CARER HELD RECORDS

Empowerment Of Carers Of Patients With Dementia Living In The Community

Thesis submitted for the degree of Doctor of Philosophy At The University of Leicester

By

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CARER HELD RECORDS: Empowerment Of Carers Of Patients With Dementia Living In The Community

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Abstract

Background

Recognition that family carers have valid personal knowledge of their relatives with dementia is very important when tailoring care packages to individual needs (Kitwood & Bredin 1992). Carers’ well being is also essential for the continued management of patients in the community. A carer held record was designed to be kept at home by carers, in which carers might contribute to care plans for their relatives with dementia, alongside all involved professional disciplines and agencies, and be recognised as equal partners with professionals in providing the best possible care. A pilot study was conducted in 1996 the results of which informed the follow up definitive research (Simpson 1996)

Aim

To establish whether there are measurable benefits for carers who hold these multidisciplinary records in the areas of health, stress, knowledge of the illness and control.

Methodology

This is a longitudinal study with a subject group of carers who hold a carer held record, and a comparison group who do not. Questionnaires were completed by both groups at four time intervals over an eighteen month period. Outcome measures concern carers’ stress and strain levels, physical and mental health, perceived burden, locus of control, and dementia knowledge, as well as their relatives’ cognitive decline.

Results

Repeated measures ANOVAS for all outcome elements were used in data analysis. Qualitative analysis of use of the carer held record is included in the results. No significant differences were found on the Burden Scale or the aspects of carer stress selected for this study from the Carer Stress Scale (Pearlin et al, 1990). No significant health gains were found. However, subjects have been shown to have significantly lower scores on the Carer Strain Index (Robinson 1983) than controls, and significant changes were highlighted for subjects in aspects of locus of control.
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A Note On Terminology

In this thesis participants in the study are referred to as “carers” and “patients”. An explanation of this language is required, as the use of these terms seems to imply that my thinking about the participants in the study revolves around the medical model, rather than the social model of dementia, and I wish to stress that this is not the case. The medical model of dementia focuses upon what is wrong with the minds of people with dementia, and their needs are often defined by their diagnosis, and by measuring them against a concept of normal function. The social model of dementia is a way of looking at people’s needs which emphasises the importance of personhood, focusing on people’s abilities rather than on their impairments (Kitwood & Bredin 1992). It is within this social model of dementia care that the research was conducted. Focus is upon people’s individual experience of having dementia, upon their family carers managing the situation at home, and on their environments which can enable or disable the process.

Participants however were recruited to the study on first contact with community mental health teams (CMHTs), seeking health service assistance about how best to manage dementia. Both carers and patients were “users” of the service. Both could be regarded as “clients”. As Oliver (1993) states, the use of the terms “carer” and “cared for” highlights associations with notions of dependency and lack of autonomy for the person with dementia, and so I chose to use the terms “carer” and “patient” which, as a nurse, I find a natural language.
Introduction

This research study concerns the empowerment of carers of patients with dementia. A main initiative of the research was the design of the carer held record document using which carers might function as equal partners with professionals in planning and implementing the best possible care for the patient. The document was designed for multidisciplinary, multi-agency use. It was to be kept at home by the carer who would contribute in writing to care plans for their relative, and to the evaluation of the patient’s progress, on an equal basis with professionals.

The aim of the initiative was that the carer held record would be available, for use and for reference, by both carers and professionals. This would be in the patient’s/carer’s home, and whenever and wherever the patient was to be seen by a caring agency i.e. voluntary sector workers as well as multidisciplinary professional health care workers. A secondary aim was that links might be made amongst diverse health, social services, and voluntary caregivers, with the family carer at the centre point, aware of the input of all to the patient’s care package. The document might also help to forge links between hospital and community professionals and thus help in the maintenance of a more seamless service. Each contributor to the care package would write in one core document, and the daily management of the patient’s care would be the role of the well-informed family carer - an equal partner. Initially a pilot study was conducted to assess the design of the document as well as the implementation process for its use, and the evaluation of effectiveness.

The main study followed the pilot, and was built upon the lessons learned. This definitive study was a three year longitudinal study in which outcome of the use of carer held records was measured in terms of levels of carer stress, strain and burden, physical and psychological well-being of carers, and the degree of control they felt in the management of their relatives with dementia.
These measures were taken at four time intervals within an eighteen month period for those carers issued with carer held records and also for a comparison group who did not have this facility.

This thesis will outline some of the issues surrounding empowerment of health service users in the NHS today; background literature about family carers' burden of care when patients have dementia; client held/carer held records and the concomitant issues and difficulties. However the main focus of the thesis is the conduct of this carer held records research, its statistical and descriptive results and conclusions reached.

**Some facts and figures about dementia**

Dementia is a clinical syndrome characterised by a widespread loss of mental function, with the following features:

- memory loss

- language impairment (having difficulty finding words especially names and nouns)

- disorientation (not knowing the time or place)

- change in personality (becoming more irritable, anxious or withdrawn, loss of skills and impaired judgement

- self neglect

- behaviour which is out of character (for example sexual disinhibition or aggression).
Dementia has a number of causes, the most common of which are:

- **Alzheimer’s disease** - this causes up to 60% of cases of dementia. It is characterised by memory loss and difficulties with language in its early stages, and gradually becomes more severe over several years.

- **Vascular dementia** - this is the consequence of strokes and/or insufficient blood flow to the brain, and causes up to 20% of cases of dementia. It has a more varied clinical picture depending on which parts of the brain are most affected. In any individual Alzheimer’s disease and vascular dementia can co-exist.

- **Dementia with Lewy bodies** - this causes up to 15% of dementia cases and is characterised by symptoms similar to Parkinson’s disease as well as hallucinations and a tendency to fall.

### Statistics on Dementia

**Table 1**  
**Prevalence of Dementia in the UK**

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Prevalence</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-65</td>
<td>0.1%</td>
<td>(1 in 1000)</td>
</tr>
<tr>
<td>65-70</td>
<td>2.0%</td>
<td>(1 in 50)</td>
</tr>
<tr>
<td>70-80</td>
<td>5.0%</td>
<td>(1 in 20)</td>
</tr>
<tr>
<td>80+</td>
<td>20%</td>
<td>(1 in 5)</td>
</tr>
</tbody>
</table>

Source: Alzheimer’s Disease Society

It is currently estimated that there are 636,000 people with dementia in the UK. Of these, nearly 500,000 will have Alzheimer’s disease.
The scale of the problem

- There are an estimated 650,000 people with Alzheimer's disease and the other dementias in the UK.

- Eighty per cent of people with dementia, whatever their impairment, live at home.

- Twenty-three per cent of people with dementia live alone.

- Although only about 3 per cent of people with dementia are under 65 years old, they have a disproportionately high morbidity and create more dramatic social consequences.

- A GP with 1,500 to 2,000 patients can expect their list to include 12 to 20 people with dementia, depending on the age profile of their list.

Alzheimer's disease and the other causes of dementia are not only psychiatric illnesses but diseases with widespread physical and social manifestations.

<table>
<thead>
<tr>
<th>Year</th>
<th>0.1%</th>
<th>2-5%</th>
<th>20%</th>
<th>Total</th>
<th>Total pop.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>15,000</td>
<td>235,000</td>
<td>386,000</td>
<td>636,000</td>
<td>22.7m</td>
</tr>
<tr>
<td>2001</td>
<td>16,000</td>
<td>235,000</td>
<td>454,000</td>
<td>704,000</td>
<td>24.5m</td>
</tr>
<tr>
<td>2011</td>
<td>18,000</td>
<td>243,000</td>
<td>512,000</td>
<td>773,000</td>
<td>27.3m</td>
</tr>
<tr>
<td>2021</td>
<td>17,000</td>
<td>304,000</td>
<td>572,000</td>
<td>894,000</td>
<td>28.4m</td>
</tr>
</tbody>
</table>

Source: Estimates based on OPCS Monitor PP2 92/1, February, 1993
The prevalence and incidence of dementia increase with age (MRC CFA Study 1998). Approximately 600,000 people in the UK have dementia. This represents 5% of the total population aged 65 and over, rising to 20% of the population aged 80 and over. Dementia can also occur before the age of 65; there are about 17,000 people with dementia in younger age groups in the UK. Of the people with dementia 154,000 live alone (ADS 1994). It is estimated that by 2026 there will be 840,000 people with dementia in the UK, rising to 1.2 million by 2050.

**Costs of care of people with dementia**

Mental health problems amongst older people exact a large social and economic toll on patients, their families and carers, and the statutory agencies. The annual direct cost to the NHS in England of caring for people with dementia was estimated at over £1 billion in 1993 (Gray & Fenn 1993). Taking into account the costs of informal caring and the costs to all statutory agencies, the total cost of caring has been estimated to be £6 billion (Ritchie 1998). While the cost of caring for an institutionalised patient is twice the cost of caring for a patient at home (Hu et al 1986), the total social costs were nearly the same when both paid and unpaid informal care were included (Stommel et al 1994). As the disease progresses the costs of care increase. Severe dementia requires more than twice the hours of informal care as mild dementia. Max (1999) goes on to say:
"Alzheimer's disease is extremely costly, no matter how it is measured and what cost is included... for patients cared for at home, most of the care is provided informally by family members and friends, and most of the burden of care is borne by their families, in the form of out-of-pocket payments for services, or in the form of hours of time spent caring for the patients without reimbursement."  

P. 367

Clearly dementia is a problem, not only in medical and psychiatric terms but one which has great psychosocial repercussions for both the patients and their carers.

Outline of current health service provision

On 1st April 1991 the NHS and Community Care Act came into being. It was derived from two White Papers, “Working for Patients” and “Caring for People”. There has been a consequent shift from hospital to community-based care for many people with long-term mental health problems including the elderly. Community Mental Health Teams (CMHTs) now arguably form the core component of NHS specialist community psychiatric care. The community mental health team initiative was developed to encompass a multidisciplinary and multi-agency structure, which would facilitate ease of access to all mental health services, whether provided by the Health Authority, social services or the voluntary sector (Onyett, Heppleston & Bushnell 1994). CMHT members include a consultant psychiatrist and medical team support, community psychiatric nurses (CPNs) social workers, occupational therapists, psychology and physiotherapy input, and voluntary agency representation. CMHTs in Leicestershire were developed to be catchment - area based and specialty-specific in order to offer an integrated co-ordinated service within each locality.
Philosophy

CMHTs in Psychiatry for the Elderly aim to provide a service to elderly people with mental health problems which includes assessment of needs, treatment, monitoring and on-going support. Older people with mental health problems are a particularly vulnerable group who may require a number of health and social care services. Using their multi-agency resources CMHTs produce packages of care, in consultation with clients and carers to support clients in the community, and to support their family carers (Ovretveit 1986). Packages of care should be seamless in that systems should be in place for different agencies to communicate with one another. The hallmark of good mental health services is that they are comprehensive, multidisciplinary, accessible, responsive, individualised, accountable and systematic (WHO 1997).

Consumers' experience of services received

It is often the case that users and carers do not have the same views as professionals about the quality of care offered. This is particularly true in the areas of information sharing and co-ordination between agencies. Many carers also feel that their needs for home support and medical care are not fully met (Coope, Ballard, Saad et al 1995 in Audit Commission 2000). Definitions of which aspects of care are "health" and which are "social" vary across the UK and lead to anomalies.

The involvement of users and carers is a crucial aspect of the delivery of good quality care. However a number of factors work against user and carer involvement. Professionals often have neither the knowledge nor the skills to implement the policy effectively. Older patients, whose carers are often old themselves, may lack assertiveness in making their needs known. Also health professionals sometimes neglect the needs of carers fearing that carers' perceptions of care may be different from their relatives, and be in conflict with their own professional views.
There is, in addition, some evidence that health professionals tend to pay lip service to the philosophy of user and carer involvement, and, whilst agreeing in research interviews that it is important, may actively (though not vindictively) work against it in their individual interactions with patients and their carers (Meyer 1999, in Caring for Older People 2001). It is important to have in place review and audit systems to monitor both the quality of service provision, and users/carers views about its efficacy in order to see, what is working well, and as a starting point from which future plans can be developed. This research study followed in response to a survey of users/carers views on the quality of care received.

Background to this research

In 1994 we conducted a survey amongst carers of patients with dementia, to look specifically at the quality of in-patient care for this client group (Simpson et al 1995). The survey was carried out using a questionnaire with an open-ended question format in individual focused interviews. Not only did carers discuss issues surrounding in-patient care, but, as in all focused interviews searching for qualitative data, other concerns were reported about other aspects of care packages, where it was felt that quality of care could be improved. Many carers reported their feelings of helplessness when managing their relatives at home. Specifically, many carers felt that they lacked knowledge about dementia and the course of the disease. Some had great difficulty in communication with the different professionals involved in patients' care plans, both in hospital and in the community. In fact they felt they lacked control over the problems of daily living, amidst powerful professionals managing care packages for their relatives, many of whom, it was felt, did not communicate with each other. This was particularly noticeable when instructions and advice were being given to relatives by both hospital and community health workers, including primary health teams. Such information sometimes conflicted, and carers were more unsure than ever of how to manage the patients' care at home.
Where did the idea of carer held records come from?

Carer held records was an idea which arose in multidisciplinary discussions about how equal partnership philosophy might be implemented in a practical way, and subject to outcome measures. Literature searches revealed very little in the early 1990s about client held records, and nothing at all specific to elderly patients with dementia and/or their carers. Similar initiatives however were found to have been launched for other specialist groups, and we sought to learn from these sources.Patients holding their own medical records was one initiative. Papers by Bird & Walji (1986), Baldry et al (1986), and Gilhooly & McGhee (1991) all describe either the process or the outcomes of patients holding their own records in GP practices. Baldry reports that most patients felt that record sharing was reassuring, informative and helpful. Gilhooly & McGhee conclude that research on patient held records shows no substantial drawback, and considerable benefit both practical and ethical was derived from the initiative.

In 1978 a process was developed in Massachusetts to encourage people to take more responsibility for their health by use of a client held record, called a Personal Life Health Plan (PLHP). A pilot study of its use, and effectiveness in changing health behaviour patterns was evaluated by Giglio et al (1978). A pilot study showed that a significant percentage of people will use a PLHP, and that health staff could incorporate its use into their care routines. However the pilot did not evaluate how effective it might be in changing health behaviours, and recommended longitudinal follow up research.

Another similar initiative which influenced thinking on client held records was that of parent held records for children aged 0 - 5 years. The underpinning philosophy involved the recognition that parents are primarily responsible for the health of their children. Therefore parents should hold the main child health records, so that the record might be available whenever and wherever a child is seen by professionals.
Parents would be active in recording their own observations, and controlling the confidentiality of the document (Macfarlane 1991). Research into the effectiveness of the parent held record showed positive outcomes.

It is acknowledged that, in dementia, the alignment of parent held records for children with carer held records for patients can only be partial. There are many dissimilarities ethically in case management. The majority of parents are holding records for healthy children growing from dependence to independence over the years. Carers of patients with dementia would be holding records for patients who were once independent, but who may be growing more dependent as the disease progresses. These may seem to be directly opposite philosophies, and it is stressed that similarities do not extend to clinical care in any form. However, if the practice of client held record keeping is examined, there is much that could be analogous.

As with parents and children, it is the carer, not the passing professional, who provides permanence in the patient’s life in many cases. The carer gives true “continuity of care”, and may be best placed, because closest placed to observe the patient’s illness development, response to treatment plans, and adaptation to general life at home. The carer is the central person managing the daily living of the patient with dementia, and may be the strongest link between the patient and the various health and welfare agencies, as is the parent of the dependent child. The practice of parent held records for children therefore had a strong influence on the thinking behind this research pilot project.
Current Literature

The body of literature on client held records has expanded a little in the last six years. Several initiatives have recently been published about joint health and social care records which are client held. However in all instances records are held by the patients who are to be empowered. Essex et al (1990) for instance described a pilot study of patient held shared care booklets for individuals with schizophrenia based in primary care. Patients in this study felt that the booklets were useful. There is still a dearth of literature however about carer held records, and empowerment of carers using similar initiatives.

Seven more recent papers have been published on the topic of which two are pilot studies about the best document design, its use, and evaluation of effectiveness within a pilot sample, similar to the pilot study conducted for this research (Simpson 1997).

Two papers concern the philosophy of a client held records initiative and the potential benefits which might ensue. McGreevy (1995) suggests that:

"A system of client held records represents a powerful and empowering therapeutic tool in community mental health practice"

He acknowledges possible obstacles to implementation, but feels these are not insurmountable, and he concludes that if only some of the possible client benefits can be realised the system should be introduced in mental health practice.

Wright & Young (1994) also focus upon potential benefits of a client held joint health and social care record, specifically for older clients. They held focus groups with clients to elicit views about the underlying philosophy of the initiative, and the scope of document design.
Many elderly people in this study felt that a client held record was not a good idea, felt worried about issues of confidentiality, and rights of people to access. However, the authors acknowledge that their results could not be generalisable, and that opinions given were based on theory and not actual practice. They felt that the information obtained however might be useful if followed up by a pilot project of the initiative in action.

One study (Stafford & Hannigan 1997) concerns theoretical client benefits. A single case history was then described about a client held record document used by one patient and the concomitant professional team. The conclusion was that this particular patient gained benefit from the initiative, and that:

"a client held record is able to promote user empowerment, and to enhance the communication process between client and professionals."  

Two British research studies were piloted with patients with enduring mental health problems in the under-65 age group. Stafford & Laugharne (1997) conducted a study in East London, and Greasely et al (2000) within a Wakefield community mental health team. Both studies report useful outcomes for some clients holding the records. Stafford & Laugharne conclude that:

"this new development has the potential to improve communication between professionals, and between patient and professional, as well as fulfilling the requirement to increase patient involvement in care."

Greasely et al made some further useful observations similar to those identified in my own pilot study. Firstly, they found that professionals did not always find it easy to cooperate with full use of the documents' potential. As a pilot study, the initiative was not an integral, routine part of their work. Also sometimes, if a client's situation were stable, professionals did not always see the need for the record.
This study also highlights the fact that simply introducing a client held record, as an additional, optional care extra, and offering the opportunity to be partners in care, does not provide sufficient impetus to ensure that the record is used to its full capacity by patients or professionals. Patients may use it as a source of information, or a diary, rather than as a joint personal record of consultations with professionals. The study points out that patients’ interest in the records needed to be encouraged and sustained, implying that the initiative might be less successful as time passes.

The last suggestion made is that the record might be most valuable to clients if introduced at first contact with services, thus to encompass a complete period of care. Currently none of the pilot studies have been followed up by published longitudinal studies; nor have any outcome measures been considered beyond design issues, clients’ and professionals’ satisfaction with the practice, and subjective opinion responses.

There has however been recently published a study by Warner et al (2000) the results of which are of great relevance to this research project. This was a longitudinal study whose aims were to identify whether carrying a shared care booklet improves the mental health of patients with long term mental illness, their service contact and satisfaction with services, and to assess whether there was any attenuation in the impact of shared care over time. The research also examined the pattern of use of the booklet by both the patients and their professional carers. Participants in the study had long term mental illnesses defined as diagnosis of psychosis, severe non-psychotic disorder, severe personality disorder or other illnesses requiring long term supervision. Subjects received the shared care booklet, and controls received usual care only. Warner’s results showed that there were no significant differences on any of the outcome measures used, i.e. no differences between the groups in terms of mental health status or client satisfaction with services. Also allocation to shared care did not predict lower readmission rates or better outpatient attendance rates.
The researchers' analysis of the patterns of booklet use showed that there was a low rate of usage amongst both patients and professionals. Patients' low usage he attributes to facets of their severe mental illnesses, such as lack of motivation, organisational disabilities and the possible stigmatising effects of the records. It is suggested that low usage by professionals could be because of uncertainty about what to write, fear of censure about the content, and a possible lack of ownership of the project despite efforts to involve them in the project. He is therefore not convinced that better communication was achieved. The conclusion reached is that one cannot assume that even if better communication is achieved via shared care records that this will have a positive impact on the outcome parameters used in the research. It is stressed however that the introduction of a shared care record does not in itself alter the culture of care throughout the service, and that it is the alteration in the culture of care which is most important in achieving more open communication.

As far as it is possible to be sure, there appear to be no published papers about the actual use of client held records within services for psychiatry for the elderly; nor has any paper been published about carer held records for patients with dementia, and the possible empowerment of both patients and carers via this initiative.

This research is a longitudinal study assessing outcome in terms of objective outcome measures, and statistical analysis of whether there are actually benefits to be gained from empowering carers via carer held records, compared with a comparison group not offered the initiative. Outcome measures, conducted with both groups at three time intervals longitudinally will reveal whether any such benefits are sustainable over time. The record was offered to clients when first contact was made with community mental health teams as was suggested as potentially the best introduction time in the Greasely paper. Also assessed is how the records are actually used by carers, and how well or otherwise carers engaged with the project.
In contrast to the research with mentally ill patients (Warner et al 2000), most carers are not themselves suffering from a mental illness, and communication between carers and professionals has different connotations to that of patients and professionals. Underpinning the whole initiative is the philosophy of client empowerment. It is possible that merely the offer of partnership in care, backed up by well-designed documentation, may have benefit for clients in terms of empowerment, regardless of how the documentation is used. However it is used by clients, whether as an information source, merely as a diary of events, or used to full capacity, clients/carers may still feel trusted and valued, and hence gain some measurable benefits in terms of health status, burden and stress levels, or in the area of feeling in control of the caring situation.
Family carers of people with dementia

A definition of a care giver proffered by Zarit & Edwards (1996) is:

"A family member (or friend) helping someone on a regular basis (usually daily) with tasks necessary for independent living."

Although there may be professional and/or paid assistance going into the home to support both the patient and carers, most of the care for patients at home is provided informally by family members and friends (Max 1999). Caring for someone with chronic mental illness has been shown to be more stressful for carers than physical illness (Mohide et al 1988). It can be a "long haul" for carers in dealing with the tragedy that is dementia. In the initial stages of the disease care giving may be very different from the care that is required as the disease progresses through middle to end stages.

The promotion of carer in the community as opposed to hospital/residential care, and a philosophy of increasingly emphasising independence and self care means that individuals living in the community are more likely to have a far wider range of needs than those who would have been supported in the community 10 years ago (Parker & Lawton 1994). Also cholinesterase inhibitor drugs for Alzhiemers disease make it more likely that people with moderate dementia will be maintained in the community for longer periods than before, their moderate, but possibly troubling symptoms deteriorating perhaps at a slower rate, placing corresponding demands on carers accordingly (Hunter et al 1997).

Frustration and resentment which may be felt in the initial and middle stages of dementia may change until carers’ lives become focused on the caring role almost exclusively, taking up most of their time. Stress and strain however may exist for carers throughout, albeit taking different forms at different times.
Stress and burden of carers of patients with dementia

The term “care giver burden” is now widely used to refer to the physical, psychological, social and financial problems which can be experienced by carers, and many studies have been published about all aspects, or individual aspects of this total concept. One way in which studies of carer burden might be grouped is by year of publication, because in different decades research into this topic has been differently focused (Loukissa 1995).

In the 1960s and 1970s researchers focused upon the patient being cared for, and considered that patients’ levels of functioning and behaviours were the source of variations in carer burden (Hoenig & Hamilton 1965, Grad & Sainsbury 1963 and others). In the 1980s studies began to include other aspects of carer burden such as social, economic and emotional problems as contributory factors in carer burden, as well as the patient focus. In the 1980s research was being conducted into whether social support and carer education might reduce levels of carer burden (McCarthy et al 1989).

From the late 1980s and early 1990s research studies into carer burden have focused more on carer characteristics, education of the extended family, social support in self help form, and the importance of family needs assessment (Parker 1993). Although the significance of patient functioning and behaviour has not been disregarded in considering burden felt by carers, the focus has changed over the years towards best methods of developing carers’ coping strategies to alleviate burden, and offering services which might best enhance carers’ abilities to cope with the stresses. It is also worth noting that as Loukissa points out, not only has the body of knowledge on carer burden changed and expanded over the years, but that it has also been influenced by the Governmental policies of shorter hospitalisations and greater community participation in care. Whatever the sociological or societal triggers however, recent studies on carer burden concentrate on what factors help family carers to cope with a dependent relative at home.
Zarit, Todd & Zarit (1986) conclude from their research that a more important determinant of caregiver burden is caregivers' appraisal of the severity of problems, rather than the severity of the problems themselves.

Thus the impact of "harmful events" is mediated by whether carers actually perceive them as "harmful" (Lazarus & Folkman 1984). This was a theme further developed in the 1980s when the phenomenon of "burden" was conceptualised in two distinct ways, i.e. distinction was made between objective burden and subjective burden. Objective burden was considered to reflect disruptions in family life, role, finances, and relationships with family/friends, whereas subjective burden refers to feelings of feeling trapped, embarrassed, overloaded, excluded and resentful (Thompson & Doll 1982). Although these distinctions are important, and have helped to delineate the many aspects of carer burden, actually measuring burden as two separate entities has proved problematical. Both subjective and objective burden may be alleviated by successful carer coping strategies, and use of services offering practical support. Carer utilisation of day care services, respite services, support groups and financial assistance may help with some of the objective burden highlighted. However this in turn may also influence subjective burden, especially in the realms of overload and exclusion. So in managing the total concept of burden, objective and subjective burden are inevitably interlinked, and thus very difficult to measure separately (Pearlin et al 1990). Other researchers (Knippscher 1989, Wenger 1990) conclude that stress is more closely related to attitudes to care rather than to either concrete or abstract delineations of the concept. Levels of stress were found to be at their highest when there was a perceived lack of appreciation from both the dependent patient, and other family members, coupled with a sense of exploitation (Wenger 1990).
When considering and researching attitudes to caring, caregiver characteristics have come more to the fore as "variables" to be taken into account in levels of carer burden. Both the capacity and the motivation to care are important (Horowitz 1985). Some carers take on the caring role out of a sense of love and reciprocity:

- "He/she would do the same for me"

Others care out of a sense of duty or guilt, feeling forced to take on the role in response to cultural or social pressures. Often these carers are most distressed (Brodaty & Hadzi-Pavlovic 1990). There is also a small group who may decide to take on the caring role out of the prospect of financial gain in future inheritance.

There is no doubt that care giving for patients with Alzheimer's disease is often extremely taxing and exhausting. However, the importance of underlying relationships between the carer and the cared-for is also now stressed (Gilley 1988, Nolan & Grant 1989). Dementia has been shown to have a deleterious effect on the relationship which forms the basis for caring (O'Connor et al 1991). There are often two clients for the Community Mental Health Teams (CMHT), the patient and the carer, and services need to be able to consider and meet the needs of both.

Support for carers, either in the form of social support from family and friends or from professional and voluntary agencies, is almost always seen as vital to carers' well-being. However, the relationship between support and carer outcome is extremely complex (Brodaty 1992). Happier carers may seek out and use social support more effectively. It may also be that unhappy carers perceive the world negatively in general and so view satisfaction with their support networks in the same way. There is also potential for carers to suffer negative effects from so-called social supports even though they may have a wide circle of friends and family (Edwards & Cooper 1988). Positive support on the other hand may provide a protective buffer against stress. Generally however, carer satisfaction with social support is associated with better health (Gilhooly 1984).
Similarly involvement in carer support groups has been found to have limited efficacy in reducing carer distress, but may lead to increased satisfaction with the support network, and increased knowledge (Brodaty 1992).

Horowitz (1985) found that care giving is primarily the role of daughters/daughters-in-law, and that this is a cultural norm. Females are assumed to be "nurturing"; that it is traditional for children to care for elderly family members; women are more orientated to the family as a whole; women are more flexible, and have more free time. However, modern living is changing perhaps more rapidly than the background cultural beliefs. Many women work full time, and have young families, leaving them very little flexible free time today. There is now less clear demarcation between men's and women's roles in family matters. But in spite of that, it is still daughters who predominate in the caring roles when elderly relatives are to be cared for in the community. This was confirmed in this present study where daughters aged 40 - 50 were the predominant group of carers. The cultural beliefs about "natural" carers still exist. Much stress and burden therefore may be felt by daughters trying to balance all aspects of very busy lives (Horowitz 1985). Strategies for coping with elderly relatives with dementia used by this group of carers may be very different from those, say, of elderly spouses with a similar caring role.

The needs of elderly carers differ substantially from those of younger carers, particularly those of elderly spouses caring for husbands or wives. Spouses almost always live with the person with dementia whereas adult children often live separately. Their needs in carer support can not be the same. Older carers have a greater likelihood of having health needs of their own, and care giving is taking place within a lifelong relationship. Within this context caring for a spouse raises very particular issues with long term reciprocity and gender roles (Parker & Lawton 1994). Researchers in the field of disability have long cautioned against a focus on the carer as opposed to the care-recipient (Morris 1991). However amongst older people carer/care-receiver roles may blur into each other and are less distinguishable.
Caring for someone with dementia can be a self-injurious process leading to stress-related health problems for the elderly carer (Pickard et al 2000).

Care packages must therefore consider individual needs of carers in their different roles, and services be tailored to best meet these varying needs to reduce carer burden. Yet community provision continues to be focused on the needs of younger carers, and thus to concentrate on services of separation, i.e. day care, respite care, institutional care, which is often less acceptable to elderly carers (Wenger 1990).

These services may be wanted and needed by elderly spouses, but certainly not by all. Increase in feelings of guilt about separation from a spouse in utilisation of such services might increase feelings of burden in the carer, especially when the dependent spouse is reluctant to attend day care, or to have a period in a hospital respite facility. In designing packages of care CMHT members need to take these issues into consideration. Older carers urgently require more real choice about the extent of their involvement in care giving, and more effective support. An understanding is needed of the context in which older carers operate, as well as the consequences of inadequate support in terms of stress and carers' general health. If such an understanding exists, professionals may be better able to anticipate carers' needs, and be proactive in offering realistic help, rather than responding only to cries of despair (Pickard et al 2000).

It is also worth noting that a relatively high level of burden experienced by some carers of institutionalised patients with dementia is inconsistent with the common belief that institutionalisation abates the stress of care giving (Thomson & Doll 1982). Demonstrable burden may remain. Burden may be related to guilt over the placement, in spite of the respite from day to day care giving which does have beneficial effect. It can be viewed as a personal failure, after many years of caring with the aim of avoiding institutionalisation.
The focus of most recent studies on carer burden is laid on coping strategies which, if successful, have an effect on the levels of burden perceived by carers, and on the meanings assigned to stressful situations (Pratt et al 1985).

Many factors ameliorate how carers feel as a result of their role. Confidence in problem-solving, the ability to reframe problems, help-seeking and low self-blame are all associated with increased well-being of carers (Neundorfer 1991). How changeable a situation is, i.e. "can it be changed, or must it just be accepted?" are important questions to tackle when considering carer stress and burden. How much a person feels at the mercy of circumstances, and therefore helpless, and with an external locus of control, all may be related to increased depression and greater burden (Saad et al 1995).

