Reverse Journey In Dementia: A clinician's research journey leading to the development of carers' diaries

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Abstract

Dementia is a progressively debilitating disorder often of insidious onset. When making the initial assessment or reviewing ongoing care of patients living at home, healthcare professionals rely on verbal information provided by person with dementia and their informal carers. Diaries have been used in very few instances to assist with gathering information about persons with dementia in the community. The review of literature found that there are very few studies that used carers' diaries in the context of dementia care and its effects on carers and patients, and there was no previous study that had used carer diaries in the assessment of dementia patients' problems in everyday life. It was also noted that no previous study has assessed the validity of these retrospective self-reporting by patients with dementia and their carers. If these self-reports are indeed unreliable and provide averaged impressions rather than actual fluctuations of frequency and magnitude of symptoms, then caregivers' diaries of these symptoms/problems can provide important and valuable additional information to clinicians.

The main aim of this study was to capture a variety of problems (cognitive, emotional, behavioural, etc.) in people with dementia, using diaries kept by carers for a week and comparing with carers' oral recollection of problems in the same week. The second aim was to examine the potential therapeutic impact that keeping a diary had on carers' quality of life as rated by the EuroQol, emotional wellbeing as rated by the Hospital Anxiety and Depression scale, as well as its impact on behavioural and psychological problems of dementia patients measured by the Neuro-Psychiatry Inventory.

Method Carers were randomly allocated into two groups, the intervention and control groups. In the intervention group, carers received a diary and instructions on how to complete

it for 7 days. A number of assessment tools and ratings scales were completed on Day 1 and Day 8. The control group carried out the same tasks except completing a diary. The scales used were questionnaires such as the Clinical Dementia Rating Scale and the Neuro-Psychiatry Inventory for carers to evaluate the problems in the person they cared for. The EuroQol and Hospital Anxiety and Depression scale were completed by carers to assess their own quality of life and screen for anxiety and depression in carers. The carers in the diary group were asked to complete a semi-structured questionnaire on their views about keeping a diary on Day 8 when they returned the diary to the researchers. On Day 28, carers in each group completed the Neuropsychiatry Inventory, EuroQol, Hospital Anxiety and Depression Scale and a semi-structured questionnaire asking about their experiences taking part in the study.

Results There was a 1 year period of recruitment from 1 May 2014 to 30 April 2015. A total of 97 couples were identified and approached to take part in the study, with 84 couples agreeing and giving written informed consent to take part. Out of these, 78 couples went on to complete the study and 6 couples withdrew. The problems reported in narratives and diary entries were content analysed by two raters independently and classed into 5 categories: cognitive, behavioural, emotional, psychiatric and other. In retrospective narrative accounts, significantly more cognitive problems were reported than any of the other four problems. In contrast, in diaries both cognitive and behavioural problems were reported significantly more often than the other problems. In addition, in the diary condition, the mean number of problems identified in the carers’ diaries was significantly higher than in the carers’ narrative accounts on Day 1 and Day 8. Furthermore, the number of problems recorded in diaries did not correlate with retrospective problems reported on Day 1 but correlated with the number of narrative problems on Day 8. In terms of therapeutic benefits of diary keeping, there were

no significant differences between diary and control groups’ mean scores in the Neuro Psychiatry Inventory, EuroQol and Hospital Anxiety and Depression Scale on Day 8. The mean Neuro-Psychiatry Inventory and Carer Distress scores were significantly lower at the end of the study for both the diary and control groups.

Discussion The findings revealed that the carers’ diaries identified a greater frequency of problems compared to retrospective information gathered from carers, with cognitive and behaviour problems being the two most common problems. Despite identifying more problems, the use of the carers’ diaries in dementia did not appear to make a difference in carers in terms of carer distress, carers’ health related quality of life or psychiatric morbidity amongst carers. This may be on account of the short period of one week that the diaries were used in this study. The positive correlation of problems identified in the narratives in diary group at Day 8 with diary entries in contrast to narratives at Day 1 where there were no correlation with diary entries suggest diary entries can enhance recollection of problems in narratives of carers who keep diaries.

Conclusions Carers’ diaries may be a useful tool in assessments of dementia patients as this study indicates that they may provide more information than obtained from a retrospective account of problems in persons with dementia. More research using diaries in dementia covering longer period than a week may be required to ascertain other benefits such as improving carers’ well-being and problems in persons with dementia.

Acknowledgements

This work has been a true journey in research, in which I have met many amazing people, from patients to Health and Social Care professionals. The devotion and love shown by family carers to their loved ones and willingness to take part in this study is something I will always be grateful for. In meeting with them and sharing their different experiences, I learnt so much more about their roles as carers and the daily challenges faced.

First and foremost, I like to express my sincerest, eternal gratitude to my principal supervisor, Professor Kunle Ashaye, who as my professional colleague and clinical supervisor initiated in me the belief that I could carry out and complete a PhD thesis. Without his motivation and encouragement, I would never have been able to have the belief that I could complete this research journey.

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There is no doubt in my mind that without the wonderful support of my husband Roshan and our lovely daughters, Hashini and Gimeshi, those long days and nights spent preparing this dissertation would not have been possible. I am grateful for everything they did to see me through to its end.

Statement of originality

This thesis represents original work that I carried out in Hertfordshire Partnership University NHS Foundation Trust.

Ethical considerations

Ethical approval was obtained from Ethics Committee East of England. The consent of all participants who were involved in the study was obtained. The participants were given verbal explanations about what the study involved. They were informed that participation / non-participation would not affect their care and that they could withdraw from the study at any time. This information was substantiated by the provision of patient and carer information sheets.

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CHAPTER 1

INTRODUCTION

Dementia is a progressively debilitating disorder often of insidious onset. When making the initial assessment or reviewing ongoing care of patients living at home, healthcare professionals rely on verbal information provided by person with dementia and their informal carers who are often their spouses, children or siblings. These assessments are often time-limited and anxiety provoking leading to the possibility that essential information about problems faced by the person with dementia and/or the carers are missed or not mentioned at all. For persons with dementia in formal care such as in hospitals and residential or nursing care homes, the information is provided not just by the verbal reports but also from patient records kept by health and care staff. This is similar in the community in cases where formal home carers are involved in which they also provide a written record of the day-to-day activities of the person with dementia as well as identify any problems. These written records provide valuable information about *what*, *where* and *when* problems occur and help healthcare professionals to identify the suitable interventions to help resolve the problems, leading to improved outcome of care.

Diary is a form of a record or documentation with distinct entries on what has happened over the course of a day or other period of time. A personal diary usually includes the diarist's experiences, thoughts or feelings, including an account of current events. Although diaries are often written for the author's own use, they can also be used to gather additional information on patients' everyday experiences, which could aid diagnosis, treatment planning and implementation. Diaries have been an essential component of some clinical studies, predominantly those that assess the frequency and intensity of symptoms, medication efficacy, frequency and intensity of target behaviours or perceived quality of life (Burton et al., 2007; Hall et al., 2009; Morren et al., 2009).

The solicited diary where the participants record their own thoughts and feelings under the direction of a researcher in health studies and unsolicited, personal diaries where the writer is writing for his or her benefit have been used for many decades. Meth (2003) argues that for a researcher to use solicited diaries as a method for data collection, the participants must have the ability to read and write in the language in which the research is being conducted. This highlights the importance of cognitive abilities when asked to record their experiences in a diary especially when people have disabilities like memory problems.

During assessments, doctors usually ask patients to recall recent health experiences and their quality of life. Research has shown, however, that recall from memory can be unreliable, inconsistent and inaccurate (e.g., Drivdahl & Hyman, 2013; Nisbett & Wilson, 1977). In clinical practice, the shortcomings associated with identification of problems through recall, has led to the use of diaries with an intention of capturing experiences or problems near the time they occur, thus reducing the retrospective bias in recall and producing more accurate information (Gorin & Stone, 2001; Shiffman et al., 2001).

The advantages of diary method were demonstrated in a study by Ben-Zeev et al. (2012) on schizophrenia patients and a control group, which compared real time experiences recorded using a mobile device with retrospective reporting. Results showed that in both groups, retrospective reporting provided an average account of experiences rather than the most intense or recent experiences captured on the mobile devices. This study, therefore, highlights how retrospective recording of problems may be unable to capture the variability of problems over time. Hence, it is essential for clinical diagnosis and treatment plans that problems exhibited by patients are recorded as and when they occur in everyday life to avoid simple forgetting or under and overestimation of these problems.

There are many types of diaries such as paper, electronic, digital and audio diaries. Amongst these, the most commonly used are the paper and electronic diaries. Researchers need to adjust the type of diary method to the target population to ensure that research participants feel comfortable with the process of keeping a diary. Paper diaries are the most traditional type of diary recording method and this format is still one of the most widely used and is considered most natural and personal, especially, for the elderly as they might not be familiar with the new technology. In health care and clinical research, paper diaries are generally used to assess patient experiences as most participants are familiar with this format which does not require complicated procedures, so it will be easier for them to fill it out. In clinical medicine however, there is concern of using diary protocols as patients do not always comply with maintaining a diary, invalidating the benefit of diary data. Many researchers tend to move away from paper format due to associated disadvantages. There are concerns over compliance of this method as well as completion, particularly due to forgetfulness. Another shortcoming of this method is the burden of data entry. Therefore, to overcome these problems researchers suggest using it for a short duration (Collins 2006; Valimaki et al., 2007).

The use of electronic format of diaries in research began in the late 1990s and has been considered to be the most common method in the past decade with the increasing use of the internet, computer and mobile devices. In many clinical trials, researchers discuss diary data and illustrate important advantages of electronic diaries over paper diaries. Findings in these studies have suggested that electronic diaries can make it very simple to enter data and the fact that it automatically records date and time of each entry as it is made (Palermo et al. 2004; Stone et al. 2003). The investigators have also found the electronic format to be more accurate as it eliminates errors associated with handwriting.

Over the past years, use of electronic diaries has become increasingly popular in medical research in many different specialities. There are several studies carried out to monitor chronic pain and Stone et al. (2003) and Jamison et al. (2001) in their studies of electronic versus paper diaries in adults with chronic pain found that participants were more compliant with electronic diaries, suggesting electronic diaries could be a more effective way of collecting information over paper diaries. They noted that compliance may be maximised by signalling participants when to complete diaries, like use of audible alarms to prompt participants to make diary entries. Hall et al. (2009) used electronic diaries to capture and predict subsequent seizures in individuals with uncontrolled seizures and Hajak et al. (2009) used them in out-patient clinics to evaluate the efficacy and safety of two drugs: Gaboxadal and Zopidem in primary insomnia. Furthermore, in Paediatrics, Whalen et al. (2008) used electronic diaries in a controlled study of children with Attention Deficit Hyperactivity Disorder who received treatment with long acting medication to examine associations between child and maternal anger and to capture the quality of their interactions. The authors found this method to be useful despite having its own methodological limitations such as feasibility in everyday life, vulnerability to reactivity and the recording burden.

An electronic method such as Interactive Voice Response Systems (IVRS) also has been used to collect data in clinical research. It allows research participants to answer automated telephone questions either by pressing the key pad or by providing a voice response. In this method, consistency of study administration in real time with storage to retrieve for later analysis and automated reminder calls has been considered as beneficial. Even though these new technology electronic data collection methods are popular and may improve the quality of data gathered, Lauristen et al. (2004) found that the completion (adherence) rate of conventional paper diaries was significantly higher than the completion rate of Interactive Voice Response Systems and telephone data capturing methods in a comparison study where the participants were advised to record their symptoms of gastro oesophageal reflux disease.

In contrast, there have been a number of studies which have found no difference between electronic and paper diaries. For example, Weiler et al. (2004) in a study using adults with allergic rhinitis, Dunn et al. (2007) in a study looking at changes of sexual functioning with antidepressants, Alemi et al. (1994) in a study on drug –addicted and alcohol dependent individuals and Agel et al. (2001) in their research on muscular skeleton function assessment found no significance differences between paper and electronic versions.

Dementia leads to increasing dependency and demands on carers. The breakdown in care at home often follows the inability of family carers to cope with the challenging behaviours of dementia such as aggression and violence. At the onset of presentation to services, assessment involves taking a history from both patients and family carers. The reason for initial presentation of persons with dementia to health care services is often based on observations of family carers or the breakdown of care at home. The initial assessments can be anxiety provoking for the person with dementia and their family (or informal) carers, which can lead to inaccurate or incomplete recall of problems or difficulties. Diaries have been used in very few studies in dementia to assist with gathering information about persons with dementia in the community. There are studies in which carers of dementia patients have used unstructured diaries to record certain problems experienced by patients (Lowery et al., 2000 McCurry et al., 2005; Merrilees et al., 2014). However, to the best of my knowledge, there are no studies which have used a structured diary method with family carers in the assessment and management of dementia to see if this will provide more information than the retrospective verbal accounts from the persons with dementia and their carers at an initial or follow-up assessment.

My reverse dementia research journey

My involvement with research in dementia has gone from the end stages to the initial break-down of care in the community. This current study involves persons with dementia at the time of initial diagnosis and follow-up in memory clinic. The three earlier studies I was involved in are now described to show how they link to the use of carers' diaries in dementia.

Study 1 - Ballale, Jayalath et al. (2010) assessed the prevalence and management of behavioural and psychological problems amongst patient with dementia in a National Health Services continuing care unit, where patients get admitted as they present with symptoms too difficult to manage in Social Services funded residential home or nursing home placements. In the study, we also looked at the treatment options available on the unit in terms of pharmacological and non-pharmacological options as there was increasing concerns over the safety of some pharmacological interventions (antipsychotics) or lack of sufficient evidence of effectiveness in managing neuropsychiatric symptoms in dementia. During this study, one of the units was redesigned, and with the support from the local carers' groups a multisensory room was also provided. In addition, two activity workers were appointed to support the occupational therapist. As a result, following regular medication reviews, we were able to successfully reduce and discontinue all the antipsychotic medication from 64% to none.

Study 2 – In a follow-up study, Jayalath et al. (2013) investigated whether reducing or stopping the prescribing of antipsychotics had any impact on the prevalence of behavioural and psychiatric problems in the same continuing care unit. We found that nearly half of the patients were deceased and this was unrelated whether they had been prescribed psychotropic medication or not. In conclusion, it was observed that in the majority of cases, the reduction and stopping of antipsychotic medication did not lead to an increase in behaviour and psychological problems.

Study 3 – Russell, Sundararaman, Jayalath et al. (2014) carried out a survey of reasons for admission to a dementia inpatients assessment ward over three years. The aim was to analyse the reasons for admission to a dementia assessment ward and identify strategies that reduce the need for admission. We reviewed the notes of all patients admitted to a 14-bed inpatient dementia assessment ward over a 3-year period. The primary reason for admission was recorded for each patient, in addition to carer-related concerns and demographic data. In total, 114 patients were admitted to the ward between January 2010 and December 2012. Aggressive and/or violent behaviour was, by far, the most frequently documented reason for admission. Prior to admission, most patients were living at home, with the vast majority of carers reporting that they felt unable to cope. Following admission, a minority of patients were discharged home, with most patients being discharged to residential homes, nursing homes or continuing care wards. Patient aggression was the most frequently identified reason for admission to a dementia assessment ward and most carers felt unable to cope in their pre-admission setting.

In all three studies, the reliance on good record keeping which aided patient care in terms of monitoring of symptoms and decisions on clinical management, frequently led to beneficial outcomes for persons with dementia. Consequently, the next stage was to investigate further the usefulness of record keeping by having carers to keep a diary of problems experienced by patients with dementia in everyday life. This would allow one to examine an important practical question about whether diaries provide more detailed and accurate information of patients' problems than their retrospective narratives of these problems during initial assessment with a clinician. In addition, I wanted to investigate whether keeping a diary of everyday problems displayed by dementia patients had any beneficial / therapeutic effects on either carers or dementia patients.

I have titled this dissertation, a reverse journey in dementia, reflecting my research activities to date through the end stages of dementia in a National Health Service Continuing Care Unit, to earlier stages when care breaks down leading to inpatients assessment and to the current study which examines persons with dementia attending memory clinics most frequently in the early stages and / or at the time of referral for initial assessment.

In our local memory assessment service where this study is carried out, patients with dementia living in the community are referred to a multidisciplinary team service. The Early Memory Diagnosis and Support Service (EMDASS) provide a pre and post diagnostic support pathway for people and their carers who have been identified as having a suspected dementia. The information gathered by team members is through retrospective interviews when during history taking in the clinical setting. Often it is observed that persons with dementia and their carers are unable to recollect all the problems faced or the patient is in denial that they have memory or associated problems. It also noted that sometimes carers do not feel comfortable providing information in the presence of the person with dementia even though verbally consent from the person with dementia has been obtained.

AIMS OF STUDY

The main rationale behind conducting the present study was to see if number and the nature of problems identified by using carers' diaries were different than those obtained in standard retrospective interviews that routinely take place in outpatients' clinics or home visit assessments. To address these main objectives, carers of dementia patients were randomly assigned to two conditions. Half of the carers kept a structured diary of the cognitive, behavioural and psychological problems of the person with dementia they cared for over a 7-day period (experimental group), while the other half did not keep a diary (control group). All participants also underwent an interview with a clinician before and after the 7-day period in which they reported retrospectively of the problems experienced by their loved ones over the previous week. In addition, to assess the potential therapeutic benefits of diary keeping, all participants also completed various questionnaires assessing mood and well-being before the 7-day period (Day 1), immediately after the 7-day period (Day 8) and three weeks after the initial meeting with the researcher (Day 28).

The following specific research questions were addressed:

1. To capture prospectively cognitive, emotional or behavioural problems in people with dementia, using diaries kept by carers.
2. To compare the content of prospective data captured through carers' diaries kept for a week and carers' retrospective oral recollection of problems in the preceding week.

3. To examine if keeping carers' diaries will make a difference in behaviour and psychological problems in persons with dementia measured using the Neuro-Psychiatry Inventory.
4. To examine if keeping a diary for a week makes any difference to carers' quality of life as rated by the EuroQol or emotional problems as rated by the Hospital Anxiety and Depression scale.

MAIN HYPOTHESES

1. Keeping carers' diaries would result in obtaining information on larger number and more diverse set of problems experienced by dementia patients than carers giving a retrospective account of these problems in one clinical session.
2. Keeping a diary may result in less distress and better quality of life in carers of dementia patients.

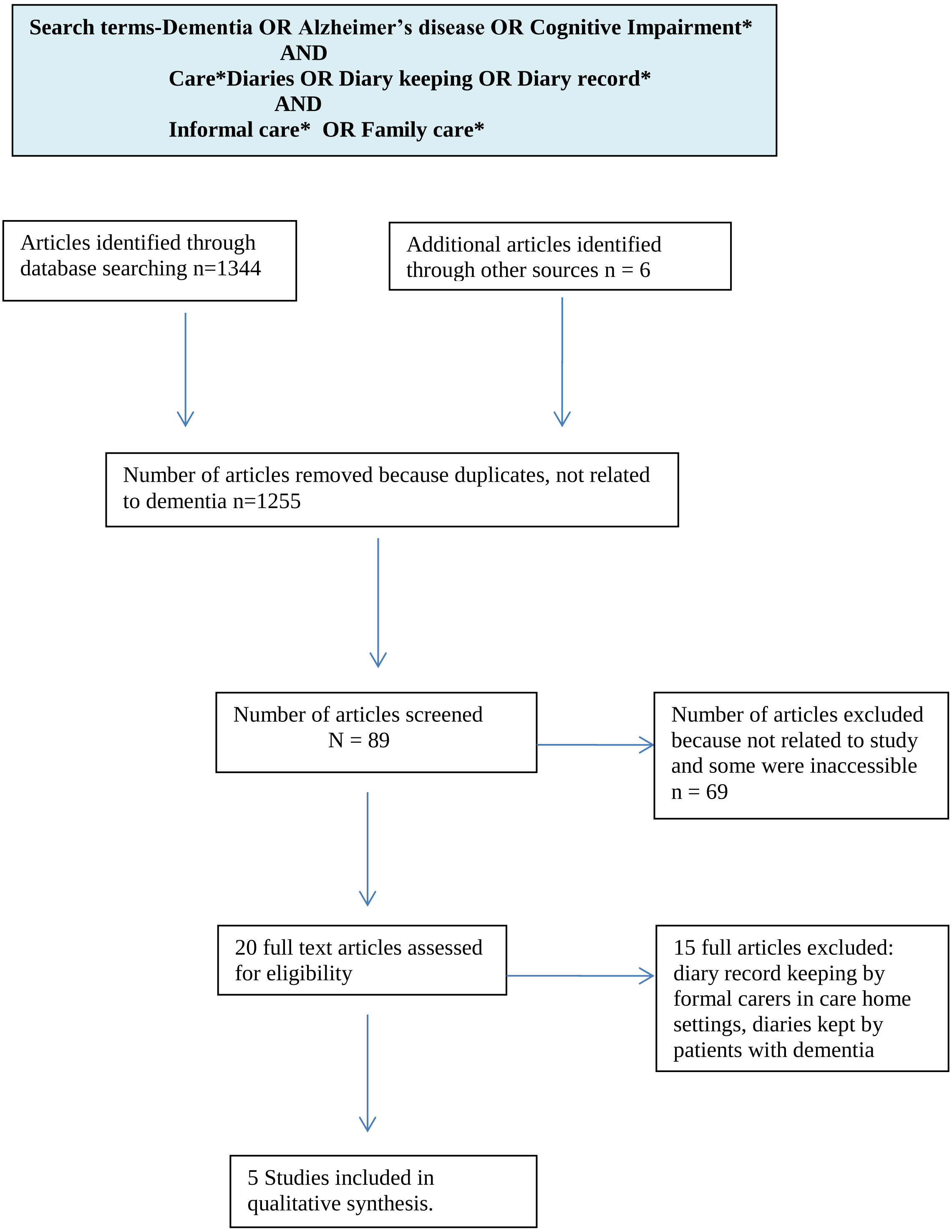
CHAPTER 2

LITERATURE REVIEW

A systematic literature search was carried out using PsychInfo, PubMed, CINALH plus, Cochrane library, Scopus and Web of Science databases using various search terms. In addition, I used Google scholar for titles, abstracts and full texts and reviewed these according to the inclusion and exclusion criteria, research question and the hypothesis. Reference lists/citations were also reviewed to identify additional publications. Finally, I used Grey literature for unpublished research and databases of ongoing research but could not find any article, which was relevant to my research question.

