresses and problems that carers experience when caring for a friend or relative with dementia in the community. I am also interested in the factors involved in carers' decisions to relinquish caregiving and admit their loved one to permanent care settings, as well as how services can support continued caring at home.

Already, as part of my study I have interviewed 20 carers face-to-face and now I am at the stage where I need to extend the implementation of my research questionnaires to a wider sample of carers. This is with the eventual aim that elements of the research questionnaires can be used by dementia care practitioners in community services to assess carers' needs in line with the 'Carers (Recognition and Services) Act, 1995' (applies UK only).

Your participation in my study would involve the completion of one of the following questionnaires:

Questionnaire 1: Current Community Dementia Carer's Stress and Care-giving Burden Questionnaire

This questionnaire is designed for people who act as the main carer for a person with dementia and live with their dependent for all or some of the time, i.e. those still caring in the community, to complete. The only criteria for participation in the study is that your dependent has been diagnosed with dementia for more than one year.

OR

Questionnaire 2: Past Dementia Carer's Retrospective Stress and Care-giving Burden Questionnaire

This questionnaire is designed for people who used to act as the main carer for a person with dementia and lived with their dependent for all or some of the time, but have relinquished care within the last year, to complete.

The only criteria for participation in the study is that your dependent has been admitted to permanent care within the last year.

Each of these questionnaires takes about 45 minutes to complete (please fill it in off-line to save on 'phone bill costs), and they can be filled in anonymously if you would prefer. There is no other commitment, although your e-mail address will be used to send you an 'Executive Summary' of my report in approximately one and a half years time.

If you do decide to participate in the study I can only thank you most sincerely from the bottom of my heart for your support. I know how busy carers are and how precious time off from caring is, so your spending time in this way is most appreciated and, hopefully, some great good will come from it.

For those of you who decide you cannot spare the time to complete the questionnaire, I fully understand and thank you anyway for visiting this web-site.

Finally, for those of you visiting this web-site seeking on-line support, please access the Signpost journal Links Page by clicking here: **Links Page**

Please note that the questionnaires are quite hefty and can take a few minutes to download. Please be patient.

If you need to talk to someone in person about your caregiving situation, you can also call the South Wales Dementia Careline, which is open every day from 10am - 10pm on 029 2052 9848

Yours sincerely

Simon O'Donovan

Nursing Practice Development Advisor, Older Peoples' Mental Health Services, Cardiff and Vale NHS Trust, Service Development Team (MHSOP), Royal Hamadryad Hospital, Hamadryad Road, Cardiff. CF10 5UQ

Appendix 4

COMPLETE TABLES FOR QUALITATIVE DATA

Statement Category	Statement	Number
Difficulty and demand (n=69)	Caregiving difficult/hard	25
	Constant/never-ending	7
	Demanding	5
	Draining	5
	Challenging	4
	Caregiving as a job	3
	Hardest thing ever done	3
	Terrible/dreadful/horrendous	3
	All consuming	2
	Time consuming	2
	Always on duty	2
	Tough	2
	Other	5
Stress and coping (n=61)	Stressful/stress/stressed	20
	Frustrating	15
	Feel guilt/guilty	7
	Test of patience/try to be patient	6
	Anger inducing/maddening	5
	Burden of care	3
	Other	5
Grief and loss (n=59)	Caring equated to child/infant care	20
	Loss of/lost person	12
	Distressing watching deterioration/suffering	10
	Dependant as child unlearning skills	5
	Watching deterioration/suffering	4
	Miss the person as was	4
	Personality change	3
	Child and parent role reversal	2
	Other	2
Depression and despair (n=36)	Depressing/depression	10
	Sad/sadness	8
	Heartbreaking/heartwrenching	4
	Frightening/worrying/scary	3
	Devastating	2
	Hell/sheer hell	2
	Other	7
Reward and satisfaction (n=34)	Caregiving rewarding/satisfying	7
	Try and be positive	3
	Made positive choice to care	3
	Able to remain calm/patient	3
	Caregiving manageable/not too difficult	3
	Enjoyable/delightful	2
	Other	13
Lost social life and isolation (n=18)	Lonely/alone	4
	Lost freedom/trapped	4
	Not able to work due to care	3
	No time for/given up own life/life on hold	3
	Caregiving isolating	2
	Other	2
Caregiving problems (n=12)	Lost conversation	3
	Behaviour problems	3
	Sleep disturbance	2
	Other	4
Exhaustion and demoralisation (n=10)	Caregiving tiring/carer tired	7
	Carer subsumed by role	2
	Other	1

Table 5.10: Categorisation of emergent themes in response to the open question, 'What is it like to care for a person with dementia/your dependant?'

"In short, this is a long walk through hell."

"Very sad and very frustrating at times. She has moments of great clarity, but it is very hurtful when she doesn't know who I am. I try to take each day as a gift. I feel like I have already started mourning the loss of who she was and will never be again."

"Caregiving is extremely frustrating much of the time. The inability to communicate or understand instructions makes care very difficult. It is like caring for a totally dependent child who is unlearning everyday skills. The joy in seeing a child grow and learn is missing and replaced by sadness in seeing a loved one slowly lose himself. It is heartbreaking and the feelings of loss never go away."

"It is very trying. No matter what you do to help them today, tomorrow it is all forgotten."

"Caregiving is frustrating, depressing and anger-inducing. My freedom is gone. The cost of help for occasional escape is threatening our finances. I feel trapped; certain that for the rest of my life I will be chained to caregiving."

"If you want a metaphor, it's like fighting a bush fire on several fronts at once, and you just have to fight each particular bit when it sticks it's head up. There can be no ground strategy for coping with this disease. You've got to ask for help when you identify a need."

"You've just got to try and be positive – count your blessings like Pollyanna. Make every moment count."

Direct quotation from current caregivers in response to the open question, 'What is it like to care for a person with dementia/your dependant?'

Statement Category	Statement	Number
Adverse change in carers' quality of life (n=74)	Loss/lack of privacy	9
	No time for self	8
	Need for caregiving constant	7
	Can't leave dependant alone	6
	Loss/lack of freedom	5
	Difficult to get a break	4
	Dependant requires 24 hour a day/7 days a week care	4
	Lost/no life	4
	No vacations/holidays	3
	Burden of responsibility heavy	3
	Caregiving dominates life	3
	Tied to caregiving	2
	Can't get away	2
	Other	13
Stress, strain and fatigue (n=41)	Suffer constant stress	9
	Sleep disturbed by dependant	4
	Problems coping with demands of caregiving	4
	Suffer constant strain	2
	Stress headaches	2
	Depression	2
	Fatigue/tiredness	2
	Incontinence difficult to manage	2
	Keeping a routine important in managing	2
	Other	12
Negative impact on family, work and finances (n=32)	Disrupted family life	7
	Increased financial burden	6
	Difficulty balancing work with caregiving	5
	Not able to spend time with spouse	3
	Marital difficulties caused by caregiving	2
	Given up work to care	2
	Other	7
Problems for carers whose dependents are living alone (n=13)	Fear of dependant safety in own home	4
	Hard to maintain visits to dependant	2
	Have to lead a double life	2
	Visiting dependant time consuming	2
	Other	3
Relationship change (n=9)	Have to sleep separately from dependant	3
	Spend too much time together	2
	Dependant anger towards carer	2
	Other	2
Positive aspects (n=7)	Easier to care living with than separate from dependant	3
	Motivation to keep dependant out of nursing home	3
	Other	1

Table 5.12: Categorisation of emergent themes in response to the open question, 'What problems have been caused by the geographical distance involved in caregiving?'

"I'm a prisoner, tied down to caring. I hate it."

"There is a need to be ever watchful that she doesn't get into something which could harm her. There are often unpleasant things to clean up. She hides things. Our family is unable to come and go from our home as a family normally would. I hasten to add, though, that our sacrifices are small in exchange for keeping her out of a nursing home."

"I have two evenings off a week when carers come in and he goes to a day hospital twice a week. Otherwise I am with him all the time. I can't leave him because if he tries to stand up from his chair he will wobble and might fall. He needs constant care and supervision. So I just live with this disease and it controls my life."

"There are not enough hours in the day. I lack time to give to my child (mother thinks my daughter is me and I am her own sister). Mother competes for attention with my daughter and pouts when she cannot have her own way. My privacy and time for myself are almost non-existent. Money can run short with additional care that is required while I am at work."

Direct quotation from current caregivers in response to the open question, 'What problems have been caused by the geographical distance involved in caregiving?'

Statement Category	Statement	Number
Negative impact on quality of life (n=89)	Little/no free personal time	16
	Life on hold/no longer have a life	13
	Loss of/restricted social life	9
	Caregiving is my life	7
	Holidays/vacation impossible	5
	Caregiving is restrictive	4
	Always tired	4
	Changed life	3
	Friendships have suffered	3
	Caregiving controls life	3
	Feel overwhelmed	2
	Life is narrowing/restricted	2
	Tied to the house	2
	Lack of freedom	2
	Disease devastating	2
	Forgo things to care	2
	Other	10
Caregiving demands (n=84)	Can't leave dependant alone	9
	Need for constant caring/supervision	8
	Stress/stressful	6
	Toileting dependant	5
	Sleep disturbance	5
	Need for assistance/supervision washing	4
	Need for assistance/supervision dressing/undressing	4
	Dependant will not accept services	4
	Things are hard	3
	Like caring for a child/infant	3
	Managing laundry	3
	Managing cleaning house/housework	3
	Cooking meals	3
	Changing dependant/bed	3
	Dependant aggressive	3
	Incontinence care	2
	Have to watch dependant to prevent falling	2
	Coping with communication problems	2
	Coping with restlessness	2
	Caregiving as a 24/7 job/responsibility	2
	Other	8
Impact on employment (n=20)	Given up/can't work due to caregiving	7
	Have had to reduce to part-time work due to caregiving	3
	Only leave house to go to work	2
	Retired early to care	2
	Additional stress of working full-time and caregiving	2
	Loss of income from work/financial hardship	2
	Other	2
Physical/psychological impact (n=15)	Caregiver suffers with clinical depression	2
	Can't relax	2
	Stress headaches	2
	Other	9
Negative impact on spouse/family (n=13)	Limited time with spouse	4
	Limited time with child/children	4
	Marital relationship problems	2
	Spouse/children help with caregiving	2
	Other	1
Positive aspects (n=6)	Chose/want to care for dependant	2
	Other	3

Table 5.14: Categorisation of emergent themes in response to the open question, 'What is the impact of the hours spent in caregiving on your life?'