Passivity of carers which may accompany feelings of powerlessness has also been shown to be linked to carer burden (Pratt et al 1985). The more immature the coping strategies the greater the likelihood of increased carer burden and psychological distress, and decreased satisfaction (Brodaty & Gresham 1989). Effective coping strategies can not only mitigate carer distress but also possibly enhance the quality of life for the patient (Pruchno & Resch 1989).

This focus on the potential alleviation positive coping strategies may have on levels of carer burden must then be translated into positive service action. Firstly there needs to be recognition amongst health and social services policy-makers as well as clinicians of the potential psychological and physical impact of long term caring on the carer. Care givers are an "at risk" population and are especially vulnerable to emotional discomfort and burden (George & Gwyther 1986). Carers need to be involved in the full process of service provision including assessing, planning, monitoring and coordination between services, and this is needed early in the caring process (Wells & Kendig (1996).
Much research has confirmed that carers often find themselves in situations of emotional, physical, practical and financial burden which can be summarised as a caring dilemma, dealing with a series of negative choices (Wilson 1989).

Less widely reported however are the positive outcomes that carers may derive from their caring role, most notably, positive feelings about themselves, generated by their being able to find patience, compassion, courage and strength in the face of the illness, and of feeling appreciated, needed and productive. An analysis of the carer satisfaction literature reveals a number of sources of satisfaction, linked to concepts such as reciprocity, strength of relationship and meaning attached to caring. These are rewards which are "diverse, pervasive and subtle" (Nolan et al 1996).

Management of the family will evolve and change throughout the course of the illness (Steele 1994). Services should be established which encourage carers to use and develop positive coping strategies. Education and other intervention programmes should be designed to increase carers' confidence in problem-solving at home, and offer help in defining problems, including teaching about how to marshall social support (Jivanjee 1994). Family members can be "co-opted" to act as therapists for patients, especially in the early stages of the illness. They can be taught practical strategies to help patients to cope which may itself bolster carers' self esteem. The carer is central to helping the individual with dementia maintain a sense of identity. If the sense of self in dementia is lost, the primary cause is likely to be the way in which others view and treat the individual. It is a challenge for carers to resist the pressure to define their relative purely in terms of the illness, and thus position them as helpless and incompetent. It can also be a daunting responsibility which can further complicate carers' lives (Sabat & Harre 1992).

Perhaps benefit may be gained from interventions which offer the opportunity to explore, and therefore resolve, some of the negative cognitions and difficult emotions surrounding issues of powerlessness, helplessness, grief and loss, as well as providing education and more generalised positive coping strategies (Saad et al 1995).
Regular contact with professionals or with expert counsellors from the voluntary sector can be of great help to some carers.

Carers do appreciate acknowledgement from the statutory services of the burden they carry. It may help to defuse the sense of exploitation Wenger described if their role is appreciated and valued. Willoughby & Keating (1991) stress the importance of increasing carer confidence through more effective interactions with professionals.

As well as advocating this direction for service development, almost all these authors go on to emphasise the importance of on-going research to underpin and expand the body of knowledge on the effects of positive coping strategies on carer burden. It is not sufficient just to make certain services available to patients and carers. It is also important to distinguish between the availability of a resource, the actual use made of it, and its outcome effect in terms of expected benefit (Pearlin & Schooler 1978). Quayhagen & Quayhagen (1988) says that:

- "more research is needed into management patterns which have the potential of benefiting both the patients' and the carers' well-being"  

Management of carers is crucial to good care for the patients with dementia. Zarit (1989) also states that researchers need to understand the goals and processes of any interventions used to enhance coping skills and strategies, in order to measure the probable effects of the interventions.

- "We are unlikely to be able to change such global constructs as coping and social supports, but probably more specific objectives can be identified and measured."

Such research can work alongside clinical objectives and in the long run will enhance a clinical programme.
Brodaty & Gresham (1992) conclude that psychosocial interventions have the capacity to reduce carer distress and should be made with the same rigour and specificity as in prescribing medications:

- "Doctors recognise that for drugs there are indications and contraindications, side effects, latency periods for onset of action, limited duration of need for the medication, and need for constant review of continuing medication. These same considerations apply to psychosocial interventions." P 360

Schultz et al (1990) and Jivanjee (1994) both consider that longitudinal studies using complex multivariate models are needed to evaluate accurately links amongst variables associated with adaptation and care giver well-being over time. Longitudinal research might determine the factors associated with "successful" care giving. In order to best support carers we must answer questions such as:

- "What kinds of coping skills are most effective, in what kinds of caring situation, and for what kinds of people?" (Jivanjee 1994). P 47

Jivanjee’s way forward seems to encompass and crystallise modern thinking about carer burden. Perhaps these are the questions which will be focused upon as research into care giver burden develops in 2000 and onwards.
Balance of Power in the Health Service

All social practices are shaped by power and different perspectives of power shape our understanding of empowerment (Foucault, in Radtke and Stam 1994). Societies marginalise those who do not conform to the norm. In developed western societies these norms include youth, health, employment and independence. Illness and disability are also social constructions. An individual patient is pathologised for failing to meet an unspoken norm, in this case able-bodied-ness. They are marginalised by the attitudes and exclusionary practices that are ingrained in the fabric of society (Morris 1991). Health and welfare professionals are members of the society which hold these beliefs as of course also are the members of the powerless groups themselves. This can lead to a self fulfilling prophecy and the maintenance of power differentials.

The power differentials in the health services and welfare state can be especially delineated. Service users are frequently in a powerless position especially when decisions are made ‘for’ them by service providers rather than ‘with’ them. There is a history of ‘the authority of position’ and ‘the authority of knowledge’ in the health service (Webb and Hobdell 1980). Professional and bureaucratic hierarchies have shaped welfare services and especially the NHS and there is no living history of either patient/carer participation or consumerism until recently. However, major changes are being required of the NHS. There has developed a declining belief in centralised solutions to health and social problems with a concomitant resurgence of enthusiasm for the rights of the consumer (Williams 1989). Patient participation in decision making is now viewed as essential to the delivery of the individualised care in the 1990s (Saunders 1995).
In health care, consumer audit has come to the fore alongside clinical and medical audit (Justice and McBee 1978). There is a move to look at health and social services from the patients' / carers' point of view, stressing the need to focus on patients and carers as consumers of health care with the same kind of decision making as are conceded to consumers of goods and services (Burgess and Burns 1990).

A major culture shift will be required if changes in the balance of power are to be achieved in the health service. There needs to be a move from provision of services based mainly on knowledge and professional judgements which many people experience as paternalistic and disempowering to the delivery of a needs lead service in which a culture of partnerships, real partnerships between service providers and recipients can flourish (Croft & Beresford 1993).

**Partnerships between professionals and clients**

A great deal has been written about the philosophies of empowerment of patients and the importance of equalising power differentials and the delivery of health care. However much more has been written about participation than is actually practised. Much time is spent in extolling the virtues of empowering service users and encouraging them in participation but little practice guidance is given on how this is to be achieved. Participation where it does exist can be little more than lip service paid to the ideal as the underlying ideology and decision making structure have never really been tackled to date. There is thus a danger that participation may remain an elusive concept (Hoggett & Hambleton 1987). Moreover human services have an enormous capacity for destructiveness. Providers set out with a set of principles and are diverted by a forest of hidden agendas, powerful vested interests and unconscious drives, all of which may lead to an ideological model of services becoming completely inconsistent with what users and staff actually experience and what they want and need (Brandon 1991). It must also be stressed that adequate resources are needed to back up consumer idealism.
A changed culture is not likely to last long if there are not the resources to underpin the initiatives; if there is not enough money available then services are likely to be budget led rather than user or needs led, shaped by financial constraints rather than by what people want or prefer. User led services are not a cheap option. However lack of money is no excuse for continuing to provide inappropriate or unacceptable services or for preventing users having their say in what happens (Croft & Beresford 1993).

The philosophy that drives the ideals of consumerism in the health service is that users should be involved in their own health care. Clients and carers should jointly agree individual care programmes and networks of support instead of people being channelled into the current limited services. Professionals need to work with clients rather than doing things “to” them or “for” them (Smith 1998). They need to listen to clients and act on the knowledge gained rather than responding to diagnoses or labels (Hutchinson, Linton & Lucas 1995).

Participation is about working in partnership. It requires professionals to recognise the expertise and experience of the person who needs support in his or her daily life. This does not mean diminishing the expertise and experience of the practitioner but rather putting this at the disposal of the clients. Participation is about sharing knowledge and experience each to the other in order to jointly establish what someone’s needs are and how they can best be met (Meethan & Thompson 1993).

The experience of illness is largely characterised by loss of control over one’s physical and or mental state, one’s environment and even one’s freedom to make decisions on one’s own behalf. If contact with professional care givers further limits people or prevents them gaining control over their lives then it challenges the legitimacy of the service. Patients’ and professionals’ interrelationships are vital in promoting a sense of worth and competence. Practitioner should use their skills and experience to promote choice and control in clients' lives (Building Bridges Collaboration for Change 1994 Chapter 2).
The last important point to make on partnership principles is that Rigge in 1994 highlights the fact that in getting users to take more responsibility in health care service planning and delivery it is important to stress that partnership is in a health service rather than an illness service. Without success in this area, increasing consumer involvement will only lead to a downward spiral of clamouring demand being met with clinical refusal, leading to dissatisfaction. Clients as partners in health care must be alert to the current political and managerial climate in NHS developments, understanding professionals' constraints as well as focusing on their own needs.

Elderly Clients and the Health Care System

In general the elderly as a group are regarded by society as fairly low in the power stakes, however ill conceived that is when applied to individuals within the group. The power differentials are greatly widened when elderly people become ill and widened even further when cognitively impaired as well as physically impaired. When these inequalities in power are taken into a health care system which has an already established power inequality between professionals and patients, the power differential is huge. It should be stated that this is a powerlessness which is compounded by the fact that it is most often accepted by many of the elderly patients themselves. Elderly patients, especially the very elderly of 85 years plus, may hold the same views of themselves as does society generally of their powerless state, and may also acknowledge and defer to the powerfulness of the professionals. They may even resist well-intentioned attempts by professionals to establish partnership principles and to involve them in their own health care, actively preferring to hand over all responsibility to those whom they believe 'know best' (Brooker 1994).

It can thus be seen that empowerment and partnership as principles and philosophies can be very difficult issues to tackle when elderly people come into contact with health and social services.
Management of the Health Care of the Elderly

As with all interactions between health professionals and clients, the key to empowerment and regaining choice and control in patients' lives is in the relationship between the professional and individual elderly patient. The role of the health professionals who work within the health care system cannot be underestimated (Morris 1997). Kitwood (1991 - 2) is referring to elderly patients with dementia when he says:

"Personal well-being is affected by the care practice ...... People can be lifted through sensitive caring or pushed towards apathy and despair by neglect or put downs." P 5

Every person whatever their disability or impairment deserves to be treated as we ourselves would wish to be treated. Good care honours personhood. This is especially important when caring for elderly clients. The acknowledgement of, and respect for their individual unique histories, abilities, tastes, preferences, vulnerabilities, strengths and needs, supportive interpersonal relationships and individual reassurance are of incalculable importance to all patients but particularly to the elderly who are frail and sick and whose physical and mental powers may be failing. This philosophy is not easy to put into practice. Health care professionals are not immune to cultural stereotypical beliefs about the elderly as a group in society. However the willingness to acknowledge that there is a disproportionate allocation of power between elderly clients and professional carers and to address that discrepancy is the battle half won.

Elderly People with Mental Illness

Society may regard elderly people suffering from mental illnesses as one of the least powerful groups of people. One quarter of those over 85 develop dementia and between 10-16% develop clinical depression (Audit Commission 2000). Both illnesses can affect a person's ability to take control over their own lives.
However ageism may have its part to play in health service staff's attitudes to the psychosocial needs of the elderly (Brooker 1994). Mental health services intervene not just at the medical level but also at a social and psychological level and so partnership principles and the encouragement of independence take on an even greater importance.

One of the most disabling barriers faced by people with dementia is the all too common assumption that it is impossible to communicate effectively with them. However communication is fundamental to good care. The multi-faceted and variable situations in which people with dementia find themselves mean that consultation with them, needs to be an integral and on-going part of what happens from day to day and week to week. It is possible for staff in busy service settings to undertake, in creative ways, meaningful consultation work with people with dementia (Allan 2001). Service planners and managers need to be proactive in supporting consultation and communication with these patients, and supporting staff who advocate this practice.

Lack of communication with professionals can lead to patients feeling isolated, depressed and with a hopelessness associated with the diagnosis and a perceived denial of opportunities (Kitwood & Benson (eds.) 1995). However dementia is a term for a cluster of symptoms and signs of intellectual and cognitive function being disrupted, and individuals vary in the way in which their conditions progress. The illness may have minimal manifestation or vary through mild, moderate to severe. People with dementia are no more a homogenous group than those with other illnesses and should be treated as individuals with equal human rights to privacy, dignity, independence, choice, rights and fulfilment (SSI 1989).

The degree of sensitive caring management has been shown to have an effect on whether or not an individual remains fairly well preserved or deteriorates through the stages of dementia that are commonly described (Kitwood & Bredin 1992). Even when people have severe dementia with a high degree of speech impairment, non verbal
signals are often exceptionally candid and revealing and in fact patients may give out many indications relating to the presence or absence of well being, especially to those who know them well. Informal family carers may be especially skilled in reading these signals and understanding the idiosyncratic nature of the patients' language (Kitwood & Bredin 1992).

Mental health services intervene not just at the medical level but also at a social and psychological level, and so partnership principles and the encouragement of independence take on an even greater significance.

**Informal Carers of Elderly Clients**

Almost all publications about clients working in partnership with professional health care providers focus on the patient as the client and not the carer. The Trent Health Guide to User Empowerment in Mental Health Care refers to service users at all stages of the document. Indeed with regard to carers it states that:

"While carers may wish to speak for their relatives, it is important to remember that their needs and perceptions are different from the needs and perceptions of patients."  P 19

However when patients have dementia their carers' views in this instance may assume a greater significance than in other disease scenarios. The patient obviously has to be the main focus of the care package. Dementia, in most instances does not obscure the individual character of the person affected, and their preferences and needs must be sought (Allan 2001). However, given the subtlety and largely unconscious nature of much of their non-verbal communication, carers who know the patients well may be experts at interpreting the signals which denote satisfaction or discomfort in the service situation. Carers have detailed knowledge of their relatives, and this is vital to producing practical care plans (Nolan et al 1996).
They are also people whose well being is vital to the continuing best management of the patients with dementia in that they carry out much of the care which the professionals have planned. Carers who look after their relatives with dementia for 24 hours a day should be considered users of the service too. Patients, carers and professionals should all be in partnership together. There was however considerable evidence from carers' reports, cited in Gillies (2000), that carers' positions were felt to be "somewhat dependent" on professionals as opposed to working with them. The reasons cited by carers for this situation included the fact that they felt excluded from the decision-making processes, and felt that communication was poor. It is possible for health professionals, by working with carers, to build up a picture of patients' lives to infer their needs more effectively, and to be able to assess their preferred options for their care and future management (Smith 1988).

Twigg & Atkin (1994) spotlight the carer and his or her relationship to the cared for and the impact on this relationship of policy and practice. They highlight the ambiguous position of carers and delineate four ways in which they may be regarded by professionals and agencies. These are 'resources', 'co-workers', 'co-clients' and as 'superseded' carers. Almost seven years on, their position in relation to formal services seems no clearer. Professionals delivering community care still struggle to achieve effective collaborative practice (Gillies 2000). These varying roles carry different implications of how much support is offered and whose interests are judged to be paramount. All these roles have power differentials. The relationships between professionals and carers is also a fraught area when attempting to instigate partnership principles. Both professional and carer may feel vulnerable in the relationship. Both may feel they have expertise in the management of patient care. Negotiation and trust are critical factors in the interactions between professionals and carers.

It is important to note that partnership with carers does not mean coercion of carers to contribute more fully to assessment and planning of patient care when they may not wish to take such an active role in the patients' care management.
Very old, or ill carers, or carers who may be dependent themselves, might prefer to rely on experts they can lean on. For this reason it is important to assess the family situation at early contact. Partnership with clients means adaptability to variations in clients' needs to exert some control, or to have more active roles at different stages of development of the patients' illnesses.

It has been documented that the element of threat posed by the idea of consumer equality with professionals is not inconsiderable. Glenister (1994) describes how patients and carers want a more active role in service planning and evaluation, and yet clinicians find more active client participation threatening, this being true for professionals in mental health care as much as professionals caring for clients' physical health.

Obstacles to good working relationships between professional and lay carers working in partnership are described by Wilson (1995). She considers that both partners, professionals and carers, lack awareness of their two different worlds. Traditions in the NHS are of professional power and control, and a lack of value placed on the experiential knowledge of users and carers living with a health problem, and experiencing the effect of service delivery. Both partners lack interaction with each other on an equal level, and lack knowledge and understanding of their different roles in caring.

Partnership requires attunement to a mutual "stock of knowledge" at hand; emotional and motivational attunement to each others' concerns; taking for granted, (and implicitly assuming the other takes it for granted), that one can contribute worthily, and feeling that ones identity is not under threat.
Is There A Dichotomy Between Patients And Carers Within The Issue Of Empowerment?

Ideally, patients, carers and professionals should all be in partnership together. By working closely with carers it is possible to build up a picture of patients' lives, to judge needs more effectively, and to be able to assess preferred options for future care and management.

Informal carers may be experts at interpreting the verbal and non-verbal cues with which their relatives attempt to communicate. However, they may not always place adequate weight upon their communications, either because they consider that their relatives' understanding of issues is impaired, or because their relatives' feelings conflict with their own. This may occur at either a conscious or subconscious level. Indeed, with regard to carers the Trent Guide to User Empowerment in Mental Health Care states that:

"While carers may wish to speak for their relatives it is important to remember that their needs and perceptions are different from the needs and perceptions of patients."

This is a difficult issue because informal carers are people whose well being is vital to the continuing best management of the patients with dementia in that they carry out much of the care which the professionals have planned. Carers looking after their relatives with dementia for 24 hours a day should be considered service users too.

Compounding the problems may be the fact that it may often be difficult for health care professionals to completely segregate the needs of the patient from the needs of the carer, when attempting to make decisions about the most appropriate packages of care for the patient with dementia. There may sometimes be real problems if the wishes of both patient and carer conflict. It is very hard to make decisions which are solely in the best interests of the patient, when confronted with an overburdened carer whose ability or willingness to continue the caring role at home may be at risk.
In recognition of the difficulties of carers, and the fact that health professionals can not always act in the best interests of both parties, government legislation (The Carers' Services and Recognition Act 1995) advises that a carer should have access to his/her own needs assessment made independently of the needs of the patient.

It is often possible however to manage to meet the needs of both patients and carers provided health professionals have understanding of all the issues involved. There are 4 aspects of promoting choice and control for both people with dementia and their carers (Meethan & Thompson 1993). These are:

- **Consultation** - asking both patients and carers what they want to happen in their lives.
- **Participation** - inviting more active involvement of both parties in the decisions to be made about how to meet both their needs.
- **Veto** - giving both the right to say "no" to plans and strategies suggested to meet needs, and offering the option to try other means. Veto is an important way of shifting the balance of power, and a key method of enabling people to make choices.
- **Negotiation** - all the issues should be discussed between patient carers and professionals to find a way forward.

Although most people have an interest in the well-being of their family, and would act in the best interests of their relative with dementia, this may not always be the case, nor is it always simple to determine what the best interests of the patient are. However positive reasons for employing the above model are that, generally, the carers are concerned about the good of the patients, knowledgeable about the patients' values and preferences, and that the family deserves recognition as an important social unit concerned with matters intimately affecting its members. (Gilhooly 1992).
Issues of patient consent to treatment, therapy and research

A. Consent To Treatment

Until a few years ago, doctors made decisions regarding treatment, alone, or in consultation with relatives. There did not seem to be much conflict, and there was little discussion about the legal and ethical issues surrounding medical decision-making. However, times have changed. Not only is consumerism in, and paternalism out, but health care professionals are becoming increasingly aware of the ethical issues surrounding clinical decision-making (Gilhooly 1992).

In the context of health care, consent is defined as:

*a voluntary and continuing permission…… to receive a particular treatment based on adequate knowledge of the purpose, nature, likely effects and risks of that treatment, including the likelihood of its success, and any alternatives to it (DoH and Welsh Office (1994)).*

The mentally competent adult

Before treatment commences English law requires that the health professional obtains the consent of a mentally competent person. The law presumes that an adult has the mental capacity to make a valid decision, and therefore has the right of self-determination. The principle of autonomy carries a great deal of weight in modern moral philosophy. It means that we respect the right of each person to determine what happens to him. Without a person's consent any treatment or care could be considered trespass to the person, and such a person has a right to bring an action for trespass to the person. This right of action holds even if no harm has occurred (Dimond 2001).

At first sight, this appears to be an empowering element within health care for patients. There are however areas within the law which are unclear.
It is stated in DOH (2001) "Your Guide to the NHS" that:

"patients are entitled to accurate, relevant and understandable explanations about their conditions, what treatment is available and what it will involve"

In the United Kingdom, however, the law allows doctors to decide how much information a patient is given, and what information it is in the patients’ best interests to give. The reluctance to give information may be seen by professionals as “acting in the best interests” of an individual, based on the simplistic belief that “what you don’t know can’t hurt you”. The arrogance in believing this is paternalistic in the extreme (Crump 1991). Without full information the patient cannot give truly informed consent, and it calls into question the whole nature of the consent process in the UK.

The adult who is mentally incapacitated

UK law on patient consent is also unsatisfactory when a patient lacks the capacity to make his/her own decisions. The Law Commission definition of mental incapacity is as follows:

“A person is without mental capacity if, at the material time, he/she is unable by reason of mental disability to make a decision on the matter in question; or unable to communicate a decision on the matter because he/she is unconscious, or for any other reason” (Law Commission Mental Incapacity 1995)

At present in this area of mental disability there is a vacuum in the law. In 1999, a White Paper was published giving guidelines on decision-making on behalf of the mentally incapacitated adult, proposing a statutory framework on which decisions should be based. But legislation to enact the proposals is still awaited.
The three stage test of mental incapacity

In a recent case brought before the Court of Appeal (1994) the three stage test of mental incapacity was put into writing. Three vital questions, it was stated, had to be answered in determining whether or not incapacity existed. These are:

1. Can the patient comprehend and retain the necessary information so that he/she can weigh the information and come to an informed choice?

This stage includes people with dementia who may display intermittent competence, and then forget the information.

2. Can he/she believe the information?

Patients with paranoia for instance might not be able to believe the information given to them.

3. Can the patient weigh the information, balancing risks and needs, so as to arrive at a choice?

Those who have cognitive disabilities may be unable to do this.

The three stage test of mental incapacity would be applied if decisions being taken were of vital importance to the life, or continuing health or well being of a person with dementia. In these situations health professionals have to rely on common law powers that they should act in the best interests of the mentally incompetent adult. When a person is incapable, the importance of individual autonomy must be acknowledged, but it would be wrong to promote autonomy into the sole and supreme value, capable of eclipsing all other considerations. What must be aimed at is a balance of values. Acting in the “best interests“ of an incapacitated adult is a key principle concerning his/her treatment and management.
"Best interests" are not confined to best *medical* interests. Other factors which need to be taken into account include the patient's values and preferences when competent, their psychological health, well-being, quality of life, relationships with family and other carers, spiritual and religious welfare and their own financial interests (DOH 2001). Where the adult's incapacity is permanent or likely to be long-standing it will be lawful to carry out any procedure which is truly in his/her best interests. When there is doubt about an individual's capacity or best interests the High Court can give a ruling on these matters, and on the lawfulness or unlawfulness of a procedure.

A relative does not have the right to make major decisions on behalf of a relative who is mentally incapacitated, and should not be invited to sign consent forms. Only the patient should sign consent, and if he is unable to do so, because he cannot communicate his wishes, or lacks the capacity to understand the issues, decisions are made by clinicians. Relatives should be consulted, because they may have information about previously declared wishes, but health professionals make the decisions based on the powers of common law, and in the knowledge that for some major issues, it is advisable to seek a decision from the court of law (Dimond 2001).

Obviously there are different levels of decision-making. People with dementia may lack the capacity to weigh information and balance risks to arrive at an informed choice about more critical decisions, but may be perfectly able to take decisions on day-to-day matters. When caring for patients with dementia, nurses also must consider issues of patient consent in managing their care. The principle of caring for patients in their best interests also covers such routine procedures as dressing, washing, putting to bed, and assisting with the consumption of food and drink. Such consent can be given in two ways, i.e. implied consent or expressed consent. The former is non-verbal and is implied by nature of the fact that the patient is compliant and does not object to his therapeutic regime. Expressed consent may be written, but also could be oral. The validity of consent does not depend on the form in which it is given. Written consent merely serves as *evidence* of consent. Regardless of the type, consent is necessary before nursing treatment is carried out.
The reasons for eliciting patient consent to treatment in non-medical management are
given as:

- Consent offers and safeguards autonomy
- Fosters respect for people
- Informed participation in health care enhances and assists the quality of care.

The nurse may have an advocacy role in that he/she is often best placed to know the
emotions and concerns of patients. She may assist if the patient has difficulty
formulating questions, and can ensure that explanations are given in plain language
so as not to further confuse the patient (Buchanan 1995).

**The Role Of Relatives**

Relatives do not have legal authority to consent to treatment for patients. Although
most people have an interest in the well being of their family, and would act in the
best interest of their relatives with dementia, this may not always be the case, nor is
it always simple to determine what the best interests of the patient are. The selection
of a relative as a “proxy” decision maker does not guarantee that the patient’s rights
will be protected.

However positive reasons are:-

- Family concerned about the good of patient
- Family knowledgeable about the patients’ preferences and values
- Family deserves recognition as an important social unit concerned with
  matters intimately affecting its member

When we think of the rights a dementing person has, do we emphasise their present
capacities and situation, or do we emphasise the fact that the person’s disorder has
occurred in the course of a wider life whose whole length must be considered in any
decisions made (McCall Smith & Nichols 1992).
B. Consent To Research

Progress in the treatment of any disease requires research, and dementia is no exception. The Department of Health gives the following guidelines for clinicians. Before any research study carried out on human beings is undertaken it should be approved by an independent research ethics committee. Wherever possible research should never be performed on incapable patients if it is possible instead to carry out the research with persons capable of giving consent.

Most writers on the subject of medical research distinguish between therapeutic and non-therapeutic research.

Therapeutic research

Therapeutic research is that which is directed towards amelioration of an illness from which the research subject suffers, and in practice, amounts to treatment of the patient. Patient consent for participation in this type of research is subject to the same rigorous procedure as for other forms of medical management. Patients with dementia fall into a group which might be called a "vulnerable category" of subjects. If a patient is incapable of consenting to conventional treatment he or she may still be entered into a therapeutic research study, and treated, on the grounds that it is in his/her best interests for the management of his/her condition. There is no legal objection to the involvement of people with dementia in therapeutic research provided that the risk involved is minimal, or of such a nature that a reasonable person, in the position of the patient would be likely to have consented (McCall Smith & Nichols 1992, The Royal College of Physicians 1996). The considerations which justify treating such vulnerable patients without informed consent justify therapeutic research as well.
Non-therapeutic research

Non-therapeutic research entails issues of a more difficult nature. It involves no possible benefit for the subjects of the research themselves, as it is incapable of relieving the condition from which they suffer. The position concerning research which does not have the potential immediately to benefit the person’s health is a legally uncharted area (DOH 2001). There is a widely recognised need for research into the condition of dementia. If absence of consent must inevitably preclude participation in research, then it would never be ethical to involve in research a person with dementia so incapacitated that informed consent was not possible.

The code of practice for the Mental Health Commission states that whenever possible research should be confined to patients with mild dementia whose capacity to give consent is not in doubt. A person with dementia can give consent to participate in research if he understands what is being asked, and feels free to refuse. However it is acknowledged that some research can only be carried out with patients with more advanced disease, or research which takes place throughout the course and progress of the disease, as in longitudinal research. The arguments on implied consent can be brought into play here, ie if the research is such to which the subject might be expected to have consented, had he/she been capable of doing so. Excluding the subject from such research is denying him/her the opportunity to participate in research which may serve the social good, an issue about which the subject may have felt strongly before the illness became severe (Whalley 1992).

However, The Code of Practice of the Mental Health Commission states that:

“No patient who being incapable in any way refuses or resists participation in a research project should be included in that project......But, a patient who being incapable nevertheless “consents” or is neutral towards participation may take part in the project.”
Guidance from professional bodies such as the Medical Research Council have suggested that it can be ethical to perform research which involves minimal intervention on incapable adults, if certain stringent conditions are met:

- The research must be approved by the relevant Research Ethics Committee
- It must relate to the condition from which the incapable adult is suffering
- It must be demonstrated that the research is not against their interests.

The conduct of this research project

This research project can be described as therapeutic research with carers of people with dementia as it aimed to ameliorate carer distress and to increase feelings of control by means of having a multidisciplinary carer held record kept at home. The primary subjects in the research were the carers, and not the people with dementia. Written consent to participate in the research was therefore sought from carers, and this was agreed by the Leicestershire Ethics Committee in 1995. The project therefore met the conditions of the Medical Research Council (MRC) at the time of its inception. Further discussion on issues of consent to participate in research relating to this study will be presented in the Discussion section of this document.
Caring about Carers

There have recently been several Directives issued by the Department of Health concerning the rights of family carers, Carers' (Recognition and Services) Act 1995, Caring for People (1996), Modernising Health and Social Services (1998) and Caring About Carers - A National Strategy for Carers (1999). The underpinning philosophy concerning carers in these documents is that the role of informal carers should be officially recognised and valued, and that they should be formally supported by services. The enactment of such a strategy should greatly empower carers, and allow their voices to be heard.

The National Strategy emphasises that all organisations involved with caring must now focus upon not just the client, patient or user, but must include the carer. The objective is to enable those who care to do so without detriment to the carers' inclusion in society, and to their health. It aims to achieve the right balance, such that "policies and procedures should ensure that both people involved in the caring relationship are valued, and the needs of one party are not made subordinate to the other."

It has been recognised that helping carers is one of the most effective ways of helping the people they are caring for.

Policy guidance has been published in response to the legislation giving detailed and practical advice to all agencies; the NHS, local government and the voluntary and independent sectors. Guidance is aimed at professionals in commissioning, strategic planning contracting and monitoring, as well as those who are managing services and improving practice (Banks & Cheeseman 1999).
This strategic approach encompasses three key elements of carer support. These are:

- **Information for carers**

  Carers need accurate, appropriately timed and accessible information. When they are better informed they feel more in control of their situation.

- **Support for carers**

  The *Carers (Recognition and Services) Act* (1995) gives the carer an entitlement to his/her own independent assessment when a local authority carries out an assessment of the person cared for. This facility empowers carers because it encompasses recognition of their role, and taking account of what they say. An integrated, family-based approach to the caring situation does not highlight either the user or the carer in isolation, but facilitates an assessment of the whole “caring system”, and the range of support available to both users and carers. The Carers’ Act was never intended to lock carers into their caring role, but to carry out an assessment process which should establish how able and willing the carer is to continue his/her caring activities (Gillies 2000).