Prisma flowchart below summarises literature search activities (Fig. 1).

Fig 1: PRISMA flowchart of literature search



2.1. Dementia and its impact on society, patients and carers

Dementia is a syndrome characterized by disease of the brain and its abilities. It is associated with progressive memory loss, thinking ability, judgement, understanding and language. It is one of the most challenging disorders in terms of both rising number of cases and the economic burden. The impact of dementia can be understood at four inter-related levels: the individual with dementia, their family/friends and carers, health economy (NHS/Social services) and wider society (Wimo & Prince, 2010).

The World Alzheimer Report 2015 estimates that 46.8 million people are living with dementia globally and this number will approximately double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2015). These new figures are 12 -13% higher than those made for the World Alzheimer Report (2009). They also estimate more than 9.9 million new cases of dementia globally every year, which indicates that there will be one new case every 3.2 seconds. However, the regional distribution of new cases has changed compared to 2012 estimates in that there has been an increased proportion of new cases arising in Asia, the Americas and Africa, whereas the proportion of new cases arising in Europe has fallen.

The reduction in Europe can be attributed to the fact that there has been a bigger emphasis on treatment strategies, prevention and improvement in dementia education. However, the impact of increasing incidence of risk factors like diabetes, strokes and cerebrovascular accidents, may outweigh the beneficial changes noted. If these risk factors can be reduced, this may lead to further reduction in the incidence of dementia.

According to the Dementia UK report in 2014, there will be 850,000 people with dementia living in the UK in 2015 (Alzheimer’s Society, 2014). It is estimated that this will increase approximately to over 1 million by 2025 and another 1 million by 2051, provided that age specific prevalence remains stable. This growth is attributed to increased life expectancy for older people with reduced mortality as older people are most at risk of developing dementia. One in every 79 of the total UK population has some form of dementia and one in every 14 in those aged 65 and over. It is important to note that 42,325 people suffer from early on-set dementia (onset before the age 65), compared to 773,502 people with late-onset. Amongst these individuals with dementia, 505,813 persons have Alzheimer’s disease, which is known to be the most common out of all types of dementias.

It is also vital to note that the average cost per person and level of care needs varies depending on the dementia severity. While people with mild dementia have an average annual cost of £26,212, those with moderate dementia have a cost of £39,294 and those with severe dementia have a cost of £41,187. It is estimated that for people with dementia aged 60 and above, the severity of impairment is mild in 55%, moderate in 32% and severe in 12%. Dementia has a huge financial impact and costs £26.3 billion a year, with an average cost £32,250 per person. Two thirds of the total cost (£17.4 billion) is taken up by people with dementia and their families and £4.3 billion is spent on healthcare costs. Furthermore, in the UK, 311,730 people with dementia are living either in residential care or nursing homes and £10.3 billion is spent on social care alone, which is 2.5 times higher than the health care cost of dementia (i.e., £4.3 billion).

In terms of the time spent, it was estimated that in 2013, a total of 1,340,000,000 hours were spent caring for people with dementia; this is equivalent to more than 150,000 years. It is also important to note that in addition to this, about 43% of carers did not receive adequate support for their role (Alzheimer's Society Dementia 2014 info graphic). Research evidence suggests that the informal caregiver time adds to the majority of the total cost of dementia care (Ernst & Hay, 1997). Langa et al. (2001) in a US study found a noteworthy association of severity of cognitive impairment to weekly hours of informal care giver time. They also found that the burden associated with caring on family members increased significantly with various stages in that those elderly with normal cognitive status received 4.6 hours compared to those with mild, moderate and severe dementia who received an additional 8.5, 17.4 and 41.5 hours, respectively.

The impact of dementia on patients' own perception of the disease has been a neglected topic in dementia research. Cotrell and Schulz (1993) noted that although vast numbers of patients with Alzheimer's disease are studied in the US, the views of the affected individuals that are vital to understand the impact and the course of the disease have not been given much attention. They attributed this to a possible unreliable nature of data that can be obtained from patients, due to their cognitive deficits. George (1989) also discussed the unreliability of data obtained from the individuals with the disease and suggested that the patients may not be competent enough to fully participate in a conventional interview when gathering information. In contrast, Cohen and Eisdorfer (1986) reported that individuals in the early stages of the disease were able to discuss their current and past experiences in interviews with researchers. They also observed that even in later stages of the disease, these individuals were still capable to provide some information about their current experience of the disease.

Furthermore, another possible barrier to find out the extent of impact of dementia on affected individuals is that some are in denial of their diagnosis and experiences. However, studies have shown that the majority of the patients who are in the early stages of dementia were happy to discuss their experience of the disease, needs and concerns (Aalten et al., 2005b; Cotrell & Schulz, 1993). Most people with dementia describe its impacts on them as a series of losses and the process of adjusting to these changes as challenging. The researchers have also emphasised the value of conducting the interviews competently in a caring manner for a successful data collection. Boer et al. (2007), in their review of the literature on this topic, found that patients generally tended to use certain strategies to overcome the challenges rather than wait passively and the experiences of living through the disease was not as bad as the assumptions that the general public had on the disease.

The people who develop dementia, realize gradually that they have difficulties with memory, and this memory loss constitutes the main concern for them initially (Aggarwal et al., 2003; Clare et al., 2005; Cotrell & Hooker, 2005). However, some dementia patients do not think the memory loss is a major problem and believe ageing is slowing them down mentally and physically. As dementia progresses, patients start to develop communication/word finding difficulties or verbalization problems (Aggarwal et al., 2003). Communicating their needs, wishes and feelings is vital to maintain their quality of life and to preserve their sense of identity. Difficulties with communication can be upsetting and frustrating for the person with dementia and for those around them.

People with dementia often become angry and agitated when they experience loss of control over day-to-day activities, especially when restrictions are imposed on certain activities like driving and when family members take over responsibilities, resulting in low self-esteem and confidence (Clare 2003). Harman and Clare (2006) discuss the impact of loss of self, self-esteem and personality in people with dementia. They also become agitated when they are subjected to increased supervision by those around them. Along with these losses when they experience loss of sense of respect and dignity, the people with dementia may feel depressed and have negative feelings. Some people experience distress and annoyance due to their ongoing disabilities and even feel embarrassed and humiliated (Clare, 2003). These people are also aware of their gradual loss of abilities and skills. In dementia, the most apparent manifestation of disease is the progressive inability to function in day-to-day activities and as the disease progresses they gradually lose their independence and identity. They also fear becoming a nuisance or a burden and become miserable as they are aware that their problems can create stresses and difficulties for their families. Harman and Clare (2006) reported that for many people with dementia, the attitude of others is of great importance, resulting in a situation where some dementia patients are concerned about people finding out about their diagnosis and, as a result, worried that they will not be listened to. This is a risk during the assessment of dementia patients, where information may be gathered from carers without also hearing from dementia patients, who may be capable to express their concerns and worries themselves.

Despite their cognitive deficits, dementia patients are able to function well in terms of maintaining their friendships and attachments, which are important aspects of good quality of life (Cahill et al., 2004 and Droes et al., 2006). Cahill et al. (2004) found that out of 88 people with mild to moderate dementia, the majority (67%) claimed that they enjoyed a “good” or “very good” quality of life.

Social services help people with dementia and provide care packages to them, mainly to individuals still living at home. In addition, they also fund and arrange care such as respite care services and care home provisions. Other services include personal care and day-to-day activities such as providing home care assistants to help with washing and dressing, laundry services, meals on wheels, aids and adaptations, and with legal and financial advice. Providing support and care for people with dementia forms a significant portion of social services activities in care management in the UK and takes a substantial amount from their budget (Moriaty & Webb, 2000). Dementia UK (2007) reports that increased needs of people with dementia, due to worsening in their health, are being met by health care services and other social needs are met by the social services. However, as some needs and care overlap, it is hard to decide which services to turn to and this could potentially have an impact on access, level of care and for the balance of funding. Therefore, social services' exact contribution to dementia support is hard to estimate, however, Dementia UK (Alzheimer's Society 2007) estimate that 244,185 people (36.5%) with late onset of dementia live in care homes and each person takes up £31,296 annually from their budget.

Early diagnosis of dementia and related behavioural problems appear to have an impact on social services (Manthorpe & Iliffe, 2003). Manthorpe et al. (2003) identified two ways in which early diagnosis of dementia can impact on social services. Firstly, older people along with their carers turn to social services for advice, information and services. Secondly, these services may receive increasing referrals from other agencies, predominantly from primary care providers. In contrast, some have reported that individuals with dementia and their carers usually seek support too late such as when in crisis (Levin et al., 1989; Marshall, 1988). Manthorpe and Iliffe (2003) have suggested that early diagnosis of dementia may help reduce the possibility of such problems.

2.2. Types of dementia and diagnostic scales

Dementia is classified in the 10th Revision of the International Classification of Disease (ICD 10) in the section on organic and symptomatic mental disorders (coded F00-F09) under the following domains (World Health Organisation 1992):

F00 Dementia in Alzheimer's disease

F01 Vascular dementia

F02 Dementia in other diseases classified elsewhere

F03 Unspecified dementia

F04 Organic amnesic syndrome, not induced by alcohol and other psychoactive Drugs

F05 Delirium, not induced by alcohol and other psychoactive substances

F06 other mental disorders due to brain damage and dysfunction and to physical Disease.

F07 Personality and behavioural disorders due to brain disease, damage and dysfunction

F09 Unspecified organic or symptomatic mental disorder.

Alzheimer's disease is the most prevalent neurodegenerative disorder. The second most common is vascular dementia, which may be caused by various types of vascular changes in the brain. Other frequent causes of dementia include Frontotemporal lobe dementia, Lewy body and alcohol dementia. It is sometimes difficult to distinguish between subtypes of dementia as most clinicians tend to rely only on a clinical history and basic examinations. The cognitive, behavioural and psychological symptoms of Alzheimer's disease and other related dementias include progressive loss of memory, loss of communication skills, impaired judgment, disorientation to time and place, gait/balance problems, urinary and faecal incontinence along with inappropriate behaviour.

Various scales are being used to help diagnose and to assess the progression and severity of dementia in the clinical setting. Amongst the most commonly used rating scales is the Mini-Mental State Examination (MMSE), which is widely used in secondary care settings (Folstein et al., 1975). It is a valid and reliable 30-point questionnaire with scores of 19 - 24 rated as mild, 10 - 18 rated as moderate and below 10 rated as severe cognitive impairment. The MMSE is popular as it is easy to administer and evaluate the major cognitive domains affected in Alzheimer's disease such as orientation, registration, attention, recall, language, and constructional praxis. Addenbrooke's Cognitive Examination Revised (ACE-R) is another cognitive assessment tool commonly used in secondary care settings (Mioshi et al., 2006). It takes 15-20 minutes to administer and assesses six cognitive domains (orientation, attention, memory, verbal fluency, language and visuospatial ability). The Clinical Dementia Rating Scale (CDRS) is another tool that is completed by secondary care clinicians and covers six domains consisting of memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care (Hughes et al., 1982; Morris, 1993).

However, the above mentioned cognitive assessment tools may not be practical to use in primary care settings, as it can take up to 20 minutes to complete during a clinical session. Hence, in general practice, general practitioners often prefer to assess cognition using either GP-COG (Brodaty et al., 2002), which usually takes less than 7 minutes to complete and contains both patient and carer questions, or the Mini-Cog assessment (Borson et al., 2000) with an estimated administration time of 2 minutes and also has an advantage of being used in people with low education level and those who do not speak English. The 6-item Cognitive Impairment Test (6CIT) is also being widely used in general practice, as it is easier and quicker to use than the MMSE (Brook & Bullock, 1999).

2.3. Issues with diagnosis: Timely diagnosis and disclosing the diagnosis

According to the Dementia UK (2014) report, early diagnosis and intervention for people with dementia and their carers has been the key focus of the National Dementia Strategy for England, which subsequently led to the formation of a nationwide network of memory clinics. Early diagnosis of dementia and its associated problems is of paramount importance to improve the physical, emotional and financial impacts of the disease. Unfortunately, most primary care providers do not routinely assess the cognitive health of their patients, leading to delayed dementia diagnosis and post diagnostic monitoring and care.

Early diagnosis empowers the person with dementia and their family to receive appropriate help in understanding and coming to terms with the diagnosis and prognosis and to prepare for the future in a suitable way. This allows the individual to have an active role in decision making when it can still be understood by the patient and planning for their future. It also enables families to have dementia related education, caregiver counselling and also to learn effective ways of interacting and supporting the person with dementia. In the early stages of dementia, legal and financial arrangements can be agreed by patients and they, along with their families and friends, can find out about support services that will enhance their quality of life. Furthermore, certain medications like acetylcholinesterase inhibitors, have shown to be beneficial in maintaining cognitive function if they are commenced at an early stage of the disease. In addition, these patients will also be able to receive benefits from other therapies, such as psychosocial interventions that are known to enhance cognitive function, leading to improvement in quality of life of patients and their carers and potentially delay institutionalisation (Prince et al., 2011).

Despite the increased awareness of dementia, it sometimes remains under-detected and sub-optimally managed in both general practice and secondary care. Concerns over delays in the diagnosis of dementia in primary care have been raised and reported for several years. In a US study, Boustani et al. (2003) reported that 50% of primary care patients over 65 had not received a diagnosis by their primary care physicians. Some patients, families and primary care physicians are reluctant to diagnose dementia, despite knowing it carries a tremendous burden and impact to the individual with dementia, their carers and to the National Health Service if not being managed properly (Iliffe & Manthorpe, 2004). Primary care doctors also think it is pointless to make a diagnosis of dementia as it is impossible to treat, makes people feel hopeless and will leave people stigmatized with the condition (Downs & Bowers 2008).

Primary care physicians' attitudes, awareness and unfavourable opinion that nothing beneficial can be done, could have an impact of dementia diagnosis and management (Iliffe et al. 2006). In a survey involving of over one thousand general practitioners across eight English regions, it was found that older general practitioners, despite being more confident in diagnosis of dementia, did not feel that early diagnosis would be beneficial and felt that these people could be a drain on resources without much positive effect. In contrast, younger general practitioners were more positive about an early diagnosis and believed that a lot could be done to enhance the quality of lives of people with dementia (Ahmad et al., 2010). Community nurses, social workers and nursing home staff can also play a vital role in identifying symptoms of dementia and reporting to relevant teams or agencies. However, Manthorpe et al. (2003) reported that other professionals in primary care fail to recognise symptoms of dementia and contribute to the delays in early diagnosis of dementia.

Moise et al. (2004), in a comparative analysis study, argued for the importance of improving the accuracy of diagnosis of dementia as there are many undiagnosed cases found in spite of the number of benefits of having an early recognition and diagnosis of dementia. In the early stage, the diagnosis of dementia is often difficult. If general practitioners suspect possible dementia, they may refer to a memory clinic or to a dementia care specialist. Assessments include obtaining narrative accounts of problems from the persons being suspected of having dementia with their carers and carrying out memory tests and/or brain scans.

The views of carers and individuals with dementia on information given by health care professionals are sparse (Pinner, 2000). Attitudes towards disclosing the diagnosis amongst psychiatrists and primary care physicians varies. However, increasing public awareness of dementia and the availability of drug therapies and other non-pharmacological interventions means that families are often informed of the diagnosis (Prince et al., 2011). Conversely, it is unclear how much the dementia sufferers themselves are informed about their diagnosis. It is the individual’s right to know the diagnosis, especially in the early stages of the disease, while they still have the capacity to make choices regarding their future care. It is also argued whether there is any point of informing the diagnosis to people who are in the late stage as knowing the diagnosis will neither benefit nor harm them as they might not have competency to understand any information given to them (Pinner, 2000). It is reasonable to ask the person with dementia routinely during assessments if they wish to know the diagnosis and to whom the information should be informed (Pinner & Bouman, 2003).

Some researchers have reported that disclosure can lead to more harm than good on patients and their carers (Husband, 2000; Young, 2002; Pratt & Wilkinson, 2003). Early diagnosis and disclosure of dementia can be anxiety provoking for people with dementia and for their loved ones. They may experience fear of their future, shame, stigma and isolation. Some studies have reported experience of disbelief, distress, detachment, anger and fear (Young, 2002; Pratt & Wilkinson, 2003). Others have noted negative impacts on self-esteem and personhood, becoming hyper-vigilant about further cognitive failure, and restriction of social activities (Bamford et al., 2004, Pratt & Wilkinson, 2003).

Milne and Wilkinson (2002) reported that the early recognition of dementia is essentially a beneficial and rational approach, in contrast to the beliefs that it might not be advantageous.

Iliffe and Manthorpe (2004) argue that the risks of early diagnosis can be described in three dimensions:

1. Risks to the individual who receives the diagnosis earlier than would have happened in the past.
2. Risks of earlier diagnosis to the family and friends of the person with dementia
3. Risks to services pursuing earlier diagnosis of dementia, as a policy objective.

The risk to the individual may be in terms of negative reactions such as increased psychiatry morbidity like developing depression and/or anxiety, which may similarly occur in close family and friends, as a consequence of their involvement in caring. In terms of services, pursuing early diagnosis policies, may lead to diversion of resources from those who may be needier in the latter stages of dementia.

Furthermore, Iliffe and Manthorpe (2004) have argued that acknowledging that these risks persist is not the same as arguing that a diagnosis should be withheld or investigations delayed. There is the opportunity for learning from other areas of illness and disability, as well as taking into account the multiple perspectives involved. The pursuit of early diagnosis and disclosure may dissipate energy needed to develop more effective support and provision of care.

2.4. Behavioural and Psychological Symptoms in Dementia

In addition to cognitive problems, people with dementia experience a variety of behavioural and psychological symptoms such as disturbed perception, thought content, and changes in mood and behaviour (Finkel & Burns, 1996; Kozman et al., 2006). They are also known as Neuro-psychiatric symptoms which include delusions, hallucinations, agitation/aggression, depression, anxiety, elation, apathy, disinhibition, irritability, aberrant motor behaviour, difficulty sleeping and change in appetite. Behavioural and psychological symptoms may be caused or precipitated by general physical health problems such as pain, discomfort, and drug induced delirium or by infections. The research evidence suggest the frequency of these symptoms may vary according to the living environment, social interactions and support as well as the quality of care the persons with dementia receive and the knowledge and the understanding of the disease by their loved ones.

Even though behavioural and psychological symptoms in dementia have not been classified or included under dementia in the current classification systems, research shows that approximately 50% of dementia patients suffer from at least four behavioural and psychological symptoms at some time during the course of their disease (Frisoni et al., (1999). Devanand et al. (1997) also found that these symptoms fluctuated in nature (except psychomotor agitation, which remained persistent) in contrast to cognitive symptoms and functional abilities, which progressively worsened over time. Almost half of dementia patients are agitated at some point during disease progression and one third exhibit aggressive behaviours which include irritability and hostility (Tariot et al., 1999).

Behavioural and psychological symptoms can be very distressing to the person with dementia, to their families and to both the informal and professional care givers (Ballard et al., 2000; Ryu et al, 2011). For example, Wood et al. (1999) found that professional caregivers reported apathy and agitation as the most distressing psychiatric symptoms in patients with Alzheimer’s dementia. On the other hand, carers find it very difficult to cope with such challenging behaviours as aggression and violence (Miyamoto et al., 2010; Huang et al., 2011). Similarly, several other studies have found that psychotic symptoms such as hallucinations and delusions along with disorderly behaviours (e.g., aggression, screaming and shouting) were the ones that carers found most troublesome or difficult to cope with (Huang et al., 2011; Miyamoto et al., 2010; Rocca et al., 2010).