"I only leave the house to go to work. We don't go away on vacation, well rarely. We don't go out to eat. We have no social life. My depression became quite severe but now I am on meds and that has helped a bit. This IS my life. Mom IS my life. Alzheimer's IS my life. It's how I think and breathe It's always there."

"I have about two evenings off a week, when carers come in, and two days off when he goes to day hospital. I'm with him all the time otherwise and could never leave him. I have to watch him all the time as he would try to get up from his chair and fall to the floor otherwise. And so I just live with this disease and it controls my life. The constancy of caring has become a way of life, but because I'm a positive person I make the most of it. I have come to accept it and just try to get on with life."

" Terrible really. I think it's sad. It's really hard for me. I'm 76 and I've had no quality of life really for years. He's gone through phases of wandering off and getting lost, and being aggressive. But now it's worse than ever because he can't talk properly, he's incontinent, he has hallucinations and I struggle to get him upstairs to bed because of his mobility problems. Every morning I have to do the laundry and change the bed as it is soaking wet. That's hard."

" This IS my life now. My friends no longer call, I am unable to pursue a single outside interest. My life, for the present, is consumed by dementia, the same as hers has been."

Direct quotation from current caregivers in response to the open question, 'What is the impact of the hours spent in caregiving on your life?'

Statement Category	Statement	Number
Caregiving problems (n=34)	Dependant totally/completely dependent on carer	9
	Carer has had to take charge of everything	8
	Caregiving is stressful	2
	Dependant gets aggressive	2
	Dependant makes upsetting false accusations	2
	Dependant has tantrums/is easily angered	2
	Other	9
Degree of closeness/attachment (n=27)	Still close to dependant	6
	No longer as close to dependant	5
	Have become closer to dependant	4
	Still love dependant	2
	Dependant can no longer show love	2
	Other	9
Relationship breakdown (n=23)	Get angry/lose temper with dependant	4
	No quality in relationship	3
	Feel sorry/pity for dependant	3
	Get impatient with dependant	3
	Get frustrated with dependant	3
	No longer have a relationship with dependant	3
	Other	4
Communication breakdown (n=21)	Lack of verbal communication	5
	Dependant can't understand what carer says	4
	Dependant can't respond to carer	3
	Can't converse about shared memories	2
	Carer can't understand what dependant says	2
	Other	5
Coping skills/management strategies (n=20)	Try to remember she is my ...	3
	Try to keep calm/patient	2
	Carer has become a more caring person	2
	Carer now has to make decisions alone	2
	Feel strained	2
	Other	9
Relationship change (n=17)	Relationship has not changed	3
	Change in quality of relationship	3
	Relationship has changed for the worse	2
	Radical change in relationship	2
	Relationship has improved	2
	Other	5
Equivalent to child care (n=16)	Parent now like a child	9
	Spouse now like a child	3
	Like caring for a baby	2
	Other	2
Role change (n=14)	Role reversal/roles reversed	12
	Other	2
Grief and loss (n=12)	Dependant different/changed person	5
	No longer my ...	2
	Feel bereaved	2
	Other	3
Lost partner/spouse (n=10)	No longer have a spousal/marital relationship	5
	Physical/sexual relationship has gone	2
	Other	3
Failure of recognition/ validation (n=10)	Dependant no longer recognizes carer	5
	Dependant does not recognize carer's needs	2
	Other	2

Table 5.19: Categorisation of emergent themes in response to the open question, 'How has your relationship with your dependant changed since he/she has been ill?'

"Hostility has replaced a long, loving relationship. There is a loss of companionship, sharing and caring. I am in charge of everything and more like a parent than a spouse. I no longer have a husband who is concerned about me."

"My mother and I never had a close relationship. However, now she doesn't recognise me as her daughter. I'm her 'friend' that cooks for and takes care of her. So, as her 'friend' I am more accepted than I was before."

"He has no conception of what I am facing. He lives in his own world. We are essentially strangers living in the same house."

"Well, he doesn't really know me now, so we're not very close. It's mainly because he doesn't recognise me now. I give him a hug sometimes, but I don't think he knows me at all. He says, 'Go and see to that other old man in there'. I don't know who he means. He's so altered as a person. I feel sorry for him, but that's about all. I suppose I've got hardened to it. You go along for so long, coping and adjusting that you just get used to it."

"I think we were very close before and in a sense that hasn't changed. But the ways of expressing closeness have changed because she needs more support and comfort which I give her through game playing and storytelling. So our relationship has changed greatly, but the attachment is still there. Of course, I have to be much more physically supportive too, helping her up and downstairs, into and out of the bath, changing her clothes etc. I try to maintain her dignity always, for example, by us both wearing an apron at meal times so she doesn't feel she is different. And then there's a parent child change in our relationship. But she remains very affectionate and trusting, which I am very grateful for."

"We have always been a very close couple. We are still close now, but there is a lack of communication. Sometimes it gets so lonely when I talk to him and get no response. I'm a very positive person and younger than him, so I try to have my own life away from him too, which helps. He was always an easy man, but sometimes now he can get a bit depressed or even aggressive. He was always such a gentle man. So we are still close, but it's not the same quality as it was before. My role has reversed. The role of lover has gone and now I am more in the role of being a nurse. It's like caring for a baby, a different type of attachment. It's been such a gradual thing."

Direct quotation from current caregivers in response to the open question, 'How has your relationship with your dependant changed since he/she has been ill?'

Statement Category	Statement	Number
Isolation and confinement (n=33)	Can't leave dependant alone/go out	14
	Caregiving has restricted life	5
	Feel trapped/like a prisoner	5
	Feel isolated/lonely	4
	Other	5
Psychological health impact (n=22)	Stress/stressed	6
	Lost confidence	3
	Suffer from depression	2
	Easily angered/irritated	2
	Other	9
Social life impact (n=21)	No longer have a social life	9
	Restricted social life	6
	Social life all but gone/practically non existent	2
	No personal or private time	2
	Other	2
Quality of life (n=20)	Have no quality of life	4
	Dementia/caregiving changes your whole life	3
	Quality of life has suffered	2
	Quality of life has improved	2
	Other	9
Grief and loss (n=18)	Changes in dependant distressing	4
	Distressing to know dementia is a progressive illness	3
	Devastated by dementia	2
	Future is uncertain and unpredictable	2
	Carer misses their dependant as they once were	2
	Other	5
Family life impact (n=18)	Little time left for family	4
	Caregiving has brought family closer together	3
	Family involved in/support caregiving	3
	Resulted in family conflict	3
	Relationship with family has suffered	2
	Other	3
Impact on friendships (n=14)	Have lost friends as a result of caregiving	4
	Contact with friends is restricted	4
	Friendships have suffered as a result of caregiving	2
	Friends supportive	2
	Other	2
Physical health impact (n=14)	Physical health has deteriorated as a result of caregiving	5
	Caregiving tiring/tired all the time	5
	Breathing affected/asthma	2
	Other	2
Satisfactions of caring (n=13)	Satisfied to know I have done everything I could	3
	Relationship with dependant still positive though changed	2
	Have learned much through caregiving experience	2
	Other	6
Motivations for caring (n=11)	Would be devastating to place dependant in care home	3
	Want to keep dependant out of care home/at home	3
	Other	5
Employment impact (n=9)	Have had to give up work to care	4
	Have had to reduce hours worked	2
	Work has suffered as a result of caregiving	2
	Other	1
Holidays (n=9)	Can't go on holiday/weekend breaks due to caregiving	6
	Other	3
Impact on marriage (n=9)	Caregiving has put pressure/stress on marriage	3
	Relationship with spouse (non dependant) has suffered	2
	Other	4
Financial impact (n=7)	Negative financial impact	4
	Reduced income/savings as a result of caregiving	2
	Other	1
Religious belief (n=6)	Belief in God	2
	Feel blessed by caregiving	2
	Caregiving as a mission/ministry	2

Table 5.40: Categorisation of emergent themes in response to the open question 'Please describe the impact that caregiving has had on your quality of life.'

"I fear that I am being sucked down a tunnel, that my immune system is suffering, that I am suddenly ageing far more rapidly. I experience fear, loss of confidence and depression in equal measure."

"The quality of my life has deteriorated in every way – physically, mentally, emotionally, socially, and to a lesser extent, financially. The future is uncertain. His condition is progressive. There's not much to look forward to as a couple."

"I have had to take over everything and learn to be strong and get on with life and being his carer. I've shed more tears this last year than I ever have in my whole life. Sometimes it takes me over and I get very tearful. We've been married 57 years after all. I seem to be able to manage the physical side of things. Thank God, I am strong. And I haven't had to consider putting him in a home yet, which I dread."

"Very bad. I never get out, you get to feel like a prisoner. I used to like going out, in the car, to tea dances together, shopping. But now I can't go anywhere unless he is in day care. I can't even leave him to go next door for a coffee. I'm totally trapped in the house with him. I feel very isolated. But this has brought us closer together as a family and we're there for each other now more than ever before."

"I think in the long run I will look back on this situation knowing I did everything I could; knowing tha I taught my children an important lesson about family, caring for each other and tolerance, and I hope that were I in the same shoes later in life, I would be treated with dignity and respect."

"My life stinks. But I have to say this. When my Mom dies, I'll know that I did what I could. That she stayed home and knew she was loved! THAT is really ALL that matters! ALL THAT MATTERS!!!!!!"

Direct quotation from current caregivers in response to the open question, 'Please describe the impact that caregiving has had on your quality of life.'