- **Care for the health and well-being of carers.**

  The carers have a right to have their own health needs met, and legislation includes new powers for local authorities to provide services for carers as well as for those they care for. These include focusing upon services which allow carers to take short term breaks from caring, and the provision of enabling grants or financial support measures to facilitate this. Legislation on partnership working, between health and social care organisations, and between organisations and the users/carers themselves is intended to create a seamless service which better reflect client wishes.

  Altogether it is clear that, in today’s climate, the importance of carer empowerment has been recognised, as has the therapeutic effects of such empowerment for both the carers themselves and for those they care for.
The Pilot Study

Introduction to the pilot study

Carer held records is an initiative designed to empower carers of patients with dementia, and to facilitate partnerships between professionals and carers. The following pilot study was conducted to assess the efficacy of the idea.

The aims of the study were:-

- To launch the initiative of carer held records. Twenty carers of patients with dementia would hold and use the document.

- To assess carers' satisfaction with the system, and to evaluate actual use of the document made by carers and by multidisciplinary team members.

- To assess carers' roles as partners with professionals in care planning via use of the record.

- To measure how suitable the designed documents are before the launch of the main study which will measure outcomes of the system of carer held records over 3 years.

Characteristics of the sample

Of the 20 respondents in the study only 16 families actually held the carer held record at home. Two families decided not to participate in the research. They, however, were interviewed to ascertain their feelings about the project. Two patients died after the families had accepted the offer to participate, and these carers were not interviewed. One carer died during the 6 month study period, and these records were examined to see how professionals and the carer had used the record, and observations included in the results.
There were 8 male patients and 12 female patients. The carers of these patients were, 3 husbands, 7 wives, 4 sons, 5 daughters, and 1 other. This latter carer was unusual in that she was really no relation at all to the patient, but was the daughter of the war evacuee who had been like a son to the patient. She and the patient lived together, and the relationship was similar to grandmother and granddaughter.

**Method**

The method of research involved issue of the carer held records to participants during explanatory initial interviews. Written consent was obtained from carers, and written notification of their participation was sent to GPs and CMHT members involved in the care of patients at home.

Evaluation interviews were carried out only by the researcher, using a questionnaire designed to obtain both quantitative and qualitative information about the use of the record, and carers' opinions of the system. Quantitative data was obtained by asking respondents to place a dash across a 10 cm. line which ranged from 0 - 10 ie. very bad to excellent. The dash was placed where respondents felt, from a visual point of view, it most accurately reflected their assessment. A precisely measured score could then be obtained. Qualitative data was obtained by note taking during interviews of respondents' comments verbatim. CMHT members were intervieweed as a separate assessment to elicit their views of the project.
Data analysis

Quantitative data analysis:

This was accomplished by calculating an average score, and a range of scores for each question in the questionnaire.

Qualitative data analysis:

The collection of qualitative data involved the carers’ giving descriptive explanations of their personal feelings about the project. This qualified the scores they gave, and allowed more in-depth analysis of the effectiveness of the study. Analysing data using qualitative techniques follows a structured framework within which guided interpretations can be made.

The qualitative data obtained in this pilot study were fairly straightforward. There was no need to code data, and themes were relatively simple, emerging steadily from the very beginning of data collection. Interviews were not taped, but data collected by note taking at interviews. The data analysis is based on grounded theory even though the links and categories were never very complex.
Results

The most significant results of the study were as follows:-

Q1 - Do you feel that the system of holding carer held records is a valuable one?
15 responses Range : 1-10 Average : 7.0

Figure 2 Do you find the carer held record system valuable?

Generally carers liked the system of having carer held records (CHR) at home. Eleven out of 16 gave high scores, although several had qualifying comments to make as will be seen in analysis of all the questions. Comments of overall satisfaction made by carers were:-

- "I wish I had had this before"
- "I feel more involved with the professionals.
- "I know what they're all doing because it is all down in the book."
- "It's easy to manage the whole package once you get used to it."
The respondents who rated the whole system as below average in value identified the following reasons:

- "The record would have been very valuable to me if I had had it at the beginning of her illness. I have had to fight to get information, and recognition of what I need to look after her properly at home."
- "I've felt a little down and depressed, and have not wanted to be too involved in what's happening to her. I can see it would be useful to others, or to me if I had felt better."
- "I did not want to be part of it. I felt it was off-putting - not the book for me!.
- "I've not had it long enough to assess the value as yet."

These individual issues will be analysed further in the Discussion section.

Q4 Do you feel that you can be assertive about your views on care planning and evaluation of care plans?

12 responses Range : 2-9.5 Average : 7.6

Figure 3 Assertiveness
The response to this question was interesting, because although it appeared that some clients still felt that they should be consulted more by professionals, and some still lacked confidence about their role as carers within the teams, having the carer held record seemed to encourage them at least to speak, and put their viewpoints forward. The average score here was 7.6. Eight out of 12 indicated that there was a considerable increase in their ability to be assertive, and, in terms of equal partnership with professionals, this was an encouraging outcome.

Format of the document

Five specific questions were asked about the format of the document. These were about size and weight, order of presentation, location of information, legibility, and language comprehensibility.

Figure 4  Size & weight of document

![Size & Weight](image-url)
Size and weight

Although 4 respondents felt quite content with the package as a whole, these were families who had made best use of the record, were satisfied with everything, and very positive with all aspects of the project.

In general, respondents felt that the format of the document was a problem, and that the design could definitely be improved. Examples of comments made are as follows:

- “It was too big and heavy. I’d have liked to see a softer binder - like leather.”
- “The whole idea is very valuable to carers, but the package is badly designed.”

Such reactions were a theme which became clear from first introduction of the carer held record to clients, and continued through the evaluation process.
Evaluation of individual sections of the document:

Professionals’ section

There was quite a range of opinion about the value of the professionals’ input to the carer held record, and it can be seen from the graph that this very much depended on the degree of professional involvement, both with the case, and with the CHR project.

16 responses Range : 0.3 - 9.2 Average : 5.5

Figure 5 Professionals evaluation

Five rated professional input as very valuable. 3 felt that its value was “middling”, and 3 felt that it was of little or no value to them. 6 respondents however could not give a quantitative score because the section had not been used at all by any professional involved in the case. It is important not to be too critical of the professionals about this issue because there were many and varied reasons for their lack of input.
Firstly, when CMHT professionals called at the home, the CHR document might be elsewhere, eg. at the day hospital, and so no entry could be made. Also the reverse might be true - that patients would be seen by keyworkers at the day centres whilst the CHR remained at home. Secondly, the duration of the study was short. In some of the less complex case histories, input by professionals was minimal, and/or infrequent, as would be expected. It emerged at evaluation that some carers would have liked professionals to be more explicit, and committed to written entries in the record. This is exemplified in the following comments:

- "I have to prompt the professionals to use it. It would be more valuable if professionals used it properly."
- "I feel that professionals do not have the time to complete it. It needs more co-operation and co-ordination to make it really work well."
- "The professionals need to be as enthusiastic about the project as the carers are."

In defence of the professionals, they had more difficulties with the format of the document than did the carers. Carers had continuous use of the book, and could constantly refer to it. Professionals, in the pilot study, perhaps only had one or two clients in their whole caseload who were project participants, and so they were less "au fait" with its format, and with their role in completing their section. Professionals considered their section was badly designed in that it was not conducive to easy completion. Professional opinions were considered with care in the redesign of the CHR, as many of their difficulties with the system were design faults.
Carers' section

Most carers had little doubt that their input into the CHR was valuable. They considered it to be important to keep records, and to write down issues to be discussed with experts. They also considered that the information they could supply would be of value to professionals in care planning for their relatives.

13 responses  Range :  4.7 - 9.6  Average :  8.2

The carers' section contained more than just a diary. It also had a "problem/answers" page, which was used by a few clients, and found to be useful for remembering special points to note, or questions they would like to ask. The diary however was the most popular part of the carers' section. It was used in totally different ways by carers, either in very detailed diary entries, or to record major changes and unusual incidents only. Clients found it valuable however they adapted it to be of best use to them.
o "I felt relieved to have everything written down, right to the last day of his life."

o "Some days there is a lot to say. Other days there's nothing. No changes - no writing."

o "Communication is better since the diary is being kept."

Of the clients who made most comprehensive use of the diary, most used it to document their own feelings about being carers, and the high and low points of looking after their relatives with dementia. They used it as direct communication with staff, as if talking directly to them. Two carers volunteered, completely unasked, to have their diaries used as publications, perhaps by the Alzheimer's Disease Society, or in any project publication I might undertake, so that their experiences might be of value to others.

It must be documented that the two families, who declined to be project participants, had comments to make about their feelings when introduced to the package. Regarding the carer section, the comment was made that, before onset of the illness, their relative would not have wanted carers to divulge private information to others. This especially applied to the personal history questionnaire, but also to use of the diary.

o "I felt it would be a nuisance to complete. I'd forget it, and have to go back and backdate entries."

One very interesting comment was made by one of these carers who found the idea of keeping a diary "frightening". She said:

o "I feel very guilty about all the complex feelings of love and hate I feel towards Mum. It's difficult enough to deal with them. I can push them all away from me now, and that's how I cope. But voicing the feelings would make them more tangible, and if I wrote them down, I should never be able to deny them or escape from them."
Such comments illustrated how important it is to remember that equal partnership between carers and professionals must take all feelings into consideration. For a few, the carer held record might not be of value at all, and this should be acknowledged and respected within the partnership.

Community key workers' assessments of the pilot study

An interview was conducted with each of the three CMHTs involved in the carer held records project. Team members may only have had one or two patients from their caseloads as subjects in the pilot study, and so it seemed more sensible to encourage open discussion in team interviews, rather than eliciting the views of one professional, about one patient/carer in single interviews. All three teams agreed that the project was useful to carers, and were supportive of the principles of partnership with carers, but they specified that the project's value and success depended on the needs of individual clients, and their individual circumstances. All CMHT members stressed, in a much more forceful way than carers, that they had had problems with the document design. This was probably because they had had far more experience with different kinds of documentation than had clients, who had nothing with which to compare it. Professionals had difficulties in locating information within the package, and in deciding which pages would be the most appropriate for professional entries. These problems experienced by professionals are fully acknowledged, and are addressed in the document re-design. The teams' opinions and their experiences of being involved in the pilot CHR project were very valuable to the research process.
Outcome of the pilot study

Overall, the results of the pilot study on carer held records showed that carers liked the system of having carer held records for their relatives with dementia. Most gained benefit from the initiative, and felt more valued by professional health care providers as a consequence of the project.

It must be acknowledged that 20 respondents constitutes a small study sample. However the characteristics of the sample reflect several of the sociological facets which one would expect, and therefore might be considered as representative of the population. There were more females than males amongst the patient sample, ie 12:8, which is representative of population survival patterns. There were also more female carers than male carers 13:7 which sociological survival studies suggest is the norm. Although the results showed the value of the project to carers, there were dissenting voices amongst the participants. 5 out of 20 assessed their experience of having CHR as not very valuable. It was important that the pilot study should address the issues raised by this minority, in order to improve the project for the main study.

Five main reasons were cited by participants to explain why the project lacked value for them. The first reason was that some carers had been looking after their relatives for a long period of time, and had already learned “the hard way” about available services, and how to access the most appropriate professional and voluntary sources of support. These respondents felt, however, that the CHR would be a valuable initiative to present to carers at the onset of their period of caring, and in the early stages of the illness. This was an issue addressed in the main study, where subjects were supplied with the carer held record, and offered equal partnership, when first referred to, and assessed by CMHTs. The records therefore were part of the whole package of care for these clients from the start.
I acknowledge that my commitment to, and enthusiasm for the project may have had some influence on carers’ acceptance of the worth of the project. However, I thought that this was of small significance in the pilot study, where multidisciplinary use of package and carers’ experiences of using the documents were what was being evaluated.

Many carers said that they would like more written input by professionals. They also would have liked more support from professionals in assessing and discussing carers’ own written comments, and reassurance that they were using the book “correctly”. Carers desperately wanted more acknowledgement from the professionals of the value of carer input into planning of care packages. This is an issue of education and training which was well noted and duly addressed in preparation for the main study

There was some genuine apprehension expressed by team members about possible legal issues surrounding written patient information, and potential repercussions in terms of patient/carer complaints, or even the issue of being sued, and records becoming evidence in courts of law. Health professionals are now very conscious of such issues, and these fears are echoed about many forms of documentation currently used in the NHS. Good record keeping is a subject requiring constant education and up-dating sessions, and this applies to the CHR as it does to all other forms of note taking.

Carers must accept that the confidentiality of the CHR is their responsibility, whilst the record is in their possession. This issue of confidentiality was discussed in depth at steering group meetings, and Trust insurers and solicitors were consulted, to ensure that no untoward risks were being taken on legal issues. However, professionals, at “hands on” patient care level, may not have been fully aware of the steps taken to address this issue.
Confidentiality of patient held records was discussed by Gilhooly & McGhee (1991) in *Medical records: practicalities and principles of patient possession*. They talk of "extended confidentiality" in the UK, where others may be entrusted with patient information, and expected to respect the confidentiality of such information. They also stress that, unfortunately the term "confidentiality" is often confused with "secrecy", and professionals are sometimes unclear about the difference. Gilhooly & McGhee conclude that:

- "Maintaining the duty of confidentiality does not preclude patient access to records, or patients having possession of their own records."

It was these principles of confidentiality that have guided this project of carer held records for patients with dementia.

The pilot study also revealed that both carers and professionals found the document design difficult to use. They were unclear as to the functions of the various pages and sections, and a bit daunted by the whole presentation of the package. This was a concern highlighted at the very beginning of the study. The documents needed constant explanation to both carers and professionals, together with reassurance that they were playing their parts effectively. There was obvious need for redesign and restructuring of the whole package. Redesign of the carer held records, (described in the next chapter), was undertaken whilst the pilot study was still in progress. This had no effect on the those involved in the pilot, as the documents were redesigned for use in the main study. The pilot sample group continued with the original CHR, and evaluation was based on this document alone. Participants were unaware that any redesign was taking place.
Several carers in the pilot project indicated that a much longer period of time than just a few months was needed to thoroughly evaluate the worth of the project. This is not disputed. Three to six months was not long enough for carers to make a really detailed evaluation. The 2 years planned for the main study is a much more realistic time scale. However, the pilot study has succeeded in meeting its aims, in spite of the limited time schedule, in assessing how suitable the document format and design was, and eliciting carers' opinions of the CHR initiative.

The final reason that a carer did not get much value from having carer held records was because he did not feel well himself, and had not the energy or motivation to want to contribute to equal partnership. In his state of mind, he preferred to leave all decision-making to the professionals. It is important to stress again, that this must be a choice carers are entitled to make. Meeting clients' needs also encompasses taking the lead in decision-making, supporting, and directing clients, when that is what is most appreciated. Allowing carers the option to hand over responsibility to professionals is also part of caring individually for people.

In conclusion, it can be said that the pilot study was successful in allowing us to find out and address some of the difficulties carers and professionals highlighted with the system of having carer held records at home. It showed that the system was of value to clients, and so paved the way for the launch of the main 2 year follow up study. The main areas of difficulty have been addressed in the redesign of the document, and in taking seriously the needs for professional and carer education and training. It was essential to gain this information so that the definitive research can be aimed at measuring health outcomes. Outcome measurements have been chosen that they might highlight and quantify areas where carer held records show definite benefit to clients, in order to substantiate and or qualify current theories that patient/carer held records are the way forward in the delivery of high quality healthcare.
Definitive Research Project

As has been described in the background literature, carer empowerment and equal partnership of informal carers with professionals is the philosophy underpinning the project. A carer held record is a practical tool which might be used by all involved with the care package to facilitate a “shared care” approach to the management of the patient with dementia.

Aims

The aims of the research were to identify whether carers who hold multidisciplinary records at home have more knowledge of dementia and its management, feel more valued, more “in control”, have fewer mental and physical health problems and stress-related symptoms than those carers who do not have this facility.

Potential benefits

- When informal carers are equal partners with professionals a better quality of life may result for both patients and carers.

- Links amongst community carers, hospital services, and voluntary agencies may be strengthened, encouraging the development of a seamless service.

- The record would be available whenever and wherever the patient was seen by all agencies.

- The carers as the daily care givers are involved in recording their own observations of the patients progress thus strengthening participatory roles.

- The document would act as an active discussion document used by all with relevant input into the family management, rather than individual professional records stored at different sites.
Development Of The Research Following The Pilot Study

Before beginning the main study ethical approval was given by the Leicestershire Ethics Committee to conduct the study. It was essential to address the major issues that arose from the conduct of the pilot study, in order to give greatest scope for benefit to patients and families, and to maximise co-operation of professionals and voluntary agencies, with the project. It had been established in the pilot study that many carers liked the idea of having a carer held record. Two main issues however required to be addressed. Firstly, the original carer held record used in the pilot project needed to be re-designed, and secondly there should be an education programme for all professionals and voluntary agencies who might be involved in contributing to carer held records during the follow up research.

Redesign of the carer held record

The adaptation and restructuring of the record was accomplished by a quorum of the pilot study steering group, and the contribution of a carer, a pilot study respondent who had professional design and marketing skills. His contribution to the revised record was substantial and valuable because, not only had he actually used the original carer held record, but also, from a professional point of view, he could see its “design faults” and how these might be corrected. There designed version of the record is much more aesthetically pleasing. It is much simpler in design and more explicit in instructions for use for both carers and professionals, being divided into sections clearly labelled for use by carers, and for the contribution of individual healthcare, social services professionals and voluntary agencies.

The whole document was enclosed in a attractive binder which included a section which permitted a carer’s diary to be removable from the main package should a carer wish to keep their thoughts and feelings private. Also included in the package was an information booklet for carers, specifically designed for the project to give practical knowledge and advice to families.
This booklet and all designed pages in the format were professionally printed. It was thought that the whole package now looked well made, well designed, and as if care had been taken to produce a valued document. There were costs attached to producing such a document however. Funding was received from the Directorate to cover printing costs, an education grant allowed us to buy the binders.

**Education programme and promulgation to professionals**

Results from the pilot study revealed that in many instances professional input to carer held records was minimal. It was hoped that the improved document design might solve some of their difficulties. However it was also decided that a determined effort should be made to involve all professionals potentially contributing to the records in the philosophy of carer participation and empowerment, and to encourage them to be “on board”. This involved not only informing them about the study, but actively discussing issues with all individual disciplines in formal teaching or presentation sessions at their professional bases. Local GPs, Social Services professionals, CMHT professionals including consultant psychiatrists were all targeted. The programme also reached out to heads of voluntary service agencies and community care organisations. Although this was a time-consuming initiative, it was considered to be worthwhile because of the pilot study experience. Trying to locally influence the culture was the aim of the pre-research education programme.
Methodology

Hypothesis
The hypothesis is that, carers of patients with dementia who have carer held records will have fewer physical and mental health problems, suffer less stress and strain, have a greater knowledge of dementia and feel more in control, than those carers who do not have this facility.

Selection of participants
Participants in the study sample were patient/carer pairs first referred to North Charnwood CMHT for the Elderly where the philosophy of equal partnership between carers and professionals had been formally introduced and discussed. Clients were issued with a carer held record if they met the inclusion/exclusion criteria for the study.

Selection of controls
Participants in the comparison group were patient/carer pairs first referred to South Charnwood CMHT for the Elderly where no formal education about equal partnership had taken place, and carer held records were not offered. The same inclusion/exclusion criteria applied to this group. Neither CMHT had been involved in the pilot study.

Inclusion/Exclusion Criteria

- The patient must be considered by the multidisciplinary team to have some degree of dementia. Patients with concurrent conditions such as depression were not excluded if dementia was also present.

- There must be a family carer although the carer may not be living in the same house as the patient. There must however be carer contact with the patient on a regular basis.
- The patient must be maintained in the community on first referral to the project.

- Carers must be of English-speaking origin.

- Carers must agree to participate in the project and sign their consent.

Three of these criteria may need further explanation.

The stipulation that the carer should be a family member was because of the confidentiality aspects of the use of a carer held record. As in the pilot study the confidentiality of information in the record was entrusted to the carer (Gilhooly & McGee 1991). It was felt that only family members should be asked to accept this responsibility. Neighbours and friends, no matter how involved in caring for a patient, should not be expected to carry this responsibility.

It was stipulated that carers should be of English-speaking origin because, as the carer held was to be used by multi-agencies as well as the carer complications might arise in comprehension if English were not the first language of all. Also major cultural differences amongst participating clients could be a confounding variable in the research.

In this research the intervention was focused upon the carers of patients with dementia. Consent to maintain the carer held record was sought from carers, and this was agreed by the Leicestershire Health Authority Ethical Committee in 1995. However, it is now thought that patient consent should be sought for the use of their information in carer held records, in the light of the current focus on patients’ rights, and in the knowledge of the legal position that carers, even though their relatives may be incapacitated, can not consent on their behalf. This is duly noted, and the issue will be debated in the Discussion section of this thesis.
Sample matching

Subjects and controls in the research could not be completely matched. It would not have been feasible to randomise clients from a single CMHT to either a subject or control group because that would have the professionals in the one team treating some clients in different ways from others, and held strong potential for confusion. It was therefore decided to allocate subjects to the research from one CMHT and controls from another similar CMHT. The care delivery administration is similar in both teams. Both have established multidisciplinary community mental health teams, with a consultant psychiatrist specialist in care of the elderly. Both have similar resource facilities and staffing levels. Furthermore the catchment areas for both teams are rural/county town rather than urban/inner city, and so the clienteles of the teams are also similar. Both teams did function with similar care philosophies at the time of team selection for the research. Use of the carer held record in the North Charnwood CMHT would be the major difference in care offered.

All newly referred patient/carer pairs to both teams were considered for inclusion in the research. This procedure should result in both groups having similar numbers taking part, and similar client characteristics. Clients in both groups were given explanatory information sheets describing their roles as participants in the research.

Presentation to subjects of the carer held record

Initially it had been decided that the CMHT keyworker allocated to a new client would present the carer held record package to the carer. However it was quickly established that this was not a realistic practice. Keyworkers might not meet family carers at first assessment of the patient necessitating a special appointment being made to introduce the document and the concept to families, which was time-consuming. Also there would be no commonality of presentation technique, as any one of 6 keyworkers could be the presenter.
Very early in the research process therefore it was decided that I would introduce the package to families myself, and give them the explanation of how the document might be used. CMHT members then only had to seek consent from families for the researcher to visit. I obtained written consent from carers following presentation of the record, and baseline data was collected at the same time. This seemed to be the most consistent and efficient approach.

To ensure equality of client management the same procedure was adopted for the control group, i.e. permission obtained from clients for a researcher to visit the family, who then introduced the research to them, got consent forms completed and baseline data collected. Once families had signed consent, letters were sent out to patients' GPs to inform them about the families participation in the research.
Longitudinal measurement criteria

For both subjects and controls it was planned that outcome measurements would be taken at baseline with follow up recordings taken at 6 months, 1 year and 2 year intervals in each case. It was found in practice however that although the 6 month intervals between follow up interviews was a realistic time span, the period between third and fourth follow ups of 1 year was too long a time interval. The progress of dementia can advance considerably within a year, with major changes occurring in clients' lives which were over by the time of the 4th interview, and therefore not picked up by the questionnaires. 18 months into the study was a more realistic time period for the 4th measurement, and the protocol was adjusted accordingly.

The questionnaires were administered in the following order:
Scales concerning the patients first ie. Crichton Behavioural Scale and Global Deterioration Scale, followed by the Carer Strain Scale, Carer Stress Scale, Knowledge of Dementia Scale, Burden Scale, GHQ, SF36 and Locus of Control(LOC). The gradual diminution in the numbers completing the questionnaires was therefore probably a reflection of the order in which the questionnaires were administered, and carers' ability to maintain concentration throughout what were very comprehensive interviews.

All measurements were made at individual interviews with carers, in some instances when the patient was present, and in others with the carer on his/her own, as was the wish of the clients. Initially interviews were conducted only by me as the lead researcher. However as the research progressed, and more clients were recruited to both participant groups, the workload of data collection became too demanding for one individual. A research assistant was therefore recruited to help with data collection.
No formal inter-rater procedure was undertaken. However, both researchers worked together during several interviews in order to ensure that questionnaires might be presented in the same manner, and, as far as possible, that both would use similar styles of interview technique. The assistant then followed up the clients allocated to her at baseline through the follow up time intervals to the end point, to ensure interviewer continuity.

**Qualitative data analysis**

When evaluating a service intervention it is helpful to ascertain how it is used, and to what extent it is acceptable to carers and professionals. Therefore the aims of the qualitative study were firstly to solicit the views of carers and staff using the carer held record, and secondly to estimate the extent to which carers engaged with the project in their use of the document, and acceptance of the underpinning philosophy. Time and resource constraints did not permit a detailed in-depth qualitative study (eg. recording and analysis of extended verbatim transcripts), so brief questionnaires were designed to collect carers' opinions, and those of the professional staff. This aspect of the study was exploratory only, and not designed to test any prior hypothesis regarding specific carer characteristics, their views of, or engagement with, the carer held records.

**Questionnaire analysis**

A questionnaire had been designed to assess how both carers and professionals used the record. When the project started it had been intended to allocate a score for "usefulness" to every individual page in the document, which would have led to quantitative data being available for analysis. This however proved to be a difficult process because firstly, there were a lot of outcome questionnaires to be completed at each interview session, which was tiring, especially for older carers. Secondly, if the record had been used little, or not at all, there was no point in allocating numerical values to each page. If it had been used extensively, carers wanted to display the record to researchers, and talk about the entries made, rather than going through it allocating scores.
At each subject follow up interview, carers discussed with the researchers the use of the record and its value to them. Researchers documented carers' views on the questionnaires, either as summaries of carers' views, or clearly placing comments in inverted commas, to be used as carer quotes in the final write up.

It is acknowledged that this method of data analysis may be subject to researcher bias. However, analysis of the questionnaires was very carefully conducted, with negative responses recorded as diligently as the positive, in order that an overall picture of carers' opinions might be obtained. Themes were extracted on the basis of this data. Quotes in italics represent carers' written comments, or carers' actual spoken words recorded by researchers on the questionnaires.
## Table 3

### Participant characteristics

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<th>Age</th>
<th>Sex</th>
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<td>60 - 94</td>
<td>M</td>
<td>F</td>
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<tr>
<td>Controls</td>
<td>46</td>
<td>56 - 91</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjects</td>
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<td>30 - 80</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Controls</td>
<td>46</td>
<td>30 - 40</td>
<td>M</td>
<td>F</td>
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</table>

## Table 4

### Relationship In Age Range

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<th>50s</th>
<th>60s</th>
<th>70s</th>
<th>80s</th>
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</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjects</td>
<td>1 lodger</td>
<td>1 son 6 daughters 1 grand-daughter</td>
<td>5 sons 6 daughters 1 niece</td>
<td>0 sons 4 daught. 1 niece 2 wives</td>
<td>0 sons 0 daughters - 2 wives 2 husb. 2 sister-in-law</td>
<td>-</td>
</tr>
<tr>
<td>Controls</td>
<td>30s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 niece</td>
<td>2 sons 4 daughters 1 dght. - in-law</td>
<td>3 sons 11 daughters 1 dght. in-law 1 husband</td>
<td>1 son 2 daught. 3 wives</td>
<td>- 5 wives 5 husb.</td>
<td>- 3 wives 2 husbands</td>
<td></td>
</tr>
</tbody>
</table>
Outcome Measures

Definition

An outcome measure is a technique designed to measure how far a projected outcome is achieved through the application of a professional effort, resource or commitment. The definition contains a forecast of what will happen as a result of an intervention.

The aims of the research require that specific aspects of the health and welfare of carers be measured, together with patients’ degree of dementia. To this end, the following outcome measures were selected.

- Carers’ knowledge of dementia, its prevalence, aetiology, and symptomology.

- The degree of strain and stress and burden experienced by carers in caring for their relatives at home.

- Whether or not carers feel “in control” of their lives in general, and of their role and function in the caring process.

- Carers’ general physical and mental health status

- The patients’ behavioural and cognitive functioning.
Measures Selected For Carer Assessment

Background and rationale for selection of each measure

Perceptions Of Dementia

The rationale underpinning use of a scale, measuring knowledge of dementia, is that carers of dementia sufferers, who have a high level of knowledge on the subject of dementia, might have lower rates of psychological and physical morbidity. Variations in knowledge levels might also affect carers' mechanisms for coping with the caring role, and their feelings of self-worth, and competence as carers.

The scale selected to measure carers' knowledge is the *Dementia Knowledge Questionnaire* (Graham et al. 1997). This questionnaire screens for the presence of irrational beliefs, and assesses knowledge of dementia in four areas. The first area is that of rudimentary knowledge which is central to the understanding of dementia. To score fully on this section carers are expected to know that dementia is a disease of the brain, affects mainly the elderly and, with rare exceptions, is not curable. The second category covers epidemiological knowledge of the disease. The third section, clinical symptoms, offers a range of bodily functions which may be altered by the disease and carers are asked how many of these they feel may be affected. The fourth section covers a range of aetiological factors, and carers are asked to identify causes of the disease. Additional to these categories, a section is included for carers to write down their personal concerns about their relatives' dementia. Analysis of the range of responses in this latter section was undertaken and also a comparison of changes in fears and concerns over time.
At baseline, carers may not only lack knowledge about dementia, but also may have acquired erroneous information about different facets of the disease. It is hoped that professional knowledge will be shared with carers, on as equal a basis as possible, and that carers will gain understanding of the illness and how to manage symptoms, throughout the period of the study.

In their study, Graham et al (1997) identified that people who have a greater knowledge of dementia when caring for a dependent with the disorder, experience significantly lower rates of depression than those carers who are less well informed. She suggests therefore that increased knowledge has a causal effect on decreasing depression rates in care givers caring for a relative with dementia, and concludes that this finding highlights the need for early intervention with an educational package to prevent the onset of depressive symptoms. A booklet, *Coping with Dementia*, designed specifically for carers in this study, was issued as an integral part of the carer held record package, to ensure a good information source, and uniformity of at least one source of information.

Although education of carers leads to lower rates of depression and to carers having more positive coping strategies, there is also the suggestion that education may lead to increased anxiety levels in carers. Investigation is on-going into relationships between anxiety, depression and knowledge acquisition, and which specific areas of knowledge are most beneficial or detrimental to carers' well-being (Graham et al 1997).
Measurement of carer strain, stress and burden

Three measures were chosen for this study in order to tap different conceptualisations of the topic. Although strain, stress and burden are highly related, they are not the same. The three scales chosen each focus upon different aspects, and require the respondents to think in different ways in order to formulate their responses.

Care Giver Strain Index (Robinson 1983)

Pearlin and Schooler (1978) provide the following definition of strain in the context of care giver strain:

"By strain we mean those enduring problems that have the potential for arousing threat, a meaning that establishes "strain" and "stressor" as interchangeable concepts."