Research also suggests that these behavioural and psychological problems can lead to poor quality of life and rapid cognitive decline, while psychotic symptoms such as hallucinations and delusions may be even associated with increased mortality in this population (Emanuel et al., 2011; Russ et al., 2011). Overall, these symptoms invariably result in care givers burden, early institutionalisation and increased utilization of health care resources. Other additional risk factors for institutionalisation include quality of the relationship, adverse life events, overload and gender of the carer (Campbell et al., 2008).

Nursing home placements associated with behavioural and psychological symptoms in dementia add significantly to the direct costs of care for the national health services. In a US study, Berri et al (2002) found that approximately 30% of the annual cost of Alzheimer's disease is invested in the direct management of behavioural and psychological symptoms of dementia. In England, dementia patients with severe behavioural and psychological symptoms usually end up in National Health Service funded care settings as they pose with symptoms too challenging to manage in social services funded residential or nursing home placements.

Katona et al. (2007) argued that behavioural and psychological symptoms in dementia are an important objective for intervention in addition to cognitive deterioration. Management of patients with behaviour and psychological symptoms in dementia may involve psychosocial interventions with patients as well as family members and other carers. Those patients with mild symptoms may respond only to environment and psychosocial interventions. In more severe symptoms, a combination of non-pharmacological and pharmacological strategies can be used. However, there are no well-established treatment models, as it is very difficult to understand the underlying etiological mechanisms of numerous neuropsychiatric symptoms. It is challenging to treat patients with severe symptoms even in a highly specialised unit due to absence of clear evidence of benefits of pharmacological as well as non-pharmacological options. As a result of this lack of effective treatment, as well as the increased concerns over the safety of some pharmacological interventions, it has become more challenging for health professionals to care for and treat patients with dementia.

The management and treatment of behavioural and psychological problems is also complicated because they cannot be easily diagnosed given the variety of symptoms. However, early identification of these problems is important because this allows those with dementia and their families to engage in supporting and planning ahead. Diagnosis of these symptoms includes a thorough assessment, using various rating scales and the exclusion of other causes, such as drug-induced delirium, physical illnesses, pain, dehydration, sleep difficulties, anxiety or infection, all of which can lead to confusion, agitation and aggression.

Different instruments (rating scales) are available in clinical settings to assess the wide range of neuropsychiatric symptoms in patients with dementia. Weiner et al. (1996) reported that there are more than 30 scales available to measure behavioural symptoms of dementia and out of these, the most useful ones are the Cohen-Mansfield Agitation Inventory (CMAI), Neuropsychiatric Inventory (NPI) and Behavioural Pathology in AD (BEHAVE-AD) scales.

Cerejeira at el. (2012) emphasised the importance of an individual interview with patients despite them having difficulties with social and communication skills as this could provide pivotal information about their underlying behaviours. The authors also discussed the significance of interviewing the caregivers to find out which behavioural and psychological symptoms were of greatest concern to them as these may be different to the individual patients' complaints or to the clinicians' priorities. However, it should be pointed out that although interviews may provide more qualitative and detailed information than rating scales, they too rely on caregivers' retrospective recall about the nature and frequency of these problems which may result in incorrect and biased views of the problems (e.g., overestimation of frequency, underreporting, etc.). Therefore, like with memory related problems, behavioural and psychological problems of people with dementia could be assessed by having carers of patients to keep diaries of their problems in their day-to-day life which can potentially provide more detailed, comprehensive and accurate picture of a variety of problems experienced by dementia patients.

2.5. The diary method in dementia research

Diary methods involve intensive, repeated reports aimed at capturing events near the time. They rely on research participants to provide details of experiences or observations on a daily basis for a specified period of time. Diary studies have become refined over the past few decades with the availability of new technology to record events, going from the pen and paper coupled with a device checking compliance (Maisal & Gable 2009), telephone interviews (Almeida 2005; Walding & Schulz 2010) to electronic response formats (Stone et al 1998). In all forms of diary, a level of capability to use a particular diary format is required, such as literacy level to write in a paper diary or having basic information technology skills in more advanced or complicated electronic diary formats.

There are several different types of diary designs. The traditional designs can be categorised into time-based and event-based protocols (Bolger, Davis & Rafaeli, 2003). In a time-based design, data collection is scheduled according to set times while in the event-based design, diary recordings are made every time a particular event occurs. In studies involving persons with dementia, a time-based design may not always be suitable as the frequency of problems and difficulties can be quite variable with some persons with dementia having several different problems over a short period of time and others going for days without any problems. This will make it difficult to record all events. The event-based design is probably better suited for recording events around persons with dementia as diary entries are made close to the time of occurrence whatever the frequency of problems or difficulties.

With the advent of more advanced information technology, the traditional diary entries involving participants stopping to report or record events may be bypassed using Device – Contingent Design diary methods (Iida et al., 2012). Examples include the use of ubiquitous cell phones or other electronic devices using cameras, Bluetooth and global positioning system (GPS). However, these may prove challenging to use in older people, especially those with dementia or caring for a person with dementia, who may find modern day technology like computers, mobile phones and global positioning system uncomfortable to use due to lack of familiarity.

At the onset of presentation to dementia care services, initial assessments often involve taking a history from both persons with dementia and their carers who are often family members. It is not uncommon that the reason for presentation is based on observations of memory loss by family carers or carer distress or breakdown. What carers recollect at an initial assessment may be quite variable and they, along with their loved ones, may find it difficult to retain and recall all the problems in the initial assessments or follow-up appointments. Some carers attend clinic with written unstructured account of problems they face in caring to help provide information at the initial assessment. From the literature that was reviewed for the thesis, only a handful of studies were found on the use of carers' diaries in the assessment and management of dementia. In addition, none of these studies involved a structured diary method where carers recorded cognitive, behavioural and psychological problems of dementia patients using an event-based diary design.

There is a precedence of carers keeping unstructured diaries in a study by Valimaki et al. (2007). This study was conducted to find out about the data produced by family caregivers of dementia patients who kept unstructured diaries and any potential benefits or limitations of doing so. The study found that diaries can potentially be used as a primary method of data collection with family caregivers. Many of the carers found completing a diary both therapeutic and pleasurable. Valimaki et al. (2007) described four types of unstructured diaries used by their participants. These were:

1. Meagre diaries - brief with only few lines recorded.
2. Reporting diaries - written like reports of daily timetables
3. Descriptive diaries - the type where family caregivers describe their daily tasks.
4. Reflective diaries - contained information about family caregivers' daily lives and emotions.

In a follow up study, Valimaki et al. (2012) examined the unstructured diaries of carers over the first six months following diagnosis of dementia. The two core themes that they found in the diaries concerned the meaning that the onset of Alzheimer's disease had on the lives of carers and the restructuring of their life. On the other hand, Mausbach et al. (2011) used a diary method to examine relationship between caregiver burdens, leisure satisfaction and affect in dementia caregivers. It involved a daily diary approach to examine the effect of stress on the relationship between leisure satisfaction and both positive and negative affect. Twenty-five dementia caregivers completed activity and affect measures four times daily for 14 days. They found that caregivers with higher burden had a stronger positive relationship between leisure satisfaction and positive affect and a stronger negative relationship between leisure satisfaction and negative affect. Mausbach et al. (2011) concluded that screening caregivers for level of burden may help identify those most likely to benefit from behavioral interventions.

The relationship between mood and daily events in a caregiving context was also explored by Malonbebeach et al. (1995). In their study, 43 family caregivers of dementia patients kept 14-day diaries recording daily events, interactions and mood. They found that some caregivers were highly distressed, others were moderately distressed and some showed no relationship between caregivers' mood and daily events in caring.

Clarke (1999) used a diary method in conjunction with an interview to collect data from 14 family carers. In addition, data was collected from professional carers by both questionnaire and interview methods and she also used nine case studies. In her paper, Clark (1999) discussed the process of achieving 'normalization' in which the family carer continuously defines and redefines their relationship with the person with dementia as if it was normal for them. She also discussed how strategies taken up by family carers with the support of professional carers could facilitate this process of normalization. The research also showed the diary method to be valuable as it provided a detailed account of factual, emotive, personal and sensitive events and emphasised the importance of it, when used in conjunction with interview data.

Only one study so far has used a diary method with people with dementia themselves (Bartlett, 2012). However, there are limitations and even drawbacks when people with dementia record their thoughts in written diaries. Bartlett (2012), for example, found that some people with dementia became aware of their diminishing skills, became frustrated and were not sure what to record in their diaries. Another limitation of this method was that it relied on participants' self-motivation and meta-awareness to notice and record their thoughts. Therefore, Bartlett (2012) suggested that this method should be used in conjunction with other methods like interviews and also to include photo and audio diaries to help the researcher to understand the many facets of a person's life (Dewing, 2007).

Although diary records capture rich source of data, Jacelon and Imperio (2005) suggested that in older adults, solicited diary recording should be limited to one to two weeks. If a diary was kept for less than a week, this could result in insufficient data. In contrast, for a period of over two weeks, the participants would get bored or tired of making entries, which could make the data inadequate or unreliable. This is of particular relevance for dementia family caregivers who may be overburdened in their roles of caring, to make the extra task of diary writing feel too burdensome, if it was covering too long a period.

In summary, the review of literature found that there are very few studies that used carers' diaries in the context of dementia care and its effects on carers and patients, and no previous study that has used carer diaries in the assessment of dementia patients' problems in everyday life. The present study proposes to compare identification of problems through carers' diaries with retrospective interviews of carers. This is of relevance, in that in the initial assessments of dementia patients, it is family caregivers who tend to provide most of the information in clinical settings. No previous study, however, has assessed the validity of these retrospective self-reports. If these self-reports are indeed unreliable and provide averaged impressions rather than actual fluctuations of frequency and magnitude of symptoms (Ben-Zeev et al., 2012), then caregivers' diaries of these symptoms/problems can provide important and valuable additional information to clinicians.

2.6. Alzheimer’s disease as a challenge for caregivers

The present study also wants to examine a novel hypothesis that asking carers to record dementia patients’ problems and symptoms as they occur in everyday life may have therapeutic effects on caregivers’ mood and well-being by giving them better insight into the problems and how to cope or prevent them. In this and subsequent sections, I will briefly review the challenges faced by dementia carers, existing approaches and interventions for improving their health and well-being, and a brief review of research on therapeutic benefits of expressive writing, before summarising the main aims and hypothesis of the present investigation.

The abilities of people with Alzheimer’s disease can fluctuate from day-to-day and they will require more help and support as the disease progresses. They frequently need assistance with daily routines like toileting, bathing, dental care, dressing and grooming. However, people with dementia may sometimes be able to perform certain complex tasks better than simple ones. As a result, the family members may attribute this to ‘not trying hard enough’ or being purposely uncooperative. Therefore, caring for these people can be a daunting task and often adapting to the carer role can be challenging. Both psychological and physical strength are required and deciding to care for the person with Alzheimer’s disease could be one of the greatest sacrifices made by caregivers.

Family carers are providing a major proportion of the help older people need and perform an important role to the health care system and their loved ones. Research suggests that the largest proportions of the caregivers are either the spouses with long history of marital relationships, often having lived with the same partner for most of their lives, children or children in-law. In the UK, it is estimated that there are more than 670,000 unpaid carers for people with dementia and they save the National Health Service approximately £11 billion annually (Alzheimer's Society, 2014).

In the United States, it is estimated that there are 5.3 million Americans with Alzheimer's disease and related dementias, and over 80% of these individuals are being cared for by their family members (Alzheimer's study group 2009; Zhu et al. 2006). Furthermore, Alzheimer's association (2008) reported that 40% of American men represented as the family caregiver, which was an increase of 21% from 1996.

Family care giving of older persons with dementia has become more common as a result of the increased prevalence of Alzheimer's disease and associated disabilities. Knapp et al. (2007) have estimated that two-thirds of people with dementia live at home with most care provided by their family. In most cases, this care will be provided by an elderly spouse who probably has health problems of their own. Family carers are also known as informal or unpaid carers and are often placed in a situation of escalating personal demands. These carers are increasingly being asked to perform complex tasks similar to those carried out by paid health workers often at great cost to their own mental and physical well-being and great benefit to their relatives and the National Health Services as a whole. Hence, it is of paramount importance to focus on family carers due to the extreme challenges associated with caring for someone with cognitive impairment due to the progressive nature of the illness. Understanding how to estimate the impact on carers is challenging and complex but providing care for people with dementia has been described as a stressful experience that may erode the psychological and physical health of caregivers. It can bring about irreversible changes to lives and relationships. Therefore, the vulnerable family caregivers should be identified early and appropriate measures, like psychosocial interventions and planned access to respite, should be provided in order to ease the burden of caring and delay nursing home admissions. Caring for a person with dementia poses many challenges and it entails emotional and physical strain as well as financial hardships. Family care givers who provide direct care to the person with the disease sometimes can be taken as hidden sufferers or victims of Alzheimer’s disease. It has been reported that caregivers' quality of life is associated with the quality of life of the dementia patients they care for (Thomas et al., 2006).

Health related quality of life is greatly affected in caregivers of people with Alzheimer’s disease who have been demented for shorter duration and it is suggested that the care givers adapt overtime, as caregivers of patients with longer duration had better quality of life (Markowitz et al., 2003; Argimon et al., 2005; Riedijk et al., 2006). Certain characteristics of the carers such as age, gender and the education level may also influence the care giving role and ability to deal with stressful situations. Schulz et al. (1995) discussed how caring for an elderly loved one with a disability could lead to stress for many family carers and how it may contribute to their psychiatric morbidity in the form of higher prevalence and incidence of depressive and anxiety disorders. This has been mostly common amongst female caregivers with lower levels of life satisfaction than the male caregivers (Yee et al., 2000). Female caregivers also reported to suffer from more physical health problems and symptoms associated with depression (Mahoney et al., 2005; Sorensen et al., 2006). In general, women in certain cultures are more likely to be engaged or actively participating in the caregiving role than men and tend to do most things themselves. In contrast, male carers tend to have more of a passive role and get themselves distant from the certain stressful situation by assigning the responsibility to another person (Draper, 2004). In a cross-European study on spouse care givers, Schneider et al. (1999) found younger caregivers to suffer from carers' burden to a greater degree.

Research evidence shows that the combination of several factors, including prolonged stress and physical demands of caring, can compromise older caregivers' physiological functioning, result in negative outcomes and increase their risk for physical health problems and mortality. Family caregivers who are overly stressed with significant depressed mood may not be able to cope with the physical demands of caring (Lu & Austrom , 2005) and this can be directly associated with certain behavioural disturbances that experienced by their loved ones. Pinquart and Sorensen (2003) reported in a meta-analysis, that caregivers of people with dementia reported significantly higher level of stress, depression and physical health problems compared to non-caregivers. Furthermore, researchers have examined the quality of life of the carers in relation to their level of knowledge and understanding. Graham et al. (1997) found that the more knowledgeable carers had lower expectations of their loved ones abilities and felt more confident and competent as the caregiver. However, some studies showed the positive effects of being a family carer. Sanders (2005) reported that as many as 72.5% of caregivers reported positive experiences such as spiritual and personal growth, as well as feelings of mastery.

In their meta-analysis, Pinquart and Sorensen (2003) also discussed positive associations for caregivers. They found that feeling useful in fulfilling responsibilities and being close to the care recipient were related to less burden and depression among the caregivers. In a cross-European study on spouse caregivers, Murray et al. (1999) reported that continued reciprocal affection, companionship and sense of job satisfaction could lead to profound satisfaction to the care givers. Spouse caregivers with greater marital cohesion and satisfaction may feel that the general atmosphere in their marriage remains good. As a result, they may regard caregiving as part of their marital duties and feel less burden compared to adult-child caregivers. Adult-child caregivers who live with a parent with dementia have greater burden as such tasks entail a significant change in their lifestyle (Conde-Sala et al., 2010).

2.7. Are carers being helped by current practices and interventions?

Alleviation of suffering and supporting caregivers with their unpaid ‘’full time job’’ may have important financial, social and humanitarian implications. Family carers need great deal of reassurance and psychological support as many people have taken on the role of a 'carer' without making any prior decision to do so. Many carers tend to ignore their own health and wellbeing as they put their loved ones’ needs first even though it is vital to look after their own needs in order to provide the best care for the person with dementia.

The demands of caring lead to almost 40% of carers of people with dementia having psychological symptoms such as anxiety and depression (Cooper et al., 2007; Mahoney et al., 2005). The Dementia UK report (2007) recommended providing an improved package of care and support. This should put emphasis on psychological therapies and training for carers, as well as, support groups. Historically, there have been various interventions implemented which aim to offer support for caregivers. These include provision of information, education and training, as well as psychological and practical support. To date, the evidence of effectiveness or benefits has been limited. Caring is a controversial subject and help that is provided to carers to improve their health and well-being by health services may not always be beneficial.

Thompson et al. (2007), in their systematic review of support interventions for caregivers of dementia patients, found only modest evidence in support of the effectiveness of group psychoeducational approaches in alleviating depression levels in carers. Cooke et al. (2001) and Ulstein et al. (2007) who evaluated the success of the different components or the combinations of psychosocial/psychoeducational interventions to support caregivers also did not find sufficient benefits. In contrast, Pinquart and Sorensen (2006), in their meta-analysis, found that psychoeducation and respite care had small but significant effect on most outcomes assessed in terms of burden, depression and subjective well-being.

In Alzheimer’s disease, the focus on any intervention is reduction in carer stress/distress as unlike in other mental health disorders, there is no relapse or amelioration of the disorder. If the carer is stressed and not in control, then there is high chance that they will act in a manner which is inconsistent and respond to their own emotional states rather than to the demands of the situation. When carers cope better with their own emotional states and have a clear potential on how best to deal with demanding and challenging situations, a reduction of carer burden can be expected and in essence, this would bring about positive impact on patient behaviour (Marriott et al., 2000).

In a recent study, Livingston et al. (2014) assessed the long-term clinical and cost effectiveness of psychological intervention in family carers. They found that STrAtegies for RelaTives (START) improved carer mood and anxiety levels over two years. It involved eight sessions with therapists working on a 1:1 basis with carers to identify individual difficulties and implement strategies. The eight sessions covered the following areas: stress and wellbeing; reasons for behaviour; making a behaviour plan; behaviour strategies and unhelpful thoughts; communication styles; planning for the future; introduction to pleasant events and your mood; and using your skills in the future.

In conclusion, carers experience significant levels of anxiety and depression and research needs to be conducted to test out simple and effective methods of therapy targeting this vulnerable (and predominantly elderly) population. There is increasing evidence on both general population and clinical samples that writing about emotional problems of keeping a diary has beneficial effects on people’s health and well-being (see below). Therefore, it is necessary to find out if having carers keep a structured diary of problems experienced by the people with dementia improves their own well-being and understanding of loved ones they are caring for.

2.8. Therapeutic effects of expressive writing and diary keeping

Research on expressive writing shows that writing about negative emotions or events can improve one’s health and well-being. There is empirical evidence showing that recording one’s problems and writing about one’s emotional experiences has beneficial effects on people’s health and well-being (Kvavilashvili & Brewin, 2013; Pennebaker, 1997). Frisina et al. (2004), in their meta-analysis of nine studies with clinical populations, found that this beneficial effect was more pronounced for physical health than psychological outcomes. Within these nine studies, there was at least one quantitative measure of health, assessing specific mental, physical, or health behaviours or general functioning. Baikie and Wilhelm (2005) in their search on studies examining expressive writing, also demonstrate some beneficial effects on physical and/or psychological health. They concluded that there is sufficient evidence for clinicians to begin applying expressive writing in therapeutic settings.

Pennebaker and Chung (2007) have found that there are substantial health improvements in people when they either talk or write about their personally unpleasant experiences. In their study, a significant number of participants reported writing experience was valuable and meaningful to them. Furthermore, they reported that writing also helped to take a step back and view their problems or themselves from different perspectives. Graybeal et al. (2002) found from research participants that writing “forced them to think about events differently and helped them to achieve a greater understanding of their problems.

In a meta-analysis of expressive writing, using healthy participants, Smyth (1998) found that the increase in the number of days over which the writing took place enhanced the positive impact on health outcomes. It was also noted that writing about emotional topics was associated with significant reductions in distress. Nicholls (2009) felt that the positive outcomes of writing may have been a result of individuals using writing as a tool to help them connect with how they feel rather than focusing on what they think about such an experience. It was also suggested that writing may be a way to break free from set views of self and open up alternative pathways to self-understanding. Other reasons for this positive outcome have also been looked at. Several studies have found that writing or talking about emotional topics, impact immune function in beneficial ways, including influencing *t*-helper cell growth (Pennebaker & Seagal, 1999), antibody response to the Epstein-Barr virus (Esterling et al., 1994), and antibody response to hepatitis B vaccinations (Petrie et al., 1995).

Pennebaker and Seagal (1999) discussed a few other possible explanations for the value and benefits of writing. They argued that writing allows individuals to express themselves and ventilate their feelings. Another broad explanation for the effects of writing is that the act of converting emotions and images into words changes the way the person organizes and thinks about the trauma or event. By putting together thoughts and feelings related to the experience the person can then build a more coherent narrative of events with regards to the experience. Having people keep a journal or a diary may help the process of creating this clearer narrative as well as aiding progress and support the changes of unhelpful behaviours.