Statement Category	Statement	Number
Preventive action (n=102)	Reassure dependant everything alright	13
	Observe dependant to ensure safety	6
	Keep to a daily routine	5
	Talk through/explain caring procedure/actions	5
	Plan ahead	5
	Gentle persuasion/suggestion	5
	Try to predict/avoid problems	4
	Use calendar/notepad to remind/re-orientate	4
	Give dependant sleeping tablets	3
	Reinforce reality	3
	Read more on the illness/coping	3
	Try to keep things calm	2
	Treat dependant with respect	2
	Spoon-feed to prevent malnutrition	2
	Fitted new locks on doors to prevent wandering	2
	Can't leave dependant alone	2
	Harden/discipline self	2
	Stopped dependant smoking as too risky	2
	Try not to remind dependant of his/her memory loss	2
	Take dependant for walks to tire him/her	2
	Other	28
Strategies to enhance carer emotional well-being (n=69)	Talking to other carers about coping – at group/individually	9
	Reading novels/listening to music	8
	Prayer/faith	6
	Taking exercise	5
	Computer/internet/in chat rooms	4
	Alcohol/smoking	3
	Individual counselling	3
	Overeating	2
	Time for relaxation	2
	Time to self when dependant has gone to bed	2
	Relaxation techniques	2
	Other	23
Dealing with consequences when strategies not effective (n=57)	Try to be patient/patience	7
	Just get on with it	6
	Ignore behaviour	5
	Raise voice/shout to get through to him/her	4
	Try not to lose temper	3
	Answer repetitive questions	3
	Try to keep a sense of humour	3
	Try to rationalise/reason with dependant	3
	Give in to him/her	2
	Leave dependant wet/soiled if refuses care	2
	Adapt to situation	2
	Try to switch off	2
	Repeat instructions	2
	Pretend can't hear/turn a deaf ear	2
	Other	11
Reframing meaning of events/problems (n=36)	Remember it's not dependant's fault	6
	Accept symptoms as part of the illness	4
	Learned to let go/look at loved one beyond illness	3
	Remember dependant as they were before illness	2
	Don't take accusations personally	2
	Other	19
Direct action - Strategies to maintain dependant independence (n=29)	Prompt dependant/talk through procedure to retain skills	7
	Extra time for self-care/work at dependant's pace	5
	Supervision with self-care	4
	Coax dependant to self-care	2
	Show dependant what to do	2
	Put clothes out in right order	2
	Other	7
Direct action - Strategies to avoid conflict/distress (n=29)	Walk away/leave dependant alone when angry	5
	Avoid confrontation/conflict	5
	Change the subject	4
	Colluding with confusion	4
	Avoid causing distress	3
	Divert/distract if upset	3

	Other	5
Emotional and/or practical support of others (n=27)	Contact with/help of friends	11
	Help of neighbours	5
	Children/friends sit with dependant	3
	Talk with spouse	3
	Talk to doctor	3
	Other	2
Direct action - Strategies to enhance dependant emotional well-being (n=26)	Engage dependant in reminiscence/recall	5
	Comfort dependant when he/she becomes upset/cries	4
	Try to foster dependant's interest in something	4
	Sit with dependant until he/she relaxes	3
	Other	10
Breaks from caregiving (n=15)	Pay carers to have regular breaks	5
	Taking time off	5
	Going to paid work viewed as a break from caregiving	4
	Other	1
Direct action - Strategies to enhance dependant physical well-being (n=13)	Have to be forceful/fight to get dependant washed/dressed	4
	Try to make dependant as comfortable as possible	3
	Toilet regularly to keep continent	2
	Other	4
Direct action - Strategies to enhance dependant communication (n=12)	Increased physical/tactile contact	3
	Use non-verbal communication to back up speech	3
	Maintain eye contact	2
	Other	4
General comments about coping (n=10)	Not coping with aspects of caregiving	8
	No coping strategy	4
	Gradually learned/learning to cope over time	3
	Have learned to cope through trial and error	2
	If something works adopt it as a new coping strategy	2
	Other	3

Table 5.43: Categorisation of emergent themes in response to the open question 'What strategies/approaches do you use to cope with/manage these most stressful/difficult problems?'

"I use a blackboard for the things he has to remember. I use a pin board in the kitchen to put all his appointments on. My son has typed us some reminders on his computer which I use so that he will not forget to take his keys out with him, close the door tightly etc. I also write things down on a pad, little notes about where I am, the day and date and so on. If something works from experience then I follow that as a new coping skill."

"The car, I try to avoid. The bathroom, I try to be quick. The reasoning, I don't even try anymore. The fear of her going out, I sleep on the couch and have fitted dead locks on all the doors. I have a sitter while I work. Getting on my meds for depression was a biggy! And I try to keep a sense of humour, try being the operative word! And I type away madly to people like you."

"There's no choice in this situation, you have to cope to survive. Some days you do better than others. Some days you just want to pull the covers up over your head and hide."

"Hug her when she is sad and help her vocalise her feelings. Find the things she has lost. I do the best I can and talk to her about the things we have done/places we have gone. I try to help her reminisce by taking her places she will remember."

"Read more on the illness and coping strategies. Join support groups to ventilate my frustrations, share our woes and amusing stories, and know that we are not alone. The mild stage is still endurable, but I am preparing myself for what is ahead."

"I have begun a stress management/meditation class and have learnt some self-control and a little patience. Thank heavens for music and books. The only way I have avoided insanity is by seeking support for myself through family, friends and organisations."

Direct quotation from current caregivers in response to the open question 'What strategies/approaches do you use to cope with/manage these most stressful/difficult problems?'

Statement Category	Statement	Number
Service providers (n=37)	Health and Social Services need to work together better	6
	No dementia services available	4
	Need increased availability of dementia services	3
	Need easier access to services	3
	Services need to be more affordable	3
	Services need to be better coordinated	2
	Need better quality in care homes sector	2
	Hard to get an initial assessment for services	2
	Need more flexibility in services	2
	Charging policy unfair	2
	Other	8
Community Psychiatric Nurse (n=31)	CPN arranges changes to services/increased support	6
	Can talk to CPN about practical/emotional problems	5
	CPN provides ongoing counselling support	4
	CPN provides advice/support re ways of coping/managing	3
	CPN has knowledge/provides information on dementia	3
	CPN advises on medication management	2
	Couldn't cope without help of CPN	2
	CPN provides support in a crisis	2
	Other	4
Carers Support Group (n=28)	Good for sharing ideas re ways of coping/managing	6
	Good place to share/ventilate feelings	4
	Good to meet others in similar situations	3
	Separate dependants' group helpful re safety/activity	3
	Can talk freely without fear of being judged	2
	Good to have companionship of other carers	2
	Provides mutual support	2
	CSG extremely helpful	2
	Other	4
Home Care/sitting services (n=27)	Need access to a night/day sitting service	6
	Home Carer pleasant and talks with dependant	3
	Feel dependant is safe with Home Carer	2
	Home Care provides some freedom	2
	Home Carer is calm and patient	2
	Home Care agency unreliable – on occasion not turned up	2
	Poor consistency in Home Carers provided	2
	Home Carer relieves carer of difficult caregiving tasks	2
	Need for dementia training for Home Care staff	2
	Other	4
Day Care/Hospital (n=23)	Day care provides some freedom/personal time	5
	Day service provides excellent care	3
	Dependant refuses to go to day care	2
	Day care under threat due to dependant behaviour/frailty	2
	Problem getting dependant to day care, but once there okay	2
	Don't know how would cope without day care	2
	Day care relieves some of my stress	2
	Need separate day services for younger people with dementia	2
	Other	3
Telephone Helpline (n=16)	Provision of information re dementia and services	3
	Need access to a telephone helpline service	3
	Improved my knowledge and understanding	2
	Helps identify problems and solutions	2
	Helped to access diagnosis and anti-dementia drugs	2
	Other	4
Respite Care (n=13)	Feel respite care has helped me cope/care for longer	6
	Need more respite care	3
	Planned respite gives a chance for a family break	2
	Other	2
Satisfaction with services (n=12)	Support available excellent	5
	Very satisfied with services	4
	Services help me continue working	3
Caregiver Training (n=9)	Would benefit from training in dementia care	4
	Need training in managing challenging behaviour	3
	Need training in activities and stimulation	2

Table 5.52: Categorisation of emergent themes in response to the open questions 'In what ways have formal support services been helpful or unhelpful?' and 'How do you feel formal support services could improve their support to you and your dependant?'.

"If you ask hard enough and long enough eventually something happens."

"I don't know how I would manage without the support I get from the day hospital or the respite care that I have. I know he is safe when he is there and this allows me to rest and do things like shopping and cleaning that I can't do when he is at home."

"The Carers Group has helped by enabling contact with other carers and has been a good place to share experiences and ideas on ways of coping/managing problems. It has been very helpful to be able to talk freely and share your emotions with others who understand."

"My CPN has been no end of help to me. She has been a rock. I couldn't have coped without her help. I couldn't have gone on much longer without regular respite care either, that helps keep me going, looking forward to my next break and planning what I am going to do with the time off."

"Crossroads have been wonderful in providing dignified and respectful care that keeps mum happy and contented. They have allowed me to continue working for sure."

"I would like him to go to the day hospital again, but this was stopped because he was so disturbed, wandering and kicking the door to get out. I had to cope with him at home on my own instead!"

"It would be really good if more funding could be found for Dementia Careline and organisations like this across the UK, so that a higher level of service could be provided. They're so kind yet so professional. I've been very impressed by the service. It has been a daily lifeline to me."

"For services to EXIST, for one thing! For them to be affordable, consistent, dependable, caring, accessible and prepared."

Direct quotation from current caregivers in response to the open questions, questions 'In what ways have formal support services been helpful or unhelpful?' and 'How do you feel formal support services could improve their support to you and your dependant?'.