Robinson compiled and validated a care giver strain index to be used as a screening instrument for detecting such strain in carers. She emphasises that this screening refers simply to the identification of strain, as a potential risk area, and is not intended as a means of arriving at a final intervention decision. Her research resulted in the production of a scale, with evidence of construct validity, which is a brief, easily-administered instrument which identifies strain in 3 areas. These are, patient characteristics, subjective perceptions of the care giving relationship by care givers and emotional health of care givers.

The research conclusion was that this simple index could be usefully included in any interview or assessment package that examines relations involving dependency and care. The research sample of carers included 38% spouses, 22% daughters/daughters-in-law, 11% sons, 14% other relatives, and 4% neighbours.

For the purposes of this study with carers of patients with dementia, the carer sample characteristics, and the above research conclusion would indicate that the Caregiver Strain Index (CSI) might be a useful measure. Its reliability and construct validity were established.
Measurements Of Carer Stress, Strain and Burden

Pearlin et al (1990) describe informal care giving as activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves. Giving care to someone is an extension of caring about that person, and therefore is present when people exist in ordinary relationships, promoting and protecting others’ well being in established roles such as husband/wife, parent/child.

However when impairment and dependency increase, as happens when a family member develops dementia, care giving assumes a major significance which can transform ordinary close relationships to what may become a dominant, unequally-distributed burden of living. Relationships may become totally reconstructed, and occupied almost solely by the care giving role. High levels of stress thus very often develop.

This stress process is very complex. it does not stem from a single event, or from one isolated problem, but from the fact that whole ways of life, and self-judgements become transformed. This multi-faceted phenomenon of stress varies in impact on carers, and may depend on the mix of circumstances, carers’ experiences and responses, and the resources available for support.

The Carer Stress Scale (Pearlin et al 1990) was designed to measure both primary and secondary stress as individual facets which affect people differently. Primary stressors are defined as the nature and magnitude of the patients’ care needs. Secondary stressors arise from these, and encompass role strains, family conflict, and constriction of social life. If carers’ self-esteem and feelings of competence are low then this is also a source of secondary stress.
The Carer Stress Scale has 15 sections (A - O), each of which assesses different aspects of the stress process. Taken as a whole questionnaire, it appeared to be too long and cumbersome to administer, and for carers to respond to, when stress was only one aspect of carers' lives being investigated in this study. Some sections were already covered by the simpler Carer Strain Index and health questionnaires. It was decided therefore to concentrate on 4 specific sections which highlighted areas of secondary stress in carers. These were sections “D” and “E” on relational deprivation and family conflict, and “J” and “O” on feelings of care giving competence and levels of expressive social support. The scale allows for such selective administration as each section is separately scored, and has established reliability and validity.

The primary and secondary stressors as described by Pearlin et al (1990) were also identified by Vitaliano, Young & Russo (1991) who label the concepts “objective and subjective burden”. They describe objective burden as the basic disruption of family life by the practical demands of caring, and subjective burden as the care giver response to the situation in terms of emotions such as feeling trapped overloaded resentful, and socially isolated and excluded. These researchers give a review of measures of burden, and emphasise how complex the relationships are between objective burden and the subjective response. The results of studies on “burden” experienced by care givers do vary, with some studies concluding that objective burden is the major stressor (Hoenig & Hamilton 1965, Grad & Sainsbury 1963, McCarthy et al 1989).

Most existing carer burden scales take 20 - 30 minutes to administer, eg. those designed by Zarit, Reever & Bach-Peterson (1980), and Vitaliano, Russo, Young Becker & Maiuro (1991). Such scales would have been too long for the purposes of this study, in view of the number of questionnaires to which carers were being asked to respond at each session. It was however thought important to include some short global assessment of burden.
A search identified one short 6-point questionnaire (unattributed) which elicited from carers their subjective views of the extent of their burden of caring. This scale, asks carers to reflect their degree of burden, on a scale of 1 (no burden at all) to 5 (a great burden), in the areas of emotional burden, physical, financial, and social burden. The scale also includes an item on satisfaction with caring which added an extra interesting dimension.

Recent research has identified the importance of subjective burden, and its role in the stress process (Lazarus & De Longis 1983, Zarit, Todd & Zarit 1986, Saad et al 1995). Most researchers now agree however that if carers develop effective coping strategies, or are supported in addressing problems of negative self-judgements, then stress can be reduced.

It is hoped that these aspects of carer stress can be alleviated to some degree by the intervention of carer held records and equal partnership philosophy. This therefore is the rationale for the selection of these specific measures of stress.
Locus of Control

Measuring locus of control involves measuring the beliefs which individuals' hold about the causes and control of everyday happenings in their lives. Locus of control has become a very complex subject since the concept was first developed by Rotter in 1966. Rotter's research had its origins in social learning theory (Bandura 1963), and is based upon the theoretical viewpoint that individuals make judgements about the likely causes and mastery of present events, and control over future events, based on their perceptions of past experiences. Locus of control has thus been defined as:-

- "the degree to which individuals perceive events in their lives as being a consequence of their own actions, and thereby controllable (internal control), or as being unrelated to their own behaviour, and therefore beyond personal control (external control)"


In order to measure belief systems in locus of control, Rotter devised the first scale measure which was the Internal - External (I - E) scale in 1966. This was a self-report inventory, in a forced choice format, in which were presented to respondees 29 items where internal belief was pitted against external belief.

Rotter's theories were massively popular in the 1960s and 1970s. However recent research has criticised the I - E scale and its rationale, for being too general a concept. It does not explain some conflicting results re. individuals' locus of control and behavioural variables (Strickland 1978, Throop & McDonald 1971). Rotter himself acknowledges this fact. The I - E scale was never intended to be situation -, or goal - specific, but an instrument to measure a problem - solving generalised belief system, that a response will or will not influence the attainment of a reinforcement (positive or negative).
Interest in the concept of locus of control has today expanded to focus on more specific situational aspects of control beliefs (Brewin & Shapiro 1984, Furnham & Steele 1993). There is now a vast body of literature about the concept. Debate is still on-going about unidimensionality versus multidimensionality; situation-specific locus of control beliefs versus person-specific beliefs; the "good guy/bad guy" dichotomy, where internal beliefs are regarded as "good" and externals seen as "bad" (Furnham & Steele 1993).

Having explored the literature on the whole topic of locus of control, there seemed to be certain aspects of the modern concept which should be concentrated upon when considering a suitable measurement of locus of control for this study.

**Internal - Powerful Others - Chance.**

Levenson (1981) argued that people with external locus of control beliefs may believe that the world is controlled by powerful others, or that the world is unordered, and that chance influences events in life. He therefore developed a tri-partite scale, which acknowledged the concept of internal locus of control, but separated the concept of external control into "powerful others" and "chance". He considered that people who believed that powerful others controlled personal life happenings at least could have the potential for having or regaining control.

However, those who believed that chance was the main controlling force were much more powerless, and thus were cognitively and behaviourally different from other externals. The Internal/ Powerful Others/ Chance (IPC) scale (Levenson 1974), was substantially different from Rotter's I-E scale in that:-

1. The three facets of the scale were statistically independent of one another.

2. The scale measures the degree to which an individual feels that he has control, and not what he feels is the case for people in general. Thus it is person-specific.
Situation - specific

Rotter's I - E scale is a device to measure generalised expectancies of control of events. If an accurate description of actions in specific events is required, then a more specifically designed scale is necessary. The embracing of this theoretical standpoint has led to a plethora of scales being produced to elicit beliefs in many different situations.

One area of research which was of definite interest for this study was health - specific scales. Many researchers had studied this field (Wallaston & Wallaston 1976, Strickland 1978, Lau & Ware 1981, Hill & Bale 1981).

The importance of relevance

Many of the questions asked, in the scales which were studied in the literature search, concerned topics which carers might find difficult to relate to, such as questions about leadership, students taking exams, and car accidents. It was decided therefore to adapt the locus of control scale specifically for this study. This contained questions taken from established scales, but concerned only topics pertinent to the lives of the client group in the current study.

The scale included a final 6 question section about perceived control in the specific area of shared care with professionals, and the ability of carers to influence care planning for their relatives. These questions adhered to the same principles of locus of control theory as the others in the questionnaire.
Construction of the scale

30 questions were selected to form the total scale. The questionnaire format is one of no forced choice. It is a 5-point Licker scale response format, i.e:

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Not Sure</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Eight relevant dimensions were included, each of which was divided into questions encompassing the concepts of the 3 IPC response options, internal (I), powerful other (P), and chance (C). These dimensions concerned:

- how carers made friendships
- how personal interests were protected
- how well carers felt they could make and keep plans
- how much they felt they were in control of their lives in general
- how carers went about getting what they wanted

These 5 dimensions were taken from Levenson (1981).

The next 2 dimensions concerned control of both physical and mental health, including a subsection on the self-blame aspect of health control beliefs. Physical health questions were taken from Lau & Ware (1981), and mental health questions were taken from Whitman et al. (1987).

The final dimension was about control of "shared care". 6 questions were devised in the same format as the others to investigate this aspect of control beliefs.
Potential outcomes of using this locus of control tool

There are many variables within the scale devised for this research. Aspects of greatest import will be:-

- Whether general I P or C beliefs have any correlation to the shared care dimension
- Whether control beliefs about shared care alter with the carer held records intervention, and/or change over time.

Physical And Psychological Health Questionnaires

Two measures were selected to be used in the study. These are:-

1. 28-item General Health questionnaire (GHQ) (Goldberg & Hillier 1972)

2. MOS Short Form - 36 item general Health Survey (SF 36) (Ware & Sherbourne 1992)
General Health Questionnaire

This instrument is designed to detect non-psychotic psychiatric illness / affective disorder in a community setting. It was designed for use in population surveys of psychiatric morbidity, and has been extensively used as a screening instrument in clinical practice (Wilkins, Hallam & Doggett 1992). It is based on the principle that psychological distress depends on a critical number of key symptoms, rather than any particular symptom.

The full version of the GHQ has 60 items. For this study the 28-item version was selected, for ease of administration, and to encourage carer compliance with the completing of a shorter questionnaire.

Statements in the GHQ represent four main areas, and one of its advantages is that it identifies in which area problems are concentrated. The four areas are: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression. The GHQ has some limitations however. The final 7 questions on severe depression can potentially cause distress to respondees, and need to be carefully handled by researchers. Also, it does not measure physical health symptoms, as such, or chronic health problems, and is best used for problems of recent onset. For these reasons the SF-36 was also selected to complement and supplement the information obtained from the GHQ.
Short Form - 36 (SF36)

Research has shown that carers' physical health can deteriorate during the course of their caring (Schultz et al. 1990), and that those with poor psychological health are more prone to physical morbity (Brodaty 1992).

The SF36 is a general health survey instrument, designed for use in studies of general populations, and for subjects in practice settings, applicable across social and demographic groups. It has been shown to have application in health policy research, and in the evaluation of the effects of health care and clinical trials (Wilkins, Hallam & Doggett 1992). The Medical Outcomes Research (MOS) team originally developed a comprehensive general health survey instrument consisting of 149 items. From this, the short form (SF-36) has recently been developed which is based on the full MOS battery. Items have been selected to reproduce the parent scale as much as possible.

Eight health concepts are included in the scale:

- Physical Health
- Mental Health
- Role
- Pain
- Social Functioning
- Vitality
- Current Health Perceptions
- Emotional Health

For a comprehensive assessment of health, more is required than just physical and mental health questions. Information is needed also on limitations in engaging in normative roles as a result of health problems. Role and social functioning sections are also therefore included in the scale to capture aspects of disability in these areas. Personal evaluations of health and general well-being are also essential qualities to measure to obtain a comprehensive, synergistic assessment of the burden of "illness" on people's everyday functioning, and feelings of well-being. The sections on current health perceptions, pain, and vitality aim to tap these feelings (McHorney, Ware & Raczek 1992).
Thus, the SF-36 scale includes health dimensions not included in the GHQ questionnaire. It also has the advantage of being more sensitive to low levels of ill health that are important to respondents.

Originally, the SF-36 questionnaire was written in American text. However an Anglicised version has now been produced in which script more suited to British people has been substituted, without altering the essence of a sentence, e.g. *yards* and *miles* are used instead of *metres* and *kilometres* (Anderson, Sullivan, & Usherwood 1990).

The scale has also been altered to one which is suitable for use with older people (Hayes, Morris, Wolfe & Morgan 1995). Their adaptations involved placing less emphasis on work-related issues in relation to stress by altering the order of presentation of options. Problems of daily living were presented first. Similarly, questions about the distance a respondent is able to walk were presented with the smallest distance first. The other significant alteration made concerns the definitions of strenuous activities. "Running, lifting heavy objects, and participation in strenuous sports" is changed to "work around the house, making a bed, moving a table, gardening"

The use of the GHQ in combination with the SF-36 scale thus will give a comprehensive assessment of health status, sensitive to both acute and chronic disability.
Measures Selected For Patients Assessment

- Crichton Behavioural Scale (CBS)
- Mini Mental State (MMS) -- Baseline only
- Global Deterioration Scale (GDS)

Modified Crichton Royal Behavioural Scale

The Crichton Geriatric Behavioural Scale was devised by Robinson in 1961 and first used by staff at Crichton Royal Infirmary in Dumfries, Scotland. It was designed to specifically measure current performance of patients with brain damage or mental impairment, rather than be a measure of particular mental or physical defects. The scale has been modified and refined since its original inception, but the format chosen for this study retains the main principles of the designers. It is a scale comprising 10 items in total. The first five items concern activities of daily living. These are:

- mobility, dressing, feeding, bathing and continence.

The second five items concern cognition, and other aspects of behaviour associated with cerebral impairment. These are:

- memory, orientation, communication, co-operation and restlessness.

Each item in the questionnaire is rated on a five-point scale, from 0 - 4, the upper end being normality, and a rating of "4" representing a complete failure of that particular function. Each item grade in the scale is described in words, and represents a "snapshot" of behaviour or cognition which is sufficiently different from the grades above and below, to accurately pinpoint a patient's current status.
The authors emphasise that these ten items do not comprise a detailed picture of the behaviour and cognition of mentally impaired individuals. They do, however, consider that the scale gives a behavioural guide to current performance levels of such patients. A more detailed analysis of behavioural function would perhaps give a more exact clinical picture, but the scale would then be too complicated for non-medical staff to administer.

Robinson (1961) cites the example item of “mobility” to illustrate this point. “Mobility” is selected as a function, and is described in the scale as:

- “a conjugation of such diverse facts as skeleto-muscular function, cardiovascular state, vision, liability to fall and volition”.

The grades within the item range from “fully ambulant” to “bedfast, or mainly so” to “chairfast”. The exact cause of the patient’s deficit in performance level could be due to many different, or multiple causes. The important facet within this scale is level of current performance.

The Modified Crichton Scale was chosen for patient assessment within the carer held records research, because it is thought to give a reliable evaluation of patients’ physical abilities and mental functioning when used by non-medical assessors. The questionnaire, in this study, is completed by family carers with interviewer support, who together are guided by the verbal descriptions given for each grading within each item.

In practice, it appears that family carers are very well able to identify their relatives’ current abilities using this scale. the descriptions of each grade appear to be sufficiently distinct from each other for carers to scale behaviour with the minimum of indecision.
Mini Mental State (MMS) (Folstein et al 1975)

The mini mental state is a short standardised questionnaire which provides a simple practical method for grading the cognitive state of patients. The scale is labelled "mini" because it is much shorter than other available assessment tools. It takes approximately 5-10 minutes to administer, and includes only 11 questions. Excluded are questions about mood, abnormal mental experiences and forms of thinking. The scale concentrates on cognitive impairment only. The validity of the MMS has been established following testing of patients with a wide variety of psychiatric disorders, it has been found to separate accurately patients with cognitive impairment from those without such disturbance. The MMS also correlates both with a standard test of cognition, and with the Wechsler Adult Intelligence Scale (WAIS). (Folstein, Folstein & McHugh 1975).

Since publication in 1976 the scale has been widely used by clinicians as it has many advantages over other cognitive assessment tools. It is ideal for use with elderly patients with possible cognitive impairment because it is short and succinct. These patients have short attention spans and may co-operate only for short periods. It is easy to administer, and administration instructions are clear, and easy to access.

Global Deterioration Scale (GDS) (Reisberg et al 1982)

The GDS, first published in 1982, is a nominal scale with 7 categories of cognitive decline, describing several groups of symptoms associated with age-related memory and cognitive impairments, labelled Progressive Degenerative Dementia (PDD), as well as the course of Alzheimer’s Disease. Reisberg et al considered that cognitive decline in these disorders had a characteristic insidious onset and progression with no remissions.
The GDS describes 7 stages of cognitive decline ranging from Stage 1 - no decline, to Stage 7 - very severe decline. The stages are all described in detail, and summaries of the characteristics of each stage are given on the measuring scale. Patient/carer subjective reports of memory deficits, clinical impressions of cognitive and functional status, and the presence of psychiatric symptoms are the basis for assigning individuals to one of the 7 cognitive stages.

Reisberg et al give evidence of validation of the GDS scale, and report that it correlates significantly with 25 other psychiatric measures, and it has significant relationships with anatomic brain changes as shown on CT scans, and with metabolic changes as determined by positron emission tomography (PET). Usefulness of the tool presupposes accurate clinical diagnosis of PDD. In this scenario, the authors consider that the GDS accurately reflects the progression of the disorder, and is cross-cultural and cross-national. They believe the scale to be of wide utility as a global measure, as it delineates all stages from early to terminal dementia, and therefore is useful for serial measurements.

Other researchers disagree with Reisberg’s evaluation of the GDS scale (Paveza, Cohen, Jaukowski & Freels 1995) They challenge claims about the linear nature of the progression of age-related and Alzheimer’s- type dementia. The results of their, and other, studies (Eisdorfer et al 1992), suggest furthermore that the type and presence of functional and behavioural impairments, present at each cognitive level on the GDS scale, are so diverse that it is virtually impossible to infer level of cognitive functioning from specific behavioural and functional changes experienced by this patient group. They consider that the loss of functional abilities and the development of behavioural symptoms are not monotonic, and reflect the general health, age, gender and general heterogeneity in any elderly population. From study results, they claim that deterioration may occur at different rates, and in different sequences, and that no single score measure can adequately categorise or account for the diversity of disease progression.
Having absorbed the literature surrounding the GDS, it was decided to include this scale in outcome measurement for this study. It is very simple to administer. Carers can place their relatives into one of the stages with reasonable confidence. However results of the GDS scale will be considered alongside the Crichton Behavioural Scale (CBS), to obtain a more in-depth assessment of patients' decline.

Measures of outcome in dementia

In a review of measures to determine the outcome of services for people with dementia, Ramsay et al (1995) considered the following domains to be important:

For patients:
- personal self-care
- activities of daily living
- physical & psychological well being
- cognitive decline
- inappropriate behaviour
- social functioning
- satisfaction

For carers:
- physical & psychological well being
- social resources
- knowledge and skills
- co-ordination & communication
- satisfaction

Satisfaction with service questionnaires were not included in this study as the interviews with clients were already fairly lengthy. All other areas were covered to some degree in the selected measurement scales.

During the actual use of carer held records, Qualitative data was gathered concerning the use made of the record in every case. Notes were made about both carer and professional input.
Data Analysis

Statistical analysis

Repeated measures ANOVA
A repeated measures analysis of variance (ANOVA) was used to analyse the data. In this model change over time is determined by three separate factors. These are:

- the individuals included in the study,
- which intervention they received, either allocated to the intervention group – subjects or the non-intervention group – controls,
- time.

A proportion of subjects in both subject and control groups did not remain in the study and had missing outcomes at six months, one year or 18 months. Firstly it was decided to focus the analysis on baseline to one year interval in order to include the greatest number of participant responses. Those remaining in the study to one year (and therefore included in the main repeated measures analyses) were compared with those who left the study at or after six months on major baseline measurements using $\chi^2$ test for categorical and binary variables and Mann-Whitney U tests for ordinal variables.

A standard repeated measures analysis of variance (ANOVA) was used to test changes over time (six months and one year) in outcomes between subject and control groups. These analyses used only subjects with complete data at all time points. Baseline values of the outcome were included as a covariate, to account for possible baseline differences in subject and control groups, and since it was expected that the intervention would need time to take effect so that differences would not be expected until at least six months. The interaction between group and time is important to elicit whether the subject and control groups differed over the six month to one year period, after adjustment for baseline values.
However the since the baseline is included as a covariate, the group effect is also of note since this significant difference between subject and control groups indicates overall different levels in outcome between the groups after adjustment for baseline. Thus a significant group effect and no significant interaction shows an early change between the groups (pre six-months), that is maintained to one year. The analysis is described in detail for the outcome variable carer strain in the Results section.

The effect of outliers was investigated using residual plots and by calculating Cook’s distance and leverage. Where appropriate outliers were omitted and the analysis repeated. Omission of outliers had no effect on the results.

All analyses were performed in SPSS (version 8). Statistically significant effects were ones which yielded a p - value of less than 0.05.

A survival analysis was performed to see if there were any differences between the groups in the rate of admission to long term care.

Qualitative Analysis

A qualitative technique was used to highlight results in two aspects of the research. Data concerning the actual use made of records by both clients and professionals was analysed using a content analysis approach (Burnard 1991), an approach adapted from Glaser & Strauss’ s Grounded Theory (1967).

Analysis was also made of the final question in the Dementia Knowledge Questionnaire which involved a personal verbal response from carers i.e. “What are your greatest worries about the disease?”
Carer responses were recorded at each time interval so that comparisons could be made between individual clients' responses over time, and common themes could be highlighted from all responses.

**Power and sample size**

The main outcome measure was carer strain and the main endpoint 12 months as any effect of the intervention should have been demonstrated by 12 months to be clinically useful. Given that the expected difference in mean level of carer strain between subject and control group was difficult to estimate beforehand, an average effect size of $d_t = |\mu_s - \mu_c| / \sigma$ of 0.5 was assumed for a two-sample t test as suggested by Machin and Campbell (1987). Assuming $\alpha = 0.05$ then 64 patients in each group would have 80% power to detect such a difference at 12 months. To allow for attrition 70 patients in each group was aimed for. Data on survival rates of patients with dementia (Heston et al 1991), and data on local referral rates revealed that such numbers could be recruited to the study in 2 years of data collection. Recruitment however proved to be far more problematic than had been assumed when the research protocol was designed. However attrition was considerably more than had been anticipated and the main analyses included around 38 patients in each of the subject and control groups. These numbers would have 80% power of detecting a difference between the groups equivalent to $d_t = 0.62$ rather than 0.5 used previously in the original power calculation.

**Recruitment**

It can be seen that client referral figures on which potential participant numbers were calculated were not an accurate guide to the numbers who finally took part in the research. Many referred patient and carer pairs did not meet the inclusion criteria in both subject and control groups. This issue will be further developed in the Discussion Section. Recruitment was also delayed because of staff shortages/sickness/absence in both CMHTs which led to the formation of waiting lists. These had not been in existence when the protocol was designed. The outcome was that recruitment to both groups in the study took much longer than had been anticipated, and the goal recruitment numbers could not be achieved.
Results Section

Data Completion

One hundred and eighteen patient/carer pairs were approached, 60 potential subjects and 58 potential controls. Of these 84, (71%) were recruited into the study (38 (63%) subjects and 46 (79%) controls). The 84 recruits completed all questionnaires at baseline interviews yielding 84 sets of baseline data.

Numbers completing questionnaires at follow-up interviews were affected by attrition. Table 5 and tables 6-13 show the comparisons of baseline scores for all subjects and controls (38 subjects; 46 controls) and for those subjects and controls with complete data and therefore included in the repeated measures analyses (21 subjects; 32 controls). Overall baseline scores between all subjects and controls and between subjects and controls who had complete scores were similar, given the number of significance tests. Moreover the distributions of scores for subjects (and controls) who completed were very similar to those for all subjects (and controls) suggesting that those with complete data were representative of the whole study population.
Table 5  
**Equivalence Of Carer Characteristics**

<table>
<thead>
<tr>
<th>All Study Population</th>
<th>Subjects</th>
<th>Controls</th>
<th>P Value</th>
<th>Completers</th>
<th>Subjects</th>
<th>Controls</th>
<th>P. Value</th>
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</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
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<tr>
<td>M</td>
<td>36%</td>
<td>36%</td>
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<td>M</td>
<td>21%</td>
<td>28%</td>
<td>0.57</td>
</tr>
<tr>
<td>F</td>
<td>74%</td>
<td>74%</td>
<td></td>
<td>F</td>
<td>79%</td>
<td>72%</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<td></td>
<td></td>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60+ - 80+</td>
<td>45%</td>
<td>46%</td>
<td>0.90</td>
<td>60+ - 80+</td>
<td>46%</td>
<td>48%</td>
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</tr>
<tr>
<td>40+ - 60</td>
<td>53%</td>
<td>50%</td>
<td></td>
<td>40+ - 60</td>
<td>50%</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>20+ - 40</td>
<td>2%</td>
<td>4%</td>
<td></td>
<td>20+ - 40</td>
<td>4%</td>
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<td></td>
</tr>
<tr>
<td><strong>Generation</strong></td>
<td></td>
<td></td>
<td></td>
<td><strong>Generation</strong></td>
<td></td>
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</tr>
<tr>
<td>Same</td>
<td>29%</td>
<td>39%</td>
<td>0.33</td>
<td>Same</td>
<td>29%</td>
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<tr>
<td>Different</td>
<td>71%</td>
<td>61%</td>
<td></td>
<td>Different</td>
<td>71%</td>
<td>62%</td>
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### Tables 6 - 13  Baseline Comparisons:
For All Subjects, Controls & For Those With Complete Data (Mann-Whitney U Tests)

<table>
<thead>
<tr>
<th>Variable</th>
<th>All Study Population</th>
<th>Completers</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Subject</td>
<td>Control</td>
</tr>
<tr>
<td>Carer Strain</td>
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<td>IQR</td>
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<td>5.5-9.5</td>
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### Table 7  Carer Stress

<table>
<thead>
<tr>
<th>Carer Stress</th>
<th>Subject</th>
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<th>P Value</th>
<th>Subject</th>
<th>Control</th>
<th>P Value</th>
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</thead>
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<td>Relative deprivation</td>
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<td>14</td>
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<td>Median</td>
<td>13</td>
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<tr>
<td></td>
<td>IQR</td>
<td>10-17</td>
<td>12-19</td>
<td></td>
<td>IQR</td>
<td>11-17</td>
</tr>
<tr>
<td>Conflict</td>
<td>Median</td>
<td>4</td>
<td>4</td>
<td>0.20</td>
<td>Median</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>IQR</td>
<td>4-7</td>
<td>4-8</td>
<td></td>
<td>IQR</td>
<td>4-5.5</td>
</tr>
<tr>
<td>Competence</td>
<td>Median</td>
<td>14</td>
<td>14</td>
<td>0.96</td>
<td>Median</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>IQR</td>
<td>12-15</td>
<td>11-15</td>
<td></td>
<td>IQR</td>
<td>12.5-15</td>
</tr>
<tr>
<td>Support</td>
<td>Median</td>
<td>27</td>
<td>27</td>
<td>0.98</td>
<td>Median</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>IQR</td>
<td>24-29</td>
<td>24-30</td>
<td></td>
<td>IQR</td>
<td>24-29.5</td>
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### Table 8  Knowledge of Dementia

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<th>Subject</th>
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<th>P Value</th>
<th>Subject</th>
<th>Control</th>
<th>P Value</th>
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<tr>
<td>Abnormal</td>
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<td>3</td>
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<td>Median</td>
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</tr>
<tr>
<td></td>
<td>IQR</td>
<td>3-3</td>
<td>3-3</td>
<td></td>
<td>IQR</td>
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<tr>
<td>General</td>
<td>Median</td>
<td>3.5</td>
<td>4</td>
<td>0.81</td>
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<td>3</td>
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<tr>
<td></td>
<td>IQR</td>
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<td>2.8-5.3</td>
<td></td>
<td>IQR</td>
<td>2-4.5</td>
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<tr>
<td>Symptoms</td>
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<td></td>
<td>IQR</td>
<td>4-5</td>
<td>4-7</td>
<td></td>
<td>IQR</td>
<td>4-5</td>
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<tr>
<td>Total</td>
<td>Median</td>
<td>11</td>
<td>12</td>
<td>0.38</td>
<td>Median</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>IQR</td>
<td>9-13</td>
<td>9-14</td>
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<td>IQR</td>
<td>9-13</td>
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Baseline Comparisons continued:

Table 9  **Burden Of Care**

<table>
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<th>Variable</th>
<th>All Study Population</th>
<th>Completers (Included In Repeated Measures Analyses)</th>
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<td>Subject</td>
<td>Control</td>
</tr>
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<td><strong>Burden Of Care</strong></td>
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<td></td>
</tr>
<tr>
<td>Total Burden</td>
<td>Median IQR</td>
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</tr>
<tr>
<td>Satisfaction</td>
<td>Median IQR</td>
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</table>

Table 10  **GHQ**

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<th>GHQ</th>
<th>Subject</th>
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<th>P Value</th>
<th>Subject</th>
<th>Control</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic</td>
<td>Median IQR</td>
<td>5</td>
<td>1.5 - 7</td>
<td>5</td>
<td>3 - 8</td>
<td>0.33</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Median IQR</td>
<td>5</td>
<td>2.5 - 10</td>
<td>7</td>
<td>3 - 10</td>
<td>0.32</td>
</tr>
<tr>
<td>Social</td>
<td>Median IQR</td>
<td>7</td>
<td>7 - 8</td>
<td>8</td>
<td>7 - 9</td>
<td>0.26</td>
</tr>
<tr>
<td>Depression</td>
<td>Median IQR</td>
<td>0</td>
<td>0 - 1</td>
<td>0</td>
<td>0 - 2</td>
<td>0.33</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Median IQR</td>
<td>18</td>
<td>12.5 - 26.5</td>
<td>21</td>
<td>15 - 27</td>
<td>0.26</td>
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</table>
Baseline Comparisons continued:

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<th>SF 36</th>
<th>Subject</th>
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<th>Control</th>
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<td>Physical</td>
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<td>97.5</td>
<td>0.91</td>
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<td></td>
<td>IQR</td>
<td>72.5-100</td>
<td>70-100</td>
<td></td>
<td>IQR</td>
<td>75-100</td>
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<td>Physical</td>
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<td>100</td>
<td>87.5</td>
<td>0.51</td>
<td>Median</td>
<td>100</td>
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<tr>
<td>Role</td>
<td>IQR</td>
<td>12.5-100</td>
<td>43.8-100</td>
<td></td>
<td>IQR</td>
<td>0-100</td>
</tr>
<tr>
<td>Emotion</td>
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<td>100</td>
<td>66.7</td>
<td>0.62</td>
<td>Median</td>
<td>100</td>
</tr>
<tr>
<td>Pain</td>
<td>IQR</td>
<td>33.3-100</td>
<td>33.3-100</td>
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<td>IQR</td>
<td>33.3-100</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>84</td>
<td>92</td>
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<td>92</td>
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<td></td>
<td>IQR</td>
<td>36.5-100</td>
<td>48.8-100</td>
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<td>34.3-100</td>
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<tr>
<td>Health</td>
<td>IQR</td>
<td>49.5-57</td>
<td>52-62</td>
<td></td>
<td>IQR</td>
<td>52-60.8</td>
</tr>
<tr>
<td>Vitality</td>
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<td>Median</td>
<td>45</td>
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<tr>
<td></td>
<td>IQR</td>
<td>40-65</td>
<td>35-65</td>
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<td>IQR</td>
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<td>100</td>
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<td>Mental</td>
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<td>66.7-100</td>
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<td>IQR</td>
<td>58.3-100</td>
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<td>66</td>
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<td></td>
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<td>60-82</td>
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Baseline Comparisons continued:

**Table 12  Locus of Control**

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<thead>
<tr>
<th>Variable</th>
<th>All Study Population</th>
<th></th>
<th>Completers (Included In Repeated Measures Analyses)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subject</td>
<td>Control</td>
<td>P Value</td>
</tr>
<tr>
<td><strong>Locus Of Control (General)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal</td>
<td>Median</td>
<td>28</td>
<td>28</td>
</tr>
<tr>
<td>IQR</td>
<td>24.3-29.8</td>
<td>24-30</td>
<td></td>
</tr>
<tr>
<td>External</td>
<td>Median</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>IQR</td>
<td>11.5-20</td>
<td>16-20.3</td>
<td></td>
</tr>
<tr>
<td>Chance</td>
<td>Median</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>IQR</td>
<td>17-24</td>
<td>20-28</td>
<td></td>
</tr>
<tr>
<td><strong>Locus Of Control (Care)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal</td>
<td>Median</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>IQR</td>
<td>6-9</td>
<td>6-8</td>
<td></td>
</tr>
<tr>
<td>External</td>
<td>Median</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>IQR</td>
<td>3-5.5</td>
<td>4-6</td>
<td></td>
</tr>
<tr>
<td>Chance</td>
<td>Median</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>IQR</td>
<td>3-6</td>
<td>4-6.25</td>
<td></td>
</tr>
</tbody>
</table>
Table 13  
GDS & CRBS

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline Scores (Patients)</th>
<th>Complete Scores (Patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subject</td>
<td>Control</td>
</tr>
<tr>
<td><strong>Total GDS</strong> (Global deterioration Scale)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median IQR</td>
<td>5</td>
<td>4-5</td>
</tr>
<tr>
<td><strong>Total CRBS</strong> (Crichton Royal Behavioural Scale)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median IQR</td>
<td>9</td>
<td>5-15</td>
</tr>
</tbody>
</table>
Carer Data

Care Giver Strain Index

The Care giver Strain Index consists of a list of things that people have found to be difficult when caring for an ill relative at home. There are 13 items:

- It is a physical strain
- It is confining
- There have been family adjustments
- There have been changes in personal plans
- There have been emotional adjustments
- There have been other demands on my time
- It is upsetting to find that he/she has changed so much from his/her former self
- Inconvenient because helping takes so much time, or a long journey over to help
- Some behaviour is upsetting
- There have been work adjustments
- It is a financial strain
- Feeling completely overwhelmed
- Sleep is disturbed

The response categories are simply “yes” (scores 1 point), or “no” (scores 0) to each individual item. Repeated measures analysis was conducted on the total score, (range 0 - 13).