The literature review above shows that diaries have been used in very few instances to assist with gathering information about persons with dementia in the community setting. No structured diary studies with carers were identified at the time of study that focussed on identifying and recording problems in dementia patients or used in assessment of dementia. Furthermore, the literature review suggested that there could be some therapeutic benefits for caregivers who keep diaries, which this present study may be able to confirm.

CHAPTER 3

METHOD

3.1. Study design

This was a randomised controlled feasibility study to examine whether the use of carers' diaries in dementia can improve the assessment process in the community. In the study, the experimental (diary group) and control participants completed various questionnaires assessing behaviour and psychological problems in people with dementia living with family carers, as well as the carers' health-related quality of life and mood. In addition, participants randomly allocated to the diary group were given a diary to record all problems displayed / experienced by the dementia patient for one week (between Day 1 and Day 8) and the control group were not asked to keep a diary. This group (diary, control) by time (Day 1, Day 8, Day 28) mixed design with repeated measures on the last factor allows us to assess (1) whether carers recording patients' problems in a diary provides more detailed information than their retrospective accounts of these problems in a face to face clinic session, and (2) if keeping a diary has beneficial therapeutic effect on caregiver's mood and well-being.

3.2. Randomisation procedure

The carers were randomly allocated to two groups, control and diary groups, respectively. Folded pieces of paper with numbers from 0 – 100 were placed in a box. Each time a new participant was recruited, the team secretary was asked to pick a folded piece of paper from the box with a number written on it. No one knew what number was on any paper and participants were allocated to the diary group if an even number was picked and control if an odd number was picked. This was a simple randomisation method carried out for pragmatic reasons as participants were allocated as recruited.

3.3. Recruitment and inclusion / exclusion criteria

The study participants were recruited from the local memory clinic. It involved carers of patients newly diagnosed and follow-up patients with Alzheimer's dementia referred to the clinic. Both patients and carers were provided with information sheet (see Appendices 2 and 4) about the study and were invited to participate. Patients were informed that their medical records would be reviewed for information pertaining to the study, which would be kept anonymous, and that they would not be interviewed. If both patients and carers expressed an interest, follow-up visits at home were arranged for Day 1, Day 8 and Day 28. Informed consent was obtained on Day 1 with both patients and carers being reminded they could opt to withdraw from the study at any time and that would not impact on their treatment in the memory clinic.

Inclusion Criteria:

1. Carers over the age of 20 years who cared for a person diagnosed with Alzheimer's dementia and resided with them at home.
2. Participation of only those persons where consent was obtained from both carer and the person with Alzheimer's dementia being cared for.

Exclusion Criteria:

1. Any carer who did not give an informed consent.
2. Any carer, who was unable to speak, read or write in English to fully participate in the study.

3.4. Study Participants

The study involved family carers of persons diagnosed with Alzheimer's dementia and were attending the North Hertfordshire and Stevenage memory clinic. According to a report by Carers in Hertfordshire in 2014 to the Mental Health Strategic Commission Group in 2014, the population of persons over the age of 65 years living in Stevenage and North Hertfordshire was 33,483. Of this number, 1329 persons were recorded on the General Practitioners Dementia register. It was estimated that there would be about 2417 persons with dementia overall.

At the time of study, there were 436 persons with dementia on the register of the Early Memory Diagnostic and Assessment Service. Of these persons, 162 (37.16%) were married, 167 (38.3%) were widowed and the rest were single, separated or divorced. 242 (55.5%) of the persons with dementia on the register were females and 194 (45.5%) were males. Over the 1 year period of recruitment from 1 May 2014 to 30 April 2015, 97 couples were identified and approached to take part in the study following which 84 couples agreed and gave written informed consent to take part and were subsequently recruited (Fig. 2). Out of these, 78 couples went on to complete the study, consisting of 39 participants in each group.

The participants on recruitment were randomly allocated into the diary and control groups. 41 participants in the control group and 39 participants in the diary group completed the 8th day assessments and / or diaries. The background variables of patients in the diary and control groups, in terms of age, gender, severity, and duration were not significantly different at Day 1 (Table 1). Likewise, amongst the carers, there were also no significant differences in the background variables (Table 2). The baseline scores for the secondary outcome measures, which included total Neuro Psychiatry Inventory (NPI), EuroQol and Hospital Anxiety and Depression Scale scores were not significantly different between the diary and control groups

(Table 3). The distribution of carers' ratings of the 5 different items on the EuroQoL at Day 1 was not significantly different between the groups (Table 4).

Fig. 2: Number of potential participants identified, recruited and withdrawals

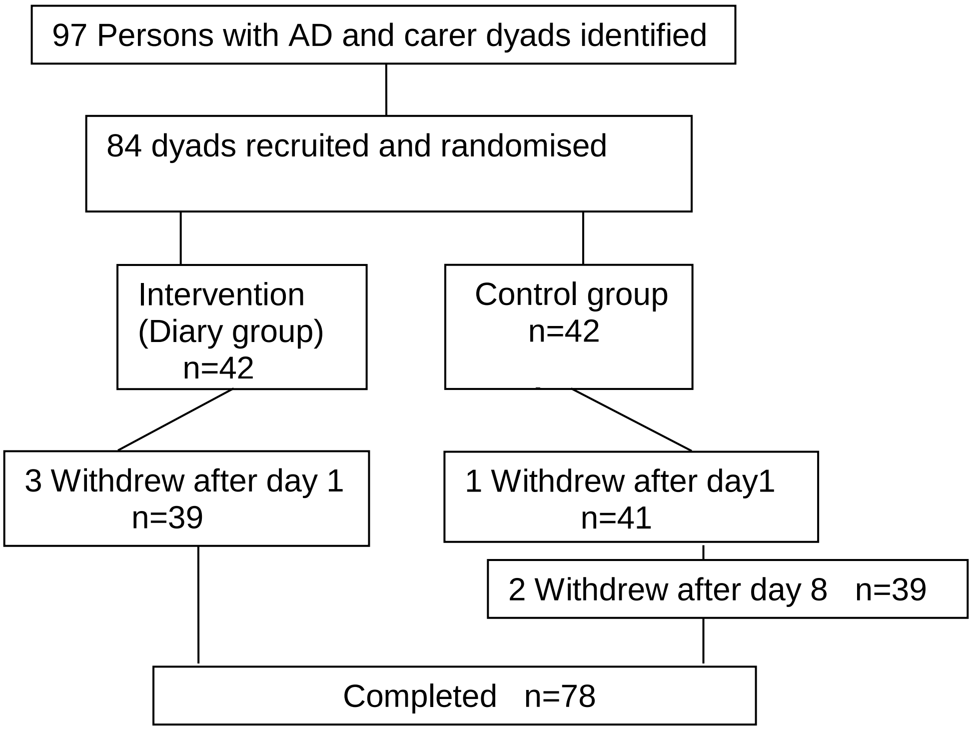


Table 1: Background variables for patients in the control and diary groups

	Control (n= 41)	**Diary (n = 39)**	**Statistical Test**	**P – value**
Mean Age in years	78.02 (5.24)	79.64 (6.09)	F = 1.78	0.206
Gender	M = 23 (56.1%) F = 18 (43.9%)	M = 25 (64.1%) F = 14 (35.9%)	χ 2 = 0.53 (1,N=80)	0.47
Severity	Mild = 21 (51.2%) Moderate = 18 (43.9%) Severe = 2 (4.9%)	Mild = 15 (38.5%) Moderate = 24 (61.5%) Severe = 0	χ 2=3.81 (2,N=80)	0.16
Duration of symptoms in years	3.33 (2.71)	3.38 (2.53)	F = 0.008	0.93
Duration of treatment in years	1.43 (1.95)	1.7 (1.87)	F = 0.396	0.531
Dementia medication use	None = 3 (7.3%) Donepezil = 28 (68.3%) Rivastigmine = 7 (17.1%) Memantine = 2 (4.9%) Galantamine = 1 (2.4%) Donepezil & Memantine = 0	None = 2 (5.1%) Donepezil = 22 (56.4%) Rivastigmine = 7 (17.9%) Memantine = 5 (12.8%) Galantamine = 1 (2.6%) Donepezil & Memantine = 2 (5.1%)	χ 2 = 4.16	0.53
MMSE	22.3 (5.47)	20.39 (5.81)	F = 2.226	0.140
Mean total initial NPI score	18.58 (16.55)	23.59 (19.64)	F = 1.524	0.221

Table 2: Background variables for carers in the control and diary groups

	Control N = 41	Diary N = 39	Statistical Test	P - value
Mean Age	75.87 (7.76)	75.08 (7.97)	F = 0.208	0.65
Gender	M = 15 (36.6%) F = 26 (63.4%)	M = 12 (30.8%) F = 27 (69.2%)	χ 2 = 0.30	0.58
Relation to patient	Spouse = 37 (90.2%) Child = 3 (7.3%) Carer = 1 (2.4%) Daughter in law = 0	Spouse = 36 (92.3%) Child = 2 (5.1%) Carer = 0 Daughter in law = 1 (2.6%)	χ 2 = 2.17	0.54
Employment Status	In employment = 1 (2.4%) Retired = 34 (82.9%) Housework = 6 (14.6%) Gave up work to care = 0	In employment = 5 (12.8%) Retired = 29 (74.4%) Housework = 4 (10.3%) Gave up work to care = 1 2.6%)	χ2 = 4.42	0.22
Six-CIT Score	1.83 (3.02)	2.2 (2.67)	F = 0.347	0.56

Table 3: Mean scores (standard deviations) on Neuropsychiatry Inventory (NPI), EuroQoL and Hospital Anxiety and Depression Scale (HADS) on Day 1 in diary and control groups and results of 1-way ANOVAs between these means

	Control N = 41	Diary N = 39	F(1,78)	P - value
Total NPI patient score	18.59 (16.55)	23.59 (19.64)	1.52	0.22
Total NPI Carer distress score	9.58 (8.66)	11.49 (10.12)	0.81	0.37
Total carer Euro-QoL score	7.10 (1.62)	6.67 (1.58)	1.45	0.23
Carer Euro-QoL (Health Rating)	71.19 (18.59)	72.72 (21.07)	0.12	0.73
HADS-Anxiety score	6.88 (3.8)	6.72 (4.1)	0.03	0.86
HADS-Depression score	4.37 (2.85)	4.74 (3.27)	0.30	0.58

Table 4: EuroQoL item ratings in carers between diary and control groups at baseline on Day 1

EuroQoL items	**Diary** **N = 42**	**Control** **N = 40**	**χ2**	**P - value**
Mobility	No problems = 22 (52.4%) Some problems = 20 (47.6%) Confined to bed = 0	No problems = 16 (40%) Some problems = 24 (60%) Confined to bed = 0	0.26	0.18
Self-Care	No problems = 40 (95.2%) Some problems = 2 (4.8%) Unable to wash or dress = 0	No problems = 39 (97.5%) Some problems = 1 (2.5%) Unable to wash or dress = 0	0.58	0.51
Usual Activities	No problems = 30 (71.4%) Some problems = 12 (28.6%) Unable to perform = 0	No problems = 32 (80%) Some problems = 8 (20%) Unable to perform = 0	0.37	0.26
Pain	No pain = 23 (54.8%) Moderate pain = 15 (35.7%) Extreme pain = 4 (9.5%)	No pain = 12 (30%) Moderate pain = 23 (57.5%) Extreme pain = 5 (12.5%)	5.21	0.074
Depression or Anxiety	None = 25 (59.5%) Moderate = 16 (38.1%) Extreme = 1 (2.4%)	None = 22 (55%) Moderate = 16 (40%) Extreme = 2 (5%)	0.48	0.79

The initial assessments comparing persons with mild and moderate dementia and their respective carers showed that the duration of diagnosis and treatment was longer in the moderate group and that carers rated neuropsychiatric problems and their distress significantly higher than the mild group (Table 5).

Table 5: Comparing initial assessments involving persons with mild and moderate dementia

	Mild **N = 36**	**Moderate** **N = 42**	**F - test**	**P - value**
Mini-mental state examination (MMSE)	23.68 (5.05)	19.65 (5.26)	12.06	0.001
Duration of symptoms in years	2.44 (1.83)	3.96 (2.95)	7.41	0.008
Duration of treatment in years	0.64 (0.85)	2.21 (2.29)	15.43	< 0.001
Mean total initial NPI score	14.16 (15.39)	27.62 (18.57)	12.41	0.001
Mean total initial NPI carer distress score	8.57 (8.85)	12.73 (9.43)	4.18	0.04
Initial EuroQol score (carers)	71.89 (19.35)	76.32 (17.3)	0.02	0.88
EuroQoL (total)	6.78 (1.71)	7.02 (1.54)	0.45	0.51
Initial HAD – anxiety score	6.11 (3.31)	7.49 (4.31)	0.55	0.11
Initial HAD – depression score	3.92 (2.61)	5.24 (3.35)	3.86	0.053

3.5. Materials

The following assessment tools used were:

1. The **Clinical Dementia Rating Scale** (Hughes et al. 1982; Morris 1993). This scale includes six domains consisting of memory, orientation, judgement and problem solving; community affairs; home and hobbies; and personal care (Appendix 8). Each domain is rated on a 5 point scale with the following scale points: 0 – healthy; 0.5 – questionable; 1 – mild; 2 – moderate and 3 – severe. Total scores give a global measure of dementia. It was used to evaluate the severity of dementia by carers in the person they cared for at the onset of study on Day 1.

2. The **Neuropsychiatry Inventory (NPI)** was developed for application to patients with Alzheimer's dementia and other dementias (Woods et al. 1999; Woods et al. 2000). It is a relatively brief interview with a carer, rating 12 behavioural areas in dementia (Appendix 10). The 12 areas are: Delusions; Hallucinations; Agitation/Aggression; Depression; Anxiety; Elation/Euphoria; Apathy/ Indifference; Disinhibition; Irritability; Aberrant motor behaviour; Sleep and night-time behaviour disorders; Appetite and eating disorders. Scores range from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed by a clinician, based on information provided by carers. Both the severity and frequency of each symptom are rated on a three (1 – 3) and four-point (1 – 4) Likert scales, respectively. The severity rating is 1=mild; 2=moderate and 3=severe. The frequency ratings are 1=occasionally, 2=often, 3=frequently and 4=very frequently. The Neuropsychiatry Inventory also assesses carer distress on each domain based on response to how emotionally distressing they found the behaviour, rating on a scale of 0 – 5 (0 = Not at all and 5 = Severe or extremely). In the present study, carers completed this questionnaire on Days 1, 8 and 28 to assess the severity of neuropsychiatric symptoms in the person with dementia they cared for.

3. The **EuroQol** (EuroQol Group, 1990) is a measure of health related quality of life and is designed for self-completion by respondents and is ideally suited for postal surveys, in clinics and face-to-face interviews. It consists of two sections (Appendix 11). In the first section, participants are asked to rate each of the following five areas: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. In the second section, participants are asked indicate the

health on a scale ranging from 0 (worse imaginable health) to 100 (best imaginable health). In this study, carers were asked to complete the EuroQoL on Days 1, 8 and 28.

4. The **Hospital Anxiety and Depression Scale (HAD)** is a 14-item scale that is self-administered and used to assess for possible anxiety or depressive symptoms (Zigmund & Snaith, 1983). There are 7 items each, for depression and anxiety, respectively (Appendix 9). Participants are asked to rate themselves in the past week to such statements rating depression, such as, '*Feel cheerful'*; '*Enjoy things that one used to enjoy*'; and '*Lost interest in appearance'*. The anxiety statements rated include '*feel tense and wound up'*; *worrying thoughts go through the mind'*; and '*Get sudden feelings of panic'*. The statement has a list of four responses, which are rated 0 (no problem) to 3 (the most severe response), making the maximum possible score for depression or anxiety 21. The carers in the study were asked to complete the HAD on Days 1, 8 and 28.

5. The **6-CIT Dementia Test** is a brief and simple test of cognition **(**Brooke & Bullock, 1999). Upadhyaya et al. (2010) reported that it correlates reasonably well with the Mini-Mental State Examination. It is reported to perform well as a screening instrument for dementia and is widely used in Primary Care and only takes approximately 2 minutes. It consists of six questions, with a total score of 28 (Appendix 7). These questions include asking for the year and month, as well as repeating a memory phrase and counting backwards from 20 to 1. Scores of 0 - 7 are considered normal and 8 or more as significant.

6. A **proforma** was also developed collecting sociodemographic details of patients and their carers which was completed on Day 1 obtaining information from carers and the patients' medical records (Appendix 6).

7. **The diary** questionnaire page was adapted for use in carers of patients with dementia from previous diary studies of involuntary autobiographical and intrusive memories (Kvavilashvili & Brewin, 2013; Schlagman & Kvavilashvili, 2008) as well as everyday memory failures in young and old participants (Kvavilashvili, Laughland & Niedzwienska, 2015). Each diary page consisted of a structured questionnaire with a mixture of closed and open-ended questions (Appendix 1). The diary was an A5 size booklet containing 7 questions per page, with participants in the diary group expected to record one problem or difficulty per page. A grid was provided on the first page of the diary for those problems/difficulties that participants were unable to record at the time the problem occurred. Participants were asked to indicate the time and date the problem/difficulty occurred and the time and the date the problem was recorded. The participants were then asked to describe the problem and the cause for it. They were also asked to rate the seriousness of the problem and how distressing it was for the participant (carer) on a scale of 0-5 (0=not at all, 5=very severe). Finally, they were asked to describe how they helped to resolve the problem or any difficulty at the time.

8. **Post Diary Debrief Questionnaire:** This questionnaire was administered in order to collect information about participants' subjective experience in keeping a diary (Appendix 12). The participants in the diary group were asked to complete a

questionnaire containing 6 questions. They were asked to write down number of days they did not keep the diaries with them; the reason for not keeping the diary with them; how they found keeping dairies with them at all times; how they found recording the problems using the diary rated on a 4-point scale (1 = very easy to 4 = very difficult); and to describe what they found difficult about recording problems. Another question assessed whether keeping a diary had any effect on their mood rated on 7 - point scale (1 = *made me feel a lot worse*, 4 = *no effect*, 7 = *made me feel a lot better*). Finally, participants were given the option to make any other comments on their experience of keeping a diary of problems.

3.6. Procedure

Participants were recruited for the study from the local memory clinic where both eligible patients and carers were provided with Information Sheets about the study and invited to participate. When both patients and carers expressed an interest, follow-up visits at home were arranged for Day 1 and Day 8. Demographic information regarding the carers and service users with dementia were recorded in a proforma (see Appendix 6).

The service users with dementia were not interviewed but their medical notes were accessed to obtain their socio-demographic details. A number of assessment tools listed below were completed by participants in both the diary and control groups (see Schedule of Assessments below). Participants in the diary group were provided with instructions on how to complete and maintain the diary for the next seven days (Appendix 1). Two follow-up sessions were arranged at the convenience of the participant; the first on Day 8, and the second on Day 28. There was some flexibility allowed in view of the busy lives of carers. The schedule of assessments is listed in Table 6.

Table 6: **Schedule of Assessments**

	Control Group	**Diary Group**
Day 1	Narrative account of problems in the preceding week Proforma CDR; EuroQol; HAD; Six item CIT, NPI	Narrative account of problems in the preceding week Proforma CDR; EuroQol; HAD; Six item CIT, NPI
Day 8	Narrative account of problems in the preceding week NPI; EuroQol; HAD	Narrative account of problems in the preceding week NPI; EuroQol; HAD Debriefing questionnaire (participants' subjective experience in keeping a diary).
Day28	NPI; EuroQol; HAD Debriefing session Questionnaire	NPI; EuroQol; HAD Debriefing session-Questionnaire

3.7. Qualitative Analysis

Qualitative content analysis has been defined as a research method for the subjective interpretation of the content of text data through systematic classification process of coding and identifying themes of patterns (Hsieh & Shannon 2005). In dementia, information is gathered from patients and carers through their verbal account of problems and experiences. Hence, the qualitative content analysis can be one of the ways researchers can provide a greater understanding of problems faced in dementia.

Hseieh and Shannon (2005) described three approaches:

1. Conventional qualitative content analyses in which coding categories derived from raw data using the grounded theory.
2. Directed content analysis in which initial coding starts with a theory or relevant research findings.
3. Summative content analysis involves counting of words or manifest content with the goal of exploring the words / indicators in an inductive manner.

In the present study, two sets of content analyses were carried out. The first analysis was on carers' retrospective narrative accounts of problems displayed by dementia patients, and the second analysis was on carers' in situ descriptions of problems in a 7-day diary booklet.

For the content analysis of narratives, a mixture of all three approaches identified by Hseieh and Shannon (2005) were used. Indeed, the initial examination of narratives was based on previous classification of neuropsychiatric problems in dementia by van der Linde et al. (2013), as well as examination of raw data for identifying a separate class of cognitive problems not included in the classification of van der Linde et al. (2013). This was followed by counting the number of different problems in the narratives and the classifying each problem into the pre-agreed categories that emerged from the initial analysis. Similar coding procedure was then employed for the content analysis of diary entries.

3.8. OUTCOME MEASURES

Both qualitative and quantitative analyses were used in the data collected. The primary outcome involved the use of content analyses in the narrative accounts of carers in the control and diary groups identifying problems associated with dementia and comparing with the diary entries.