Statement Category	Statement	Number
Caregiving satisfactions (n=49)	Dependant still happy sometimes	9
	Condition stable/dependant still alive due to care provided	6
	Have learned skills through caring	4
	Feel I am doing something positive/worthwhile	3
	Learned patience/understanding	3
	Dependant grateful to carer	3
	Feel closer now to dependant	2
	Do a good job	2
	Satisfied with the standard of care I give	2
	Rewarding when others say carer is coping well	2
	Dependant still recognises carer	2
	Other	11
Maintain at home/keep out of a care home (n=46)	Desire to keep dependant out of a care home	14
	Desire to keep dependant in own home	13
	Provide better care than hospital/care home	5
	Know where dependant is and safe/protected	4
	Dependant happier with carer	3
	Poor standards of care in care homes	3
	Previously deteriorated when in hospital/care home	2
	Money/financial benefit to keeping at home/out of care	2
Love and affection (n=39)	Love/affection as the main motivation to care	21
	She/he is my ...	9
	Remember love dependant gave	3
	Love is reciprocated by dependant	2
	Feel compassion towards dependant	2
	Other	2
Caregiving motivations (n=29)	Know I am doing the right thing	6
	To maintain dependant's quality of life	6
	Doing my best for dependant	4
	Preserve dignity of dependant	3
	Dependant needs me	3
	Want the best for dependant	2
	Being there for dependant	2
	Other	1
Commitment to care (n=28)	Want to care for ...	9
	Repaying/giving back love/care	7
	If situation were reversed dependant would provide care	3
	Provide one to one/individualised care	3
	My turn to care for ...	2
	Care about dependant	2
	Other	2
Duty and obligation (n=23)	It is my duty/obligation	11
	Promises made earlier in life	3
	No way I could desert/abandon dependant	2
	Marriage vows cited	2
	Sense of responsibility	2
	Other	3
Future (n=20)	Considering relinquishment of home caregiving/placement	15
	Want to carry on/continue caregiving	3
	Other	2
Faith (n=15)	Faith/belief in God as a motivation to care	8
	Aspects of care a blessing	3
	Prayer helps carer to care	2
	Religious imperative to care	2
Lack of choices (n=12)	No other option/no choice	6
	As an only child have to care	2
	No-one else to care	2
	Other	2
Support enabled continued caregiving (n=11)	Community care services have enabled continued caregiving	4
	I am not alone	3
	Family support has enabled continued caregiving	2
	Support of friends has enabled continued caregiving	2
Lack of satisfactions (n=4)	No reward/satisfaction	2
	No positive aspects	2

Table 5.53: Categorisation of emergent themes in response to the open questions 'What are the main satisfactions that you can identify within your caring situation?' and 'What are your main motivations/reasons for continuing in the caring role?'

"I can't think of any positive sides to this terrible disease at all. I would far rather have him back as he was before."

"The fact that I love my wife. It's simple."

"Well, I think that apart from it being a duty, should the situation be reversed I know that she would do now what I am doing for her."

"Well, money I suppose. To pay out for a nursing home would be at least £300 a week and I cost nothing. And I don't think he would be happy in a hospital or care home."

"Mom still recognises me and appreciates my attention. She's always at the door when I get back from work. A great welcome home each evening."

"That according to my GP and our district nurse we are thought to be looking after him extremely well. And my father telling me how grateful he is for everything I have done for him."

"My wife and I can take some pride in knowing that we are doing what we feel that God would have us do. We are caring for a family member instead of placing her in a nursing home, where in all likelihood she would have passed away a long time ago."

"This is my mother we are caring for. She stood by me all my life and helped me live as normal a life as possible despite a severe congenital defect. Could I do less for her? Plus I believe there is a Godly mandate for an adult child to care for a parent if at all possible."

"The good days, the laughter, helping her feel better, soothing her. Having her know that if she needs me I will be here. Knowing that despite the isolated aspects of her calm and happy moments, somewhere an overall sense of well-being and safety is reaching her."

"I love my grandfather immensely and want him to have the best care he can get, but also to allow him to stay in the most comfortable environment he knows. This man has been there for me every step of my life and afforded me opportunities that I would never have gotten anywhere else. I feel that I owe him the same."

"Knowing that I have done what I could for her for as long as possible, but that I have also reached my capability limits. I am now looking for a care home for her."

"Years of hearing 'don't ever put me in a nursing home', and knowing how awful most extended care facilities are. Many abuses have recently been documented here in ...."

"Having no other choice at the time. And knowing that at some point it will come to an end."

Direct quotation from current caregivers in response to the open questions, questions 'What are the main gains/satisfactions that you can identify within your caring situation?' and 'What are your main motivations/reasons for continuing in the caring role?'

Appendix 5

THE RARER DEMENTIAS

Huntington's disease

Huntington's disease is a hereditary degenerative neurological disorder which usually develops in adulthood, with symptoms occurring between the ages of 30 and 50, although late onset and juvenile manifestations are seen. The illness affects both sexes equally. Prognosis for life expectancy is usually between 15-20 years from the onset of symptoms (Stanley, 2000).

The illness is caused by a faulty gene on chromosome 4. The gene, which produces a protein called Huntingtin, was discovered in 1993. In some way, not yet fully understood, the faulty gene leads to damage of neurones in the basal ganglia and cerebral cortex of the brain (Huntington's Disease Association, 2000). This leads to gradual physical, mental and emotional changes, including fidgetiness, which progresses to the choreaform movements synonymous with the illness; alterations in behaviour, typically with delusions and personality change; declining reasoning and problem-solving abilities, and a progressive loss of memory. Communication becomes increasingly difficult as motor symptoms become more advanced, as does swallowing. Depression (and suicide) is not uncommon (Bayer and Reban, 1996).

Each person whose parent has Huntington's disease is born with a 50-50 chance of inheriting the autosomal dominant faulty gene. Anyone who inherits the faulty gene will, at some stage, develop the disease. A genetic test is now available from regional genetic clinics throughout the country. This test will usually be able to show whether someone has inherited the faulty gene presymptomatically, but it will not indicate the age at which they will develop the disease. Prenatal testing is also now available, meaning that an unborn child can be tested to see if they carry the gene and selectively aborted, which brings many ethical and psycho-social challenges for affected families.

Down's syndrome and Alzheimer's disease

The connection between Down's syndrome and premature ageing dates back to 1876 when it was first reported that a 'mongol' had died from a sort of 'precipitated senility' (Fraser and Mitchell, 1876). It was not until 1948, however, that premature ageing in Down's syndrome was directly linked to Alzheimer's disease (Jervis, 1948).

Research has established a link between Alzheimer's disease and chromosome 21. As people with Down's syndrome have an extra chromosome 21, this may explain their vulnerability to developing Alzheimer's disease (Wischik, 1989). Apparently, all people over the age of 40 with Down's syndrome develop the typical neuropathology of plaques and tangles that is associated with Alzheimer's disease, but only a proportion of them will develop the behavioural changes associated with dementia. A British study found that up to 45% of people over the age of 45 with Down's syndrome suffered with Alzheimer's disease (Lai and Williams, 1989). Another study in Leicestershire (Collacott, Cooper and McGrother, 1992) found that the average age of onset was 54 years old.

Apart from having to cope with the gradual loss of self-care skills, increasing disorientation, communication impairments and onset of behaviour problems associated with Alzheimer's disease, perhaps one of the biggest challenges that people with this dual dignosis and their carers is a lack of specialist services. Longstanding care workers are often ill equipped to deal with the additional needs that are manifested and breakdown in community placements often result, with many people with Down's plus Alzheimer's being inappropriately placed in older persons' care homes/hospital units. As more people with Down's syndrome are living longer and prevalence of Alzheimer's disease in this group increases, the need for specialist services will become greater.

Alcohol related dementia

Korsakoff's syndrome is the most common form of alcohol related brain injury and, unlike other dementias, there is an understood route to degeneration. Before permanent damage results, Wernicke's episodes occur. These are acute phases characterised by extreme confusion, difficulties with gait (ataxia), and involuntary jerky eye movements (nystagmus). These are extremely serious and can lead to Korsakoff's syndrome (and sometimes death) if not immediately treated by intravenous vitamins (Pabrinex) (Elleswei, 2000).

Korsakoff's syndrome is caused by a lack of thiamine (Vitamin B1). Many chronic alcohol users have poor diets and become malnourished. Alcohol also erodes the lining of the stomach, limiting the body's ability to absorb the limited vitamins that are taken. Korsakoff's syndrome occurs if Wernicke's encephalopathy is untreated or treated too late. Damage occurs in important small areas in the mid part of the brain, resulting in profound memory loss, especially for events after onset; difficulty in acquiring new information or learning new skills; lack of insight into the condition; confabulation to fill in gaps in memory; and apathy _or_ talkativeness; and repetition. Language and life skills may be well preserved, thus clients may be self-caring with support (Alzheimer's Society, 2001). About 60% of people with Korsakoff's syndrome also have damage in the frontal lobes of the brain, causing problems with speed of thought, attention and concentration, poor planning and sequencing of tasks and behavioural changes, e.g. impulsiveness, disinhibition, agitation and recklessness.

Alcohol can also cause diffuse damage to the brain, which is termed alcohol related dementia. Additional symptoms to those above are severe disorientation, marked personality change and loss of ability to control motor action. Alcohol related brain injury is mostly non-progressive. Once drinking stops, damage stops. With good nutrition the person's condition may improve significantly over 12-24 months, though once brain cells have been destroyed they cannot be replaced. Often, other body systems may also have been damaged, with stomach, liver and pancreatic disease being commonplace.

Harvey (1998) claims that 12.5% of all young onset dementia is alcohol related, meaning that there are more than 2000 people below the age of 65 with alcohol related dementia in the UK. However, a far higher figure may be affected as this group is often excluded from health services and is less likely to seek treatment. 50% of all long-term heavy drinkers over the age of 45 have evidence of brain damage. 8-10 units per day (4-5 pints or 8-10 glasses of wine) for 15 years is sufficient to cause significant brain damage (Elleswei, 2000).

Creutzfeldt Jakob disease

Creutzfeldt Jakob disease was first reported by two German doctors, Creutzfeldt and Jakob, in 1920. It is caused by prions, abnormal proteins that cannot be destroyed by normal sterilisation procedures, which have the ability to mutate, causing the death of brain cells. Their presence in the brain causes spongiform encephalopathy (sponge like tissue seen under microscope). There are 4 main types of CJD: Sporadic CJD, which has an unknown cause, a rapid progression, with the course of the illness usually measured in months, and affecting people mostly in their 50s; Familial CJD, which is the inherited form with an earlier age of onset and a longer life expectancy than Sporadic CJD; Iatrogenic CJD, which results from contamination from an infected person, usually through a medical procedure, e.g. corneal graft or use of growth hormone, or the use of contaminated neurosurgical instruments (this form is now limited by the availability of synthetic growth hormone and safer surgical procedures); and New Variant CJD, caused by ingesting meat infected with BSE found in cattle. vCJD affects younger people than other forms, with an average age of death at 29, but one case reported in a 74 year old man. As of April 2001 there were 97 cases – in 1995 the first 2 cases were reported, in 1996 there were 10 cases, in January 2000 there were 52 cases (Alzheimer's Society, 2001).

Symptoms of CJD include early lapses of memory, mood changes and loss of interest. Within weeks the person complains of feeling muddled, unsteady in walking and has slow or slurred speech. This progresses to more severe symptoms including jerky movements, shakiness, stiffness of limbs, incontinence and loss of ability to speak. Full nursing care is needed by this stage and the person has no awareness of their surroundings. People affected by CJD usually die within 6 months, often from pneumonia. In a minority of patients life expectancy is up to two years. There are at present no treatments for this condition, other than drugs aimed at minimising symptoms and promoting comfort (Alzheimer's Society, 2000).