Table 14

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Degrees of freedom</th>
<th>Mean square</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Between subjects</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental group</td>
<td>1</td>
<td>31.00</td>
<td>5.01</td>
<td>0.03</td>
</tr>
<tr>
<td>Strain baseline</td>
<td>1</td>
<td>182.5</td>
<td>29.49</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Error</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjs. Within groups</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Within subjects</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>1</td>
<td>9.62</td>
<td>3.22</td>
<td>0.79</td>
</tr>
<tr>
<td>Group by time</td>
<td>1</td>
<td>1.34</td>
<td>0.45</td>
<td>0.51</td>
</tr>
<tr>
<td>Strain (base by time)</td>
<td>1</td>
<td>18.47</td>
<td>6.19</td>
<td>0.016</td>
</tr>
</tbody>
</table>
Using repeated measures analysis there was no statistically significant group by time interaction found (p = 0.51) and there was no significant time effect (p = 0.08). There was however a significant difference in mean strain level at six months and twelve months between the groups (p = 0.03).

Figure 9: Difference In Mean Strain By Groups With Adjustment For Baseline

Estimated difference in carer strain by group (adjusted for strain at baseline)
Care Giver Strain Index

The repeated measures analysis conducted on the total score (range 0-13) is described in detail for this outcome, as an example for the remaining outcomes following. The analysis included as dependent variables the six month and one year values of the index with the baseline values as covariates. The results for this outcome are presented as two tables, Table 15 showing the full results of the repeated measures analysis whilst Table 14 shows the mean values for both groups (subjects and controls) at baseline, six months and one year, the values at six months and one year being unadjusted for the baseline and summaries of the key effects from the repeated measures analysis. In addition Table 14 shows differences at 6 months and one year between subject and control groups, adjusted for baseline values, together with 95% confidence intervals. The "group effect" tests the overall level of the index averaged over time between the two groups after adjustment for baseline and suggests a significant difference between the groups (p=0.03), the mean values (Table 14) showing an overall lower level for subjects than controls over the time period six months to one year. The "group by time" interaction is non-significant (p=0.51) thus the subject and control groups have not changed differentially between six months and one year. The difference between subject and controls groups at one year, adjusted for baseline is -0.88 (95% CI -1.98, 0.22) showing that subjects had a lower carer strain index, though not significantly so. However by one year the difference is -1.34 (95% CI -2.67, -0.02), thus by one year subjects had a significantly lower carer strain than controls (Figure 9). For the remaining outcomes only the equivalent of Table 15 will be shown.

Conclusions on Care giver strain index

The overall mean level of strain between 6 and 12 months was significantly different between subject and control groups after adjustment for baseline scores. Differences at six months were lower for subjects (0.88) though not significantly so. However subjects appeared to maintain this level whilst controls increased their scores further
(though this interaction was not significant), resulting in significantly lower scores for the subjects who had received a carer held record by 12 months (1.34, 95% CI 0.02, 2.67).

There is no way of knowing in which specific areas reduced strain has occurred. It was not appropriate to further break down the Care giver Strain Index and analyse individually each of the 13 items on the scale, as this would increase the likelihood of any significance found having occurred by chance. In clinical terms however, a reduction in carer strain of between 2.3 - 2.8 points on a potential total scale score of 13 is an important finding, and one which would suggest that having a carer held record did result in positive benefit to carers in this area.

**Sex and generation**

As a significant difference between the groups in overall level of carer strain between 6 and 12 months was found, the potential role of explaining this through sex and generation effects was examined. However, this difference remained after inclusion of a sex effect (p=0.04) and no other main effects or interactions were significant suggesting that this difference in not due to differences between the sexes either over time or in overall mean level of carer strain.

A similar analysis with generation showed a significant difference in overall mean level of carer strain between 6 and 12 months for the generations within subject and control groups (p=0.03). This appears due to a difference between the generations in the control group. No other main effects or interactions were significant.
Figure 10  Estimated Marginal Means of Measure

Estimated Marginal Means of MEASURE_1
At 1st 2nd or third generation = 1

Estimated Marginal Means of MEASURE_1
At 1st 2nd or third generation = 2

OCC
Carers' Stress Scale - Sections D, E, J and O

Section D: Relational Deprivation

The degree to which caregivers felt that they had lost important things in life because of their relatives' illness was determined by assessing how much they felt that they had lost the following:

Deprivation of intimate exchange

- Being able to confide in their relatives
- The persons they used to know
- Having someone who really knew them well

Deprivation of goals and activities

- The practical things their relatives used to do for them
- The chance to do some of the things they had planned
- Contact with other people

The response categories (1 - not at all, 2 - somewhat, 3 - quite a bit and 4 - completely) were summed to give a single measure of "relational deprivation" as advised by the original authors Pearlin et al (1990).

<table>
<thead>
<tr>
<th>Table 16</th>
<th>Relative deprivation</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>Means</td>
</tr>
<tr>
<td></td>
<td>Base</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
</tr>
</tbody>
</table>

S = subject, C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of relational deprivation between 6 months and 12 months (p=0.46) and no significantly different change over time between the two groups (p=0.26).
Section E: Family conflict

The degree to which there is disagreement between carers and other family members about how relatives who are ill are handled was determined by assessing how much disagreement there was concerning the following issues:

A. The seriousness of the relatives’ memory problems
B. The need to watch out for the relatives’ safety
C. What things they (the relatives) can do for themselves
D. Whether they should be placed in a nursing home

The response categories (1 – not at all, 2 – somewhat, 3 – quite a bit & 4 – completely) were summed to give a single measure of “family conflict” as advised by the original authors.

Table 17  Family Conflict

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by time interaction</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>5.3</td>
<td>5.4</td>
<td>4.8</td>
<td>0.78</td>
<td>0.38</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>6.7</td>
<td>6.3</td>
<td>5.9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of family conflict between 6 months and 12 months (p=0.38) and no significantly different change over time between the two groups (p=0.67).
Section J Care giving Competence

The degree to which carers felt competent in their caring roles was determined by assessing how much they agreed/disagreed with the following:

- Have learned to deal with a very difficult situation
- Feel that all in all they are good caregivers
- Are competent
- Are self confident

The response categories (1 - not at all, 2 - just a little, 3 - somewhat and 4 - very much) were summed to give a single measure of "care giving competence) as advised by the original authors.

Table 18 Competence

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>13.7</td>
<td>13.9</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>12.9</td>
<td>13.0</td>
</tr>
</tbody>
</table>

After adjustment for baseline levels, there was no difference between the groups in overall mean level of care giving competence between 6 months and 12 months (p=0.14) and no significantly different change over time between the two groups (p=0.62).
Section O  Expressive support

The degree to which carers felt that they were well supported by friends and family (other than their relatives for whom they were caring) was determined by asking how much they agreed/disagreed with the following statements:

- There is really no-one who understands what you are going through
- The people close to you let you know they care about you
- You have a friend or relative in whom you have confidence
- You have someone you feel you can trust
- You have people around you who help to keep your spirits up
- There are people in your life who make you feel good about yourself
- You have at least one friend or relative you can really confide in
- You have at least one friend or relative you want to be with when you are feeling down or discouraged

The response categories (1 - strongly disagree, 2 - disagree, 3 - agree and 4 - strongly agree) were summed to give a single measure of "expressive support" as advised by the original authors.

Table 19  Support

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>95% CI</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td>Group effect</td>
<td>Time</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>26.6</td>
<td>27</td>
<td>26.8</td>
<td>1.01</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>25.8</td>
<td>25.9</td>
<td>25.7</td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of expressive support between 6 months and 12 months (p=0.32) and no significantly different change over time between the two groups (p=0.99).
Conclusions on Carers’ Stress Scale Analysis

No significant differences were found between the subject and control groups in any of the four sections selected as outcome measurements for this study. These 4 sections were selected from a possible 15 sections contained in the complete stress scale as devised by Pearlin et al (1990). Selection of individual sections of the scale was possible because each section had been validated independently. Because of the large number of different outcome questionnaires to be completed by carers at each time scheduled interview, it was felt that administration of more than 4 sections of the Stress Scale would make interviews too time-consuming, and wearisome for respondents. It was thought that the areas of "competency and confidence", "family conflict", "expressive support" and "relative deprivation" would be the most likely sub-sections of the scale to reveal any possible benefits of having carer held records. In view of the fact that there was a significant difference found between the groups on the Carer Strain Index, it is perhaps surprising that no significance was revealed in any of these specific areas of carer stress. Further research into possible benefits of carer held records should perhaps include the administration of all 15 sections of the total Pearlin Stress Scale, to see if different aspects, and which aspects, of carer stress might prove to be ameliorated if carer held records are offered.
Level Of Burden Scale

The extent of carers' subjective level of burden was determined by assessing scores on a Likert scale:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No burden At all</td>
<td>A great burden</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Scale scores were obtained for each of the following facets of burden:

- Physical burden
- Financial burden
- Emotional burden
- Social burden

Carers were then asked to assess, on the same scale, their overall level of burden, taking into account the previous scores allocated. These five scores were then summed to give a single measure of subjective burden.

The final question on the questionnaire asked carers to assess, on a similar scale how much satisfaction they found from looking after their relatives:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No satisfaction</td>
<td>A great deal of satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This final score was analysed separately from the total burden score. Comparisons could thus be made between levels of burden and satisfaction with caring to investigate whether the relationship between burden and satisfaction differed between subject and control groups.
This scale was chosen because it seemed the most appropriate for use in this study; it was short, easy to administer, easy for carers to respond to, and was of a format which would elicit global measures of burden (i.e. it had face validity). However the scale was unattributed, and there was no evidence available about other types of validity. It was therefore important to assess whether the scale had at least convergent validity, in terms of its correlating with such factors as carer strain and mental ill health, and behavioural disturbance in the person cared for. To address this issue a Spearman’s rank correlation analysis was undertaken comparing the results of this burden scale with other scales used in this study namely, the Carer Strain Scale (Robinson 1983), the GHQ (Goldberg & Hillier 1972), and the CRBS (Robinson 1961).

There were significant correlations as follows:

When the burden scale was correlated with the strain scale, results were:-

\[ r_s = 0.59, \ p < 0.001. \]

When the burden scale was correlated with the GHQ, results were:-

\[ r_s = 0.55, \ p < 0.001. \]

When the burden scale was correlated with the CRBS, results were:-

\[ r_s = 0.42, \ p < 0.001. \]

These results indicate that the construct of burden as measured by this scale varies as would be expected with these measures of carer strain and mental health, and the patients’ level of behavioural disturbance. However the correlations are not so high as to suggest it is simply a proxy for these measures.
Table 20  
Level of burden

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>Group by time interaction</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1 yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12 1yr</td>
<td>Group effect Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td>18</td>
<td>12.9 13.9 14.3</td>
<td>2.48 0.12 0.60 0.44</td>
<td>0.09 0.77</td>
<td>-1.49</td>
<td>-3.34</td>
<td>0.36</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>12.6 15.7 15.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of total burden between 6 months and 12 months (p=0.12) and no significantly different change over time between the two groups (p=0.77).

Table 21  
Satisfaction

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>Group by time interaction</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1 yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12 1yr</td>
<td>Group effect Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td>19</td>
<td>2.37 2.65 2.90</td>
<td>0.0 0.97 0.02 0.89</td>
<td>0.57 0.45</td>
<td>-0.17</td>
<td>-0.83</td>
<td>-0.50</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>2.97 2.84 2.72</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of satisfaction between 6 months and 12 months (p=0.97) and no significantly different change over time between the two groups (p=0.45).

Plots of total burden were examined to make sure that normal assumption was reasonable. Analysis of covariance, with total burden as the dependent variable was used to see whether the relationship between burden and satisfaction differed by group.
There was no evidence of an interaction between satisfaction and subject and control groups (CF = 1.28, p = 0.26). When a parallel model was fitted there was no evidence of a difference in level of burden between groups, with adjustment for level of satisfaction (F = 0.79, p = 0.38).

It was also found that there was no evidence that burden decreases as satisfaction increases:

\[
\text{Burden} = 13.83 - 0.35 \times \text{satisfaction}
\]

95% CI for gradient (-1.05,0.35).

**Conclusion on Burden Scale Analysis**

The relationship between burden and satisfaction is perhaps much more complicated than a simple linear alignment. This will be further elaborated within the Discussion Section.
The Dementia Knowledge Questionnaire tests respondents knowledge on the subject of dementia in four separate areas or domains. These are:

**Rudimentary knowledge.**
This expects the carer to have a very basic grasp of the disorder. If a person scores poorly in this section he/she would be seen as holding irrational beliefs on the subject of dementia.

- Epidemiological knowledge
- Clinical symptoms
- Aetiological factors

For scoring purposes these are grouped into 3 discrete sections:

A. Abnormal knowledge
B. Epidemiological knowledge and knowledge of aetiology
C. Symptom knowledge

Carers' responses on the individual knowledge domains are described in the following tables:
Section A - Abnormal knowledge

Respondents were asked about what part of the body was affected by dementia, whether it was infectious, and whether there was a cure. Each correct answer scored 1 point.

Table 22 Abnormal knowledge

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12 Yr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by</td>
<td>Diff.</td>
<td>95% CI</td>
<td>Diff.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>F</td>
<td>P</td>
<td>F</td>
<td>P</td>
<td>interaction</td>
<td>Mean</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6/12</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2.63</td>
<td>0.11</td>
<td>0.43</td>
<td>0.52</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>2.9</td>
<td>2.9</td>
<td>3</td>
<td>2.63</td>
<td>0.11</td>
<td>0.11</td>
<td>2.63</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of abnormal knowledge between 6 months and 12 months (p=0.11) and no significantly different change over time between the two groups (p=0.71).

Section B - Epidemiological knowledge and knowledge of aetiology

Carers were asked about:

- the age range at which most people were affected by dementia,
- how many types of dementia there were,
- the percentage of people over 65 years who would have dementia,
- which factors on a list of 7 potential causal factors might cause dementia.

The first 3 questions scored 1 point if correct, and 0 points if wrong. The 4th question scored 1 point for identification of each causal factor.
After adjustment for baseline levels, there was no difference between the groups in overall mean level of epidemiological knowledge between 6 months and 12 months (p=0.85) but there was a significantly different change over time between the two groups (p=0.02) with the control group increasing knowledge between 6 months and 1 year and the subject group reducing their scores.

**Section C - Symptom knowledge**

Carers were asked which of the following aspects of life were affected when someone is suffering from dementia:

- eyesight
- hearing
- personality
- memory
- mobility
- speech
- bladder/bowel control
- life expectancy

1 point was scored for each correct response.
Table 24

Symptom knowledge

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base 6/12 1yr</td>
<td>Group effect</td>
<td>Time</td>
</tr>
<tr>
<td>S</td>
<td></td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>C</td>
<td></td>
<td>5.3</td>
<td>5.5</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of knowledge of symptoms between 6 months and 12 months (p=0.96) and no significantly different change over time between the two groups (p=0.92).

Dementia Knowledge - Total Score

A total score for the questionnaire was obtained by summing the scores for individual sections to give a single measure of “knowledge of dementia” as advised by the original author Graham et al (1997).

Table 25

Total knowledge

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base 6/12 1yr</td>
<td>Group effect</td>
<td>Time</td>
</tr>
<tr>
<td>S</td>
<td></td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>C</td>
<td></td>
<td>12.2</td>
<td>12.4</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of total knowledge between 6 months and 12 months (p=0.96) and no significantly different change over time between the two groups (p=0.08).
Conclusions on Dementia Knowledge Scale

Differences between the subject and control group were significant only in terms of the change between 6 and 12 months for epidemiological knowledge. This will be discussed further in the Discussion section.
General Health Questionnaire (GHQ)

The GHQ is designed to detect non-psychotic psychiatric illness/ affective disorder. The questionnaire has 28 items divided into 4 distinct sections each of 7 statements. Each section measures aspects of psychological distress in 4 different domains. These are:

- somatic symptoms
- social dysfunction
- anxiety and insomnia
- severe depression

The response categories (0 - better than usual, 1 - no more than usual, 2 - worse than usual and 3 - much worse than usual ) are summed for each section to give a single measure of psychological distress within each domain. All 4 sections are then summed to give a total score for the GHQ.

Section A - Somatic symptoms

Statements concern respondents' subjective opinions about their general health and include some questions on specific symptoms such as headaches.

Table 26  Somatic symptoms

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td>Group effect</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>P</td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>5.6</td>
<td>5.4</td>
<td>5.1</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>5.6</td>
<td>5.4</td>
<td>4.7</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of somatic symptoms between 6 months and 12 months (p=0.80) and no significantly different change over time between the two groups (p=0.68).
Section B - Anxiety and Insomnia

Statements concern respondents' subjective feelings of being nervous, edgy and bad-tempered, and finding things getting on top of them. Some statements specifically concern current sleep patterns.

Table 27  Anxiety

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group effect</td>
<td>Time</td>
<td>Group by time interaction</td>
<td>Diff. Mean 6/12</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>P</td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>7.2</td>
<td>6.4</td>
<td>5.5</td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>7.0</td>
<td>6.5</td>
<td>6.6</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of anxiety between 6 months and 12 months (p=0.45) and no significantly different change over time between the two groups (p=0.47).
Section C - Social dysfunction

Statements concern respondents' subjective opinions about how well they are dealing with daily facets of life, and how satisfied they were with life in general; whether they felt they were playing a useful part in things and whether they could make decisions.

Table 28  Social Dysfunction

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>Iyr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by time interaction</td>
<td>Diff. Mean 6/12</td>
<td>95% CI</td>
<td>Diff. Mean 1 yr</td>
<td>95% CI</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>21</td>
<td>8.0</td>
<td>8.2</td>
<td>8.4</td>
<td>0.02</td>
<td>0.89</td>
<td>1.14</td>
<td>0.29</td>
<td>0.59</td>
<td>-0.13</td>
<td>-0.98</td>
</tr>
<tr>
<td>P</td>
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<td></td>
<td></td>
<td></td>
<td>0.72</td>
<td>1.64</td>
</tr>
<tr>
<td>S</td>
<td>32</td>
<td>7.8</td>
<td>8.3</td>
<td>8.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of social dysfunction between 6 months and 12 months (p=0.89) and no significantly different change over time between the two groups (p=0.59).

Section D - Severe depression

Statements in this section concerned respondents' feelings of worthlessness, despair, suicidal feelings and suicidal intent.

Table 29  Severe depression

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>Iyr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by time interaction</td>
<td>Diff. Mean 6/12</td>
<td>95% CI</td>
<td>Diff. Mean 1 yr</td>
<td>95% CI</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>21</td>
<td>1.7</td>
<td>1.2</td>
<td>2.0</td>
<td>0.03</td>
<td>0.87</td>
<td>4.41</td>
<td>0.04</td>
<td>2.8</td>
<td>0.10</td>
<td>-0.76</td>
</tr>
<tr>
<td>P</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.57</td>
<td>2.04</td>
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<tr>
<td>S</td>
<td>32</td>
<td>1.5</td>
<td>1.8</td>
<td>1.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control
After adjustment for baseline levels, there was no difference between the groups in overall mean level of severe depression between 6 months and 12 months \((p=0.87)\) and no significantly different change over time between the two groups \((p=0.10)\). The significant time effect \((p=0.04)\) suggests that scores changed over time but not differentially between subject and control groups.

**General Health Questionnaire - Total Scores**

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>22.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>32</td>
<td>21.7</td>
</tr>
</tbody>
</table>

*S = subject  C = control*

After adjustment for baseline levels, there was no difference between the groups in overall mean level of total GHQ score between 6 months and 12 months \((p=0.81)\) and no significantly different change over time between the two groups \((p=0.64)\).
Short Form Health Questionnaire (SF 36)

The SF36 questionnaire is designed to measure more aspects of general health than simply the physical and mental. Emphasis is placed in this questionnaire on personal evaluations of health and well being. Also included are questions about social role and vitality. The scale therefore attempts to encompass assessment of health in its widest sense. Eight health concepts are included in the scale:

- physical health
- role
- social functioning
- current health perceptions
- pain
- mental health
- emotional health
- vitality

Response categories varied depending on the question. Some questions required "yes" or "no" responses. Others asked respondents to select the appropriate response on a scale graded from 1 - 5. Each response category was designed to be appropriate to the individual question. Carers read the questions, or they were read to them, together with the individual response sections from which they made their own most appropriate choices.

Calculation of the SF36 scores was more complicated than for other scales used in this study. Questions in the scale are not all presented in category order. The data has first to be sorted into the specified 8 health domains before any further calculations are made. Scores for the SF36 scale are not summed. The scale is designed for examination of each of the 8 health concepts as individual entities. A computer programme in SPSS was written to calculate the SF 36 scores as advised by the Medical Outcomes Trust (1993). The calculations were checked firstly by cross-tabulating questionnaire responses against final item values for all items, and secondly by calculating all subscales manually for a sample of ten individuals. Results for mean scores are given on a percentage scale.
### SF 36 General Health - Current Health Perceptions

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by</td>
<td>Diff. Mean</td>
<td>95% CI</td>
<td>Diff. Mean</td>
<td>95% CI</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>time interaction</td>
<td>6/12</td>
<td></td>
<td>1 yr</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td>16</td>
<td>55.7</td>
<td>56.2</td>
<td>54.5</td>
<td>1.71</td>
<td>0.20</td>
<td>0.17</td>
<td>0.68</td>
<td>0.10</td>
<td>0.76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>26</td>
<td>55.8</td>
<td>53.9</td>
<td>53.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of general health between 6 months and 12 months (p=0.20) and no significantly different change over time between the two groups (p=0.76).

### SF 36 Role

### SF Role

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th></th>
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<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>6/12</td>
<td>1yr</td>
<td>Group effect</td>
<td>Time</td>
<td>Group by</td>
<td>Diff. Mean</td>
<td>95% CI</td>
<td>Diff. Mean</td>
<td>95% CI</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>time interaction</td>
<td>6/12</td>
<td></td>
<td>1 yr</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td>16</td>
<td>64.1</td>
<td>67.2</td>
<td>73.4</td>
<td>1.17</td>
<td>0.29</td>
<td>0.13</td>
<td>0.72</td>
<td>3.11</td>
<td>0.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>26</td>
<td>73.1</td>
<td>76.9</td>
<td>57.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of physical role between 6 months and 12 months (p=0.29) and no significantly different change over time between the two groups (p=0.09).
After adjustment for baseline levels, there was no difference between the groups in overall mean level of social functioning between 6 months and 12 months (p=0.66) and no significantly different change over time between the two groups (p=0.18).

After adjustment for baseline levels, there was no difference between the groups in overall mean level of vitality between 6 months and 12 months (p=0.71) and no significantly different change over time between the two groups (p=0.43).
After adjustment for baseline levels, there was no difference between the groups in overall mean level of mental health between 6 months and 12 months ($p=0.54$) and no significantly different change over time between the two groups ($p=0.77$).

After adjustment for baseline levels, there was no difference between the groups in overall mean level of emotional health between 6 months and 12 months ($p=0.65$) and no significantly different change over time between the two groups ($p=0.29$).
After adjustment for baseline levels, there was no difference between the groups in overall mean level of pain between 6 months and 12 months ($p=0.83$) and no significantly different change over time between the two groups ($p=0.65$).

**SF 36 - Physical Health**

After adjustment for baseline levels, there was no difference between the groups in overall mean level of physical health between 6 months and 12 months ($p=0.35$) and no significantly different change over time between the two groups ($p=0.65$).
Conclusion to GHQ and SF 36 scales

Results for both health questionnaires show no differences between the groups within the domains of health described and so it can be said that no definite health gains followed from use of the carer held record. Results of both scales will be further elaborated within the Discussion Section.
Locus of Control

Measuring locus of control involves measuring the beliefs which individuals hold about the causes and control of everyday happenings in their lives. A detailed description of the theory behind this measure has been given in the section on "Outcome Measures". This scale was designed to measure to what extent carers believed that:

- events in their lives occurred as a consequence of their own actions, and were thereby controllable (internal control).

- events in their lives were unrelated to their own behaviour, and were therefore beyond personal control. People who believe that events in their lives are controlled by powerful others at least have the potential for regaining control (external control).

- Events in their lives are controlled by chance, and they are therefore much more powerless (chance).

The questionnaire contained 24 statements grouped into topic sets of 3 responses each of which had an "internal", "external" and "chance" focus. This scale had been validated in previous research studies (Levenson 1981). Carers were asked to give their appropriate responses to all 24 statements.

Six further statements were added to the scale phrased to conform with the 3 topic sets to assess carers' feelings about control in relation to caring for their relatives with dementia at home. Responses to these six statements were scored separately from the main scale, but using the same method.
Response categories were:

<table>
<thead>
<tr>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>

Scores for the first 24 statements were summed to give total scores in the three aspects of control. Each carer thus had 3 scores assessing to what extent he/she believed that events in his/her world were internally or externally controlled, or controlled by chance. Similarly scores for the last six statements were summed to give an estimation of feelings of control about care giving.

**Table 39  Locus of Control - Internal**

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>P</td>
</tr>
<tr>
<td>S</td>
<td>19</td>
<td>27.0</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>26.8</td>
</tr>
</tbody>
</table>

After adjustment for baseline levels, there was no difference between the groups in overall mean level of internal locus of control scale between 6 months and 12 months (p=0.58) and no significantly different change over time between the two groups (p=0.73).
After adjustment for baseline levels, there was a significant difference between the groups in overall mean level of external locus of control scale between 6 months and 12 months (p=0.01). Since there was no significantly different change over time between the two groups (p=0.28) this difference was maintained over the time period. Subjects had scores on average 2.5 points lower at six months than controls (95% CI 0.18 to 4.82 points lower) and 3.43 points lower at 12 months (95% CI 1.29 to 5.57 points lower).

After adjustment for baseline levels, there was no difference between the groups in overall mean level of chance locus of control scores between 6 months and 12 months (p=0.24) but there was a significantly different change over time between the two groups (p=0.05) with the control group increasing scores between 6 months and 1 year and the subject group reducing their scores.
Further analysis of data on external control

Sex and generation

As a significant difference in overall mean level of external locus of control was found between subjects and controls, the potential role of explaining this through sex and generation effects was examined. No significant difference between the sexes was found in mean level of external locus of control from 6 to 12 months \((p=0.81)\). However the overall mean level between subject and control remained significant \((p=0.02)\).

A similar analysis with generation showed no significant difference between generations \((p=0.32)\) but the overall difference in mean levels between 6 and 12 months between the groups was also no longer significant \((p=0.16)\). This suggests that some of the difference in overall levels could be explained by generation effects.

Further analysis of chance control

Sex and generation

As a significant difference between the groups over time in chance locus of control was found, the potential role of explaining this through sex and generation effects was examined. A significant difference between the sexes over time was found \((p=0.02)\) and the previously significant group by time interaction was no longer so \((p=0.52)\). However there was no evidence that the group by time interaction was different between the sexes \((p=0.07)\).

A similar analysis with generation showed no significant difference between generations over time \((p=0.51)\) and the previous group by time interaction was no longer significant \((p=0.27)\).
Table 42  
Locus of Control - Internal control of care

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base 6/12 1yr Group effect</td>
<td>Time Group by time interaction</td>
</tr>
<tr>
<td>S</td>
<td>20</td>
<td>7.4 7.6 7.8</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>7.3 7.8 7.3</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of internal control of care between 6 months and 12 months (p=0.61) but there was a significantly different change over time between the two groups (p=0.04) with subjects continuing to maintain a higher level of internal control of care whilst the control group reduced.
**Table 43**  
**Locus of Control - External control of care**

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>6/12</th>
<th>1yr</th>
<th>Group effect</th>
<th>Time</th>
<th>Group by time interaction</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1 yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
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<td>4.8</td>
<td>4.8</td>
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<td>0.20</td>
<td>0.08</td>
<td>0.78</td>
<td>0.01</td>
<td>0.91</td>
<td>-0.59</td>
</tr>
<tr>
<td>C</td>
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<td>5.3</td>
<td>5.5</td>
<td>5.7</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.52</td>
</tr>
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</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of external control of care between 6 months and 12 months (p=0.20) and no significantly different change over time between the two groups (p=0.91).