The secondary outcome measures involved the use of quantitative analyses in comparing health related quality of life and psychiatric morbidity amongst carers as well as neuropsychiatric problems amongst the persons with dementia. Both descriptive and statistical analyses were used to evaluate the findings from the secondary measures using the various questionnaires.

3.9. DATA MANAGEMENT AND STATISTICAL ANALYSES

Computerised records of data collected for the purpose of the study were anonymised and kept securely with access available only to the research team. Data analysis involved the use of SPSS for a variety of tests such as analysis of variance, chi-squared and correlations.

Sample size

We used NPI, our main rating scale, to carry out the sample size calculation. The sample size that was calculated was 46 for each group, based on estimated 10 point difference in mean Neuro Psychiatry Inventory total scores in diary and control groups on day 8, with sigma (common standard deviation) of 17.1; with 80% power and 5% significance (alpha). Below are estimates for various differences and sample sizes for each group.

2	3	4	5	6	7	8	9	**10**	11	12	13	14	15
1135	505	284	182	127	93	71	57	**46**	38	32	27	24	21

We targeted to recruit 2-3 participants per week for 12 months averaging 100 participants for our study.

3.10. Ethical Considerations

Ethics approval was obtained from NRES Committee East of England - Cambridge East (REC reference: 14/EE/0008 – see Appendix14). The UH Protocol number for REC (NHS) approved study is HSK/PGR/NHS/02469 (Appendix 15).

An information sheet was handed out to potential participants (carers) and the person with dementia before recruitment if they indicated a wish to take part in the study (Appendices 2 and 4). The information sheet included contact details of the research team in order for carers to contact the researchers and arrange a mutually convenient time for the first session of the study to take part. The information sheet contained the investigators’ contact details for any future reference. Participants were informed that the data they provided would remain anonymous and could not be traced to their identity. The information sheet explained their right to withdraw at any time. Following NHS ethics guidelines, participants at the initial session were asked to read and sign a consent form (see Appendices 3 and 5).

Standard procedures to ensure the anonymity and the confidentiality of the data were adhered to. All participants were made aware that they could withdraw from the study at any point including after the study commenced. Participants were informed that their decision to withdraw at any stage of the study would not affect in any way the treatment they or the person they cared for were receiving. All carers had access to investigators and the local mental health services if in distress or if the person with dementia needed a review or support during and after the study. Both patients and carers had their usual access to health services maintained. The patients’ General Practitioners were informed of their participation in the study.

CHAPTER 4

RESULTS

4.1. The content analysis of carers' narratives

(a) Identifying the number of unique problems in each narrative

Before conducting the content analysis on carers' narratives, the numbers of words in each narrative were counted and the diary and control groups were compared in terms of the length of narratives. On Day 1, the mean number of words in narratives of the diary group (*M*=107.90; *SD*=51.92) was not significantly different from that of the control group (*M*=91.21, *SD* = 62.44), F (1, 82) = 1.77, p = .19, η_p^2 = .02. Similarly, the means on Day 8 were 88.18 (SD = 52.53) and 84.10 (SD = 51.57), respectively, and did not differ from each other (F <1).

Next, all of the Day 1 and Day 8 narratives (n=160) were read through to get a sense of the data by two independent raters. This initial examination supported the raters' expectations of types of problems described, based on previous classifications of neuropsychiatric problems (e.g., by van der Linde et al., 2013) and the researchers' focus on cognitive problems. Both raters arrived at the same number of types of problems, which were 'behavioural', 'cognitive', 'emotional', 'psychiatric' and 'other'. However, there were some differences in terms of types of problems that were counted into a particular category, especially the 'other' category. For example, rater 1 counted all sleep related issues into behavioural problems whereas rater 2 had a more refined approach by classifying some into behavioural (e.g., wandering at night) and purely sleep-related problems into the 'other' category (e.g., sleeps a lot, or not sleeping well at night). At this point, it was also decided that only the patients' dementia-related problems would be included, while problems experienced by carers themselves would not be considered (e.g., feeling unable to cope or extremely stressed). In addition, if a problem reported was not related to the patient's diagnosis (e.g., *'since she broke her hip it is rare for her to get up unaided'*) or was the result of their medication (*'she has been hallucinating and having the shakes on the higher dose of Rivastigmine patches for her memory*'), then these were also excluded from the analysis.

After this, the two raters read through all the narratives again and made a note of a number of problems they thought each narrative contained. Once they had completed this, they came together to discuss each narrative in terms of the number of problems that they had segmented them into. Each narrative was carefully discussed even when both raters had put down the same number of problems for that narrative. This was essential as it was necessary to segment each narrative into clearly defined problem units, which would then enable the raters to code each of the identified problems in the narrative in Step 2 of the content analysis. Out of 160 narratives, raters agreed on the exact number of problems for 117 narratives (73%). For further 9 narratives (6%) raters arrived at a different number of problems after joint discussion even when they had initial agreement on the number of problems in the narrative. This indicates that segmenting each narrative into a number of clearly defined problems was not straightforward and justified the detailed and thorough approach in coding adopted for the data. The initial disagreements in the number of problems in a narrative for 34 narratives (21%) were resolved by discussion. The majority of disagreements (26 out of 34 narratives, 76%) were apart by only one problem, with only 7 disagreements being apart by 2 problems and one disagreement by three problems.

(b) Coding of problems identified in each narrative

The second stage of content analysis involved assigning each problem that was agreed upon in Stage 1 as a separate problem, into one of the five categories: behavioural, cognitive, emotional, psychiatric or ‘other’ problem. Behavioural problems covered a variety of problems such as aggressive behaviour, increased agitation, irritability, inappropriate behaviour (e.g., smearing faeces, impulsive buying, throwing things). Cognitive problems were mainly concerned with the patient forgetting things, time and space disorientation, asking the same questions, misplacing things, forgetting medications, etc. Emotional problems usually involved reports of the patient being angry/anxious or upset, and psychiatric symptoms included hallucinations, delusions/false beliefs and confabulations. The problems that fell into the ‘other’ category mostly involved sleep problems, apathy, incontinence, etc.

Two raters independently coded each of the identified problems in narratives of Day 1 and Day 8. There was almost perfect agreement between the raters at this stage (98% and 97% for Day 1 and Day 8 data, respectively). Thus, out of 319 problems identified for Day 1 narratives, raters had initial disagreement for only 5 problems, and out of 207 problems identified for Day 8 narratives, raters initially disagreed on 6 problems (see Table 7). All disagreements were solved by discussion.

Table 7: The problems in the carers' narratives on Days 1 and 8 where the 2 raters had different opinions and their final agreed classification

Participant number	Day	Problem description	Rater 1	Rater 2	Agreed
23	1	Rings children repeatedly	C	B	C
23	1	Goes out without telling children;	C	B	B
24	1	Wakes up crying	B	E	E
29	8	Accuses carer of moving things;	C	P	P
34	8	Inappropriate action (pouring cat food on the floor)	C	B	C
38	8	Has been pushing carer on occasions	O	B	B
46	8	Got irritated by a TV programme.	E	B	B
50	1	Speech problems (erratic speech)	B	C	C
59	1	Slowed down, cannot do anything in hurry;	B	C	C
67	8	Inappropriate actions (tried to close the car door when his feet were still out)	C	B	C
82	8	Left his soiled pants on the floor;	C	B	C

Key: B – Behaviour; C – Cognition; E – Emotions; P – Psychiatric; O - Others

4.2. Number of narrative problems in the diary and control groups

Mean number of each type of problems (behavioural, cognitive, emotional, psychiatric and other), as well as the total number of problems reported in narratives of carers on Day 1 and Day 8, are presented in Tables 8 and 9, respectively, together with the results of one-way ANOVAS on these means with the condition (diary vs. control) as an independent variable. There were no significant group differences in these means either on Day 1 or Day 8.

Table 8: Comparing the number of problems identified in narrative accounts of carers on Day 1 in the diary and control groups

Problems	Diary N=39	Control N=41	F (1,78)	P - value
Behaviour	0.64 (0.93)	0.73 (1.21)	0.14	0.71
Cognition	2.56 (1.68)	1.95 (1.28)	3.38	0.07
Emotional	0.28 (0.56)	0.24 (0.58)	0.09	0.77
Psychiatric	0.23 (0.85)	0.32 (0.72)	0.23	0.63
Others	0.36 (0.63)	0.18 (0.39)	2.48	0.12
Total	4.05 (2.06)	3.41 (2.31)	1.68	0.20

Table 9: Comparing the number of problems identified in narrative accounts of carers on Day 8 in the diary and control groups

Problems	Diary N=39	Control N=41	F(1,78)	P - value
Behaviour	0.31 (0.57)	0.49 (0.78)	1.38	0.89
Cognition	1.49 (1.30)	1.29 (1.12)	0.52	0.48
Emotional	0.26 (0.50)	0.34 (0.62)	0.46	0.50
Psychiatric	0.26 (0.55)	0.24 (0.80)	0.01	0.94
Others	0.31 (0.61)	0.2 (0.46)	0.87	0.35
Total	2.62 (1.66)	2.56 (1.88)	0.02	0.89

In order to examine any differences between types of problems reported on Day 1 and Day 8, an additional 2 group (diary, control) x 2 Day (Day 1, Day 8) x 5 type of problem (behavioural, cognitive, emotional, psychiatric, other) mixed ANOVA with the repeated measures on the last two factors. This ANOVA resulted in the significant main effect of type of problem reported, F(2.85,213.87) = 74.63, p<.00001, η_p^2 =.50.[1] The post hoc comparison between these means, using Bonferroni adjustment for multiple comparisons, showed that the mean number of cognitive problems reported was significantly higher than any of the other four problems (all p_s<.0001). All other comparisons between the means were non-significant except the comparison between behavioural (M=.53) and other problems (M=.25), with the former being significantly higher than the latter (p=.03). In addition, there was a significant main effect of day (F(1,75) = 31.40, p<.00001, η_p^2 =.295), which was qualified by a significant day by type of problem interaction, F(2.29,172.01) = 10.31, p =.00002, η_p^2 =.12. Tests of simple main effects showed that the main effect of day was present for only cognitive problems (p=.00001) and behavioural problems (p=.02) with the number of these problems being significantly higher on Day 1 (M=2.34 and M=.66, respectively) than on Day 8 (M = 1.35 and M=.39, respectively). The effect of day was not significant for any of the other three types of problems reported. None of the other effects were significant (all Fs <2.05).

It was also interesting to examine the number of problems reported on Day 1 and 8 as a function of severity of dementia. Out of 80 patients whose carers provided narratives, 36 patients (21 in the control and 15 in the diary condition) were classed as having mild dementia on the basis of their scores on the Clinical Dementia Rating Scale, and 42 patients were classed as having moderate dementia (18 in the control and 24 in the diary group). Two patients in the control condition were classed as having severe dementia. The results of these two patients were not included in the analysis reported below.

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[1] Degrees of freedom for this analysis reflect the Greenhouse-Geisser adjustment due the violation of sphericity assumption for this variable.

Given that there were no significant differences between the number of reported problems in the control and the diary conditions, the data across this variable were collapsed and patients with mild and moderate dementia were compared on the number of reported problems separately for Day 1 and Day 8. The means and results of one-way ANOVAS are presented in Tables 10 and 11, respectively. For Day 1, the total number of reported problems, as well as, behavioural and psychiatric problems was significantly higher in patients with moderate dementia than in those with mild dementia. There were no differences between the two groups in the number of cognitive, emotional and other problems. For Day 8, only the total number of reported problems was higher in the moderate than in mild dementia patients, with no reliable group differences on any of the specific type of problem.

Table 10: Comparing the number of problems in mild and moderate dementia identified in narrative accounts of carers on Day 1

Problems	**Mild** **N=36**	**Moderate** **N=42**	**F (1,76)**	**P - value**
Behaviour	0.25 (0.50)	1.05 (1.31)	**11.92**	**0.001**
Cognition	2.22 (1.38)	2.31 (1.66)	0.06	0.80
Emotional	0.19 (0.47)	0.31 (0.64)	0.79	0.38
Psychiatric	0.08 (0.37)	0.45 (1.02)	**4.25**	**0.04**
Others	0.19 (0.40)	0.32 (0.61)	1.05	0.31
Total	2.94 (1.43)	4.40 (2.55)	**9.29**	**0.003**

Table 11: Comparing the number of problems in mild and moderate dementia identified in narrative accounts of carers on Day 8

Problems	Mild N=36	Moderate N=42	F (1,76)	P - value
Behaviour	0.25 (0.50)	0.52 (0.80)	3.13	0.81
Cognition	1.17 (1.03)	1.60 (1.34)	2.43	0.12
Emotional	0.31 (0.52)	0.31 (0.81)	0.00	0.97
Psychiatric	0.19 (0.55)	0.24 (0.80)	0.53	0.47
Others	0.17 (0.45)	0.29 (0.60)	0.97	0.33
Total	2.08 (1.44)	3.02 (1.96)	**5.67**	**0.02**

Examples of narratives to show case the above reported reduction in behaviour and cognitive problems from Day 1 to Day 8 include accounts from the participants 08 from the diary group (DG) and 41 from the control group (C).

08 (DG) narrative in Day 1: '*His anger is what is most upsetting. He gets very angry and very adamant he does not want to go to any day centre. Does not want anybody to come to the house. He cannot tolerate the grandchildren playing at home. He does not want me to do anything. I had a very bad fall last year and fractured my wrist bone and cheek bones leading to admission to hospital. On account he often tries to stop me doing things. I can find I am very lonely because I do not have a conversation with him. I do not sleep at night because there is so much going round my head. He does not eat much for breakfast, saying he does not want to eat, does not want to talk and does not want watch telly.*

First in the morning he is very irritable and does not want to get up from bed. Often says he does not want to be here. It does not seem right after all these years (47 years of marriage).

He refuses to help and when asked to put the kettle on, he forgets and takes the rubbish out instead. Often argues when asked to help. I have to keep him out of the kitchen.'

08 (DG) narrative in Day 8: *'He has been brilliant this past week. As you can see I am not tearful. I can honestly say I do not get much of a conversation and finds it difficult with words like he says 'I have put something on the desk when he means worktop. Sometimes goes the wrong way, like he goes out of the living room in the wrong direction when intending to go to the kitchen. He does not have any interest in TV and just wants to sleep. He does not want to get up in the morning. I have to give him his pills.'*

41 (C) narrative in Day 1: *'I felt a bit under pressure looking after her. We have come head to head a couple of times as Mum always knows best. Sometimes unhappy with my cooking. She has been losing things like her lower dentures. Puts food in the wrong place like vegetables in the freezer. She gets a bit down sometimes and as temper tantrums. She is completely out of character and this has changed her personality.'*

41 (C) narrative in Day 1: *'It has been pretty good. We have had a couple of lost things but no real problems. I think her memory is getting worse quite quickly but it means she is getting more compliant'*

4.3. Diaries completed by carers in the diary group

4.3.1 Diary entry analysis

In the diary condition, 39 carers (12 males, 27 females) recorded problems over a 7-day period. Eight carers (20.5%) made no entries claiming there were no problems to record (Fig. 3). The remaining 31 participants completed a total of 168 diary pages. The mean number of diary pages (entries) completed was 4.30 (*SD* = 3.97) (Table 12). The maximum number of diary pages (entries) completed by a carer was 17. It is interesting that there was a gender effect with female carers completing on average 5.18 (*SD* = 4.11) diary pages in comparison to 2.33 pages (*SD* = 2.90) completed by male carers, $F(1,37) = 4.69$, $p = 0.037$, $\eta_p^2 = .11$.

Fig. 3: Distribution of number of completed diary pages by carers

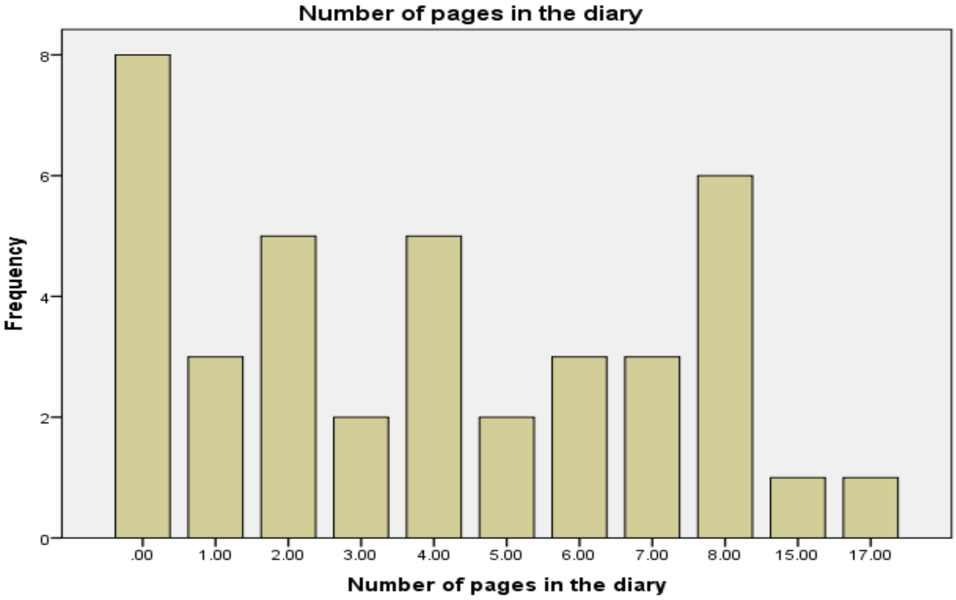


Table 12: Number of Diary pages (entries) and problems identified

	No. of carers	Minimum	Maximum	Sum	Mean	Standard Deviation
Number of pages in the diary completed	39	0	17.00	168.00	4.31	3.97
Total number of problems in a diary	39	0	42.00	309.00	7.92	9.13
Total number of behavioural problems	39	0	16.00	111.00	2.85	3.57
Total number of cognitive problems	39	0	16.00	107.00	2.74	3.66
Total number of emotional problems	39	0	11.00	42.00	1.08	2.19
Total number of psychiatric problems	39	0	4.00	16.00	0.41	.91
Total number of other problems	39	0	6.00	34.00	0.87	1.54

4.3.2 The content analysis of diary entries

Although participants were instructed to record one problem per diary page, initial examination of diary entries indicated that often participants' description of a problem involved not just a single, but two or more problems. Therefore, it was necessary to carry out the content analysis of diary entries in two stages similar to the content analysis of narratives (see above). Initially, two raters independently read through the descriptions of problems on each diary page completed. At initial assessment by each rater, of the 168 pages completed, there were a total of 119 (71%) diary pages in which there were agreements in the total number of problems. In 49 (29%) diary pages, there were differences in the total number of problems identified by each rater. In 41 cases (84%), the disagreement on number of problems involved a difference in one problem only, in 5 cases (10%) it involved a difference in two problems, in two 2 cases (4%) a difference in 3 problems and in one case (2%) - 4 problems. All disagreements were solved by discussion, resulting in a total of 309 problems, with the mean number of 1.84 problems reported on each diary page.

Once the two raters agreed on the number of problems, the next step involved the classification of each identified problem into one of the five categories used in the analysis of narratives (i.e., behavioural, cognitive, emotional, psychiatric and other). Of the 309 problems, the raters agreed on the classification of 291 problems (94%). There were differences in classification on only 19 problems (6%). All disagreements were solved by discussion (Table 13).

The mean numbers of problems in each of the five problem category were entered into a 1-way within subjects ANOVA with the type of problem as an independent variable. This analysis resulted in a significant main effect of type of problem, $F(2.85,108.45) = 11.16$, $p = 0.000003$, $\eta_p^2 =.23$. Post hoc comparisons between these means, using Bonferroni correction for multiple comparisons, showed that there was no statistically significant difference between the mean number of recorded behavioural and cognitive problems ($p = 1.00$), but the number of both behavioural and cognitive problems was significantly higher than either emotional, psychiatric or other problems (all $p_s < 0.02$), which did not differ from each other (all $p_s > 0.53$). This pattern is different from the one obtained in Day 1 narratives, which showed that cognitive problems were reported significantly more often that any of the other four problems including behavioural problems.