Other rarer dementias

There are a number of other rarer dementias that will not be covered in great detail in this chapter, as these in themselves could form the basis of another detailed thesis. Information sourced from Holden (2000) and Bayer and Reban (1996).

Dementia in Parkinson's disease: About 15-20% of people with Parkinson's disease will develop dementia. Patients who become demented are usually older at onset of Parkinsonian symptoms, have greater bradykinesia and gait disturbance, a more rapid downhill course and an unpredictable response to levodopa. Symptoms are similar to Alzheimer's, but language and praxis may be less disturbed. Treatment is especially difficult as anti-Parkinsonian drugs may worsen confusion and cause visual hallucinations. Neuroleptic drugs which would usually be administered to lessen such psychotic symptoms will also worsen extrapyramidal signs. Thus the condition is difficult to manage and distressing for patients and their families.

Progressive Supranuclear Palsy: This is a sub-cortical and mid brain disorder associated with Parkinson's disease. Steele Richardson Olsewski syndrome, described in 1964, is the best defined. Symptoms are as in dementia in Parkinson's disease, plus rigidity of neck and trunk, mask-like face, paralysis of vertical eye movements, unsteadiness and falls, dysarthria, drooling and dysphagia, forgetfulness and personality change, but language skills may be preserved.

Wilson's disease: This is an inherited abnormality in the metabolism of copper, described in 1912, resulting in accumulation of it in the brain and other organs. 'Kayser-Fleischer' rings are seen in the eyes (green, yellow or brown deposits). The condition can be reversed with life-long treatment. Physical signs include rigidity, tremor, loss of coordination, dysarthria, dysphagia and drooling. Particular neuropsychological signs include problems in abstract thought and concept formation.

Binswanger's disease: A sub-cortical vascular disorder named after the man who first described it in 1894, also known as Sub-cortical Arteriosclerotic Encephalopathy. This illness is characterised by motor problems – asymmetrical weakness with pyramidal signs (spasticity, tremor and increased sudden reflexes), confusion, gait disturbance, dysarthria, slowed thinking and action, poor judgement, apathy, and perseveration (repetitive speech and behaviour).

Sub-cortical Vascular dementia: Usually seen in older people. Similar to Vascular dementia, but here strokes occur deeper within the brain and brain stem. Also known as Lacunar States, this disorder is characterised by smooth wall cavities in sub-cortical brain tissue where ischaemic damage has occurred. Pseudo-bulbar Palsy is one Lacunar State, consisting of impaired facial movement, dysarthria, dysphagia, upper motor problems, possibly hemiparesis, and short step gait. The person may remain sensible and capable, depending on the actual site and number of the lesion/s.

AIDS related dementia: AIDS related dementia is caused directly by the HIV virus actively infecting brain cells as a late complication of AIDS (HIV-infected macrophages in the brain). Symptoms may be similar to clinical depression in the early stages, with cognitive and motor problems, mutism, paralysis and incontinence in the later stages. Damage occurs in the thalamic and basal ganglia areas of the brain. Treatment is by anti-HIV drugs that cross the blood/brain barrier.

Normal Pressure Hydrocephalus: This is characterised by ventricular enlargement with normal or slightly raised CSF pressure. It is diagnosed by CT scan and sometimes develops secondary to previous brain pathology, e.g. meningitis, head injury, subarrachnoid haemorrhage. There is a triad of features – dementia, gait disturbance, and urinary incontinence. Surgical intervention with a shunt is indicated and symptoms are largely reversible.

Primary Progressive Aphasia: This presents with slowly progressive dysphasia but otherwise intact cognition. It is caused by left frontal lobe atrophy. After several years a more generalised dementia develops.

Multiple Sclerosis: Mild and slow cognitive impairment often occurs in MS, but rarely it can lead to dementia. People with the chronic progressive form of MS show more deterioration than those with the remitting-relapsing form.

Motor Neurone Disease: Rarely MND is associated with a severe and rapidly progressing frontal lobe type dementia, but normally cognitive function is unaffected and physical features predominate.

Dementia Pugilistica: This is suffered by boxers 30-40 years after the end of their career. The risk of developing the condition is as high as 80-90%, depending on the number of fights and knock-outs. Poor memory, slowness of thought, difficulty in speech, and unsteadiness are features followed by progressive cognitive impairment. Cortical atrophy and neurofibrillary tangles are present but plaques and Lewy bodies are absent.

Appendix 6

CURRENT AND PAST CAREGIVERS QUESTIONNAIRE

Current Caregivers Questionnaire

- This questionnaire is designed to be completed by people who act as the main carer for a person with dementia and live with their dependent for all or some of the time, i.e. those still caring in the community.
- The only criteria for participation in the study is that your dependent has been diagnosed with dementia for more than one year.
- Please fill the 4 parts of the questionnaire in separately and e-mail them each in turn. Once you have submitted each section a 'Confirmation Form' will appear. Press the 'Go Back' button to the previous page and you will be taken back to the questionnaire at the place at which you left it.
- Please give your e-mail address in each section so that I can check all sections have been received and there are no duplicates.
- Please note that you can switch off and fill each section of the questionnaire in off-line. If you wish, you can also complete each section of the questionnaire in at different times, when you have some spare time.
- Please also note that whilst it is desirable for the whole questionnaire to be completed, if you are uncomfortable answering certain questions it is fine for you to not complete them.
- Sorry if this is complicated, but thank you for your co-operation.

Part 1: Caregiving Situation Details

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. Where do you live?	☐ England ☐ Scotland ☐ Wales ☐ Northern Ireland ☐ Other (please specify)
2. Who do you care for?	☐ Wife
	☐ Husband
	☐ Father/father in-law
	☐ Mother/mother in-law
	☐ Nephew / Niece
	☐ Sister/Brother
	☐ Grandparent/grandparent in-law
	☐ Other Please specify relationship if it falls outside range
3. What is your gender?	☐ Male ☐ Female
4. What is your dependant's gender?	☐ Male ☐ Female

5. What is your age?	☐ < 50
	☐ 51 - 60
	☐ 61 - 70
	☐ 71 - 80
	☐ 81 - 90
	☐ > 90 Please specify age if below 50 or above 90 ☐
6. What is your dependant's age?	☐ < 50
	☐ 51 - 60
	☐ 61 - 70
	☐ 71 - 80
	☐ 81 - 90
	☐ > 90 Please specify age if below 50 or above 90 ☐
7. What is your dependant's diagnosis?	☐ Alzheimer's disease
	☐ Vascular (multi-infarct) dementia
	☐ Mixed AD/VD
	☐ Pick's (Frontal Lobe) dementia
	☐ Lewy body dementia
	☐ Huntington's dementia
	☐ Parkinson's dementia
	☐ Creutfeldz-Jakob disease
	☐ Other Please specify dementia if it falls outside range ☐
8. When was your dependant diagnosed?	☐ < 1 year ago
	☐ 13 months - 2 years ago
	☐ 25 months - 3 years ago
	☐ 37 months - 4 years ago
	☐ 49 months - 5 years ago

	☐ 61 months - 6 years ago
	☐ > 6 years ago
9. How many months/years before the diagnosis did your dependant have memory problems?	☐ < 1 year
	☐ 13 months - 2 years
	☐ 25 months - 3 years
	☐ 37 months - 4 years
	☐ 49 months - 5 years
	☐ 61 months - 6 years
	☐ > 6 years
10. Who gave the diagnosis?	☐ Neurologist
	☐ Psychiatrist
	☐ Old Age Psychiatrist
	☐ Memory Clinic
	☐ GP/Ordinary Doctor
	☐ Not sure
	☐ Other Please specify
11. How would you assess the degree of your dependant's dementia?	☐ Minimal
	☐ Mild
	☐ Moderate
	☐ Severe
	☐ Very severe
12. What additional illnesses/diseases does your dependant suffer with?	☐ Stroke
	☐ Heart Condition
	☐ Cancer
	☐ Other Please specify
13. What is it like to care for a person with dementia?	
14. What is the geographical distance in your caring relationship?	☐ Living With: (Same house)

	☐ Living Nearby: (Less than 15 mins. away)
	☐ Living Locally: (16 mins. to 1 hour away)
	☐ Living Long Distance: (1 hour + away)
15. What problems does this cause you?	
16. How many hours a day/week do you spend in direct hands-on care-giving (including time spent in supervision)?	☐ Up to 20 hours per week
	☐ 21 - 40 hours per week
	☐ 41 - 60 hours per week
	☐ 61-84 hours per week (8.5 - 12 hours per day)
	☐ more than 85 hours per week (13 hours + a day)
17. What impact does this have on your life?	
18. What is your occupational status?	☐ In Full-time work
	☐ In Part-time work
	☐ Unemployed
	☐ Given Up Work to Care
	☐ Retired
	☐ Never Worked/Housewife
19. Do you provide care for anyone else, eg. young children/other elders?	☐ Yes ☐ No If 'yes', please list them
20. How is your current physical/emotional health?	☐ I have a disability
	☐ I am generally frail or infirm
	☐ I have a diagnosed non life threatening illness or disease
	☐ I have a diagnosed life threatening illness or disease
	☐ I am being treated for clinical depression
	☐ I am generally in good health
	☐ Other

	Please specify
21. What medications are you currently taking?	Please list:
22. What was the quality of your relationship with your dependant like before the onset of their illness, and what is it like now?	
Previously (one year before illness onset):	*Now:*
☐ Extremely close	☐ Extremely close
☐ Very close	☐ Very close
☐ Reasonably close	☐ Reasonably close
☐ Not very close	☐ Not very close
☐ Distant	☐ Distant
23. How has your relationship with your dependant changed since he/she has been ill?	
24. What do you think are your main strengths as a carer?	
25. What do you think are your main weaknesses as a carer?	
26. What effect do you think your caring has on your dependant's emotional well-being?	☐ Very positive effect
	☐ Positive effect
	☐ It varies
	☐ No real effect
	☐ Negative effect
	☐ Very negative effect
	Please give reasons for this answer:
27. What effect do you think your caring has on your dependant's physical well-being?	☐ Very positive effect
	☐ Positive effect
	☐ It varies
	☐ No real effect
	☐ Negative effect