**Table 44**  
**Locus of Control - Chance re. control of care**

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>6/12</th>
<th>1yr</th>
<th>Group effect</th>
<th>Time</th>
<th>Group by time interaction</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1 yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>S</td>
<td>20</td>
<td>4.2</td>
<td>3.9</td>
<td>4.0</td>
<td>0.84</td>
<td>0.37</td>
<td>0.17</td>
<td>0.68</td>
<td>0.12</td>
<td>0.73</td>
<td>-0.40</td>
</tr>
<tr>
<td>C</td>
<td>31</td>
<td>5.0</td>
<td>4.5</td>
<td>4.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.39</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of chance control of care between 6 months and 12 months (p=0.37) and no significantly different change over time between the two groups (p=0.73).
Further analysis of internal control of care

Sex and generation

As a significant difference between the groups over time in internal control of care was found, the potential role of explaining this through sex and generation effects was examined. A significant difference in overall mean level of internal control of care between 6 and 12 months was found for men (and women) within subject and control groups (p=0.04). The previous group by time interaction was no longer significant (p=0.12) suggesting that differences in overall level for men and women between groups accounted for the previous difference. No other main effects or interactions were significant.

A similar analysis with generation showed no significant difference between generations over time (p=0.98) and the previous group by time interaction was no longer significant (p=0.15).
Interpretation of Locus of Control Analysis

Locus of Control (global)
The interpretation of the locus of control results is quite complicated.
There is no change in either group effect or interaction effect for belief in internal control.

In external control beliefs however, subjects had scores on average 2.5 points lower at six months than controls (95% CI 0.18 to 4.82 points lower) and 3.43 points lower at 12 months (95% CI 1.29 to 5.57 points lower).

In chance control, there was a significantly different change over time between the two groups (p=0.05) with the control group increasing scores between 6 months and 1 year and the subject group reducing their scores.

Because the questionnaire has a “neutral” option which respondents can choose in making their responses, it is possible that some carers in the subject group were less sure of control by external forces, in global terms, and opted for the neutral response. Similarly, over time, subjects had become less sure of the chance influence on their lives.

Locus of Control (shared care dimension)
In the shared care dimension of locus of control, there was no significant group effect demonstrated in belief in any of the three loci, (internal, external or chance). However, in the internal control of care dimension, whilst there was no difference between the groups in overall mean level of internal control of care between 6 months and 12 months (p=0.61) but there was a significantly different change over time between the two groups (p=0.04) with subjects continuing to maintain a higher level of internal control of care whilst the control group reduced. It appears therefore that carers in the subject group, who have the carer held record, feel that they have more control within the shared care of their relatives with dementia over time than controls do.
Locus of Control (Sex and generation effects)

Results from this study suggest that further analysis of the potential role of differences in sex and generation in affecting carers' locus of control beliefs would be useful in any future research on this aspect of the effect of having carer held records.
Patient Data

Assessment of the deterioration in patients' cognitive and behavioural symptoms was made at each time interval for both subject and control groups. The main reason for collecting this data was to check that there was no statistical difference between the groups in terms of patients' dementia. If differences were found on the GDS and Crichton Behavioural scales at baseline, or on repeated measures analysis, then this could be a confounding variable in the study results.

Global Deterioration Scale (GDS)

The GDS is designed to detect cognitive decline. The questionnaire describes seven stages of cognitive decline:

- Stage 1 - No cognitive decline (score 1)
- Stage 2 - Very mild cognitive decline (score 2)
- Stage 3 - Mild cognitive decline (score 3)
- Stage 4 - Moderate cognitive decline (score 4)
- Stage 5 - Moderately severe cognitive decline (score 5)
- Stage 6 - Severe cognitive decline (score 7)
- Stage 7 - Very severe cognitive decline (score 7)

Carers decided on the allocation of their relatives' scores, having read, or had read to them, the detailed summaries of the characteristics of each stage.

Table 45 GDS Results Table

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
<th>Group effect</th>
<th>Group by time interaction</th>
<th>Diff. Mean 6/12</th>
<th>95% CI</th>
<th>Diff. Mean 1 yr</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
<td>1yr</td>
<td>F</td>
<td>P</td>
<td>F</td>
<td>P</td>
<td>F</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>4.4</td>
<td>4.9</td>
<td>5.4</td>
<td>0.02</td>
<td>0.89</td>
<td>5.11</td>
<td>0.03</td>
</tr>
<tr>
<td>C</td>
<td>27</td>
<td>4.5</td>
<td>4.8</td>
<td>5.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of global deterioration between 6 months and 12 months (p=0.89) and no significantly different change over time between the two groups (p=0.59).
Modified Crichton Royal Behavioural Scale (CRBS)

The CRBS is designed to measure patients' performance in ten domains where deterioration in cerebral function might have an effect. The first 5 sections concern activities of daily living:

- Mobility
- Dressing
- Feeding
- Bathing
- Continence

The second 5 sections concern cognition and other aspects of behaviour which might affect such patients:

- Memory
- Orientation
- Communication
- Co-operation
- Restlessness

Within each domain are 5 graded alternatives from which to choose the score which best represents the patient's functioning, ranging from 0 - 4, where 0 = "normality" and 4 = complete failure of that particular function.

As in the administration of the GDS, carers allocated scores in each section having read, or had read to them, detailed descriptions of the five possible scores within each section.
Table 46 CRBS Results

<table>
<thead>
<tr>
<th>N</th>
<th>Means</th>
<th>Test for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base</td>
<td>6/12</td>
</tr>
<tr>
<td>S</td>
<td>21</td>
<td>9.6</td>
</tr>
<tr>
<td>C</td>
<td>27</td>
<td>9.8</td>
</tr>
</tbody>
</table>

S = subject  C = control

After adjustment for baseline levels, there was no difference between the groups in overall mean level of CRBS between 6 months and 12 months (p=0.76) but there was a significantly different change over time between the two groups (p=0.02). Subjects deteriorated more rapidly than controls between baseline and 6 months but between 6 months and 1 year controls deteriorated more rapidly than subjects.

Conclusions on patient data statistics

The results from both questionnaires show that there were substantial levels of deterioration in those patients being looked after by their carers on both measures, and for both subjects and controls. Results show a progressive deterioration in patients' conditions comparable for both groups on the GDS scale. The CRBS scale also shows deterioration in both groups, although the rates of change varied for subjects and controls, subjects undergoing most of the change before the 6 month follow up interval, and change flattening out between 6 months and the 1 year time interval, whilst controls deteriorated in a more linear manner. There are therefore no grounds for suggesting that statistical differences found in carers' questionnaire responses may be due to differences in their relatives' levels of dementia.
In the literature about the GDS some researchers (Eisdorfer et al 1992, Paveza et al 1995) suggested that in dementia, deterioration can occur at different rates and in different sequences, and that no single score can adequately categorise this. In this study it has been shown that, as a global measure, the GDS does pick up deterioration over time. It was as effective as the CRBS in showing disease progression.

Is the study hypothesis proven?

As a short summary paragraph to the Results Section of this thesis, it can be said that, of the health benefits listed in the hypothesis, only reduction in some areas of strain levels, and gains in feelings of control, were identified in this study. There were no significant gains in knowledge of dementia and no health benefits for carers demonstrated in this research. Further elaboration on the significance of these findings is undertaken in the Discussion Section of this document.
Long term Care Admissions

Eight subjects and twelve controls were admitted to long term care at different time points during the study period (See table 53). A survival analysis was performed on this data to see if there were any differences between the groups in the rate of admission to long term care. Cox regression was used to analyse the data with the dependent variable being time spent living in the community, and the event being entry into long term care. Observations were censored at death, or no entry into care at the time of the last interview.

The results showed that the risk of being admitted to long term care for controls compared to subjects was 1.02. (95% CI 0.43, 2.38). This means that there was very little difference between the groups, and the fact that carers have carer held records does not appear to result in these patients staying longer in the community than controls.

Table 47 Long Term Care Admissions

<table>
<thead>
<tr>
<th>Participants</th>
<th>Time period</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before 6/12</td>
</tr>
<tr>
<td>Subjects</td>
<td></td>
</tr>
<tr>
<td>1 x 2/12</td>
<td>1 x 11/12</td>
</tr>
<tr>
<td>1 x 3/12</td>
<td>1 x 11/12</td>
</tr>
<tr>
<td>Total 8</td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td></td>
</tr>
<tr>
<td>1 x 5/12</td>
<td>1 x 10/12</td>
</tr>
<tr>
<td>1 x 9/12</td>
<td>1 x 14/12</td>
</tr>
<tr>
<td>1 x 9/12</td>
<td>1 x 17/12</td>
</tr>
<tr>
<td>Total 12</td>
<td></td>
</tr>
</tbody>
</table>
Qualitative Data Analysis

Client Engagement

Engagement is defined as embracement of the idea of carer held records, and agreement in principle with the underpinning philosophy. It also encompasses willingness to put the carer held record into practical use. Assessment of client engagement with the project was made from data about clients’ actual use of the carer held record, and their stated interest in the whole concept.

Engagement analysis was not related to how long participants remained in the study. Some carers who continued to participate in the study did not fully engage with the philosophy, and made very little use of the document. Others, who left the project because the patient died at some point within the study period, had indicated by their document use, and verbal and written comments, that they had indeed engaged with the project. In 2 cases, although the carers had embarked on the project enthusiastically, the patient died before the first follow up appointment, and so it could not be determined whether these families would have engaged with the project or not.

Table 48

<table>
<thead>
<tr>
<th>Engagement</th>
<th>No Evidence</th>
<th>Non-Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wives</td>
<td>4</td>
<td>Wives 3</td>
</tr>
<tr>
<td>Husbands</td>
<td>0</td>
<td>Husbands 2</td>
</tr>
<tr>
<td>Daughters</td>
<td>11</td>
<td>Daughters 6</td>
</tr>
<tr>
<td>Sons</td>
<td>5</td>
<td>Sons 0</td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
<td>Others 2</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>Total 13</td>
</tr>
</tbody>
</table>

A breakdown of reasons for withdrawal from the research, and timescales at which discontinuation occurred is shown on the Figure 7 - flow chart overleaf and table 55.
**Flow Diagram Of Recruitment And Attrition**

Total Pop. who met research criteria 146

<table>
<thead>
<tr>
<th>Group</th>
<th>Excluded Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjects</td>
<td>Did not wish to participate</td>
</tr>
<tr>
<td></td>
<td>Long Term care imminent</td>
</tr>
<tr>
<td></td>
<td>Carer not close geographically</td>
</tr>
<tr>
<td></td>
<td>Carer unwell</td>
</tr>
<tr>
<td></td>
<td>Diagnosis not dementia</td>
</tr>
<tr>
<td></td>
<td>Carer unresponsive at contact</td>
</tr>
<tr>
<td></td>
<td>Carer does not accept diagnosis</td>
</tr>
<tr>
<td></td>
<td>Carer refusing all support</td>
</tr>
<tr>
<td></td>
<td>Carer felt patient not ill enough for record to be of benefit</td>
</tr>
<tr>
<td></td>
<td>Carer felt patient too ill for record to be of benefit</td>
</tr>
<tr>
<td></td>
<td>Case closed before consent could be obtained</td>
</tr>
<tr>
<td></td>
<td>Professionals considered carers too distressed to be approached</td>
</tr>
<tr>
<td></td>
<td>Profs. considered relatives too</td>
</tr>
<tr>
<td></td>
<td>Unco-operative to be included</td>
</tr>
</tbody>
</table>

| Controls   | Did not wish to participate                           | 7  |
|            | Long term care imminent                                | 3  |
|            | Carer not close geographically                         | 2  |
|            | Carer unwell                                          | 2  |
|            | Diagnosis not dementia                                 | 2  |
|            | Carer unresponsive at contact                          | 2  |
|            | Carer does not accept diagnosis                        | 2  |
|            | Carer refusing all support                             | 3  |
|            | Carer felt patient not ill enough for record to be of benefit | 2  |
|            | Carer felt patient too ill for record to be of benefit | 1  |
|            | Case closed before consent could be obtained           | 1  |
|            | Professionals considered carers too distressed to be approached | 2  |
|            | Profs. considered relatives too                        | 2  |

Subjects Numbers receiving carer held record 38

Controls Numbers receiving control management 46

Attrition numbers 14

<table>
<thead>
<tr>
<th>Reason</th>
<th>Subjects</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death of patient</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Death of carer</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Moved from area</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Withdrawals</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

No. reaching end point 17

No. included in final analysis 38

Attrition numbers 16

<table>
<thead>
<tr>
<th>Reason</th>
<th>Subjects</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death of patient</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Death of carer</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Moved from area</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Withdrawals</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

No. reaching end point 24

No. included in final analysis 46
Table 49  Discontinuation in use of record

<table>
<thead>
<tr>
<th>Discontinued Before 6/12 FU</th>
<th>N</th>
<th>Characteristics</th>
<th>Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Husband</td>
<td>Did not like idea of project</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Son</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Daughter</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total 3 carers</td>
</tr>
<tr>
<td>Discontinued Before 1 year FU</td>
<td>1</td>
<td>Wife</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Daughters</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Son</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Grand daughter</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Niece</td>
<td>Death of carer</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Daughters</td>
<td>Never used book at all</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Son</td>
<td>Patient moved from area</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Wife</td>
<td>Book seemed a burden to her</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Daughter</td>
<td>Used at 6/12 no use later</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total 11 carers</td>
</tr>
<tr>
<td>Discontinued Before 18/12 FU</td>
<td>1</td>
<td>Lodger</td>
<td>Death of patient</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Daughter in law</td>
<td>Did not wish to go on writing</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Husband</td>
<td>Pt admitted to long term care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total 4 carers</td>
</tr>
<tr>
<td>Continued to end point</td>
<td>5</td>
<td>Wives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>Husbands</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Sons</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>Daughters</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Niece</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total 20 carers</td>
</tr>
</tbody>
</table>

% completion =53%

Further analysis reveals that:

engagement/non-engagement with the project of wives was fairly equal (4:3.)

Husbands tended not to engage well, although it is a very small sample ie only two subjects. They started on the project fairly willingly and accepted the carer held record, but withdrew before the first follow up interview, not wishing to continue. One husband whose wife was admitted to long term care felt that he would like to continue with the record, but found it inappropriate and of little use to him after her admission.
More daughters engaged with the project than not (11 : 6). The 5 sons who took part in the project all engaged well. This was interesting because the other group of male contributors, the husbands, did not engage well. Also, sons were a difficult group to recruit to the study at the beginning. It seems therefore that sons, if they made the decision to accept the carer held record, were conscientious about its maintenance.

Four carers in less direct relationships to patients took part in the research. Of these, 2 engaged well and 2 did not. Those who engaged had unusually close relationships with their relatives, (1 niece and 1 granddaughter).

The one non-family member in the study was a lodger who had been living with the patient for several years. He felt it inappropriate to use the record; that it was not his place to record details about his friend, although he continued in the study until the patient died, thinking that he might at some point change his mind. His feelings about the project gave credence to the decision to exclude non-family carers from the project in the research protocol. His inclusion in the research came about because of his unusually close relationship to his friend, the patient having no other relatives. It was an exceptional case. However, it soon became clear that this lodger felt quite uncomfortable in actually maintaining the record after starting the project. He did not think it appropriate.

20 carers continued with the project, answering questionnaires till its end point at 18 months. However, of these, 3 carers (1 wife, 2 daughters) had made very little use of the record. All three kept the record at home, but never felt the time appropriate either to write much themselves or to present it to professionals for their contributions. Although all three stated that the book might be useful to them in the future, they have to be regarded as “non-engagers” during the period of the study. Six carers (2 wives, 5 daughters) rejected the record and withdrew from the study at different time points during the research. The total number of carers who did not engage was 13 i.e. 36%.
No evidence of engagement

2 carers (1 son, 1 daughter) whose relatives died before the first follow up interviews could not be included in engagement analysis as there was no evidence of actual use of the document. Both however had embarked on the project with enthusiasm.

Engagement with the project

23 participants (64%) who held the care held records did engage with the project and used the record to varying degrees, and in individual ways.

How assessment was made

How individual carers used the package was recorded at each time-scheduled interview session. In most cases the package was there for researchers to examine. This was particularly so for those carers who engaged strongly with the project. Sometimes the record was at the day hospital/day centre with the patients, when their carers were interviewed. On a few occasions carers had left records at patients' homes for easier completion by professionals, and had not brought it to the interview.
The questionnaires were therefore used to record qualitatively the use individual carers made of records, and how professional and voluntary agency staff had contributed. Text in italics in the analysis represents carers' written comments, or actual words spoken by carers, recorded by researchers.

The ways in which carers had used their packages were indeed very individual. Aspects of the record which worked for one carer may not have worked for another. The "medication" page for instance was in some instances well used and highly valued:

- "The medication page was useful to complete and show to others"
- "Reminds me of what he's on."
- "Useful to have written down all the medication he's on, and has been on. I was able to show this to the locum GP when I called the doctor out."

When patients were on no medication, or on stable regimes, the page was not regarded as being of much use to carers. Any numerical analysis of how each page was used therefore might have been misleading. Pages were used if required, or desired by carers, and disregarded if not individually relevant.

**Carers' Actual Use Of The Record**

It is very difficult to generalise about common themes arising in examination of this qualitative data. What emerged most strongly in the analysis was the individuality of carer use, depending on carers' circumstances and inclinations. Common themes which will be discussed may be viewed by carers in differing ways. An attempt will be made to report and clarify these issues within the overall analysis.
Value to carers of the total package

Generally those who engaged with the project found it useful to have the carer held record as a total package. 64% of participants used aspects of the package and subjectively felt that they had gained benefit from its use:

- "It is useful to have the whole package. I’ve completed all the carers’ pages, and use them."
- "The whole package is useful. We can look and see what’s happening."
- "I think the book is excellent - 9½ out of 10!!"

There were however a few less enthusiastic reactions regarding the package as a whole some of which concern professionals' input. This will be discussed later in a separate section. Other comments made about the package include:

- "The overall package is cumbersome."
- "It’s a bit repetitive when you’ve nothing to write about."
- "The book is too big for handling. There are too many pages to fill in."

It can therefore be seen that although negative reactions were very much in the minority, the structure and design of a document like a patient/carer held record is unlikely to appeal to all patients/carers. There will always be aspects that some carers like, and others do not. On the whole the package design was well received by carers in this study.
The concept of having a carer held record

As has been shown in previous research (Greasley et al 2000, Warner et al 2000) carers generally liked the idea of having a carer held record. This was true especially at the beginning of the research, when most participants embarked on the project with varying degrees of enthusiasm. It must be remembered however that many of those potential subjects who declined to participate may not have liked the idea behind the initiative. Seventeen potential subjects who met the research criteria declined to participate with no specific reasons given compared with 7 potential controls (See Figure 7). This suggests that the idea of keeping a carer held record may not appeal to all. I think it is important to state this at this point in the analysis.

Is enthusiasm for the project maintained?

In most instances enthusiasm was maintained to some degree, but not for all participants. Three carers (1 wife, 3 daughters and 1 sister in law) withdrew before the 1 year follow up date, not wishing to continue. One daughter who had kept the package for a year, no longer wanted to go on “writing it up” beyond that point. 3 participants (1 wife, 2 daughters) actually found that the practicality of keeping the document was at odds with the concept which they maintained they still believed in:

- “I really don’t like writing. I have arthritis in my fingers and it is difficult.”
- “It has become a burden to me. I can see it would be useful for some people, but it’s not for me.”
- “I don’t like putting down details.”

Three carers wrote in the record enthusiastically at the beginning of the research, but found it less useful as time went on:

- “I use it when I feel like it. After a while you forget to do it.”
Two daughters found that they didn't want to spend the time necessary to contribute to the document:

- "I'm too tired after work."
- "I don't want to think about mother's problems in my free time."

The majority of participants however did continue to believe that the idea of having a carer held record was a good one. Twenty participants maintained their interest in the concept over two years, and most continued to use the package. Other carers whose relatives died during the study period had also maintained their support for the project during their participation periods.

Value to carers of the diary section

This was the part of the package about which there was most consensus of opinion. Nineteen participants reported how useful they found it to keep a diary. There was great variation in how the diaries were used. Some carers recorded daily entries; others documented only major changes or incidents. All 19 however rated their diary as valuable. The following comments illustrate this:

- "I use it fairly regularly. I write down how he is and how I feel."
- "It's really good to have kept the diary. When I read it myself I don't know how we managed."
- "Useful to write your feelings down. You write down things you could never say. It's a way of letting off steam."
- "I use the diary to relieve my feelings when I feel the need. It's the most useful part for me."
No-one expressed very negative views about the diary. Some however felt that they got little benefit from writing things down.

- "I use the diary intermittently, generally from a sense of duty."
- "I feel a bit guilty that I’m not writing more."
- "I only write the dates of important incidents, and what happened."

Several participants said that they used the whole package as a record of events, the diary section particularly:

- "I keep everything in the book - health and social work contacts, appointments etc.; letters and plans for long term care. I keep it as a file of what’s happening now."
- "I use the diary as a log"
- "I keep everything in the package."

This last quote was from a carer who typed up all her entries and clipped them in place in her package.
Contribution Of Professionals And Voluntary Agency Workers To The Package

Contributions to the carer held records of professional health care givers, social services and workers from voluntary agencies, although not at optimum level, were much more in evidence than had been the case in the pilot study.

CMHT keyworkers

CMHT professionals were the group who most consistently recorded details of their visits to patients and carers, and ensured that care plans were completed and appropriately situated within the files. Documentation by CPNs and other disciplines who were keyworking was in place in 19 of the records in use. This represented 70% of the cases open during the course of the study. In every instance this professional input to the record was rated by carers as very useful:

- “It is useful when you don’t actually see the people who are visiting her. In my case Mum doesn’t even remember who has been, let alone what was said.”

Some of the patient/carer pairs had little input from CMHTs beyond initial assessment. In other instances carers kept the record in their homes, and CMHT workers visited patients elsewhere where the record was not available. It is true too that some keyworkers were more conscientious than others in making their entries, but generally professional input by keyworkers was well documented.

CMHT medical staff

Entries from medical staff were less in evidence. Notes were made of hospital visits on 3 occasions, and a consultant made a detailed entry in 1 record.

General Practitioners

In 5 records there were entries made by GPs. When asked by carers most GPs were willing to document their input. Two carers however reported occasions when GPs declined to contribute. The reason for the small numbers of GP entries was that often carers forgot to take the record with them to appointments.
Day Hospitals And Day Centres

Contributions from health workers in day hospitals and day centres were also fairly regular. 8 records contained input from day care keyworkers, and this was greatly valued by carers:

- "The day centre record was useful, to see what had happened there; whether lunch was eaten, and what he did."

One day hospital keyworker recorded the content of discussions with a carer about the patient’s care. Some entries were quite detailed. One carer told how she and the day hospital staff had decided together that hospital entries should be made once a month:

The day hospital nurse now only writes once a month. It is helpful for me to have that information, but there was no need for them to write at every visit unless something unusual happened."

Hospital Admissions And Respite Services In Hospitals

When patients were admitted to hospital the idea was that the carer held record would be made available for hospital keyworkers to write their care plans and evaluations in it. This did not work very well, mainly because carers did not leave their records at the hospital, rather than the fact that nurses were unwilling to participate. Perhaps because of the unusual nature of a hospital admission in patients/carers daily lives the continuity of making regular entries was interrupted. What tended to happen was that carers documented the fact of a hospital admission. Then there was a gap till the patient came home when carers started to make entries again. A few carers did take the record to hospital with the patients. One carer sent it to a general hospital ward when the patient was admitted, and it was sent with the patient when he was transferred to a psychiatric ward.
Hospital keyworkers were very co-operative in general in making entries in the records during patients 'respite admissions. On one particular ward where several of the research patients had been admitted for regular respite periods, staff were quite used to accepting the carer held records on the patients' admission, and making entries about their care. Discussion with staff on this ward about the project prior to the commencement of the research had clearly paid dividends.

Social Services

In one file there was a social services care plan, but this was unusual. Entries from social services professionals were rare. Carers themselves documented their visits, but little was written by the professionals themselves.

Home Care Workers

Home care workers were a group of contributors from whom I had not expected much input. They proved however to be conscientious entry makers. They wrote their notes on the pages designed for social services to use. One carer used her diary section to leave messages for home carers about aspects of the patient's care, and home care entries were written in response:

- "It's a diary of daily care. The home carers feel valued too because their work is written down in it."
Residential And Nursing Home Care.

Six patients in the subject group and 7 in the control group were admitted to long term care during the interview period of the study. Of these 5 subjects and 7 controls continued in the research, as those carers wanted to retain some input into patient management, and to feel they still had some control over the way patients were cared for in long term care facilities. 2 in the subject group were admitted to long term care early in the research process, and the carers of these patients were very conscientious in their maintenance of the carer held record. Both families left the record with the nurses in the care home, and regularly requested that entries be made. Care home staff responded well, and both sets of carers were pleased to have that professional information documented in their record books.

One of these carers kept her diary at home and maintained her own entries.

"It was useful to have the package both at home and when she went into care. We learned things by reading the entries from the nurses that we hadn't been told verbally."

Were Carers Satisfied With Professional Input To Carer Held Records?

Some carers had more enthusiastic professionals involved in the patients' care than others. Some were satisfied, but probably most carers would have appreciated more professional input. This was particularly the case when the carers themselves were highly motivated to take part in the project. Perhaps because the onus was on carers to ask professionals to contribute, several carers felt that professionals co-operated only on demand, constantly needing reminders to maintain the record entries. From an objective point of view, the fact that professionals forgot that some carers held these records, and did not actively volunteer to make entries is understandable. It was a research project, and only a few of professionals' clients had been given the opportunity to have the records.
But some participating carers felt that “it was a bit of a battle to get them to write.”

- “I worked hard at getting the book filled in by the professionals”
- “I made the professionals write everything down.”
- “I’m not sure that staff were really committed to it.”

It is probably true that carers who were confident and willing to remind professionals did elicit the best responses. Less assertive carers were less comfortable about this:

- “I felt a bit pushy when asking them to write in it.”

Two carers described instances when professionals were reluctant to write entries. One GP, when asked, refused:

- “He said he had no time. I wish though that he would have done.”

In the other case a patient had fallen whilst attending the day hospital, and her carer found that the nurses were extremely reluctant to write down anything about the episode in the carer held record. When she insisted they wrote a short sentence recording the date and time of the fall, but would put down no further details.

The information booklet

Written in the evaluation questionnaires were comments from 14 carers about the usefulness of this booklet.
The great majority of responses were positive. A selection of comments:

- Useful insight into the difficulties of managing. It gives an idea of what to expect.”
- “The booklet was very useful. It covered everything.
- “Very informative”
- “Glad to have it for the future.”
- “I liked it. - read it all.”
- “Very useful, but I could have done with it earlier.”

Two carers were not so enthusiastic:

- “Love the book. Hate the cover!!”
- “The booklet was not very nice. I dig into it for information on special problems, like night wandering. But I just don’t like reading about dementia.”

The last comment perhaps underlines how individual carers’ attitudes will always be a factor in how they respond to service developments like working in partnership with professionals, and user / carer empowerment. How people feel about the fact that their relatives’ have dementia, and about their own caring roles with all the concomitant stresses and burdens is such an individual experience. It is thus very difficult to meet the needs of all clients in a single initiative like patient/carer held records. Services that are useful to some are of no value to others.

Although there are themes which could be highlighted in this qualitative analysis of how the carer held record was used, within each theme are positive and negative impressions and opinions from carers. No two carers used the record in the same way. Each brought their individual ideology and style to their use of the package, as of course also did the professionals involved in each case.

Whether carers were positive or negative about aspects of the initiative none was intrinsically right or wrong. The carer held record package was made available to be used as each carer felt best suited him/herself and the patient.
Professionals' views about carer held records

Qualitative analysis

This study was conducted to measure carer outcomes of having carer held records. When the protocol was designed, it was not originally planned to survey professionals' views about the project. However, their role in supporting and encouraging carers to use the documents, and in being proactive in promoting the initiative, or otherwise, was shown to affect carers' beliefs about the worth of the project. The importance of professional input to carer held records became clear when analysis of carers' opinions was conducted.

It was not possible to send questionnaires to all professionals and agencies who had contributed to the records at this stage of the research. However it was possible to ask members of the CMHT who had given records to carers what their opinions were about the value of the project, in order to get a "flavour" of professional feelings, and to assess how the project worked in practice. Questionnaire responses were obtained from 5 CPNs, 1 Occupational therapist (OT) and 1 voluntary worker attached to the CMHT, all of whom had participated in the project for two years. Text in italics represents professionals' written responses and comments.

Analysis of the questionnaires

All seven respondents had had clients who had carer held records.

When asked about entries which they had made in carer held records the following responses were made:

- "I wrote down actions to be taken, and when my next visit was due."
- "How I found the client when I visited; what I discussed with them; any suggestions for improving function in the activities of daily living, or minor adjustments to care giving. (I would follow this up with phone calls to relevant agencies)."
"Developments in the care package and current mental health state."

"What I was doing, and if I needed the carer to do anything."

Care plan inclusion in the carer held documentation was mentioned several times as was the writing down of details about individual treatments. Responses to this section were positive in all but one case. One person stated that they did not make entries.

When asked about entries made by other professionals and agencies, three people said that they had seen contributions from:

- home care workers
- mental health workers
- district nurses
- day hospital staff
- staff in respite facilities

Three respondees had seen no entries by others. One person said that GP entries were notable by their absence.

Professionals were asked how carers had used the documents. All said that carers had made use of the facility, and made the following comments:

- "Used as a diary, and to inform me of developments."
- "Diary of concerns and feelings."
- "To communicate with care staff, and to "offload" how they were feeling about their caring role in some cases."

Two comments however were less positive:

- "Sometimes carers wrote, but mostly used as a resource to contact people from."
- "Filled in assessment section. No on-going notes."
It is acknowledged that themes highlighted in this analysis are based on all the available responses made by carers during the study period. Thus those who were interviewed four times, for example, had more opportunities to express their feelings than those who were interviewed on fewer occasions. Focus has been laid on the similarities and contrasts amongst all responses however, rather than on the number of times individuals were interviewed. As carers' worries often changed between interviews, their responses have been regarded as individual responses rather than the responses of an individual. The data on serial responses however was taken from those who completed all four sets of questionnaires. This is included as a point of interest, but should not be given a weighting as such, in any numerical way.

Themes

Worries Remaining Constant Over Time

Fifteen subjects and twenty four controls completed the questionnaires at all four time intervals.