Table 13: The problems in carers' diaries where the 2 raters had different opinions and the final agreed classification

Participant	Problem description	Rater 1	Rater 2	Agreed
3	Wake up too soon	B	O	O
19	Had a disturbed night	B	O	O
19	Unable to pull up continence pants and pyjama trousers	B	C	C
25	Went to the beach where all his memories are as a young boy with his dad	P	C	C
28	Wet two pairs of trousers at the day centre	B	O	O
29	He was very, very angry	E	B	B
29	Angry because he thought I had hidden it	E	B	E
29	Wanted soap for lunch. Made soup then did not want it	C	B	B
29	Pains that are in his imagination	B	P	P
29	Difficulty laying paving slabs and refusing offer to look for help	E	B	B
29	Really angry response as wanted me to help him	E	B	E
29	He said hot soup had given him a sore throat	P	B	B
29	He said hot soup had given him a cold	P	B	B
29	He said sore throat sweets were out of date and gave him an allergy	P	B	B
37	Told me off because I did not tell him I was going to town	E	B	B
38	Moody all evening and annoyed because he could not remember appointments on the board	E	B	B
46	He became irritated with the television	E	B	B
50	Loss of balance	O	C	O
50	He talked about the need to return to his house (he was at home)	P	C	C

Key: B – Behaviour; C – Cognition; E – Emotions; P – Psychiatric; O - Others

4.4. Comparing the number of problems reported in narratives and in diaries in the diary group

To evaluate the effectiveness of a diary method, as a data gathering tool for clinicians, in comparison to a currently used standard narrative method, total number of problems and the number of different types of problems (behaviour, cognitive, emotional, psychiatric and others) recorded in the diary were compared to the number of problems reported by carers in the diary group in their Day 1 and Day 8 narratives. Table 14 reports relevant means and the results of 1-way within subjects ANOVAS with the type of recording (diary vs. narrative) as an independent variable. The results show that the total number of problems recorded in a diary was significantly higher than those reported in narratives before keeping a diary for 7 days. Similarly, significantly more behavioural, emotional and other problems were recorded in diaries than reported in Day 1 narratives. No significant differences were found in the number of reported cognitive and psychiatric problems.

Table 14: Mean number of problems (standard deviations) in diaries and Day 1 narratives of carers in the diary group, and results of 1-way ANOVAS between these means

Problems	**Diaries**	**Narratives**	**F (1,38)**	**P value**	**Effect size (η_p^2)**
Behaviour	2.85(3.56)	0.64(0.93)	16.15	**0.0003**	0.30
Cognition	2.74(3.66)	2.56(1.68)	0.09	0.77	0.002
Emotional	1.08(2.19)	0.28(0.56)	5.19	**0.03**	0.12
Psychiatric	0.41(0.91)	0.23(0.87)	1.04	0.31	0.03
Others	0.87(1.54)	0.36(0.63)	4.77	**0.04**	0.11
Total	7.92(9.13)	4.05(2.06)	7.42	**0.01**	0.16

Table 15 reports similar means and results of 1-way ANOVAS for number of diary problems and problems reported in narratives on Day 8. The significant differences were again obtained for not only the total number of problems as well as for behavioural, emotional and other problems, but also for cognitive problems with fairly large effect sizes. These results are even more surprising given that carers were asked to recall all the problems experience in a preceding week, which coincided with their diary keeping. This should have increased the accuracy of their recall and the number of reported problems should not have been different from that recorded in diaries, but nevertheless carers reported significantly fewer problems in Day 8 narratives than the number of problems recorded in diaries.

Table 15: Mean number of problems (standard deviations) in diaries and Day 8 narratives of carers in the diary group, and results of 1-way ANOVAS between these means

Problems	**Diaries**	**Narratives**	**F (1,38)**	**P value**	**Effect size (η_p^2)**
Behaviour	2.84(3.56)	0.31(0.57)	22.22	**0.00003**	0.37
Cognition	2.74(3.66)	1.49(1.29)	5.34	**0.03**	0.12
Emotional	1.08(2.19)	0.26(0.50)	5.26	**0.03**	0.12
Psychiatric	0.41(0.91)	0.26(0.55)	2.32	0.14	0.06
Others	0.87((1.54)	0.31(0.61)	5.78	**0.02**	0.13
Total	7.92(9.13)	2.62(1.66)	15.79	**0.0003**	0.29

4.5. Correlations between numbers of problems reported in narratives and diaries

Two sets of correlations were calculated to examine relationships between the numbers of problems reported in narratives on Day 1 and Day 8 on the one hand on the entire sample of 80 carers, and the number of narrative problems and problems recorded in diaries in a sample of 39 carers who kept a diary for seven days. Table 16 shows correlations between the total number of problems as well as each of the five types of problems (behavioural, cognitive, emotional, psychiatric and other) reported by carers on Day 1 and Day 8. Positive and statistically significant correlations were obtained for the total number of problems reported, as well as for behavioural, cognitive and psychiatric problems reported on Days 1 and 8. This supports the test-retest reliability of carers' reports and these specific types of problems at least over this relatively short time period.

Table 16: Pearson correlations between the total numbers of narrative problems on Day 1 and Day 8 and each type of problems on Day 1 and Day 8 in a sample of 80 carers who provided narrative accounts of problems on both Day 1 and Day 8.

	Day 8 **Number of problems**
Day 1 total number of problems	**0.58*****
Day 1 number behavioural problems	**0.45 ****
Day 1 number of cognitive problems	**0.27***
Day 1 number of emotional problems	0.19
Day 1 number of psychiatric problems	**0.62*****
Day 1 number of other problems	0.17

* p<.02; **p<.0001, ***p<.000001

Next, correlations between the number of problems recorded in diaries and problems reported by carers in their Day 1 and Day 8 narratives were examined. If carers had poor insight and/or memory of problems of the dementia patient they cared for, then the number of problems in Day 1 narratives would not necessarily correlate positively with the total and specific types of problems recorded in diaries in the subsequent seven days that followed

Day 1 narratives. On the other hand, the act of completing a diary should have increased their insight and/or memory of problems recorded throughout the week, so that problems reported in diaries and Day 8 narratives would be more likely to be positively correlated. Table 17 shows correlations between the number of problems recorded in diaries and Day 1 and Day 8 narratives. The results supported predictions in that there were no statistically significant correlations between the number of problems in Day 1 narratives and problems recorded in diaries, except for the number of other problems. In contrast, almost all the correlations between diary and Day 8 narrative problems were positive and significant (except for the number of emotional problems). Taken together, findings support the idea that retrospective self-reports of carers may not accurately reflect the number and types of problems experienced by dementia patients' in their daily life, and emphasise the importance of diary as a useful data collection tool for clinicians.

Table 17. Pearson correlations between total number of problems and different types of problems in diaries and Day 1 and Day 8 narratives in a sample of 39 carers who kept a diary between Day 1 and Day 8.

	Narrative problems Day 1	**Narrative problems Day 8**
Diary: total number of problems	0.23	**0.54*****
Diary: number of behavioural problems	0.28	**0.43****
Diary: number of cognitive problems	0.16	**0.38***
Diary: number of emotional problems	0.15	0.03
Diary: number of psychiatric problems	0.24	**0.73******
Diary: number of other problems	**0.32***	**0.32***

* p<.05; **p<.01, ***p<.001; ****p<.000001

4.6. Assessing therapeutic benefits of diary keeping

The second major objective of this study was to examine if keeping a diary of patients' problems had any therapeutic benefits on carers and patients. To assess this novel idea, a number of secondary outcome measures were used, assessing carers' well-being such as the

NPI carer distress, EuroQoL and Hospital Anxiety and Depression scores. In addition, the total NPI scores for patients were also examined.

As indicated in the method section (section on participants) there were no significant differences between the diary and control groups on Day 1 it terms of variables assessing carers' well-being (total EuroQol, NPI carer distress and HAD scores) or patients' neuropsychiatric problems as assessed by NPI (see Table 3). First of all, diary and control groups were compared on Day 8 in terms of the mean patient total scores on Neuropsychiatry Inventory, mean carer NPI distress scores as well as carers' mean scores on EuroQoL and Hospital Anxiety and Depression Scale (Table 18). No significant differences between the groups were found. Similar comparisons on these scores were conducted for the scores obtained on Day 28 (Table 19).

To examine any within group changes across assessments, the mean scores of the outcome measures were compared between Days 1 and 8 and between Days 1 and 28 in the diary and control groups separately. The means for patient NPI scores on Days 1 and 8 are presented in the upper panel of Table 20 and the means for Days 1 and 28 are presented in a lower panel of this table. One-way within subjects ANOVAs on these means showed that in the diary group, the mean NPI scores dropped significantly from Day 1 to Day 8 whereas the drop in the control group over the same period was not statistically significant. In the diary group, the significant drop in NPI scores from Day 1 to Day 8 was maintained over subsequent weeks so that the difference between the NPI scores on Day 1 and Day 28 were still significant with very large effect sizes. Interestingly, in the control group the NPI scores also declined over subsequent weeks so that the drop in NPI scores became statistically significant by Day 28. Since carers in the control group did not keep a diary, this improvement in NPI scores of patients in the control group could be ascribed to visits and extra attention from clinicians making assessments for this study.

Table 21 displays the mean NPI Carer Distress scores on Day 1 and Day 8 (upper panel) and Days 1 and 28 (lower panel). There was a statistically significant drop in carer distress from Day 1 to Day 8 in both the diary and control groups. This improvement was maintained across subsequent weeks in the diary and control groups with significantly lower distress scores on Day 28 than Day 1 (Fig. 4). In both groups, there were no statistically significant differences across the time periods in terms of carers' mean EuroQol scores and mean anxiety and depression scores on the Hospital Anxiety and Depression Scale.

Table 18: Mean scores on Neuropsychiatry Inventory (NPI), EuroQoL and Hospital Anxiety and Depression Scale (HADS) on Day 8 in diary and control groups

	DIARY (N=39)	**CONTROL (N=41)**	**F(1,78)**	**P value**
Total NPI score	17.436 (15.87)	14.95 (17.3)	0.45	0.51
NPI Carer Distress score	8.49 (8.3)	7.17 (8.39)	0.50	0.48
EuroQoL Health score	74.87 (19.56)	74.71 (15.29)	0.002	0.97
HADS – Anxiety score	6.51 (3.57)	6.02 (3.7)	0.36	0.55
HADS – Depression score	4.56 (2.41)	4.19 (3.1)	0.35	0.56

Table 19: Mean scores on Neuropsychiatry Inventory (NPI), EuroQoL and Hospital Anxiety and Depression Scale (HADS) on Day 28 in diary and control groups

	Diary **N= 39**	**Control** **N= 38**	**F(1,75)**	**P value**
Total NPI score	16.08 (14.8)	14.43 (14.99)	0.23	0.63
NPI Carer Distress score	8.05 (8.23)	7.51 (7.37)	0.09	0.77
EuroQoL Health score	74.87 (19.56)	74.71 (15.29)	0.002	0.97
HADS – Anxiety score	5.95 (4.92)	6.24 (3.43)	0.09	0.76
HADS – Depression score	4.18 (3.15)	4.38 (3.13)	0.07	0.79

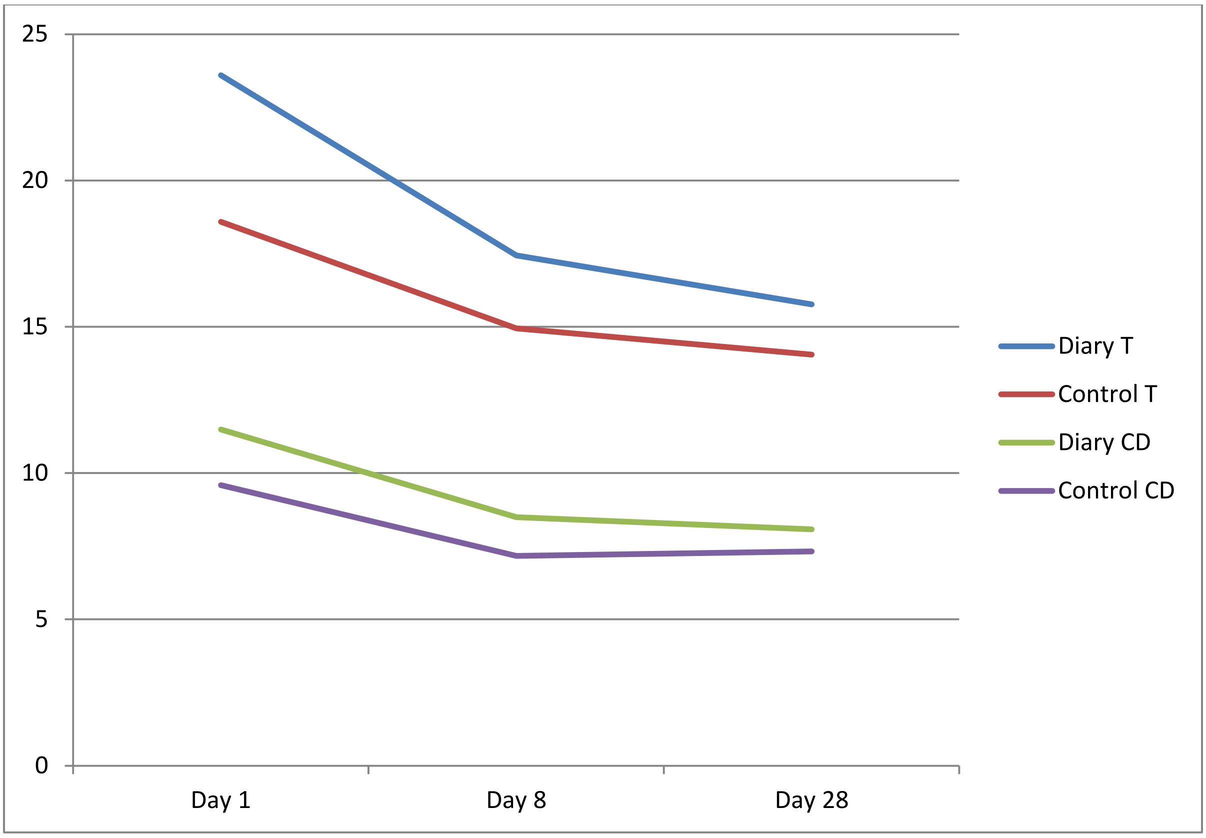
Table 20: Mean Neuro-Psychiatry Inventory (NPI) scores (standard deviations) on Days 1 and 8 (upper panel) and Days 1 and 28 (lower panel) in diary and control groups and results of 1-way within subjects ANOVAS on these means

	Day 1 (NPI total)	**Day 8 (NPI total)**	**F- test**	**P values**	**Effect size (η_p^2)**
Diary (N=39)	23.59 (19.64)	17.44 (15.88)	**5.56**	**0.02**	**0.13**
Control (N=41)	18.59 (16.55)	14.95 (17.30)	2.57	0.12	0.06
	Day 1 (NPI total)	**Day 28 (NPI total)**	**F- test**	**P values**	**Effect size (η_p^2)**
Diary (N=39)	23.59 (19.64)	15.77 (14.73)	**10.89**	**0.002**	**0.22**
Control (N=38)	18.13 (16.72)	14.05 (14.98)	**6.50**	**0.015**	**0.15**

Table 21: Mean Neuro-Psychiatry Inventory (NPI) Carer Distress scores (standard deviations) on Days 1 and 8 (upper panel) and Days 1 and 28 (lower panel) in diary and control groups and results of 1-way within subjects ANOVAS on these means

	Total NPI Carer Distress score at Day 1	**Total NPI Carer Distress score at Day 8**	**F - test**	P value	**Effect size (η_p^2)**
Diary (N = 39)	11.49 (10.17)	8.49 (8.30)	**4.41**	**0.042**	**0.10**
Control (N = 41)	9.59 (8.66)	7.17 (8.39)	**8.04**	**0.007**	**0.17**
	Total NPI Carer Distress score at Day 1	**Total NPI Carer Distress score at Day 28**			
Diary (N = 39)	11.49 (10.17)	8.08 (8.11)	**8.76**	**0.005**	**0.19**
Control (N = 38)	8.97 (8.39)	7.32 (7.37)	**3.06**	**0.009**	**0.08**

Fig 4. Mean total NPI (T) and Carer Distress (CD) scores for days 1, 8, and 28 in the diary and control groups



4.7. Carers' experience in keeping diaries

Of the 39 carers who were asked to complete a diary, 37 said they kept the diary every day. The reasons given for not keeping a diary every day by the two carers who failed to keep it every day, were that the person with dementia got agitated about it, the diary was too big to carry about and a son was visiting for a couple of days. Both carers failed to keep the diary for two of the 7 days they were expected to complete the diaries.

Over 60 % of the carers reported that they found it easy or very easy to keep a diary with them and complete the diary entries (Table 22).

Table 22: Experience of keeping and recording in the carers' diaries

	Very Easy	**Easy**	**Difficult**	**Very Difficult**
Experience of keeping diary	14 (35.9%)	13 (33.3%)	9 (23.1%)	3 (7.7%)
Experience of recording in diary	11 (28.2%)	15 (38.5%)	11 28.2%)	2 (5.1%)

4.8. Participants' Experience of taking part in the study

Over 50% of carers had a positive experience from taking part in the study for both the diary and control groups. More carers found they had a greater understanding of dementia and felt they had more patience along with being more tolerant. There were no significant differences on the carers' experiences between the two groups (Table 23).

Table 23: Participants’ experiences of taking part in the study

Questions	Diary	Control	χ^2	p
How did taking part affect your understanding of dementia?	No change = 10 (26.3%) Slight increase = 7 (18.4%) Moderate increase = 10 (26.3%) Significant increase = 11 (28.9%)	No change = 11 28.9%) Slight increase = 6 (15.8%) Moderate increase = 10 (26.3%) Significant increase = 11 (28.9%)	0.125	0.99
Did taking part have any effect on your patience and tolerance?	Less tolerant = 3 (7.9%) No effect = 12 (31.6%) More tolerant = 23 (60.5%)	Less tolerant = 2 (5.3%) No effect = 16 (42.1%) More tolerant = 20 (52.6%)	0.98	0.96
Any difference in day to day difficulties?	Increase = 9 (23.7%) No change = 26 (68.4%) Decrease = 3 (7.9%)	Increase = 8 (21.1%) No change = 27 (71.1%) Decrease = 3 (7.9%)	0.78	0.91

CHAPTER 5

DISCUSSION

This study involves the use of carers' diaries in dementia using a mixed qualitative and quantitative design. A review of the literature suggests that it appears to be the first of its kind. It includes a randomised control study comparing real-time recording of problems using carers' diaries with the retrospective information gathered in the usual clinical assessments in clinics or domiciliary visits of persons with dementia living at home.

The study set out to answer the following research questions:

1. To capture prospectively cognitive, emotional or behavioural problems in people with dementia, using diaries kept by carers.
2. To compare the content of prospective data captured through carers' diaries kept for a week and carers' retrospective oral recollection of problems in the preceding week.
3. To examine if keeping carers' diaries will make a difference in behaviour and psychological problems in persons with dementia measured using the Neuro-Psychiatry Inventory.
4. To examine if keeping a diary for a week makes any difference to carers' quality of life as rated by the EuroQol or emotional problems as rated by the Hospital Anxiety and Depression scale.

Comparing the narrative accounts of carers in both the diary and control groups showed no significant differences in number of problems identified. However, in the diary group, there was positive and significant correlation between the numbers of problems identified in the narrative and dairy entries by Day 8 but not on Day 1. This suggests that by keeping a diary, carers were able to recollect similar problems in their narrative accounts to what was recorded in the diaries on Day 8, in contrast to Day 1 narratives where there was no correlation with diary entries. The study findings also revealed that the carers' recorded a greater number of problems in diaries compared to retrospective information provided in narratives with memory and behaviour problems being the two most common problems reported in both the diaries and narrative accounts. Carers' diaries identified more cognitive, behaviour, and emotional problems as well as 'other' problems such as insomnia and incontinence. Despite identifying more problems, the use of the carers' diaries in dementia did not appear to make a difference in carers in terms of carers' health related quality of life or psychiatric morbidity amongst carers.

Another important finding highlighting the advantages of diary method with this population was that the behaviour problems tended to be highlighted much more in the diaries compared with the narrative accounts. The reasons for this is uncertain, but could include difficulty talking about these problems in front of their loved ones, sense of betrayal, embarrassment or feeling ashamed. Whereas writing such problems down may be easier, as it is likely the patients were unaware of what was being recorded in the diaries. This is sometimes evident in clinical settings where some spouses or relatives who are carers bring written records of problems because they feel unable to mention problems in front of the loved one they care for. Alternatively, it is possible that in everyday life carers are more affected by (or notice) patients' cognitive problems which are then easier to recall retrospectively than behaviour problems.

Earlier studies involving carers’ diaries in dementia were mainly qualitative and involved the use of unstructured diaries in comparison to this study (Valimaki et al. 2007; Mausbach et al. 2011; Valimaki et al 2012). They found that there were beneficial effects on carers affects and experience of caring. These earlier studies mainly focused on carers’ problems and impact of caring whereas this current study investigated both, as well as the impact carers’ diaries may have on the persons with dementia. In our study, on the use of carers’ diaries in dementia, we did not find any significant differences between the diary and control groups. The observed improvement in the neuropsychiatric problems and carer distress identified by the Neuropsychiatric Inventory could be on account of the increased contact with health professionals during the period of study leading to the therapeutic changes observed. The patients with dementia were also on medication, such as cholinesterase inhibitors, antidepressants and other psychotropics, which may have also contributed to the observed improvement. In a study involving carers’ diaries, Clarke (1999) described the process of achieving normalisation in which the family carers continuously defined and redefined their relationship with and the person with dementia as normal for them. The diaries may have contributed in that they provided detailed account of factual, emotive, personal and sensitive events which carers were now able to ventilate or express in their diary recording. This could be a possible explanation for the reduction in observed neuropsychiatric problems and carer distress as rated by the Neuropsychiatric Inventory. Other contributory factors to the improvement in behavioural and psychological problems could be the ongoing treatment persons with dementia were receiving and the support for both carers and persons with dementia following referral to the memory clinic service. This can include carers’ assessments and support as well as the offer of relevant services to the person with dementia like home care and day care support.