	☐ Very negative effect
	Please give reasons for this answer:
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 2: Caregiving Problems Analysis

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. Which of the following 'Communication Problems' does your dependant have?	
Is your dependant able to start and maintain a sensible conversation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to understand what is said to him/her?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to respond sensibly when spoken to?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant repeat things over and over again?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant talk all the time?	☐ Never
	☐ Rarely

	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant talk nonsense which you can't understand?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant have periods when he/she doesn't speak much at all?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to read newspapers, magazines, etc., or watch and follow TV?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to take part in family conversations?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant talk aloud to him/herself?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
2. Which of the following 'Confusion Problems' does your dependant have?	
Does your dependant get mixed up about where he/she is?	☐ Never

	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant get mixed up about the day, date, year?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to recognise familiar people, e.g. family and friends?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to recognise you and know who you are?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant get mixed up about the time of day/night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant able to hold his/her attention for more than a few minutes?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant seem lost in a world of his/her own?	☐ Never

	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant try to get up and dressed/go outdoors during the night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant get lost and can't find his/her way home when outside of the house/do you have to keep them indoors?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant see or hear things which aren't really there?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
3. Which of the following 'Behaviour Problems' does your dependant have?	
Does your dependant wander indoors or outdoors?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant tend to collect things and hoard them?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently

	☐ Always
Does your dependant become angry and resistive to care?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant endanger him/herself by engaging in risky behaviours?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant falsely accuse people/you of things?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant become irritable and get easily upset?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant shout/swear/scream at people/you for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant hit out at you/other people for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently

	☐ Always
Does your dependant display inappropriate sexual activity/ demands?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant wake you/others during the night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
4. Which of the following 'Mood Problems' does your dependant have?	
Does your dependant show an interest in doing things?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant appear to be restless and agitated?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant pace up and down in a worried or troubled way?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant cry/become tearful for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
Does your dependant appear to be unhappy and depressed?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant have difficulty settling to sleep or wake unusually early in the morning?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant's mood change suddenly for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant isolate him/herself and avoid social contact?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant never leave your side/shadow you?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant look frightened and anxious?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
5. Which of the following 'Physical/Self-care Problems' does your dependant have?	
Does your dependant have problems in standing/walking - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant have difficulty washing/bathing - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant have difficulty dressing/undressing - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant incontinent of urine during the night (may wear pads)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant incontinent of urine during the day (may wear pads)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant incontinent of faeces (day or night)?	☐ Never
	☐ Rarely

	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant have problems feeding him/herself/swallowing - need assistance/special diet?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant partly/completely immobile and needs lifting?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Is your dependant prone to having falls/fits/choking attacks?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Does your dependant suffer with pain/need analgesic medication?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
6. What additional problems does your dependant have which are not covered above?	
7. What medication is your dependant currently taking?	Please list:
8. Thinking of all the problems above, which are the most stressful/ difficult to cope with, and why. i.e. what impact do they have on	1.

you?	2. 3. 4. 5.
9. What strategies/approaches do you use to cope with/manage these 5 most sressful/difficult problems?	
10. Apart from the direct caregiving problems experienced, what would you say are the most distressing aspects of caring for a person with dementia?	
11. How do you cope with these most distressing aspects of caring?	
12. Thinking about the stresses and practicalities of caring, what is the overall impact of caregiving on your emotional and physical well-being?	
Emotional well-being:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
Physical well-being:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
13. Thinking about the stresses and practicalities of caring, what is the overall impact of caregiving on your personal relationships/ family life and social/work life?	
Personal relationships/family life:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact

	☐ Negative impact
	☐ Very negative impact
Social/work life:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
14. What would you say was the impact of care-giving on your overall quality of life?	☐ Extremely positive impact
	☐ Very Positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
	☐ Extremely negative impact
15. Please describe the impact that caregiving has had on your quality of life:	
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 3: Caregiver Stress & Burden Questionnaire

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. Do you feel that you need a holiday (a long-term break from caring)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
2. Do you worry about safely leaving your dependant on his or her own?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently

	☐ Always
3. Do you find it difficult to get away for a break for a few hours?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
4. How much has your social life been affected by caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
5. Is your sleep disrupted by your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
6. Do you have family arguements/difficulties associated with your present situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
7. Have your financial circumstances changed or your standard of living been reduced as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
8. Do you have difficulty in continuing your relationships, eg. having visitors or meeting friends, due to your caring commitments?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
9. Do you find that your caring responsibilities adversely affect other aspects of your life, eg. your role as a parent/ grandparent, your employment/ other commitments?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
10. Do you have to undertake caregiving tasks that you feel are beyond your capabilities?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
11. Has your own physical health suffered as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
12. Do you feel there will be no end to your problems?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
13. Do you feel you can no longer cope with your situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
14. Do you feel overwhelmed by your situation?	☐ Never

	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
15. Do you feel trapped in the caring role?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
16. Do you feel that you are alone in coping with your caring situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
17. Do you find it distressing that your dependant has changed so much from his or her former self?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
18. Do you have feelings of grief and loss associated with your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
19. Do you find yourself becoming tearful or crying?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always

20. Do you feel exhausted and demoralised in your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
21. Are you depressed about your situation?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
22. Do you feel like giving up caring?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
23. Do you feel embarrassed by your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
24. Do you feel frustrated with your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
25. Do you get cross and angry with your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always

26. Are you resentful about the change in the quality of your own life/missed life opportunities?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
27. Are you emotionally distant from your dependant?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
28. Do you view caring for your dependant as being like caring for a child?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
29. Do you have feelings of guilt associated with your caring role?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
30. Do you feel helpless and as if things are outside of your control in your situation?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
31. Do you have a sense of achievement or fulfilment as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot

	☐ Considerably
32. Do you have a sense of purpose and direction in your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
33. Do you derive personal satisfaction and reward from your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
34. Do you have feelings of positive self-worth/self-esteem arising from caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
35. Do you feel that being a carer has provided an opportunity for personal growth and development?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
36. Do you feel that caring is a positive way of expressing your love and affection for the person you care for?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
37. Do you feel that you adopt a positive, problem-solving approach to caring?	☐ Not at all
	☐ A little

	☐ Moderately
	☐ Quite a lot
	☐ Considerably
38. Do you feel that you manage your stress well and overcome it?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
39. Do you feel the help you receive from services, family and friends has enabled you to carry on in the caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
40. Are you feeling hopeful about your future?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
41. Reflecting on your overall caregiving situation, all in all would you say you are:	☐ 0 - Coping well / with no stress
	☐ 1 - Coping fairly well / with a small amount of stress
	☐ 2 - Just about coping / with a moderate level of stress
	☐ 3 - Having difficulty coping / with a great deal of stress
	☐ 4 - Finding it almost impossible to cope / with an extremely high level of stress
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 4: Exploration of Available Resources

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. How do you feel you could be helped to better cope with your situation?	
2. How do you feel your stress could be relieved?	
3. What formal support services do you receive? (Statutory, Voluntary & Private)	☐ No Formal Support Services Received ☐ Case Manager (Overall Community Care Co-ordinator, e.g. Community Psychiatric Nurse, Social Worker) ☐ Home Care Worker/s (practical assistance) ☐ Home Sitter/s ☐ Day Centre/Day Hospital ☐ Respite Care (Long-term breaks) ☐ Carers' Support Group ☐ Telephone Helpline ☐ Other Please specify
4. How often do you receive the above formal supports?	
Case Manager	☐ Fortnightly ☐ Monthly ☐ Bi-monthly ☐ Infrequently
Home Care Worker (practical assistance)	☐ Twice Daily ☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly
Home Sitter	☐ Twice Daily ☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly

Day Centre/Day Hospital	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly
Respite Care (Long-term breaks)	☐ Fortnightly ☐ Monthly ☐ Bi-monthly ☐ Infrequently
Carers' Support Group	☐ Fortnightly ☐ Monthly ☐ Bi-monthly ☐ Infrequently
Telephone Helpline	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnighly ☐ Monthly ☐ Bi-Monthly ☐ Infrequently
Other	Please specify frequency of use:
5. What informal supports do you receive? (Family, Neighbours, Friends, Church, etc.)	☐ No informal supports received ☐ Close family support received ☐ Distant family support received ☐ Neighbours support received ☐ Friends support received ☐ Other support received Please specify
6. How often do you receive support from the above informal supporters?	
Family support received	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly

	☐ Monthly ☐ Bi-Monthly ☐ Infrequently
Neighbours/friends support received	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly ☐ Bi-Monthly ☐ Infrequently
Other support received	Please specify frequency of use:
7. What is your view on the quality of support/s you receive?	
Formal support services	☐ Extremely Helpful ☐ Very Helpful ☐ Helpful ☐ Unhelpful ☐ Very Unhelpful ☐ Extremely Unhelpful
Informal supporters	☐ Extremely Helpful ☐ Very Helpful ☐ Helpful ☐ Unhelpful ☐ Very Unhelpful ☐ Extremely Unhelpful
8. In what ways have formal support services and informal supporters been helpful or unhelpful?	
Formal support services	
Informal supporters	
9. How do you feel formal support services could improve their support to you and your dependant?	
10. What are the main gains/satisfactions that you can identify within your caring situation?	

11. What are your main motivations/reasons for continuing in the caring role?	
12. What helps you to keep going/carry on in the caring role?	
13. How do you expect things to go in the future? What outcomes would you expect within a year from now?	
14. How are you feeling about your future?	
Submit Reset	Please submit this section when completed. Thank you.

If there is anything that has not been covered in the questionnaire that you would like to add, or any comments that you would like to make, please do so in the spaces below.

What time of day/night did you fill in this questionnaire?

Where was your dependent as you filled it in?

What sort of day did you have?

How were you feeling before you filled it in?

Please add your comments about the questionnaire and how it was to complete it:

Submit Reset

Well, that's it. Thank you ever so much for your valuable time and invaluable contribution.