In the first analysis, before categorisation of common themes, examination of responses involved establishing whether any carers' "worries" remained constant to any individual carer over time. Surprisingly, in 18 instances (8 subjects and 10 controls) carers consistently worried about the same issues, and repeated that these were their greatest worries at each time interval. The most common "worry" remaining constant for carers over time was to do with fear of the future, how long caring at home would go on, and doubts about their abilities to cope. Seven carers (1 subject and 6 controls) continued to cite variations on this theme at each interview session.
Other worries persisting for individual carers were:

- Fear for the patients' safety in their own homes
- Fear that the carer might get ill and not be able to care
- Seeing the patient's distress
- Fear that the patient may have to go into long term care
- Fear that the patient may no longer recognise and know the carer

These worries are all highlighted again in the themes which emerged from the analysis, but appear for other carers amongst other worries at different time intervals.

**Disease Progression**

The most common response was basically that carers worried about the fact that the dementia would get worse. (26 responses, 13 subjects, 13 controls). Some respondents simply stated that as their greatest worry:

- "that he'll get worse and worse"

It was not lack of knowledge which triggered this response. Carers were aware of the normal course of the disease. It was the implications of patients' worsening conditions, linked to fears about the patients' distress and their own abilities to cope with the situation. One carer's series of responses illustrates this:

- "that she'll get worse and worse"
- "How will she end up?"
- "How will I cope if she doesn't know me?"
- "She might have to go into a home if she gets much worse."

This response series shows that the connotations attached to the patient's worsening condition cause the carer different kinds of anxiety at different times.
Uncertainty about the future is also very much associated with the response "worsening of the disease". Worries about disease progression were qualified by carers with explanatory corollaries in 17 out of 26 examples.

- "The unknown, and long term effects for us both."
- "He's getting worse. What's going to happen? It's the uncertainty!"

Fear of disease progression was associated strongly with fears about how bad the disease may become. These worries could be focused upon both the patients suffering from the disease and on themselves in their roles as carers:

- "What the future holds. How bad is she going to get?"
- "How bad it's going to get, and the consequences to the family"

Another strong connotation here is the length of time that may be involved:

- "How bad is she going to get, and for how long?"
- "It will go on and on, and she'll get worse and worse"
- "That she gets to 105 and still has it!"

This was the most common theme highlighted by carers. Other themes that emerge from the analysis may be so strongly linked to it maybe they all should be seen in the light of worry about disease progression as an underlying factor.

**Deterioration In Patients' Quality Of Life**

Some carers' worries were mainly focused upon the patients; their suffering and distress because of the disease, and not focused upon their own problems as carers. 18 participants (9 subjects and 9 controls) expressed this as their main worry at different time intervals.
For 14 of these carers (7S & 7C) worries about the patients' suffering were paramount, constant, and consistent over time at all 4 time intervals over two years:

- "The distress it causes her."
- "Her happiness, because she is unhappy, and can see what's happening to her."
- "Her distress – not mine"
- "Being the way she is now."
- "Her distress if she were totally reliant on others for living."
- "Loss of dignity for her."
- "Loss of quality in her life"
- "That it will go on and on for her, and she is aware of it all."

In these series of responses carers are showing stress in their caring roles, but the stress arises more from watching their relatives' deterioration. Worries about their own situation are secondary to the patients' distress.

**Worries About Whether Carers Can Cope**

For other carers (21 participants: 8 S, 13 C) the main focus of their worry was whether or not they themselves could cope with the situation, and the stresses of their caring roles. This is not to say that they did not have concerns for their relatives, but when asked about their greatest worries their own stressful situations, the deleterious effect on relationships and the difficulties of caring emerged as the most troubling:

- "Worry that I've reached my limit: that I can't cope much longer."
- "If she gets worse, how will I cope?"
- "How long is it going to last before I can't cope?"

Within the 21 responses which included the "I can't cope" response are probably many mixed emotions perhaps fighting for expression, some of which exist altogether in an individual carer. The analysis of this aspect is admittedly influenced by the fact that I as the researcher came to know many of the carers' individual situations over the study period, and am aware of some of the main reasons behind their distress.
In the following series of responses the carer, a wife, desperately wanted to continue to be able to care for her husband at home although his condition was deteriorating rapidly:

- "Am I always going to be able to cope?"
- "Worry about being able to cope in the later stages"
- "The future and can I cope?"
- "How long can I cope with it?"

For others, worry about not being able to cope stemmed more from their feelings of responsibility which they felt that they had for their relatives with dementia, and the fact that his had to be balanced with the needs of other family members:

- "How I'll cope if he gets worse: the effect on the immediate family."
- "How it affects family life. Feeling helpless!"

**Negative Feelings About Caring**

As was highlighted in the literature (Brodaty 1992) several carers revealed that they felt burdened by the fact that they had had to assume the roles of carers whether because it was expected by other family members, outside social pressures, or mainly from a sense of duty. Some of *their* feelings about not being able to cope were based on underlying feelings of discontent

- "That I'll be left looking after her if she's terribly bad, and the DSS won't put her in a home. How will I cope?"
Three carers voiced their feelings of resentment quite strongly at the role they felt they had had to assume:

- "See myself tied to the house and can't get out."
- "That I'll be trapped looking after him and can never do the things I want to do: -- pure anger!!"

These were very negative perceptions of caring which, as the literature highlights, have their own stresses in the situation. The latter two responses were from spouses in which relationships it might be thought that feelings of love and affection might be the strongest driving force behind decisions to care. If the underlying relationship between carer and cared-for is not one of love and willingness to care, feelings of resentment may be strong, whatever the relationship between the two may be.

**Fears For Patients' Safety At Home**

20 carers highlighted this aspect of caring for patients as the one which caused them most anxiety. There were 4 different subdivisions of this theme. Worries that patients might fall emerged six times; worries that they might hurt themselves, with the risk that they also might hurt others were also prominent. 3 carers were very concerned that their relatives might be vulnerable to "unscrupulous others" who might take advantage of them. These carers, at some time point in the research, felt that they carried the major responsibility for their relatives' safety in the community in their varied vulnerable states. This was true both of carers who lived in the same homes as patients and for those who lived separately. This burden of responsibility sometimes weighed quite heavily.
Worries That Patients Might Eventually Need Admission To Long Term Care

Thirteen carers (6 S, 7 C) found this issue the most worrying aspect of their caring roles. It obviously is strongly linked with fears of not coping in some cases. But when directly mentioned worries were concentrated around two specific aspects of the situation. These were, feelings that carers might fail the patients, and worries about how the patients themselves would cope if long term care became necessary.

- “I worry that I might have to put her in a home.”
- “He gets so bad I might not be able to keep him at home.”
- “A home would finish him”
- “If she had to go into a home she would die.”

It may be that, generally, much carer stress is relieved when a patient actually does go into care, but carers’ worries about the prospect, before the situation arises, can be very great. Even if finally the decision is taken about admission to long term care, many carers continue to be concerned about the quality of care patients receive, the quality of life they may have, and their inability to help patients if they relinquish control to the care homes:

- “That she’ll end up in a poor nursing home and not be cared for properly.”
- “If she had to go into care and I couldn’t help her.”
- “I worry about her on-going loss of quality of life”
- “Her safety and quality of life in care now.”
Dementia And Hereditary Factors

Eleven carers (5S, 6C) were most concerned about whether dementia was hereditary. This was not only a worry for children caring for their parents, but was also true for spouses who worried that the children of the marriage might inherit the disease. Although relatives may be concerned about the heredity factor if any severe disease affects a family member, maybe the frequency with which this issue was raised reflects the severe difficulties carers faced in the tragedy that is dementia.

Challenging Behavioural Symptoms

Specific aspects of patients' difficult behaviour were cited as the greatest concern for carers in 11 cases (3S, 8C). Worries that aggression might become unmanageable were mentioned twice. Coping with incontinence caused worry for two carers, and patients' wandering was stated as being especially troublesome five times. Difficult though these behaviours were for carers, these objective facets of care were highlighted far less frequently than were carers' subjective feelings about the problems. As described in the literature, carers' perceptions of problems gave rise to more anxiety than the severity of individual symptoms (Lazarus & Folkman 1984).

Patients No Longer Knowing Or Recognising Carers

This one aspect of patients' deteriorating mental states was cited most often as a source of heartache for carers (7 participants - 5S, 2C). It seems this epitomised for them the sadness of patients' decline, and the final breakdown of relationships, and that this was their dread:

o "That she might not remember me."
Carer Illness Leading To Inability To Continue Caring At Home

Amongst older carers this was a significant worry:

- "What will happen if I'm not well?"

It was worry for the patients that was paramount, and not concern for themselves.

- "I worry that I can't keep well enough to look after him."
- "That I'd get ill, and he'd be left behind."

Death Of Patients

Three carers worried about patients dying, and whether they would die with dignity. In each case patients had become severely ill:

- "I hope she dies with dignity"
- "That there should be no pain at the end"
- "That he has a dignified end now."

Four carers felt very sad at anticipated loss when patients were dying:

- "I worry that he hasn't long to live now."
- "I worry about losing him"
- "I'll miss him when he dies."
Carers Who Stated That They Had No Worries

Four carers stated that they had no worries at different time intervals in the research. One carer said she had no worries initially at baseline interview, but did have concerns at later stages. At one carer’s final interview he stated that he now had no worries because the patient was in a residential home, and settled there. He had had severe worries at earlier stages. One daughter felt she had no worries throughout the research time span. She appeared however to be more “detached” from the situation than “unworried”. In the final instance the carer had been looking after her husband for many years and was genuinely calm and able to cope.

Conclusions

The main conclusion that this analysis reveals is that carers have a great many and varied worries about both the patients with dementia and about their own caring situations. Anxieties put into words may have far-reaching connotations which some carers could never adequately express. Different reasons for caring, and differing perceptions of the caring role have been highlighted in this analysis much of which accords with published views and the evidence in the literature. What emerges most clearly however is the complex nature of individual carers’ stresses, and the different subjective feelings that may be attached to allegedly common themes. The emotional dynamics involved in every caring situation are unique.
Discussion

The aims of this research project were to establish whether carers who are given multidisciplinary carer held records have less stress-related symptoms, fewer health problems, more knowledge of dementia and its management, and feel more "in control" than those who do not have the records. Measurement scales were used to assess these outcomes for carers. Qualitative analysis of both carers' and professionals' use of the documents was conducted.

Methodological Issues

Recruitment

Fewer numbers were recruited to the study than had been expected from calculations about potential recruits made before the research began, for both participating CMHTs. This pre-research assessment was based on the yearly numbers of referrals to both CMHTs with diagnosed dementia. From this it was estimated that 50 participants could be recruited to each group within 18 months. Not enough weight however was placed on the inclusion/exclusion criteria as barriers to recruitment, particularly that of patient/carer consent to participate.

Barriers to participation

Client Issues

Many carer/patient pairs who met the inclusion/exclusion criteria were approached to participate, but declined to take part in the research. 40 potential subjects were excluded and 28 controls. By far the largest group of patient/carer pairs excluded were those who did not consent to participate, and of those there were more subjects (17) than controls (7).
This implies that a proportion of potential subjects felt that they did not want to have a carer held record when it was suggested to them, as opposed to merely not wishing to be part of a longitudinal research study as was the case for controls. This is perhaps not surprising in the light of this study’s results on engagement with the initiative by those who agreed to be participants. Shared care in the form of carer held records was not uniformly embraced as potentially valuable by everyone. This alone however was not the complete picture of non-participation.

The design of the study, with its repeated measures at interviews over 2 years was not acceptable to all potential recruits. The idea of participating for as long as 2 years was off-putting for some. Some clients did not wish to respond to questionnaires. Some clients opted for minimal professional contact when dementia was first diagnosed, and this applied to researcher contact too.

There were also other issues which acted as barriers to participation, which related in some part to the timing of individual clients’ referral to the CMHTs. Some clients (4 subjects, 3 controls) were referred to CMHTs late in the development of the dementia, when long term care was imminent, and participation was felt to be inappropriate. A few clients actually died between referral to the study and researcher contact. This issue suggests that recruitment to similar studies should be focused upon patient/carer pairs where dementia is less advanced.

Two carers in the subject CMHT declined to participate however because they felt that their relatives were not ill enough for the carer held record to be of value. There is therefore no easy answer to the question of the optimum timing for carer held records to be offered to clients. As was shown in the qualitative analysis of engagement, individual carers’ attitudes will always be a factor in how they respond to developments such as user/carer empowerment, and initiatives like carer held records.
Professional issues

Another barrier to recruitment emanated from attitudes of some professionals in the subject CMHTs regarding recruitment of clients "suitable" for the research. Some professionals instinctively felt that particular clients would not wish to have carer held records. Reasons for non-referral of two families were that they were too distressed at that point in time. Clinical judgement in these cases overrode the research protocol requirements. Also, and more controversially, two families were not referred, as professionals considered the families to be unco-operative and "difficult". They had felt that carer held records would cause problems, and made decisions to exclude them. These issues were addressed as the study progressed by underlining the importance of protocol adherence, and explaining that client engagement with the project was to be explored as part of the research design. It was however an area of conflict for professionals in the subject CMHT. Some remained uncomfortable about the referral of some families. It also highlights the fact that professionals as well as clients consider carer held records to be useful for some clients and not others, and at different stages of the caring process for individual carers. As care plans are individualised to client needs, so perhaps should be the case with carer held records, the offer made early in the caring process, and if declined, re-presented at future dates, to meet the needs of patients and families.

Staff illness and vacancies in both CMHTs also affected recruitment. Both teams had to create waiting lists which had not been a factor considered in pre-research calculations.

For all these reasons, recruitment continued for much longer than had been anticipated, and terminated before the target numbers were reached. 38 subjects and 46 controls were actually recruited in three years. The power of the study results may thus be affected by participant numbers being lower than the ideal.
Follow up interviews issues

Client issues

Pre-research calculations about attrition rates of participants in the study were also misleading. This had been based on dementia survival statistics. More factors however than patient deaths contributed to attrition in this research. Four subjects withdrew from the research because maintenance of the carer held records seemed of little value at different time points. For eight controls “questionnaire fatigue” was a factor. Controls perhaps perceived a less important focus to the research than did subjects, leading to more controls withdrawing for this reason.

Admissions to long term care during the study period were also higher than expected. No reference was made in the protocol to this client group either continuing in or withdrawing from the study. It was decided that both subjects and controls should continue in the research, if they still felt involved in clients’ care. Only one subject and one control withdrew from the study for this reason. The others opted to continue. It was decided very early in the research process that the interval of one year between the third and fourth interviews was too long. Many patients in both groups had moderate to severe dementia, and much deterioration occurred within that period, which would not have been pinpointed by outcome measures if the time period had not been shortened. The fourth interview was therefore rescheduled to be at 18 months.

Researcher issues

As the research progressed through the data collection phase the workload became very heavy. Participants in both research groups were at all four different time stages of the research, and the number of client interviews required every month was rising. A second researcher was recruited to assist in data collection. Although steps were taken to ensure interviewer continuity in terms of interviewer style, and client follow through, it is acknowledged that no official interrater measures were enacted.
Were the questionnaires selected as outcome measures appropriate?

There are several points to be made on this topic. The first is that, because so many aspects of possible benefit to clients were considered, there of necessity had to be multiple questionnaires. Completing these with clients made interviews both lengthy and tiring for both clients and researchers. There is little doubt that this led to some participant withdrawals due to "questionnaire fatigue". Although all the outcome domains were of interest, the number of questionnaires presented was perhaps rather overwhelming for some respondents.

Patient questionnaires

The GDS and CRBS: Both were both easy to administer and did not take much time to complete. They gave an adequate guide to patient decline for the purposes of this study.

Carer questionnaires

GHQ and SF 36: One health questionnaire would have been adequate. Although these health questionnaires measure different aspects of health, and as such were thought to be important, carers felt that the completion of two scales on health status was unnecessary.

Dementia Knowledge: This was easy to administer and easy for clients to relate to.

Strain stress and burden scales:
Three different scales were chosen for inclusion in this study from the plethora of questionnaires available. Each of the scales measured different aspects of carer stress, and although the inclusion of all 3 measures seemed excessive, it was thought important to attempt assessment of a broad spectrum of stress and strain.
The presentation of the 3 questionnaires to carers did not cause problems for either carers or researchers. Fortunately all 3 scales were quite short, and carers related to the concepts of stress and strain when caring for relatives with dementia.

**Locus of control**: This scale was included because measuring locus of control was an important aspect of the study. However it was the scale that was the least understandable for clients. They could not see the relevance of some of the questions on the global scale, although they did certainly relate to the specific questions on control within their caring situation. This questionnaire was presented at the end of the interview session when some respondents were tired, and could not continue with the session. In retrospect, in view of the importance of the analysis results, I would suggest that any locus of control assessment be made in the middle of the interview session to facilitate maximum response levels.

It was perhaps ambitious to attempt to examine so many aspects of outcome within one research study. However, at the outset, all domains seemed equally as important. It is only with hindsight and knowledge of the results of this study that adaptations to the number of questionnaires, and their order of presentation can be clearly seen.
Data Input

Input of data to the database was straightforward, and for all but two questionnaires, caused no problem for analysis. For the locus of control scale and the SF 36 it would have been useful to consider data analysis guidance instruction before finalising the data base design. Both were complicated scales to analyse. For the SF 36 analysis particularly, reference to the official scoring guide was required throughout the analysis. For correct scoring of the scale data had to be sorted into the right categories which were different from the order in which questions were presented and entered into the data base.

Data Analysis

Although data were collected from participants at the fourth time interval of 18 months after commencement in the study, these results were not used in the final analysis. There were two reasons for this. Firstly, when using a repeated measures technique, only data from those still in the study at 18 months could be used in analysis, and the numbers of participants remaining in the study at this time point were too low in this research project. The second reason was that, if benefit from the use of carer held records were to be demonstrated, it was thought that results at one year post commencement might be the most informative. If no differences between subject and control groups were found at one year, it was unlikely that benefit would be shown at 18 months. The data are available however if it should be later decided that further analysis might be undertaken. Two more statistical measurements might prove useful, but were not undertaken in this project because of time restrictions for the completion of the research. These are analysis of the Last Observation Carried Forward (LOCF), and Intention To Treat (ITT) both of which are analyses currently used in drug trials.
Results

Discussion on the results found on strain, stress, and burden

*The Carer Stress Scale*

Four sections were selected from Pearlin's carer stress scale which consists of 15 sections in total. The sections chosen asked carers to focus upon specific aspects of the stress of caring not covered in detail on the other scales. Areas covered were:

Relational deprivation
Carers' individual support networks
Feelings of competence and confidence in their caring roles
Family conflict

Carers were asked to give a severity rating on these topics within a range of 0 - 4.

*The Carer Burden Scale*

In this measure carers were asked to give an overall subjective rating of recognised aspects of the stress experienced when caring for a relative with dementia. These were broad concepts such as "emotional strain", "physical strain" etc. within which no specific details were highlighted. As with Pearlin's stress scale carers were asked to give responses indicating severity within a range, in this scale, of 1 - 5.

*The Carer Strain Scale*

The format of this scale was different. In this questionnaire specific questions were asked about facets of carer strain and stress which required either a "yes" or a "no" response. In order to formulate an answer carers had mentally to weigh up factors involved in a focused question, and come to a definite conclusion. For instance, the question "Is your sleep disturbed?" required respondents to decide whether their sleep was disturbed enough to choose the answer "yes".

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The alternative was that the occasional sleep disturbance was not sufficiently troublesome, and carers opted for the answer "no". This scale thus required more definite responses on very specific aspects of carer strain which was quite different from the previous two scales. It was analysis of this scale which revealed a significant difference between the groups in levels of carer strain, whilst no significant differences were found on analysis of the other two questionnaires.

Perhaps this result occurred because of the specificity of this scale, and the fact that carers had to be focused in their thinking to select the most accurate response. The other scales were focused upon general aspects of stress, and offered a response range on which carers could opt for an option of generally "somewhat stressed". The Carer Strain Index possibly tapped more sensitive issues of the experience of strain when completed by this group of carers. This is merely a possible explanation for the differences found between the scales. The important point to make is that the three scales on carer stress were not interchangeable. One could not be used in place of another, as each scale measured different aspects of stress, and required different assessment mechanisms from carers responding.

The analysis of the Carer Strain Index has shown that, in this study, the overall mean level of strain between 6 and 12 months was significantly different between subject and control groups after adjustment for baseline scores. Differences at six months were lower for subjects (0.88) though not significantly so. However subjects appeared to maintain this level whilst controls increased their scores further (though this interaction was not significant), resulting in significantly lower scores for the subjects who had received a carer held record by 12 months (1.34, 95% CI 0.02, 2.67). Although reduction in carer strain was not found to be due to differences between the sexes of carers, a significant difference was found in overall mean level of carer strain between 6 and 12 months within subject and control groups. This variation appears to be due to a difference between the generations in the control group. Further research perhaps needs to be undertaken to investigate this more thoroughly.
Burden of caring v. satisfaction with caring

A special mention should be made of the analysis of the Carer Burden Scale. This scale was chosen because it seemed the most appropriate for use in this study; it was short, easy to administer, easy for carers to respond to, and was of a format which would elicit global measures of burden (i.e. it had face validity). However the scale was unattributed, and there was no evidence available about other types of validity. It was therefore important to assess whether the scale had at least convergent validity, in terms of its correlating with such factors as carer strain and mental ill health, and behavioural disturbance in the person cared for. To address this issue a Spearman’s rank correlation analysis was undertaken comparing the results of this burden scale with other scales used in this study namely, the Carer Strain Scale (Robinson 1983), the GHQ (Goldberg & Hillier 1972), and the CRBS (Robinson 1961). The results indicate that the construct of burden as measured by this scale varies as would be expected with these measures of carer strain and mental health, and the patients’ level of behavioural disturbance. However the correlations are not so high as to suggest it is simply a proxy for these measures.

This burden scale also was the only questionnaire used which included a measure of satisfaction with caring as well as the burden of caring. Analysis of the data included consideration of whether a relationship could be shown between levels of subjective total burden and feelings of satisfaction with the caring role. Results from this study showed that no such relationship could be demonstrated. There was no evidence that levels of burden decrease if satisfaction increases. Nor was there evidence to show that high levels of total burden were associated with low levels of satisfaction.

From a researcher’s subjective viewpoint, I was sometimes surprised that carers who identified very high burden levels could also be adamant that, in spite of this, they gained great satisfaction from their caring roles.
Conversely, there were also those carers who identified that their total burden level was at an acceptable level, but they derived no satisfaction at all from the role in caring which they had undertaken to perform. The findings on the relationship between burden and satisfaction in this study correspond with much of the literature published on the topic. Gilley (1988) and Nolan & Grant (1989) highlight the importance of the underlying relationship between carer and cared-for when burden and satisfaction with caring is being considered. If the relationship is a loving one, and the caring role has been willingly adopted, satisfaction is likely to be higher than if caring is seen only as a duty that has to be performed.

For older carers, care giving may be taking place within a lifelong partnership relationship where motivation to care may be high, and feelings of reciprocity within this relationship remain steadfast, increasing feelings of satisfaction:

"He/she would do the same for me."

Also, feelings of love and reciprocity are not the exclusive domain of spouse relationships. Some sons and daughters in this study also highlighted the importance to them of the loving relationship they had with parents, and their commitment to continuing to care.

Nolan et al (1996) also points out that carers can derive positive outcomes from undertaking a caring role in that they may feel positive about themselves, and feel needed and appreciated within their roles. The fact that these rewards are "diverse, pervasive and subtle" perhaps explains why, although experiencing quite high levels of burden whilst caring for their relatives with dementia, feelings of satisfaction also may pervade some carers' lives.

As with the Carer Stress scale, however, the global nature of this burden scale may be a limitation in that it might not have been sensitive enough to pick up differences between subjects and controls.
Results on the Knowledge of Dementia Scale

No significant gains were demonstrated in this study on increased knowledge of dementia by subjects as compared with controls, as measured on the Knowledge of Dementia scale (Graham et al 1997). The carer held record pack contained a specially designed booklet of information for carers, the aim of which was to make practical advice available to everyone in the subject group on a regulated basis. However, the availability of information on dementia is really quite widely available to carers, in multiple formats, including contacts with health professionals, media information and internet access. The mean scores of both groups, on the questionnaire selected, gradually increased over time, as would be expected. Carers' knowledge of the epidemiology, aetiology and symptomatology of dementia increased gradually as their period of caring for their relatives lengthened.

In section A (abnormal knowledge), as would be expected, most carers were correct in their responses. Controls made incorrect responses at two time intervals, but this was not significant.

In section B (epidemiology and aetiology), after adjustment for baseline levels, there was no difference between the groups in overall mean level of epidemiological knowledge between 6 months and 12 months (p=0.85) but there was a significantly different change over time between the two groups (p=0.02) with the control group increasing knowledge between 6 months and 1 year and the subject group reducing their scores. It is possible that, in both groups, people were guessing at the correct answers in this domain at each interview. Significance therefore in the interaction effect should be viewed with caution.

In section C (symptom knowledge), although no difference was found between the groups it is interesting that the mean scores of both groups on symptom knowledge gradually increased over time. One would expect this result purely because carers were becoming more aware of the issues with time. However, in my experience of administering the questionnaires, I found that carers, in both groups, tended to base their responses on symptoms that their relatives were actually suffering from, even though the question specifically asked about dementia in general.
It seemed that carers were denying knowledge of symptoms which might affect their relatives in the future. This was true especially of “bladder and bowel control.” “Mobility” was also an area which caused relatives some dilemma. Some could not reconcile mobility being affected with the restlessness and excessive movement which were the symptoms their own relatives were displaying. Perhaps the steady increase in knowledge shown by both groups of carers reflects the increase/variations in patients’ symptoms over time.

The results of the dementia knowledge questionnaire analysis should thus be interpreted conservatively. It would be unwise to place too much importance on any of the sub-scale results in view of all the participants’ idiosyncratic interpretation of the whole scale.

General Health Scales

No significance was identified in either carers’ physical or mental health, as measured either on the GHQ or the SF36 scales. This is an area of future research on the topic of carer held records which perhaps should be further investigated. No sub-analysis was undertaken of different carer characteristics in this study. The number of participants was too small in this research sample for such subdivisions to be valid. However, it would be very interesting to investigate in the future whether health benefits of having carer held records might exist within sex groups and/or age groups of carers. Analysis of the SF36 scale in particular is designed for consideration of such sub-analyses.

Conclusions On GHQ Results

The GHQ is designed to measure symptoms and feelings of recent onset and not more chronic psychological or physical health problems. However, when the questionnaire is repeated at 6 month intervals some more chronic symptomology emerges.
Carers who reported sleeping difficulties, for instance, at baseline interviews often continued to report this problem at subsequent interviews, thus showing a more chronic pattern of psychological distress. The GHQ total score is the important measure of psychological distress. A critical number of key symptoms combine to cause distress rather than any particular symptom on its own (Goldberg & Hillier 1972). Although the questionnaire is divided into sections which are each summed individually, the main advantage of this is not that each section might stand alone, but that patterns can be seen within the sub-divisions where problems may be clustering. In this study it seems that the most critical areas, for both groups are those concerning anxiety and sleeplessness. Although the scores on social dysfunction seem to be equally as high, in fact this is perhaps a limitation of the scoring method. In this section a score of “1” is given if things are the “same as usual”, as opposed as “no more than usual” which is the wording used in other sections. This seemed to act like a “neutral” option with many respondents in both groups choosing this wording to denote that there was no change. The total scores are therefore high in comparison to other sections.

Scores on somatic symptomology were low for both groups, as were scores on the severe depression section. In the latter section however, although most carers scored “0” for the whole section, any scoring response was worrying as the statements were strongly indicative of depression with possible/probable suicidal ideology. I did not find it difficult to ask carers these questions. If no depression was present, carers cheerfully scored nought. If depression was present, it often became fairly obvious during the interview, before the GHQ was administered. There was no difference between the groups in overall mean level of severe depression between 6 months & 12 months, and no significantly different change over time between the two groups. The significant time effect (p=0.04) suggests that scores changed over time but not differentially between subject control groups. Depressed carers mostly responded to the statements honestly, and did not seem distressed by revealing their feelings. In several cases they gave permission for me to discuss their feelings with the patients' keyworkers.
The physical difficulties which elderly carers may have are not measured by the GHQ, but the SF36 questionnaire does address this aspect of health.

**Conclusion on SF 36**

The scale certainly does encompass more aspects of health than the GHQ, particularly in the area of physical health problems. Although in this study some of the older carers did have physical limitations, many regarded themselves as relatively fit and well. Most of the younger carers had no physical limitations at all.

Because the SF 36 was presented near the end of the interview, and was the second of the health questionnaires, fewer of the participants completed the SF 36 than completed the GHQ. Scores for each of the questionnaire sections are calculated individually, and some sections contain very few individual questions. The section on pain for instance has only two. Larger numbers than took part in this study are required for completion of the SF 36. Type two errors therefore in these results can not be discounted.

The SF 36 scale was easy to administer, but much more difficult to score than other questionnaires chosen for use in this study.

Results for both health questionnaires show no differences between the groups within the domains of health described and so it can be said that no definite health gains followed from use of the carer held record in this study.
Discussion on results found on Locus of Control

In this study the aims were:

a. to see if any differences could be shown between subjects and controls in their global beliefs about locus of control.

The results show that, after adjustment for baseline levels, there was a significant difference between the groups in overall mean level of external locus of control scale between 6 months and 12 months (p=0.01). Since there was no significantly different change over time between the two groups (p=0.28) this difference was maintained over the time period. Subjects had scores on average 2.5 points lower at six months than controls (95% CI 0.18 to 4.82 points lower) and 3.43 points lower at 12 months (95% CI 1.29 to 5.57 points lower).

Also, after adjustment for baseline levels, there was no difference between the groups in overall mean level of chance locus of control scores between 6 months and 12 months (p=0.24) but there was a significantly different change over time between the two groups (p=0.05) with the control group increasing scores between 6 months and 1 year and the subject group reducing their scores.

No differences were found in the area of internal control.

b. to see if control beliefs about shared care altered over time with the carer held records intervention.

After adjustment for baseline levels, there was no difference between the groups in overall mean level of internal control of care between 6 months and 12 months (p=0.61) but there was a significantly different change over time between the two groups (p=0.04) with subjects continuing to maintain a higher level of internal control of care whilst the control group reduced.

c. to see if global locus of control beliefs are linked in any way to locus of control in the shared care dimension.
It is possible that carers feelings about the last section of six questions were different for carers from their more global belief systems. The last section was focused upon beliefs about their caring role, a practical and current event, to which they could relate more closely than they could to theoretical, more philosophical concepts. The last section had not been validated for inclusion in the total questionnaire, and probably should not be linearly aligned with it. It was hoped by inclusion of the last section to obtain a measure of carers feelings of control about their caring situation which would be comparable with the established scale, and responsive to repeated measures analysis. Perhaps however this was not the ideal way to achieve this. It would be unwise therefore, in view of these facts, to correlate global locus of control beliefs with those of the shared care dimension.