The Hawthorne effect also cannot be eliminated completely in both the diary and control groups. This can be due to the fact that the patients having some insight into the study try to minimising their behavioural problems by behaving well, knowing that they are being observed closely by their family carer. The impact of learning from repeated exposure to the assessment tools or familiarity with the research process may also contribute towards changes observed (McCarney et al. 2007). Furthermore, after initial assessments, the carers would have had greater awareness of the problems identified by the Neuropsychiatric Inventory and other assessment tools, including diary recording in the diary which in itself can be an educative tool, as carers begin to identify problems and what helped to resolve them.

The lack of changes in health related quality of life scores using the Euro-QoL, along with the anxiety and depression ratings using the Hospital Anxiety and Depression scales over time or between the two groups, may be on account of the short period of one week that the diaries were used in this study. Families of relatives with dementia are at increased risk of health problems. The impact of dementia on health related quality of life in Alzheimer's disease patients and their caregivers have been increasingly recognized in a number of studies (Andren & Elmstahl 2008, Martin-Carrasco et al. 2009 and Papastavrou et al. 2007). This is further compounded by the economic burden of caring, as it has been reported that 75% of the total cost of caring in Alzheimer’s dementia is for unpaid informal care, with patients and family carers having to pay out of pocket (Rice et al. 1993).

One of the strengths of this study is the mixed qualitative and quantitative design. The qualitative data through the narratives and diary entries provided carers' lived account of living with a person with dementia, which quantitative method is unable to provide. For example, consider in the following narrative: '*He had a funny turn on the 2nd day but he got over it. He was not too bad apart from the chaos trying to sell our home. He has been very helpful when people came to view the property. I find the recycle bins frustrate me in trying to remind him what recycle materials going into which one every day. I find I am not very patient but no it is better not to shout. The move will be helpful as our daughter is a lot more patient. He is okay with the same routines. I find it frustrating that he goes to bed early, but I have got used to it now. We have been married for 47yrs. I love him, because of love I tolerate and put-up with him, otherwise it will be chaos.*' This narrative account provides unique details of what this carer is experiencing in contrast to what quantitative data provides, in terms of ratings of severity of problems, with little description on their nature. For the researcher and potentially the carers, it puts into words just how much they are faced with in their caring roles which rating scales fail to do. It might also explain the normalisation process carers go through as described by Clarke (1999), as through talking about the problems and time, carers get used to them. The quantitative part of the study involved the use of standardised outcome tools which enabled researchers to compare findings with other studies that used similar tools. The mixed design study allows comparison between qualitative and quantitative data for similarities or differences, as well as offers the potential to explain such differences, which would not have been available if only one design was used. As clinicians, the design of the study with its use of carers' diaries made one realise how much information may be missed from undertaking just a clinical interview through the traditional history-taking and use of rating scales.

The mixed design of the study revealed a gender difference in the carers reporting problems. The male carers tended to under report problems in their narratives and diary entries, which became apparent when reports were compared with the Neuropsychiatry Inventory scores. This under reporting may have an impact on the usefulness of diaries and narrative accounts in male carers or the need to put this into consideration, when taking accounts from male carers. It may be that male carers tend to normalise things much more than female carers, or a reflection though not confirmed in this study or the literature, that female patients with dementia may be less demanding on family carers. A number of studies indicate that male caregivers are more susceptible to physical illnesses as a result of caring while female caregivers are more susceptible to psychological symptoms like loneliness and depression (Beeson et al. 2000; Pinquart et al. 2006; Scholzel-Dorenbos et al. 2009). In our earlier study (Russell et al. 2014), the male to female ratio of admissions was 1:1, a possible reflection that breakdown of care was as likely for both males and females.

The Research Journey Continues

As mentioned earlier, this reverse research journey in dementia has gone from the later stages of dementia to the time of initial referral and assessment of persons with memory problems. Patients in the earlier studies were inpatients in National Health Service continuing care units and assessment wards where they had presented with predominantly physical aggressive behaviour problems (Ballale et al 2010; Jayalath et al 2013; Russell et al 2014). The patients had moderate to severe dementia with high degrees of dependency. In contrast, in this current study involving the use of carers' diaries, patients were in the earlier stages of assessment and treatment of dementia with the predominant reasons for referral to the memory clinic service being forgetfulness, though in the study, it was observed that behaviour problems were more common than expected, featuring mainly verbal aggression. The following narrative accounts from two participants in the study highlight the challenges family carers faced:

Narrative account from participant 21 (C) on Day 1, *‘Things have been awful. This week, one morning he said he did not sleep because of the bedclothes claiming he was cold. I do not really know. Face flannels disappear and do not where they are going to. I cannot get him to bath. I walk on cotton wool just to keep the peace around me. In the past I had tried to divorce him and he threatened to cut his wrist and commit suicide. Toilet paper goes so quick and do not know what he is doing with it. This morning he reckoned there were two other people in bed. I tried too explaining to him that when you have dementia your mind goes back to your childhood. I explained to him this experience may be due to his childhood when he had to share a bed with his two brothers’.*

Narrative account from participant 22 (DG) on Day 1, *‘Having to repeat things time and again and it is difficult to keep my cool. I can’t help showing my impatience. I do not think I am too bad. This upsets him. He constantly asks questions over and over again. It is difficult to carrying out a normal conversation like things in the news he forgets quite quickly and cannot converse. Our conversations are now much less than they used to be. He cannot follow a film through as he forgets likewise in a TV serials. These make conversations much less. This morning a neighbour rang from the Isle of Wight who died but he could not remember him so could not discuss about the deceased person with him as he has forgotten. We had our 50th wedding anniversary and had a big party which he has totally forgotten about so cannot refer back to and it is difficult to carry on life as one would like.*’

The study has shown how carers' diaries enhance the information provided by identifying more problems and increasing the recollection of carers providing a retrospective account. The potential for diaries to improve patients' problems and benefit carers though not established in this study is still worthwhile exploring further with future research, in light of the highlighted challenges faced and some research studies suggesting diary writing may be therapeutic.

Implication for practice and research

Our findings of potential benefit in the use of carers' diaries in dementia, is likely to lead to our local dementia care service, pilot the use of carers' diaries in the initial assessment of people with dementia. There is also the potential for the use of carers' diaries in primary care, where they may prove to be a useful screening tool for persons who present with memory clinics to their general practitioners. This can be an area of future research in collaboration with general practice colleagues.

Limitations

The short duration of diary keeping for a week may not have enabled the researchers see the full benefits on carers' quality of life and emotional state. The carers were not involved in the development of the diary so their views or perceptions were not obtained, which may have led to a more user friendly design. A choice of diary method was not available and this could have impacted on some carers who may have preferred or found electronic diaries easier to complete, especially in the case of younger carers.

SUGGESTIONS FOR FURTHER RESEARCH

More research using diaries in dementia covering longer period than a week may be required to ascertain other benefits such as improving carers' well-being and problems in persons with dementia. In undertaking further research, the involvement of carers as well as persons with dementia, in developing or modifying carers' diaries to help take into consideration their perceptions and preferences is essential and may enhance the positive impact of carers' diaries. As there were too few newly diagnosed persons with dementia in this study, future studies on newly referred or diagnosed patients with dementia may help to evaluate impact of carers diaries may have on new patients yet to have any other treatment interventions. With the advancement in information technology, there is the potential to look at other formats of diary keeping such as audio or electronic diaries, which may enhance use or give options to carers in any future studies.

CONCLUSIONS

Both carers' diaries and their retrospective narrative accounts have highlighted behaviour and cognitive problems to be the most prominent problems. The carers' diaries are able to provide more information on problems faced in caring for dementia than history taking in clinics. By using diaries, carers may also provide better account of problems compared to those who do not keep diaries when providing a retrospective narrative like what takes place in most clinical settings during assessment of dementia. They may be useful tool to complement the assessment of people with memory problems, as well as lead to a reduction in the perception of problems faced by carers. There is a need for a longer period of study involving carers' diaries in the assessment of dementia and in other settings like primary care, to see if carers’ diaries can have a beneficial effect on persons with dementia and their family carers.

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APPENDIX

Appendix 1: The diary

The diary to be completed by carers – page to be completed for each problem

1. When did the problem with one you care for happen? Time:______ Date:________

2. When did you record the problem in the diary? Time:______ Date:_______

3. Please describe the problem(s)

4. What caused the problem(s)?

5. How serious was the problem?

Encircle one appropriate response 0 1 2 3 4 5

Not serious → → Very serious

6. How distressing was the problem for you?

Encircle one appropriate response 0 1 2 3 4 5

Not at all → → Very severe

7. What did you do at the time to help resolve the problem?

Acknowledging any problems you were unable to record

Please acknowledge any problems you were unable to record by ticking in the appropriate box below

	Behaviour	**Emotion**	**Beliefs**	**Memory**	***Other**
Day 1					
Day 2					
Day 3					
Day 4					
Day 5					
Day 6					
Day 7					

*Please specify others…………………………………………………………..

Subject Number……   Subject Initials……..

Use of Carers' Diaries in Dementia Study

Instructions for completing the diary

Thank you for agreeing to take part in this study for which you have been selected to complete a diary of the difficulties or problems faced by the person with dementia you care over the next 7 days

The following will be expected:

1. You are to record all difficulties or problems faced by the person you care for over the next seven days.
2. You should keep the diary with you at all times to enable you to record any difficulties or problems as soon as they happen.
3. If you are unable to record any difficulties or problems you can use the tick box on the 1st page to indicate what problems you were unable to record each day.

Hertfordshire Partnership NHS
University NHS Foundation Trust

Appendix 2: Carer Information Sheet

Subject Number……. Subject Initials……..

Carer Information Sheet

Version 1 August 11 2013

Use of Carers' Diaries in Dementia

You and the person you care for are being invited to take part in a research study. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. If you do decide to take part in this study, we ask that you will be with the person you care for during the initial visit concerning this study. It is important that you know this person well enough to confirm information we gather at the person's visit. It is important that you and the person you care for understand the research study before you agree to participate.

Please take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

Despite substantial research we know relatively little on patients' problems in everyday life. This is because we rely on carers' memories which may fail to recollect most problems. This study is one of the first of its kind using carers' diaries to identify everyday problems. We aim to examine if keeping a diary will make a difference to carers in caring for their loved ones at home. This information will be collected by researchers who will complete a number of questionnaires about you and the person you care for at home or in the clinic.

2. Why have I been chosen?

You have been chosen because you care for a person who has been diagnosed with Alzheimer's disease.

3. Do I have to take part?

No, it is up to you to decide whether or not to take part. The researchers will go through the information sheet with you. If you decide to take part, you will be asked to sign the consent form at the end of this document. You are still free to withdraw from the study at any time without giving a reason. Withdrawing will not affect the standard of care, you or the person you care for, receive. Participation in this study is entirely voluntary and if you decide to withdraw from the study, no new information will be collected, but we will use the data collected up to the time of your withdrawal unless you specify otherwise. You and your study partner will each be given you own copy of the Information and Consent Form.

4. What will happen to me if I take part?

If you do decide to take part in this study, an appointment will be made for you and the person you care for to meet with the researcher. The visit will be in the home of the person you care for or in the clinic, based on your preference and that of the person you care for. If you have to come to the clinic, your travel expenses will be refunded to you.

You will be asked questions about the person's medical history, mental performance, ability to conduct activities of daily life, behaviour and quality of life. You will also be asked questions about the potential burden for you and your quality of life. In addition, it may be necessary to consult the medical notes of the person you care for to establish their use of medical services and check some of the data collected during the research visit. You may or may not be asked to keep a diary of problems encountered in caring for seven days.

You will need to take part in an initial assessment lasting 30 – 45 minutes. This will be followed by two further sessions, one and four weeks later, lasting up to 30 minutes each time.

5. What are the possible benefits of taking part?

It could provide crucial missing information about problems dementia patients have in everyday life. The study will be one of the 1st of its kind, as no similar study has been conducted. It could potentially show the positive benefit keeping a diary has on carers and in dementia care. The findings could help clinicians improve clinical diagnosis. In addition if you are asked to complete a diary it may give insight in dealing with problems.

6. What are the possible disadvantages and risks of taking part?

The nature of some problems may be ones you wish to avoid thinking or discussing about. Such research is not undertaken lightly however, so it is crucial that you keep in mind the following information at all times during the study:

You may withdraw from the study at any time, whether before, during, or after a task. If at any point you feel you would like to continue but could use a break first, by all means take a rest. If you have any concerns or questions at any point, please do not hesitate to raise them.

The researcher will check on your welfare throughout the study: your comfort and wellbeing are of paramount importance, and this will be monitored and ensured throughout your participation over and above any other consideration regarding the study.

If after the study is over you feel distressed in any way, please ask a care team member for help. If you feel any distress, please contact either the Glaxo Day Hospital staff, or your own G.P. If you feel distressed out of normal office hours please contact the NHS Mental Health Helpline on **01438 843322**, this is a service provided free to carers as well as patients throughout Hertfordshire. If you are unsure of any of these details please tell the researcher and your care team member now so we can ensure you have access to help and support when needed.

If it becomes apparent from your participation in this study that you may require some assistance regarding your well-being, Dr. Ashaye at the Lister Hospital may contact you regarding meeting with you to discuss your situation.

7. Will the fact that I am taking part in the study be kept confidential?

If you join the study, some parts of the medical records of the person you care for and the data collected for the study, will be looked at by the researchers. At all times, the data collected will be anonymised and your records and that of the person you care for will be identified by a unique number. Everyone will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

8. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You will be able to contact the study team at the Mental Health Unit on 01438285247. If an issue arises which cannot be resolved by the research team you can contact Hertfordshire Viewpoint for independent advice on 01707 328014.

9. Compensation:

The medical practitioners involved in this study have current medical insurance cover. Nothing in this document restricts or reduces your rights.

10 Who is organising and funding the study?

The study is self-funded by the researchers

11 Who has reviewed the study?

The study has been reviewed and given a favourable opinion by the Local Ethics Committee who are an independent group of people tasked with protecting all research participant's safety, rights, wellbeing and dignity. They look at research projects, which are to be conducted in the NHS.

Finally,

Thank you for taking the trouble to read this information. If you have any further questions or if any other issues arise during your participation in the study please do not hesitate to contact Dr Kunle Ashaye on 01438285247 and we will do our best to help.

Investigators

1. Dilini Jayalath – Speciality Doctor in Old Age Psychiatry
Hertfordshire Partnership University NHS Foundation Trust
2. Kunle Ashaye – Consultant in Old Age Psychiatry
Hertfordshire Partnership University NHS Foundation Trust
& Visiting Professor at University of Hertfordshire
3. Prof Lia Kvavilashvili
Department of Psychology
School of Life and Medical Sciences
University of Hertfordshire

Appendix 3: Consent form for carers

CARER CONSENT FORM

Study Number:
Subject Identification Number for this study:

SHORT TITLE: Use of Carers' Diaries in Dementia

Name of Investigators: Drs Dilini Jayalath, Kunle Ashaye & Prof Lia Kvavilashvili

1. I confirm that I have read and that I understand the Carer Information Sheet dated, August 11 2013, Version1, for the above study and have had the opportunity to consider the information, ask questions, and have had such questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐
3. I expressly consent to the inclusion of the data I provided in a database which may be used for the purposes of the study and personal data will only be seen by the research team. ☐
4. I agree to take part in the above study. ☐

Printed Name of Study Participant	Signature of Study Participant	Date

Name of trained personnel   Signature:

Date:

Appendix 4: Patient Information Sheet

Subject Number……. Subject Initials……..

Patient Information Sheet

Version 1 August 11 2013

Use of Carers' Diaries in Dementia

You and your carer are being invited to take part in a research study. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. It is important that you and caregiver understand the description of the research study before you agree to participate.

Please take time to decide whether or not you wish to take part.

2. What is the purpose of the study?

This study proposes to look at carers' diaries in dementia care. We aim to examine if keeping a diary will make a difference to carers in caring for their loved ones at home. This information will be collected by researchers who will complete a number of questionnaires with your carer at home or in the clinic.

2. Why have I been chosen?

You have been chosen because you have been diagnosed with dementia.

3. Do I have to take part?

No, it is up to you to decide. The researchers will go through the information with you. If you decide to take part, you will be asked to sign the consent form at the end of this document. You are still free to withdraw from the study at any time. You do not have to give a reason. If you do decide to withdraw, this will not affect the standard of care you receive. Participation is entirely voluntary and if you decide to withdraw from the study, no new information will be collected, but we will use the data collected up to the time of your withdrawal unless you specify otherwise. You and your study partner will each be given a copy of the Information and Consent Form to take home.

4. What will happen to me if I take part?

If you do decide to take part in this study, an appointment will be made for you to meet with the researchers to obtain your written consent. The visit will be in your home or the clinic, based on your preference. You will not be expected to answer any other questions as the study involves obtaining information from carers.

Your carer will be asked questions about you by completing a number of questionnaires rating the severity of your dementia. Your carer will also be rated on their quality of life, mental function and screened for any anxiety or depressive symptoms. In addition, it may be necessary to consult your medical notes to establish your use of medical services and check some of the data collected during the research visit.

Your carer may also be asked to complete a diary for seven days regarding any problems experienced in caring for you.

5. What are the possible benefits of taking part?

This study could potential show the positive benefits of keeping a diary has on carers and the persons with dementia they care for. It could also provide more information for the assessment in dementia.

6. What are the possible disadvantages and risks of taking part?

This study involves collecting information from you and the person you care for, so there are no physical risks involved.

7. Will the fact that I am taking part in the study be kept confidential?

If you join the study, some parts of the medical records of the person you care for and the data collected for the study, will be looked at by the researchers. At all times, the data collected will be anonymised and your records and that of the person you care for will be identified by a unique number. Everyone will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

8. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You will be able to contact the study team at the Mental Health Unit on 01 438 285247. If an issue arises which cannot be resolved by the research team you can contact Hertfordshire Viewpoint for independent advice on 01707 328014.

9. Compensation:

The medical practitioners involved in this study have current medical insurance cover. Nothing in this document restricts or reduces your rights.

10 Who is organising and funding the study?

The study is self-funded by the researchers

11 Who has reviewed the study?

The study has been reviewed and given a favourable opinion by the Local Ethics Committee who are an independent group of people tasked with protecting all research participant's safety, rights, wellbeing and dignity. They look at research projects, which are to be conducted in the NHS.

Finally,

Thank you for taking the trouble to read this information. If you have any further questions or if any other issues arise during your participation in the study please do not hesitate to contact Dr Kunle Ashaye on 01438285247 and we will do our best to help.

Investigators
1. Dilini Jayalath – Speciality Doctor in Old Age Psychiatry
Hertfordshire Partnership University NHS Foundation Trust
2. Kunle Ashaye – Consultant in Old Age Psychiatry
Hertfordshire Partnership University NHS Foundation Trust
& Visiting Professor at University of Hertfordshire
3. Prof Lia Kvavilashvili
Department of Psychology
School of Life and Medical Sciences
University of Hertfordshire

Appendix 5: Patient Consent Form

PATIENT CONSENT FORM

Study Number:
Subject Identification Number for this study:

SHORT TITLE: Use of Carers' Diaries in Dementia

Name of Investigators: Dr Dilini Jayalath, Dr. Kunle Ashaye & Prof Lia Kvavilashvili

Please initial box

1. I confirm that I have read and that I understand the Information Sheet dated August 11, 2013 Version 1, for the above study and have had the opportunity to consider the information, ask questions, and have had such questions answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. I understand that sections of my medical notes and data collected during the study may be looked at by the researchers. I give permission for these individuals to have access to my records. ☐

4. I consent to the inclusion of my data and records in a database which may be used for the purposes of the study ☐

5. I agree to take part in the above study. ☐

_______________ _____________________________

Printed Name of Study Participant Signature of Study Participant

Date

Appendix 6: Proforma for patients & carers sociodemographic details

PROFORMA

		Tick when appropriate (* Delete)
Participant Code no.		
Carer Age / Gender		
Patient Age / Gender		
Carer relationship to patient	**Spouse** **Child** **Sibling** **Grandchild** **Friend** **Others (specify)**	
What kind of diary do you keep?	**None** **Electronic – mobile phone** **Electronic – computer** **Others (specify)**	
Duration of symptoms: **Years \ months** **Date started**		
Duration of treatment **Years \ months** **Date started**		
Reasons for referral		

MMSE on initial assessment		
Diagnosis	**Alzheimer's dementia** **Vascular dementia** **Lewy Body dementia** **Fronto-temporal lobe dementia** **Others (specify)……………………**	
Severity of dementia	1. Mild 2. Moderate 3. Severe	
Current Abode of patient	Home alone Home with family carer Residential \ nursing home	
Homecare package	1, 2 or 3 times a day Live in carer (Yes / No)	*Yes / No *Yes / No
Day Care Package	Any Details please provide	* Yes / No/
Medication		
Other Interventions recorded		

Appendix 7: The 6CIT Dementia Test

Question	**Score range**	
What Year is it	0-1	
What month is it	0-1	
Give the memory phrase e.g. (John/Smith/42/West Street/Bedford)		
About what time is it	0-1	
Count back from 20-1	0-2	
Say months in reverse	0-2	
Repeat the memory phrase	0-5	
Total score for 6CIT	**0-28**	

Rating of Total Scores

0-7 = normal - referral not necessary at present

8- 9 = mild cognitive impairment - probably refer

10-28 = significant cognitive impairment - refer

Appendix 8: Clinical Dementia Rating Scale

	NONE 0	QUESTIONABLE 0.5	MILD 1	MODERATE 2	SEVERE
Memory	No memory loss or slight Inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss: more marked for recent events; defect interferes with everyday activity	Severe memory loss, only highly learned material retrained: new material rapidly lost	Severe memory loss only fragments remain
Orientation	Fully oriented	Fully oriented but with slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only
Judgement and Problem Solving	Solves everyday problems and handles business and financial affairs well; judgement good in relation to past performance	Slight impairment in solving problems, similarities and differences	Moderate difficulty in handling problems, similarities and differences; social judgement usually maintained	Severely impaired in handling problems, similarities and differences; social judgment usually impaired	Unable to make judgements or solve problems
Community Affairs	Independent function as usual in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection	No pretence of independent function home; appears well enough to be taken to functions outside the family home	Appears too ill to be taken to functions outside the family home
Home and Hobbies	Life at home, hobbies and intellectual interests well maintained	Life at home, hobbies and intellectual interests slightly impaired	Mild but definite impairment of functions at home; more difficult chores, and complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in the home
Personal Care	Fully capable of self-care		Needs prompting	Requires assistance in dressing hygiene and keeping of personal effects	Requires much help with personal care; frequent incontinence

Morris, J.C. (1993)

Appendix 9: Hospital Anxiety and Depression Scale.