If you have problems filling this form in on-line, please send a completed hard copy to this address:

(Caregiver Survey) Service Development Team (EMI), Royal Hamadryad Hospital, Hamadryad Road, Cardiff, Wales, UK CF10 5UQ

Past Caregiver Questionnaire

- This questionnaire is designed to be completed by people who used to act as the main carer for a person with dementia and lived with their dependent for some or all of the time.
- The only criteria for participation in the study is that you relinquished caring and your dependent was admitted to permanent care within the last year.
- Please fill the 4 parts of the questionnaire in separately and e-mail them each in turn. Once you have submitted each section a 'Confirmation Form' will appear. Press the 'Go Back' button to the previous page and you will be taken back to the questionnaire at the place at which you left it.
- Please give your e-mail address in each section so that I can check all sections have been received and there are no duplicates.
- Please note that you can switch off and fill each section of the questionnaire in off-line. If you wish, you can also complete each section of the questionnaire in at different times, when you have some spare time.
- Please also note that whilst it is desirable for the whole questionnaire to be completed, if you are uncomforatble answering certain questions it is fine for you to not complete them.
- Sorry if this is complicated, but thank you for your co-operation.

Part 1: Caregiving Situation Details

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. Where do you live?	☐ England ☐ Scotland ☐ Wales ☐ Northern Ireland ☐ Other (please specify)
2. Who did you care for before they were admitted to permanent care?	☐ Wife
	☐ Husband
	☐ Father/father in-law
	☐ Mother/mother in-law
	☐ Nephew / Niece
	☐ Sister/Brother
	☐ Grandparent/grandparent in-law
	☐ Other Please specify relationship if it falls outside range
3. What is your sex?	☐ Male ☐ Female
4. What is your past dependent's sex?	☐ Male ☐ Female
5. What is your age?	☐ < 50

	☐ 51 - 60
	☐ 61 - 70
	☐ 71 - 80
	☐ 81 - 90
	☐ > 90 Please specify age if below 50 or above 90
6. What is your past dependant's age?	☐ < 50
	☐ 51 - 60
	☐ 61 - 70
	☐ 71 - 80
	☐ 81 - 90
	☐ > 90 Please specify age if below 50 or above 90
7. What is your past dependant's diagnosis?	☐ Alzheimer's disease
	☐ Vascular (multi-infarct) dementia
	☐ Mixed AD/VD
	☐ Pick's (Frontal Lobe) dementia
	☐ Lewy body dementia
	☐ Huntington's dementia
	☐ Parkinson's dementia
	☐ Creutfeldz-Jakob disease
	☐ Other Please specify dementia if it falls outside range
8. When was your past dependant diagnosed?	☐ < 1 year ago
	☐ 13 months - 2 years ago
	☐ 25 months - 3 years ago
	☐ 37 months - 4 years ago
	☐ 49 months - 5 years ago
	☐ 61 months - 6 years ago
	☐ > 6 years ago

9. How many months/years did you spend in the role of care-giver?	☐ < 1 year
	☐ 13 months - 2 years
	☐ 25 months - 3 years
	☐ 37 months - 4 years
	☐ 49 months - 5 years
	☐ 61 months - 6 years
	☐ > 6 years
10. How would you assess the degree of your past dependant's dementia in the month before their admission to permanent care?	☐ Minimal
	☐ Mild
	☐ Moderate
	☐ Severe
	☐ Very severe
11. What additional illnesses/diseases did your past dependent suffer with?	☐ Stroke
	☐ Heart Condition
	☐ Cancer
	☐ Other Please specify
12. What was it like to care for a person with dementia?	
13. What was the geographical distance in your caring relationship?	☐ Living With: (Same house)
	☐ Living Nearby: (Less than 15 mins away)
	☐ Living Locally: (16 mins to 1 hour away)
	☐ Living Long Distance: (1 hour + away)
14. What problems did this cause you?	
15. How many hours a day/week did you spend in direct hands-on caregiving (including time spent in supervision)?	☐ Up to 20 hours per week
	☐ 21 - 40 hours per week
	☐ 41 - 60 hours per week
	☐ 61 - 84 hours per week (8.5 - 12 hours per day)

	☐ More than 85 hours per week (13 + hours a day)
16. What impact did this have on your life?	
17. What was your occupational status when you were still caring, and what is it now?	
☐ In Full-time work	☐ In Full-time work
☐ In Part-time work	☐ In Part-time work
☐ Unemployed	☐ Unemployed
☐ Given Up Work to Care	☐ Recommenced work after caring
☐ Retired	☐ Retired
☐ Never Worked/Housewife	☐ Never Worked/Housewife
18. Did/do you provide care for anyone else, e.g. young children/other elders?	☐ Yes ☐ No If 'yes', please list them
19. What was the quality of your relationship with your dependant like before their admission to permanent care, and what is it like now?	
Previously (within month prior to admission):	*Now:*
☐ Extremely close	☐ Extremely close
☐ Very close	☐ Very close
☐ Reasonably close	☐ Reasonably close
☐ Not very close	☐ Not very close
☐ Distant	☐ Distant
20. How had your relationship with your dependant changed since he/she had been ill?	
21. What was your physical/emotional health like just before your dependent was admitted to permanent care, and how is it now?	
Physical health one month prior to admission	*Physical health now*
☐ Extremely poor	☐ Extremely poor
☐ Very poor	☐ Very poor
☐ Fairly poor	☐ Fairly poor
☐ Fairly good	☐ Fairly good
☐ Very good	☐ Very good

☐ Extremely good	☐ Extremely good
Please give reasons for this answer ☐	Please give reasons for this answer ☐
Emotional health one month prior to admission	*Emotional health now*
☐ Extremely poor	☐ Extremely poor
☐ Very poor	☐ Very poor
☐ Fairly poor	☐ Fairly poor
☐ Fairly good	☐ Fairly good
☐ Very good	☐ Very good
☐ Extremely good	☐ Extremely good
Please give reasons for this answer ☐	Please give reasons for this answer ☐
22. What physical/emotional health problems do you currently have?	☐ I have a disability
	☐ I am generally frail or infirm
	☐ I have a diagnosed illness or disease (non-life threatening)
	☐ I have a diagnosed illness or disease (life threatening)
	☐ I am being treated for clinical depression
	☐ I am generally in good health
	☐ Other Please specify: ☐
23. What medications are you currently taking?	Please list: ☐
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 2: Caregiving Problems Analysis

Your e-mail address please (or unique identifier if you wish to remain anonymous):	☐
1. What were the main care-giving problems you were experiencing just prior to your dependent's admission to permanent care? A. Which of the following 'Communication Problems' did your dependant have?	
Was your dependant able to start and maintain a sensible conversation?	☐ Never
	☐ Rarely

	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to understand what was said to him/her?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to respond sensibly when spoken to?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant repeat things over and over again?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant talk all the time?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant talk nonsense which you couldn't understand?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant have periods when he/she didn't speak much at all?	☐ Never
	☐ Rarely

	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to read newspapers, magazines, etc., or watch and follow TV?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to take part in family conversations?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant talk aloud to him/herself?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
B. Which of the following 'Confusion Problems' did your dependant have?	
Did your dependant get mixed up about where he/she was?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant get mixed up about the day, date, year?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to recognise familiar people, e.g. family and friends?	☐ Never

	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to recognise you and know who you are?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant get mixed up about the time of day/night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant able to hold his/her attention for more than a few minutes?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant seem lost in a world of his/her own?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant try to get up and dressed/go outdoors during the night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant get lost and couldn't find his/her way home when outside of the house/did you have to keep them indoors?	☐ Never

	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant see or hear things which weren't really there?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
C. Which of the following 'Behaviour Problems' did your dependant have?	
Did your dependant wander indoors or outdoors?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant tend to collect things and hoard them?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant become angry and resistive to care?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant endanger him/herself by engaging in risky behaviours?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always

Did your dependant falsely accuse people/you of things?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant become irritable and get easily upset?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant shout/swear/scream at people/you for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant hit out at you/other people for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant display inappropriate sexual activity/ demands?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant wake you/others during the night?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always

D. Which of the following 'Mood Problems' did your dependant have?	
Did your dependant show an interest in doing things?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant appear to be restless and agitated?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant pace up and down in a worried or troubled way?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant cry/become tearful for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant appear to be unhappy and depressed?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant have difficulty settling to sleep or wake unusually early in the morning?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently

	☐ Always
Did your dependant's mood change suddenly for no obvious reason?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant isolate him/herself and avoid social contact?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant never leave your side/shadow you?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant look frightened and anxious?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
E. Which of the following 'Physical/Self-care Problems' did your dependant have?	
Did your dependant have problems in standing/walking - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant have difficulty washing/bathing - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
Did your dependant have difficulty dressing/undressing - need assistance?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant incontinent of urine during the night (may wear pads)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant incontinent of urine during the day (may wear pads)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant incontinent of faeces (day or night)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant have problems feeding him/herself/swallowing - need assistance/special diet?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Was your dependant partly/ completely immobile and need lifting?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
Was your dependant prone to having falls/fits/choking attacks?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
Did your dependant suffer with pain/need analgesic medication?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
2. What additional problems did your dependant have which are not covered above?	
3. What medication was your dependant taking just before their admission to permanent care?	Please list:
4. Thinking of all the problems above, which were the most stressful/difficult to cope with, and why, i.e. what impact did they have on you?	1. 2. 3. 4. 5.
5. How were you coping with and managing these most stressful/difficult problems?	☐ Extremely well
	☐ Very well
	☐ Fairly well
	☐ Fairly poorly
	☐ Very poorly
	☐ Extremely poorly

6. What strategies/approaches did you use to cope with/manage these 5 most stressful/difficult problems?	
7. Apart from the direct caregiving problems experienced, what would you say were the most distressing aspects of caring for a person with dementia?	
8. How did you cope with these most distressing aspects of caring?	
9. Thinking about the stresses and practicalities of caring, what was the overall impact of caregiving on your emotional and physical well-being?	
Emotional well-being:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
Physical well-being:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
10. Thinking about the stresses and practicalities of caring, what was the overall impact of caregiving on your personal relationships/ family life and social/ work life?	
Personal relationships/family life:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
Social/work life:	☐ Very positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact

	☐ Very negative impact
11. Thinking back on the time just before your dependent's admission to permanent care, what would you say was the impact of care-giving on your overall quality of life?	☐ Extremely positive impact
	☐ Very Positive impact
	☐ Positive impact
	☐ No real impact
	☐ Negative impact
	☐ Very negative impact
	☐ Extremely negative impact
12. Please describe the impact that caregiving had on your quality of life:	
13. Apart from the direct caregiving problems experienced above, were there any other factors involved in your being unable to continue in the caring role at home?	Please describe them:
14. Looking back, if you had to identify one care-giving problem or other factor that contributed most to your decision to admit your dependent to permanent care, what would it be?	
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 3: Caregiver Stress & Burden Questionnaire

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. Did you feel that you need a holiday (a long-term break from caring)?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
2. Did you worry about safely leaving your dependant on his or her own?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always

3. Did you find it difficult to get away for a break for a few hours?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
4. How much was your social life affected by caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
5. Was your sleep disrupted by your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
6. Did you have family arguments/difficulties associated with your caring situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
7. Had your financial circumstances changed or your standard of living been reduced as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
8. Did you have difficulty in continuing your relationships, e.g. having visitors or meeting friends, due to your caring commitments?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently

	☐ Always
9. Did you find that your caring responsibilities adversely affect other aspects of your life, eg. your role as a parent/ grandparent, your employment/ other commitments?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
10. Did you have to undertake caregiving tasks that you felt were beyond your capabilities?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
11. Had your own physical health suffered as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
12. Did you feel there would be no end to your problems?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
13. Did you feel you could no longer cope with your situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
14. Did you feel overwhelmed by your situation?	☐ Never
	☐ Rarely
	☐ Sometimes

	☐ Frequently
	☐ Always
15. Did you feel trapped in the caring role?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
16. Did you feel that you were alone in coping with your caring situation?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
17. Did you find it distressing that your dependant had changed so much from his or her former self?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
18. Did you have feelings of grief and loss associated with your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
19. Did you find yourself becoming tearful or crying?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
20. Did you feel exhausted and demoralised in your caring role?	☐ Not at all
	☐ A little
	☐ Moderately

	☐ Quite a lot
	☐ Considerably
21. Were you depressed about your situation?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
22. Did you feel like giving up caring?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
23. Did you feel embarrassed by your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
24. Did you feel frustrated with your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
25. Did you get cross and angry with your dependant?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
26. Were you resentful about the change in the quality of your own life/missed life opportunities?	☐ Not at all
	☐ A little
	☐ Moderately

	☐ Quite a lot
	☐ Considerably
27. Were you emotionally distant from your dependant?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
28. Did you view caring for your dependant as being like caring for a child?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
29. Did you have feelings of guilt associated with your caring role?	☐ Never
	☐ Rarely
	☐ Sometimes
	☐ Frequently
	☐ Always
30. Did you feel helpless and as if things were outside of your control in your situation?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
31. Did you have a sense of achievement or fulfilment as a result of caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
32. Did you have a sense of purpose and direction in your caring role?	☐ Not at all
	☐ A little
	☐ Moderately

	☐ Quite a lot
	☐ Considerably
33. Did you derive personal satisfaction and reward from your caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
34. Did you have feelings of positive self-worth/self-esteem arising from caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
35. Did you feel that being a carer had provided an opportunity for personal growth and development?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
36. Did you feel that caring was a positive way of expressing your love and affection for the person you cared for?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
37. Did you feel that you adopted a positive, problem-solving approach to caring?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
38. Did you feel that you managed your stress well and overcame it?	☐ Not at all
	☐ A little

	☐ Moderately
	☐ Quite a lot
	☐ Considerably
39. Did you feel the help you received from services, family and friends enabled you to carry on in the caring role?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
40. Were you feeling hopeful about your future?	☐ Not at all
	☐ A little
	☐ Moderately
	☐ Quite a lot
	☐ Considerably
41. Reflecting on your overall caregiving situation, all in all would you say you were:	☐ 0 - Coping well / with no stress
	☐ 1 - Coping fairly well / with a small amount of stress
	☐ 2 - Just about coping / with a moderate level of stress
	☐ 3 - Having difficulty coping / with a great deal of stress
	☐ 4 - Finding it almost impossible to cope / with an extremely high level of stress
Submit Reset	Please submit this section when completed and move on to the next. Thank you.

Part 4: Exploration of Process & Outcome of Admission to Permanent Care

Your e-mail address please (or unique identifier if you wish to remain anonymous):	
1. How do you feel you could have been helped to better cope with your situation?	
2. How do you feel your stress could have been relieved?	

3. What formal support services did you receive? (Statutory, Voluntary & Private)	☐ No Formal Support Services Received ☐ Case Manager (Overall Community Care Co-ordinator, e.g. Community Psychiatric Nurse, Social Worker) ☐ Home Care Worker/s (practical assistance) ☐ Home Sitter/s ☐ Day Centre/Day Hospital ☐ Respite Care (Long-term breaks) ☐ Carers' Support Group ☐ Telephone Helpline ☐ Other Please specify
4. How often did you receive the above formal supports?	
Case Manager	☐ Fortnightly ☐ Monthly ☐ Bi-monthly ☐ Infrequently
Home Care Worker (practical assistance)	☐ Twice Daily ☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly
Home Sitter	☐ Twice Daily ☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly
Day Centre/Day Hospital	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly
Respite Care (Long-term breaks)	☐ Fortnightly ☐ Monthly

	☐ Bi-monthly ☐ Infrequently
Carers' Support Group	☐ Fortnightly ☐ Monthly ☐ Bi-monthly ☐ Infrequently
Telephone Helpline	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly ☐ Bi-Monthly ☐ Infrequently
Other	Please specify frequency of use:
5. What informal supports did you receive? (Family, Neighbours, Friends, Church, etc.)	☐ No informal supports received ☐ Close family support received ☐ Distant family support received ☐ Neighbours support received ☐ Friends support received ☐ Other support received Please specify
6. How often did you receive support from the above informal supporters?	
Family support received	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly ☐ Bi-Monthly ☐ Infrequently
Neighbours/friends support received	☐ Daily ☐ Three to Six Times a Week ☐ Once or Twice a Week ☐ Fortnightly ☐ Monthly

	☐ Bi-Monthly ☐ Infrequently
Other support received	Please specify frequency of use:
7. What is your view on the quality of support/s you received?	
Formal support services	☐ Extremely Helpful ☐ Very Helpful ☐ Helpful ☐ Unhelpful ☐ Very Unhelpful ☐ Extremely Unhelpful
Informal supporters	☐ Extremely Helpful ☐ Very Helpful ☐ Helpful ☐ Unhelpful ☐ Very Unhelpful ☐ Extremely Unhelpful
8. In what ways were formal support services and informal supporters helpful or unhelpful?	
Formal support services	
Informal supporters	
9. How do you feel formal support services could have improved their support to you and your dependant?	
10. When was your dependent admitted to permanent care?	Date
11. All in all, would you say the decision to resort to admission to permanent care was:	☐ Planned in advance with your full agreement
	☐ Planned in advance with your reluctant agreement
	☐ Made primarily as a result of a deterioration in your dependent's physical well-being
	☐ Made primarily as a result of a deterioration in your dependent's mental state
	☐ Made primarily as a result of a deterioration in your dependent's behaviour
	☐ Made primarily as a result of your

	deteriorating physical state and ability to cope
	☐ Made primarily as a result of your deteriorating emotional state and ability to cope
	☐ A crisis admission due to a critical incident in the care-giving situation
	☐ Other Please specify
12. Please outline in brief detail what led up to the decision to admit your dependent into permanent care:	
13. Who arranged the admission of your dependent to permanent care?	☐ I did
	☐ My Social Worker did
	☐ MY CPN did
	☐ Another Professional did
	☐ A Voluntary Organisation did
	☐ A Private Organisation did
	☐ Other Please specify
14. To which type of permanent care setting was your dependent admitted?	☐ Local authority run home
	☐ Private residential home
	☐ Private nursing home
	☐ Hospital continuing care ward
	☐ Sheltered housing
	☐ Other Please specify
15. Were you satisfied with your level of involvement in the decision-making process to admit your dependent to permanent care? Please give your reasons:	☐ Yes
	☐ No
16. All in all, are you satisfied that it was the right thing to do at the time? Please give your reasons:	☐ Yes

	☐ No
17. How well has your dependent settled in the permanent care setting in which they currently reside?	☐ Extremely well
	☐ Very well
	☐ Fairly well
	☐ Fairly poorly
	☐ Very poorly
	☐ Extremely poorly
18. How has your dependent's condition changed since their admission to permanent care?	☐ Deteriorated greatly
	☐ Deteriorated slightly
	☐ Stayed the same
	☐ Improved slightly
	☐ Improved greatly
19. How satisfied are you with the quality of care your dependent receives within their current permanent care setting?	☐ Extremely satisfied
	☐ Very satisfied
	☐ Fairly satisfied
	☐ Fairly dissatisfied
	☐ Very dissatisfied
	☐ Extremely dissatisfied
20. How would you wish to see things changed in your dependent's permanent care setting?	
21. How often do you visit your dependent within their current care setting?	☐ I don't visit
	☐ I visit infrequently
	☐ I visit bi-monthly
	☐ I visit monthly

	☐ I visit fortnightly
	☐ I visit weekly
	☐ I visit several times a week
	☐ I visit daily
22. Please explain why you visit this often or don't visit at all:	
23. What is your input to care in the permanent care setting, eg. do you feed your dependent, attend review meetings, attend a carers' group, etc.?	
24. What are things like for you now, eg. do you have any residual guilt or depression, have you restarted your life, etc.?	
25. What would you say your overall quality of life was like now?	☐ Extremely good
	☐ Very good
	☐ Fairly good
	☐ Fairly poor
	☐ Very poor
	☐ Extremely poor
26. Please give your reasons for this answer:	
27. How are you feeling about your future?	
Submit Reset	Please submit this section when completed. Thank you.

If there is anything that has not been covered in the questionnaire that you would like to add, or any comments that you would like to make, please do so in the spaces below.

What time did of day/night did you fill in this questionnaire?

What sort of day did you have?

How were you feeling before you filled it in?

Please add your comments about the questionnaire and how it was to complete it:

Submit Reset

Well, that's it. Thank you ever so much for your valuable time and invaluable contribution.

If you have problems filling this form in on-line, please send a completed hard copy to this address:

(Caregiver Survey) Service Development Team (EMI), Royal Hamadryad Hospital, Hamadryad Road,
Cardiff, Wales, UK CF10 5UQ