Results have indicated that there may be gains for carers using carer held records in that they feel, in a global way, less externally controlled, and less controlled by chance than those who do not hold the document. There is no evidence that feelings of internal control increased either between the groups or within the subject group as compared with controls. There is a possible explanation for these results in that respondents may have opted to select the “neutral” response option of, “I am not sure”, if their feelings about control mechanisms were changing, rather than demonstrating certainty about events in their lives being totally within their own control.

Within the shared care dimension of the locus of control scale however, the results are more robust. A significant increase over time was demonstrated by the subject group in feelings of control over their caring situations, compared with the control group.
It had been hoped, when this study commenced, that carers would feel more in control of caring, having been given a carer held record in which they might document their own input to caring for their relatives. It was hoped that having a document in which all disciplines contribute their input would effect better communication amongst disciplines, and between carers and professionals in general, all of which would help carers to feel more in control. Empowerment of carers by means of this initiative was one of the major aims of the whole project.

In both the areas of global locus of control, and control of care, some differences were found to be explainable by sex and generation effects. In external control (global), the differences in overall mean levels of external control were found to be explainable by generation effects. In the internal control of care dimension, the sex of carers had an effect on the results. Further analysis of sex and generation effects would therefore be interesting in any future study.

It was not possible within this research project to further analyse the data, to see whether those who engaged with the idea and practice of using carer held records gained more in terms of control feelings than those who did not engage. The analysis was conducted on the subject group as a whole, and it included everyone who had been given the document, and who kept it throughout the study time period. It is therefore not possible to presume that any relationship exists between engagement with the project and feelings of being in control.

It would be interesting to focus upon that hypothesis in any future development, and evaluation, of the carer held records initiative. It is however quite possible that engagement with the project is not such a powerful indicator of feelings of control in caring as one might think. The offer to carers of equal partnership with professionals, in caring for their relatives with dementia, accompanied by the presentation of the means to achieve this in the form of a carer held record, may have, in itself, achieved some degree of carer empowerment which was reflected in the study results.
The whole concept of locus of control is a difficult one however, and one in which further research into such specific foci in locus of control requires researchers who are experts in this field.

Patient Data Results

Conclusions on patient data statistics

The results from both questionnaires show that there were substantial levels of deterioration in those patients being looked after by their carers on both measures, and for both subjects and controls. Results show a progressive deterioration in patients' conditions comparable for both groups on the GDS scale. The CRBS scale also shows deterioration in both groups, although the rates of change varied for subjects and controls, subjects undergoing most of the change before the 6 month follow up interval, and change flattening out between 6 months and the 1 year time interval, whilst controls deteriorated in a more linear manner. There are therefore no grounds for suggesting that statistical differences found in carers' questionnaire responses may be due to differences in their relatives' levels of dementia.
Qualitative Data Collection And Analysis

It has been acknowledged in the methodology section that formal qualitative methods were not used to analyse the qualitative data in this study. Nevertheless, careful assessment was made of the data recorded on the questionnaires used to elicit carers' and professional made of the documents, and their opinions of the value of the initiative. The intention was not to test any prior hypothesis about client engagement with the project, but to gain a general overview of qualitative aspects of the project which might be considered alongside the quantitative analysis which was the main focus of the study. Comments and judgements based on this study's qualitative analysis should be seen in the light of the limitations of the methodology.

Carers' greatest worries

This section is included in the thesis as the data were obtained from use of the Dementia Knowledge Questionnaire (Graham et al 1997). Analysis of this qualitative data was not published by the original researchers as it was considered an addendum to the scale, and not an integral part of knowledge acquisition. A simple analysis of this was carried out, in the form of a post-hoc coding frame from which an insight could be gained into carers' perceptions of the stresses of caring for their relatives with dementia at home. The value of this analysis lies more in its accordance with facets of carer stress and strain published in the literature than it does to any connection with carer held records. It was not intended that any numerical weighting should be given to the themes highlighted. The numbers of responses within the themes are given merely to give a guide to their prevalence.

Analysis was made of all the responses available which meant that some participants responded to the question more often than others. Those who completed the questionnaires on four occasions responded four times, whilst others had the opportunity to tell of their greatest worries on fewer occasions.
It was not thought that this was important because individuals’ worries altered over
time in many instances. The fact that some carers serially cited the same concerns at
different time points was unusual, and thus this was included as a theme of interest.
The point of analysing this data was to examine a large number of responses and to
see how these responses reflected issues highlighted on the topic of carer stress.

Details of the analysis have been given in the appropriate section. However it is worth
mentioning in discussion how frequently highlighted concerns did reflect issues
specified in the literature. Feelings of powerlessness in their caring situations was a
common source of stress, as was fear that they might not be able to cope with their
caring situation.

As Brodaty & Gresham (1989) point out, immature coping strategies often lead to
increased carer stress. Fear of the unknown, in terms of progressive deterioration of
their relatives’ dementia, also was a pervasive source of stress which underpinned
many of carers’ individual ways of articulating their worries. Whilst this can never be
eliminated, it perhaps can be ameliorated by information sharing, encouraging carers
to adopt positive coping strategies, and empowering them to feel more in control of
their situation.

Some carers highlighted very negative feelings about caring, whilst others were full of
concern for their relatives’ well being. The latter stance within loving relationships
was by far the most common feeling expressed by this sample of carers in their own
individual phraseologies. Negative feelings were expressed by carers who felt
trapped in their caring roles, or had taken on the role of carer unwillingly as has been
highlighted by Gilley (1988), Nolan & Grant (1989) and others.
One unexpected recurring theme was that carers feared the possible hereditary aspects of dementia. This was highlighted not only by offspring of people with dementia, but also by spouses who feared for the children of the marriage, and future generations.

Within this topic it might have been useful to have sub-divided this sample into different sexes and different generations, and compared these specific responses for themes and links, both within the sub-groups and between them. This study however was not designed for detailed sub group analysis. In view of the fact that no formal qualitative methods were employed, it would probably be unwise to push the analysis too far! The inclusion of a simple analysis of the data however does give an overall "flavour" of the issues.
Use of the carer held record

Assessment of how the carer held records were used by both carers and professionals was made by examination of individuals' use of the documents, professionals' as well as carers' input, at every time-scheduled interview. Engagement analysis was not related to how long participants remained in the study. Some carers who continued to participate in the study did not fully engage with the philosophy, and made very little use of the document. Others, who left the project because the patient died at some point within the study period, had indicated by their document use, and verbal and written comments, that they had indeed engaged with the project. In 2 cases, although the carers had embarked on the project enthusiastically, the patient died before the first follow up appointment, and so it could not be determined whether these families would have engaged with the project or not.

Results of engagement analysis showed that 13 subject participants (36%) did not engage well with the project, made little use of the documents, and did not feel subjectively that they gained much benefit. However 23 subjects in the sample (64%) did engage and used the documents to varying degrees, and in individual ways, feeling that subjectively they were glad to have had the opportunity to have carer held records at home. One of the conclusions therefore of the qualitative analysis is that having a carer held record is not an initiative which suits all carers of patients with dementia. Not only do the results on engagement demonstrate this, but it is also shown by the descriptive statistics on the numbers of potential subjects who declined to participate in the research; 17 subjects compared with 7 controls. If carer held records is to become an initiative that is further developed within the Trust following this research project, an issue to emphasise is the importance of patients'/carers' choice of whether or not they wish to take advantage of the facility.
Loss of carer held records by families

In comparison to other studies on use of client held records in the community loss of the documents was far less frequent in this research. Warner et al (2000), in his study of shared care for individuals with long term mental health illness, reported that 39% of subjects lost their document at least once. 10 subjects who reported losing records at first follow up were given a replacement, and 9 of these lost it a second time. Only one carer in this study reported loss of her record, and this was in the course of house removal. Loss of the record in this research was more comparable to, but better than, results reported by Gilhooly (1991) on loss of parent held records for children. There are two reasons which can perhaps be put forward for carers of patients with dementia being more diligent in not losing their documents. The first is that, unlike Warner’s research group, carers are not generally ill themselves, and so are better able to accept responsibility for care of the document.

The second reason is that, unlike parents who hold records for well children, carers who are looking after patients with dementia have responsibility for people who may require frequent multidisciplinary input into care packages, regular assessments, and adjustments to medical management and medication. Therefore use of the record may be more regular and relevant to daily living. Many of the carers in this study were concerned that their relatives should have the best possible management, and so might feel that their contributions to the document were relevant to the care prescribed.

Also pertinent to care of the document is the inclusion in the package of a diary in which carers may write about their own personal feelings as well as their thoughts about patients conditions. This probably contributes toward ownership of the record and thus influences the care taken to keep it safe.
Professionals' opinions about the value of the initiative

From the small staff survey conducted amongst participating professionals mixed views are expressed about the value of carer held records both for carers and for professionals themselves. Some of the professionals remain enthusiastic about empowerment of carers in this project two years after commencement of the research. Others are not so sure, and, freed from the restrictions of the research protocol, are likely to make judgments about which carers might benefit, which carers would not wish to contribute to carer held records, and which families might conceivably have problems themselves, and/or cause problems for professionals if carer held records were offered.

In the study (Warner et al 2000) results showed low usage of shared care documents by professionals for which he suggests the following possible reasons:

- The time-consuming nature of duplication of information
- Uncertainty about what to write, and in which parts of the package
- Lack of ownership of the initiative amongst professionals

In this study only the issue of time commitment may perhaps be a factor in professional non-engagement with the project. The CMHT for the subject group of carers were well-informed about the design of the carer held package, and had responded well to the education sessions on equal partnership principles. They certainly did own the project, and had been pleased at the start to be active contributors to the research. On the part of most key workers this commitment was maintained. Frequent contact between participating CMHTs and the researchers probably helped to maintain professional interest, as there was much discussion amongst us all during the course of the study. Beyond CMHT professionals participating disciplines and agencies did not have this contact. Although initially consulted and involved no follow up contact could be maintained.
There are two other factors which may contribute to low usage of records by some professionals. The first is that this was a research initiative in which only a small number of professionals' clients were involved. Carer held records therefore were not at the forefront of their minds when contact with families was made, and was not a part of routine care delivery. On many occasions it was up to the carers to remind professionals that they had the records, and ask them to contribute. This was particularly true for GPs. If asked by carers to write in the records most GPs complied.

The second factor which is important is that the success of carer held records very much depends on the ability of professionals, and their willingness, to accept the ideology of empowerment of carers and patients and the principles of equal partnerships in health care delivery. As was discussed in the literature (Hoggett & Hambleton 1987) there is always the danger of lip service being paid to the ideal, whilst the practice of care delivery is in conflict with this.

The contribution of carers to the success of carer held records

In the qualitative analysis of this study it was shown that those carers most committed to the project, who reminded and “bullied” professionals to contribute to their records, elicited the best response from professionals. For them, the offer of equal partnership was accepted and acted upon. Possibly also professionals were thus made aware that for such carers the initiative was important. Less committed carers, or those less able or willing to remind professionals of their ownership of carer held records were those whose documents were less well completed by professionals. Interestingly, this was also the group who wished that professionals would contribute more. It needs to be emphasised that equal partnership is a two way phenomenon. It requires acceptance from users and carers as well as the offer genuinely being made by professionals. Health service clients, especially those in the field of psychiatry, are as “unpractised” in such a culture change as are professionals, and, like professionals, some clients do not embrace the philosophy as enthusiastically as others.
The social model of dementia

As was mentioned earlier in the introductory note to this thesis, people with dementia have often been defined in terms of the disease of dementia from which they are suffering, and its symptomology, which identifies them as "ill. This way of thinking, often known as the medical model of dementia focuses upon the illness itself, and measures people with dementia against a concept of normal functioning. The social model of dementia, in contrast, focuses upon people's abilities and emphasises the importance of personhood as opposed to highlighting their impairments.

These are two totally diverse ways of viewing a person who has dementia, and the way in which society views dementia can have a great effect on how people with dementia feel about themselves. In the medical model the picture is rather bleak, emphasis being placed upon a condition which will continue to deteriorate, and incur more and more lost abilities as time goes on. This model of dementia can have a disabling effect both upon a person who has the disease, and also on their families. The element of hopelessness can easily pervade the situation in which some families find themselves. As was mentioned in the previous paragraphs, many of the worries identified by carers centred around fear of the condition itself, how it would worsen, and how, as carers, they would be able to cope. These fears would definitely be intensified if a medical model was employed as the major view of the situation.

The social model of dementia carries within its aura a much more positive message when dementia is diagnosed. If focus is placed on the individual person, and his/her strengths and abilities the future may appear much brighter. There is, after all, no regular pattern which everyone who has dementia automatically follows. There are strategies which can be tailored to meet individual needs, to maintain people's functioning in spite of the diagnosis, and roles for family carers to play in positive reinforcement. This is a viewpoint which not only encourages people with dementia and their families, but also serves to foster positive feelings about the value of individuals within society, and encourages them to maintain an active role in life.
With the advent of cholinesterase inhibitor drugs for Alzheimer's disease which aim to slow the disease process within individuals, it is even more important that care packages should be centred within the social model of care, as it is expected that people might be maintained in the early stages of dementia, and able to function well, for longer periods of time. It is especially important that positive messages from society are received by these individuals and their families.

**Issues of carer/patient consent to participate in this research**

The section on empowerment of service users focused in detail upon patient consent to treatment and on consent to participate in research, particularly when people were mentally incapacitated. This issue is very relevant, not only in connection with this research study which has now been completed, but also to future developments of the initiative of carer held records.

At the time of application to the Leicestershire Ethics Committee in 1995 for permission to conduct the study, it was considered that obtaining consent from carers to participate in the research adequately met MRC conditions, since carers were the focus of the research project, and would be the people who would maintain the carer held records. Carers were the primary focus of the research, and not the patients. However, there have been, in the last few years, several publications (Dimond 2001) outlining the rights of people incapacitated by dementia to consent to research, or to withhold their consent to participate in research. Emphasis today is placed on the centrality of patients' views, and the legal position regarding their rights.

Unfortunately, the legal position is not clear with regard to incapacitated patients, and even the most recent government directive on the issue can only give guidelines to practitioners. It does not have definitive answers. (DOH 2001). However there are strong recommendations included in the guidelines which include the direction that, whenever possible, research should always be conducted with people who *can* give informed consent for their participation. It is acknowledged however that this is not always possible.
Research with people who have dementia is very important if progress is to be made in managing the condition, and such research can not always be conducted solely with those people in the early stages of the disease. Emphasis however is placed on the importance of making sincere efforts to communicate with potential research subjects who have dementia, and recent publications stress that, if carefully managed, such communication with patients with dementia is often successful (Allan 2001). Family carers may not give consent on behalf of their relatives with dementia, although it is acknowledged that their views should be considered, because they may have prior knowledge of the views which the person with dementia had before the onset of cognitive decline. They should not however be the people who make major decisions, as carers and patients may have different agendas which could underpin decision-making.

Although this research into carer held records was focused upon carers, who signed their consent to participate in the research, there is an issue surrounding patients’ personal information within the carer – maintained package. The people with dementia themselves were not asked to give official consent to its use in this way. In many instances the patients knew of the contents of the documents and expressed no dissatisfaction. In other cases, when in the early stages of the disease, the people with dementia actively contributed to the document. There were however patients in the later stages of dementia who may not have been aware of the conduct of the research, or its purpose, and thus the issue of patient consent must be addressed in any future development, or extension of the project.
Caring for the Carers

The current Governmental stance on the role of informal carers has highlighted the important part family carers play in caring for their dependent relatives at home, and recent legislation advocates that carers should be formally supported by services. DOH(1999) The Carers' National Strategy emphasises that now all organisations involved with the health and welfare of a patient must focus upon, not just the client, but must include the carer. The philosophy is that both people involved in the caring relationship are valued, and that neither party's needs should be made subordinate to the other.

Carer held records for patients with dementia fits into this philosophy well, and if future developments of the initiative involve presentation of the idea to families when patients' dementia is in the early stages, it could be a powerful practical enactment of the strategy. In a document that is jointly agreed upon by both the patient and carer the needs and wishes of both might thus be considered together.

However, a carer held record is not a universal strategy that will be a positive benefit for all. This research study has shown that the initiative does not appeal to all families, and that even if the idea of the document seems a good one to carers, it's practical maintenance both by families and professionals is not without problems in some instances. The dichotomies that might exist between the needs of patients and carers within certain families will still need to be discussed and managed. The carer held record however might act as a tool which increases communication between all parties, and stimulates discussion of the difficulties. It can also be offered to families, in the knowledge that, for some, positive benefits may accrue for both patients and carers via its use.
Carer held records compared to other carer intervention initiatives

Several studies report reduction in carer burden levels as a result of specific carer interventions such as:

- Support group membership (Pratt et al. 1985)
- Education courses for carers (Brodaty & Gresham 1989)
- Counselling courses (Mittelman et al. 1995)
- Developing carer coping strategies (Quayhagen & Quayhagen 1988, Hinchcliffe et al. 1995)
- Social and professional support (Gilhooly 1984)

There is no consistency however in the use of measurement scales between these studies. Some researchers used the Caregiver Burden Scale (Zarit & Zarit 1983) to measure outcome. Others used the Life Satisfaction Scale (Wood et al. 1969). The GHQ and Geriatric Depression Scales were also used in some studies as measures of well being. None of these research studies involved longitudinal follow up of carers, and so no precise comparisons can be made in weighting different interventions against each other in terms of outcome measures. It can only be said that the intervention of carer held records was also found to have a positive effect on carer strain levels as measured by the Carer Strain Index (Robinson 1983).

No studies were found which used a Locus of Control Scale as a measure of outcome.

Limitations of the study

It has been acknowledged that the aims and objectives of carrying out a qualitative analysis within this study were relatively limited. This aspect of the study was explorative only. Time and resources did not permit a detailed in-depth qualitative analysis. Qualitative data in this thesis therefore are presented to illustrate and assist interpretation of the quantitative findings. This research attempted to go beyond the realms of subjective patient and carer satisfaction with the practice of maintaining client held records, to examine possible benefits as measurable outcomes in terms of health and well being of carers using the documents.
It must be remembered however that the research was carried out within a culture of care which aimed to promote client empowerment, but which was still based within a national health service for which this culture remains idealistic, largely untried, and difficult for professionals, patients and carers to fully embrace. The study results must therefore be seen in the light of this current ideology.

The introduction of client held records does not in itself alter the culture of care delivery. It is not the mere fact of having carer held records which may best promote client benefits, but the principles of equal partnership, mutual acknowledgement of the value of both professional and informal carer roles, and good communication between the two. The client held documentation in itself does not achieve this. It may however be that promotion of the initiative on a wider scale within the service as a whole could be a useful strategy towards effecting such a culture change. If client held records became normal practice, and not a research initiative, health care delivery may be affected by use of the tool.

In spite of these limitations carers in this study who were given carer held records did show positive outcomes in the domains of reduced strain levels, reduction in feelings of external and chance control, and an increase in feelings of control over their caring situations. These results were found within a sample group of whom 36%, on qualitative analysis of the data, did not fully engage with the practice. If the client held record initiative does become more widely embraced as routine practice however, future research could be undertaken comparing a random sample of those already established in engagement with a random sample of controls who have not been offered the initiative.

Although the results of this study indicate possible carer benefits from having carer held records when patients have dementia, the study was limited in that the number of families participating in the research over the full eighteen months of the study period was small, and the results have to be viewed in the light of possible inadequate power. However, significant findings were made despite the small numbers.
Clinical implications of the study results

The degree of reduction in carer strain by 2.3 points at six months and 2.8 at twelve months following commencement of maintaining carer held records does seem to be clinically important. Although unable to specify in which areas carer strain was reduced in this study, this result, when the possible total for the scale is 13, would seem to indicate a clinically valuable reduction in carer strain. The results of the locus of control analysis does also indicate an area of significant gain for carers.

How the study results might inform policy and practice

There is evidence from this study to make a strong case for extending the initiative to a wider clientele, emphasising, in any future policy guidelines aspects of the practice learned from the conduct of this study and related research issues. Of particular importance will be the topic of patient consent to participate in the carer held records initiative. It would seem that giving out the carer held records to families when patients are in the early stages of dementia might be good practice. As people are now being referred for assessment early in the disease progression because of treatment availability, there is a powerful opportunity now to introduce the intervention in these early stages. Great stress and strain is often demonstrated by patients and their families around the time of diagnosis, and this can pervade their thinking, and strongly affect their lives at the very beginning of the journey through dementia. It would seem to make sense to offer the intervention, and the philosophy of equal partnerships with professionals at this stage, particularly in the light of carer gains in feelings of being in control which were demonstrated by this study.

Patients could give genuinely informed consent in the early stages of dementia for families to have the carer held record, not only being aware of the contents, but also personally contributing to the document. The carer held record could then be a patient and carer held record, at least at the outset.
There is also the advantage that, informed consent having been received from the people with dementia themselves, implied consent can be inferred to continue in later stages. Consent to participate is already in place.

Early introduction of the initiative to families might also increase engagement with the project, and thus lead to genuine partnerships developing between professionals, carers, and the people with dementia themselves.

Clinicians and managers in the Trust will need to weigh these advantages that carers may gain against the costs of extending the initiative of carer held records. Such costs are not just the material costs of greater production of records files, but also implementation costs which include multidisciplinary education programmes so that the initiative, if extended, may have the best chance of success. Ideally such a development should be introduced under the aegis of a dedicated co-ordinator to guide the implementation process.

**Recent Advances In The Clinical Management Of Dementia**

The clinical management of dementia has been changing in recent years for several, perhaps inter-related reasons. Techniques such as magnetic resonance imaging (MRI), provide a harmless and non-invasive means of viewing the brain, and assessing the location and degree of atrophy, an indicator of a neurodegenerative process. Neuropsychological testing probes specific areas of cognitive functioning, and has the power to detect early cognitive change. Serial assessments, using both these techniques, allow clinicians to track patterns and rates of both neuroanatomical change, and patterns of impairment (Crutch & Isaacs 2001)

Although both techniques have been available for diagnosing early dementia, they have, until recently, not been widely offered to patients displaying early signs of memory loss, principally because there was little therapeutically which could be offered to treat the condition.
Also, it was often felt that, as there was nothing that could be done medically, there was nothing to be gained by telling patients about the diagnosis as they might be frightened or distressed by the information. This philosophy has been greatly altered today by three factors.

Firstly, the emergence of cholinesterase inhibitor drugs for Alzheimer's disease has provided a treatment which can retard the progression of symptoms such as memory loss in up to 40% of patients. If administered early, these compounds can improve cognitive function and quality of life at a stage when a person with Alzheimer's disease is still able to live a rich and fulfilling life. Since the National Institute of Clinical Excellence (NICE) has recommended that this group of drugs should be licensed for use in the NHS, their availability has been greatly expanded within the NHS.

Secondly, there has gradually been a change in the management philosophy for people with dementia. Within the social model of dementia, focus placed on the essence of personhood, and on people's abilities and strengths, carries a much more positive view of dementia than the medical model of "illness". It is interesting that this social model is emerging as a strong philosophical stance in spite of the new drug therapy available to treat a "disease" as defined in medical terms.

Thirdly, public awareness of the existence of a new drug treatment, and its current availability, has led to an increased demand both from people with early memory loss, and their families, for assessment and early diagnosis of dementia, in order to maximise benefits of possible drug therapy. The significance of early diagnosis for families is that it enables patients and their carers to plan ahead, organising psychological and social interventions, and obtaining the appropriate advice and information. Even if a person is diagnosed as non-Alzheimer's dementia, the latter benefits of early diagnosis still apply.
The growth of memory clinics

It is recommended in the DOH (2001) National Service Framework for Older People that local protocols for assessment, diagnosis and monitoring of early onset dementia should be implemented, and that memory clinics should be the focus of this development, thus becoming an integral part of the service offered within old age psychiatry. With the development of primary care trusts general practitioners have the opportunity to influence future NHS spending, being actively encouraged to focus on services they perceive to be of most benefit to professionals, their patients and clients. The traditional role of memory clinics will have to change to accommodate this development. Facilities will be required such as memory clinics focusing on intensive assessment, diagnosis, treatment and monitoring in early dementia. Small, local memory clinics with a primary clinical focus may be a future development of the service, rather than there being one central memory clinic within a Trust. It is however important to point out that there is a danger that the traditional academic perspective of memory clinics, in research and professional training, might be lost by these developments, and it is important that these functions should remain part of the future plan for services (Lindesay 2001). Opportunities for research to further develop dementia management have never been more available, or research more relevant than it is today.

The role of carer held records within memory clinics

It is within this developing structure and function of memory clinics that carer held records for people with dementia might become an integral element of care for both patients and carers. The records can be offered at early stages of dementia, and used as families wish throughout the development of dementia, presented to various health professionals and care agencies as a continuing family record of the care of the person with dementia over time.
Future research

There are several areas where future research into the topic of client held records will be important. In view of the low numbers of participants in this study, future projects should aim to recruit higher numbers over perhaps a longer period of time. In this study, overall predictors of benefit in the realms of sex of carers & generation of carers in relation to the cared for, were difficult to interpret globally. Results of the research do not indicate that any carer group has characteristics which if specifically targeted might gain maximum benefit. As the overall number of participants was small, breakdown of the sample into further sub-groups meant even smaller numbers of results to analyse. Larger numbers in future studies may allow this analysis, and clarify any potential effects of sex and generation.

Further research using locus of control scales is indicated from the results of this study, particularly by researchers well versed in the intricacies of the topic. Comparisons between a random sample of clients who engage with the practice of maintaining client held records, and a similar control group of clients not offered the facility would be interesting. It may be that engagement with the philosophy and practice of keeping carer held records may be the best indicator of client benefit, but this could not be assessed in this research.

Qualitative data collection and analysis in this study was limited, and served only to illustrate and assist interpretation of the quantitative findings. The qualitative findings can perhaps be regarded as an "audit trail" which other researchers may wish to replicate in a much larger study, and in a more focused, detailed protocol.

It is hoped that the future development of this project will be in the use of a "patient and carer" held record, issued in the early stages of dementia, at memory clinics. Then, a different evaluation of possible health & social benefits for both patients & carers will be required. This study has only focused upon carers, and in most cases where their relatives' dementia was well established. A clientele of both patients and carers, at a much earlier stage in the development of dementia, would require a different research evaluation process.
Conclusions

This is a study about potential benefits which may accrue for families from having carer held records when a family member has dementia. What does it reveal about the issue of client held records, and the body of knowledge on the topic in general, particularly within the field of dementia care?

There are very few studies which have attempted to measure objectively whether clients gain any demonstrable benefit from the use of client held records beyond feelings of satisfaction with care delivery and the service as a whole. The results of this study show that there is some objective evidence to support the idea that, when their relatives have dementia, carers benefited from the initiative by reduction in some facets of the strain of caring, and increased feelings of control of their caring situation.

This study was focused upon carers, and the outcomes when carer held records were given to them. This is an aspect of research into client held records which has not previously been focused upon, different from research into patient held records, but relevant to the whole body of literature. In the future development of the initiative it is hoped that the record will be a carer and patient - held document, where both carer and patient endorse its relevance at an early stage in the progress of the disease, and into which both might contribute their ideas and feelings. The documents might be in active use, therefore, throughout the period of the patients' dementia, the carers contributing more extensively than patients as time goes on.

Both carers and professionals who participated in this research displayed facets of the inequalities which are embedded in the National Health Service. The belief that professionals have the knowledge and power, especially in the field of mental health, is still prominent in health care delivery and it influences, perhaps subconsciously, carers and professionals alike. However slowly the culture is changing. Recent Government publications have been focused upon user/carer involvement in health care services.
Recent directives such as Audit Commission (2000) *Forget me not* and the DOH (2001) *National Service Framework for Older People* have set standards which must be met in order to deliver a quality care service, and have provided direct guidance about how to promote client empowerment, and choice. Within this changing culture, client held records for people with dementia could be a facility which has an influence on achieving this ideal.

It is highlighted in the National Carers' Strategy (DOH 1999) that the needs and wishes of both client and carer in a caring relationship should be considered. The importance of working in partnership with carers and users underpins many of the recommendations of recent Government legislation (Carers’ (Recognition and Services) Act 1995, Audit Commission (2000) *Forget-me-not*). Clinical implications of this study include the fact that the initiative of carer held records may assist professionals to meet the requirements of these Government Directives in their delivery of care.

The clinical management of dementia has been changing in recent years for several, perhaps inter-related, reasons. The availability of anti-dementia drugs has influenced the clinical management of dementia in its early stages. This new treatment development, together with widespread public awareness of its availability, has led to a great increase in referrals of people with possible dementia for assessment, in the very early stages of the disease. It is expected that, in the future, services for the care of people with dementia will be focused as intensely on managing the early and progressive stages of dementia as they currently are on the end stages of the disease. This change in focus will certainly influence care in the community. Memory clinics will probably become the focus of early disease management, the development, and multidisciplinary staffing of which might need to become high priority. Presentation of the carer held record initiative to families at this early point of contact with the service offers an good opportunity to meet client needs (both carer and patient), meet user/carer demands for involvement in the care process, and comply with recent legislation on the role of carers.
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References


Building Bridges: Collaboration for change. Discussion Paper, Partnerships between service users, planners and managers of the NHS (1988). King’s Fund Centre No. 0871/140


Court of Appeal Re MB (an adult: medical treatment) (1997) 38 BMLR 175 CA.


HTTP://www.DOH.UK


Gilhooly MLM (1984), The impact of care giving on caregivers: factors associated with psychological well being of people supporting a demented relative in the community. *British Journal Of Medical Psychology,* 57, 35 -44.


Goldberg DP & Hillier VF (1972), A scaled version of the General Health Questionnaire. *Psychological Medicine,* 9, 139 - 145.


Hill D & Bale R (1981), Measuring beliefs about where psychological pain originates, and who is responsible for its alleviation. *Research with the Locus of Control Construct*, 1, 281 - 321


Kitwood T & Bredin S (1992), A new approach to the evaluation of dementia care, *Journal of Advances in Health and Nursing Care, 1 (5),* 41 – 60.


Lau RR & Ware JF (1981), Refinements in the measurement of health-specific locus of control beliefs. *Medical Care, XIX,* No. 11, Nov. 1981, 1147 - 1157


McHorney CA, Ware JE, Rogers W & Raczek AE (1992), The validity and relative precision of the MOS short and long form health status scales: results from the medical outcome study. *Medical Care 30* (supplement) MS 253-265

Medical Outcomes Trust (1993), *How to score the SF 36 Health Survey*, Medical Outcomes Trust, PO Box 1917, Boston, MA 02205.


Nolan M & Grant G (1989), Stress is in the eye of the beholder: reconceptualising the measurement of carer burden. *Journal of Advanced Nursing,*


Saunders P (1995), Encouraging patients to take part in their own care. *Nursing Times, 91*(9), March 1, 42 – 43.


Wright F & Young E (1994), Focusing on client held joint health and social care records. *Journal of Interprofessional Care*, 8(3),