Read each statement below and underline the reply which comes closest to how you have been feeling in the past week.

I feel tense or 'wound up'

Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy

Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind

A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful

Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed

Definitely
Usually
Not often
Not at all

I feel as if I am slowed down

Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things

As much as I ever did
Rather less than I used to
Definitely less that I used to
Hardly at all

I get sudden feelings of panic

Very often
Quite often
Not very often
Not at all

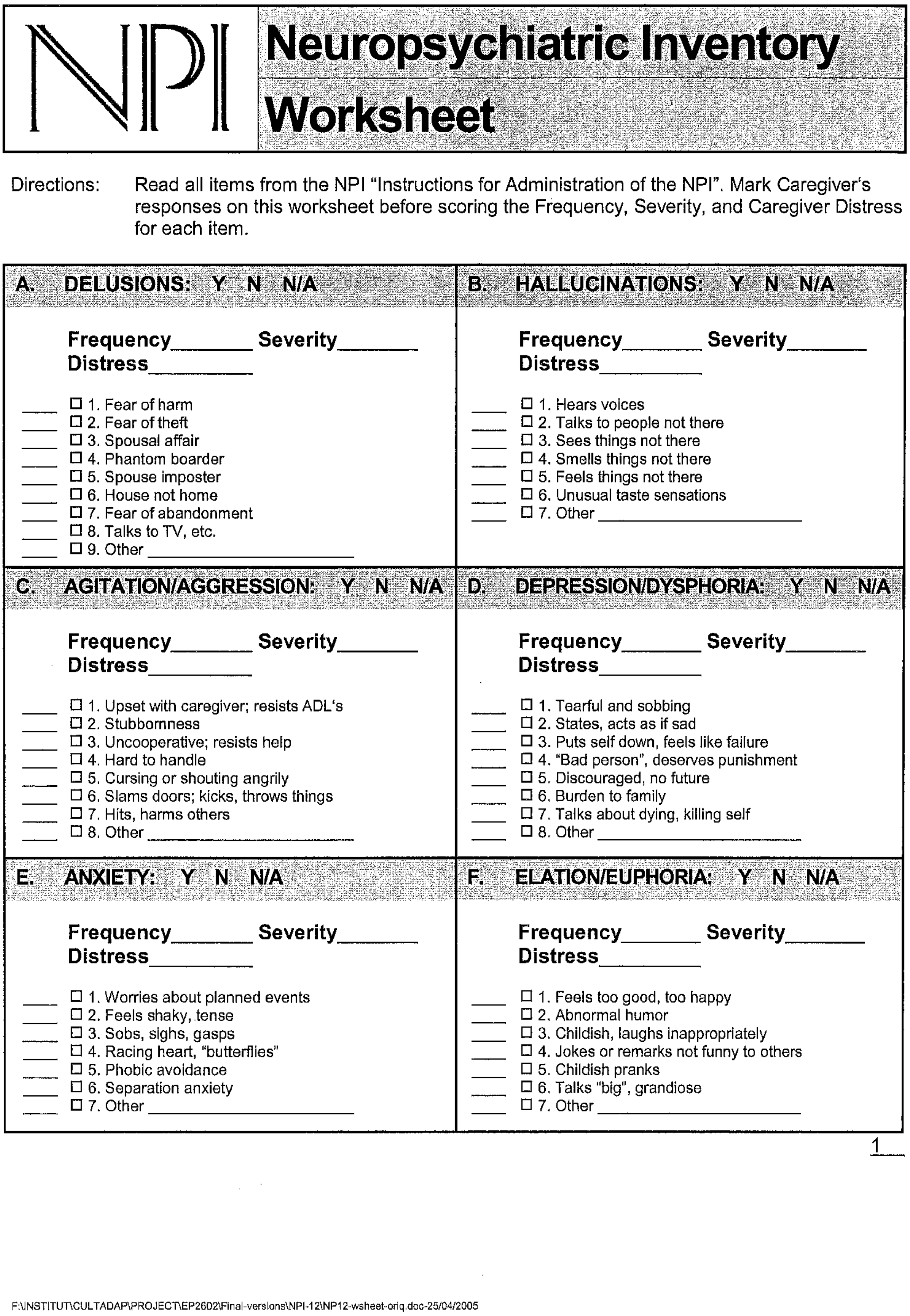
I can enjoy a good book or radio or television programme

Often
Sometimes
Not often
Very seldom

Zigmund, A., & Snaith, R. (1983).

The Hospital Anxiety and Depression Scale

Appendix 10: Neuropsychiatry Inventory Worksheet



NPI

Neuropsychiatric Inventory Worksheet

Directions: Read all items from the NPI "Instructions for Administration of the NPI". Mark Caregiver's responses on this worksheet before scoring the Frequency, Severity, and Caregiver Distress for each item.

A. DELUSIONS: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Fear of harm
____ ☐ 2. Fear of theft
____ ☐ 3. Spousal affair
____ ☐ 4. Phantom boarder
____ ☐ 5. Spouse imposter
____ ☐ 6. House not home
____ ☐ 7. Fear of abandonment
____ ☐ 8. Talks to TV, etc.
____ ☐ 9. Other ____________________

B. HALLUCINATIONS: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Hears voices
____ ☐ 2. Talks to people not there
____ ☐ 3. Sees things not there
____ ☐ 4. Smells things not there
____ ☐ 5. Feels things not there
____ ☐ 6. Unusual taste sensations
____ ☐ 7. Other ____________________

C. AGITATION/AGGRESSION: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Upset with caregiver; resists ADL's
____ ☐ 2. Stubbornness
____ ☐ 3. Uncooperative; resists help
____ ☐ 4. Hard to handle
____ ☐ 5. Cursing or shouting angrily
____ ☐ 6. Slams doors; kicks, throws things
____ ☐ 7. Hits, harms others
____ ☐ 8. Other ____________________

D. DEPRESSION/DYSPHORIA: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Tearful and sobbing
____ ☐ 2. States, acts as if sad
____ ☐ 3. Puts self down, feels like failure
____ ☐ 4. "Bad person", deserves punishment
____ ☐ 5. Discouraged, no future
____ ☐ 6. Burden to family
____ ☐ 7. Talks about dying, killing self
____ ☐ 8. Other ____________________

E. ANXIETY: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Worries about planned events
____ ☐ 2. Feels shaky, tense
____ ☐ 3. Sobs, sighs, gasps
____ ☐ 4. Racing heart, "butterflies"
____ ☐ 5. Phobic avoidance
____ ☐ 6. Separation anxiety
____ ☐ 7. Other ____________________

F. ELATION/EUPHORIA: Y N N/A

Frequency_______ Severity_______
Distress_________

____ ☐ 1. Feels too good, too happy
____ ☐ 2. Abnormal humor
____ ☐ 3. Childish, laughs inappropriately
____ ☐ 4. Jokes or remarks not funny to others
____ ☐ 5. Childish pranks
____ ☐ 6. Talks "big", grandiose
____ ☐ 7. Other ____________________

1

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NPI

Neuropsychiatric Inventory Worksheet

G. APATHY/INDIFFERENCE: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Less spontaneous or active
____ ☐ 2. Less likely to initiate conversation
____ ☐ 3. Less affectionate, lacking emotions
____ ☐ 4. Contributes less to household chores
____ ☐ 5. Less interested in others
____ ☐ 6. Lost interest in friends or family
____ ☐ 7. Less enthusiastic about interests
____ ☐ 8. Other ____________________

H. DISINHIBITION: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Acts impulsively
____ ☐ 2. Excessively familiar with strangers
____ ☐ 3. Insensitive or hurtful remarks
____ ☐ 4. Crude or sexual remarks
____ ☐ 5. Talks openly of private matters
____ ☐ 6. Inappropriate touching of others
____ ☐ 7. Other ____________________

I. IRRITABILITY: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Bad temper, "flies off handle" easily
____ ☐ 2. Rapid changes in mood
____ ☐ 3. Sudden flashes of anger
____ ☐ 4. Impatient, trouble coping with delays
____ ☐ 5. Cranky, irritable
____ ☐ 6. Argues, difficult to get along with
____ ☐ 7. Other ____________________

J. ABERRANT MOTOR BEHAVIOR: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Paces without purpose
____ ☐ 2. Opens or unpacks closets or drawers
____ ☐ 3. Repeatedly dresses and undresses
____ ☐ 4. Repetitive activities or "habits"
____ ☐ 5. Handling, picking, wrapping behavior
____ ☐ 6. Excessively fidgety
____ ☐ 7. Other ____________________

K. NIGHTTIME BEHAVIORS: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Difficulty falling asleep
____ ☐ 2. Up during the night
____ ☐ 3. Wanders, paces, inappropriate activity
____ ☐ 4. Awakens others at night
____ ☐ 5. Wakes and dresses to go out at night
____ ☐ 6. Early morning awakening
____ ☐ 7. Sleeps excessively during the day
____ ☐ 8. Other ____________________

L. APPETITE/EATING BEHAVIORS: Y N N/A

Frequency_______ **Severity**_______
Distress_________

____ ☐ 1. Loss of appetite
____ ☐ 2. Increased appetite
____ ☐ 3. Weight loss
____ ☐ 4. Weight gain
____ ☐ 5. Change in eating habits
____ ☐ 6. Change in food preferences
____ ☐ 7. Eating rituals
____ ☐ 8. Other ____________________

Appendix 11: EuroQoL-5D-3L

EQ-5D-3L

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

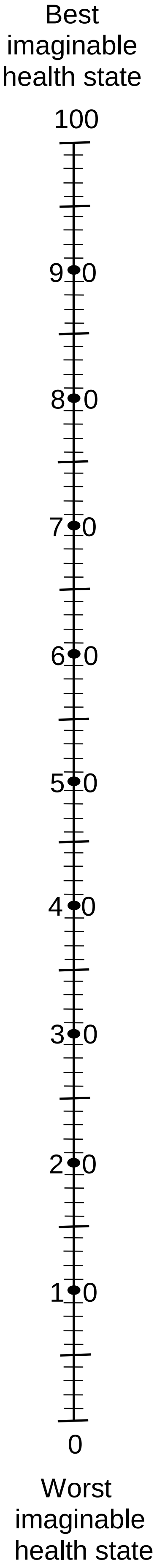
Anxiety/Depression

I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix 12: Post Diary Debrief Questionnaire

Below is a list of questions that relate to your experiences of keeping a diary for a week. For each question please tick the answer that best applies to you. The purpose of this questionnaire is to find out whether the use of a diary method worked well or not and if you felt this was a useful or interesting experience. ***There are no right or wrong answers so please answer honestly.***

1. Did you keep your diary with you every day of the week?

○ Yes ○ No

If your answer was NO, on how many days did you not have the diary? Please be specific

2. If you did not keep your diary with you all the time, were there reasons for this and if so please write what the reason was/were? (Did you forget? Was it inconvenient or inappropriate?)

3. How did you find keeping your diary with you at all times?

○ Very easy ○ Somewhat easy ○ Somewhat difficult ○ Very difficult

4. What percentage, out of all the difficulties/problems over the 7 days, do you think you recorded and acknowledged (on the days when you had the diary with you all the time)?

5. How did you find recording difficulties/problems using the diary provided?

○ Very easy ○ Somewhat easy ○ Somewhat difficult ○ Very difficult

If you found it difficult, what made it difficult for you?

6. Do you think that keeping a diary had any effect on your mood and how you feel?

1 2 3 4 5 6 7

Made me feel No effect Made me

feel

A lot worse a lot

better

7. Any other comments?

Appendix 13: Narrative accounts of carers on problems and difficulties at Day 1 and Day 8.

Patient & Group	**Participant no.**	**Day 01**	**Day 08**
WA **DIARY**	01	We had tea at 1 o'clock in the morning. I did drink it then I told him to go back to bed. He wanders to find the toilet but there again I am alert to say go. He is really basically when he is fast asleep he wanders, he is very restless at night so we have to sleep in separate rooms. We went to a wedding on Saturday. It was not a real problem but he does not speak. I am used to it and my family are too but no other people. I do not think he is a real problem but I do get irritated at times. It seems his co-ordination has gone. I have learnt to be less irritated to give him time to think what he is doing.	He had a funny turn on the 2nd day but he got over it. He has not too bad apart from the chaos trying to sell their home. He has been very helpful when people came to view the property. I find the recycle bins frustrates me in trying to remind him what recycle materials going into which one every day. I find I am not very patient but no it is better not to shout. The move will be helpful as our daughter is a lot more patient. He is okay with the same routines. I find it frustrating that he goes to bed early, but I have got use to it now. We have been married for 47yrs. I love him, because of love I tolerate and put-up with him, otherwise it will be chaos.
GM **DIARY**	02	There is nothing wrong with his sleeping. He gets up and goes into a chair and sleeps again. Like to get out when we can. He does not communicate with other people too well. He goes to the farm house but does not talk to anyone except when one lady asks him questions. When we go to Bridge I usually go through things because still he forgets. Sometimes remind him to brush his teeth or gets dressed. I have to make sure he is prompted to have a bath. Very good at keeping a change of clothing and is quite smart. He helps with the ironing and does not do washing up as she sometimes has to redo them. Forgets names. Does not remember people's names.	Nothing more than the usual has happened in the past week. His memory is not good, sometimes he can recollect others on other occasions he cannot. For instance he used to go horse racing and over the weekend kept asking when they were going despite not going for many years to Cartmill Horse Racing which he used to go years ago. We went shopping one morning and one particular time I said I was going to get seeds for the birds and he went to the hospice shop where he bought a watch though he already had lots of watches and I was not pleased as it was a lady's watch. He argued that it was only £7. He did something similar where he bought a child watch which was useless and not working. The only other thing that was remarkable he had not been smoking since Xmas because he

			had a chest infection and we went out for lunch with our daughter and friends from Wales and as we were leaving the pub he went to the bar and bought a packet of cigarettes. His daughter took them from him and he was not pleased but accepted it though he said it was not very nice taking them from him.
JW **DIARY**	03	Her memory is poor. She cannot remember a thing. She gets the breakfast things ready but I have to make sure she does not forget some things. Normally she is all right. She has recently had trouble with her feet with in growing toenails. Often she forgets to wear her shoes and I often have to remind her to wear her stockings or socks about six weeks ago. We have got over that the problem as the doctor told me not to worry once she in growing toenail was healed. She does the washing but I have to set the washing machine. She makes the bed and does some of the house work. She does not remember to take tablets.	There have been no major problems. On the Sunday morning she did not where she was. She usually makes the table for breakfast but lay it if for dinner time on one morning. She did not feel alright one particular time, cannot remember what happened and refused to eat her dinner for one day.
BM **CONTROL**	04	He cannot remember to put the television on. His memory is not as good as it used to be. He does know the day or things like that. If he has seen something on TV he does not remember that he has seen it before. I have to give him all his medication apart from the insulin which he is able to administer. He once took his medication when he should not. When I do go out I leave a sandwich for him so he does not have to look for what to eat.	Nothing drastic but not sleeping due to pain. He appears a bit better since starting the tablets as he is not asking as many questions. He has been quite good at remembering things except today when he kept asking when we were going to the hospital for a Physio appointment. Once we get his leg sorted with the pain I think it will be a lot better. At least two hours each night he is up and not sleeping. Sometimes he is just sitting in the living room writing things he wants to do. Finds it difficult to use the computer and relies on his grandson to switch it on.
JC **CONTROL**	05	She repeats questions over and over again. Going on holiday and got very anxious about packing and when I am not around. Someone asks her the questions and she looks to me to	I started on Sunday. I got up at 7.30 and got breakfast for Jean. I had dishwasher session and sorted the airing cupboard. Helped my wife had a wash. I get clothes laid

		answer it. The main problems are anxiety and reliant on me. She will not take a shower where she is unable to grab things because she is frightened of falling inside and outside. If we go outside together she is always holding on to me in case she trips. I have taken over all the house chores from cooking, house cleaning, washing her down as she does not go into the shower because she is frightened of falling. She cannot get into the bath. I had to take her about in a wheelchair as we were on holiday and she got very immobile. Seen in A&E following a fall and said she had bruises over her back. The anxiety also occurs during the night and she wakes up saying she is worried	out. She is frightened of falling so cannot get into the bath so she has wet towel wash and I have to help her with it. Prepared lunch at midday. Made various phone calls. I did a little bit of shopping and cleared up. Did a bit more gardening and made tea in the evening. Helped wife change and get into bed. Went to see a lady I care for. On Monday and other days of the week did the same but also did ironing. As the week went by she became more independent and able to dress herself except needing help with the tights.
EC **DIARY**	06	His problem is very short term memory loss. He can often remember things from 60 yrs. ago but not recent things. For instance I tell him to put things out in the bin or refuse but he cannot remember. He is also colour blind does not know which recycle box. I think he eats too much. He has something to eat and goes back to eat again forgetting he has eating all day. I am trying to reduce his weight because he has high blood pressure. If I tell him to do something it is a waste of time as he will not remember. He cannot use the phone as I cannot remember the phone number. He tells her to phone that woman but cannot remember who he wants to ring. He is going deaf in his left ear so things have to be repeated. He has stopped helping in the house completely. He also sleeps a lot as well.	Withdrew from study as admitted to hospital physically unwell.
SW **DIARY**	07	In the past week, there were two episodes of hallucinations, ‘dogs in the bedroom and cat in living room’. They were so real to him. He has been misplaces things like pair of glasses, charger of phone. He cannot remember dates and came this morning shall I have shower now (did not know what time of day it was) and asked did I	The week has been hectic. I have to do everything now. Get him dressed and do his breakfast. He has developed gout and had to take him to the surgery. Told he may have to go into hospital for intravenous antibiotics if it has not cleared up by Monday.

		have my breakfast when he had not. As far as I know he has been taking his medication and I do not like to take this responsibility from him. He goes to bed at night, settles for a while but later wanders about the house at night. Cannot remember people like his granddaughter and his son. Asked his son who the two boys were (his grandsons). He has been quite placid today. He left the gas cooker on for 2 ½ hours once a week and had to insist he not use the cooker and do not like him touching anything now. He cannot remember how to switch the TV on and believes the living room fire controls the TV. Six weeks ago he got lost in the car and they had to call the police out to find him. Family decided they had to take the car off him.	Now have to do all his meals and his tablets to as he forgets to take them. Saw a GP on Wednesday and given a list of medication he has to take. He has had a blood test this morning and will have another when the gout clears. I had to fetch my son out when I saw my husband's inflamed foot. My son was so good to take us to the surgery. Problems are just ongoing with times to give him his tablets as well.
GC **DIARY**	08	His anger is what is most upsetting. He gets very angry and very adamant he does not want to go to any day centre. Does not want anybody to come to the house. He cannot tolerate the grandchildren playing at home. He does not want me to do anything. I had a very bad fall last year and fractured my wrist bone and cheek bones leading to admission to hospital. On account he often tries to stop her doing things. I can find I am very lonely because I do not have a conversation with him. I do not sleep at night because there is so much going round my head. He does not eat much for breakfast, saying he does not want to eat, does not want to talk and does not want watch telly. First in the morning he is very irritable and does not want to get up from bed. Often says he does not want to be here. It does not seem right after all these years (47 years of marriage). He refuses to help and when asked to put the kettle on, he forgets and takes the rubbish out instead. Often argues	He has been brilliant this past week. As you can see I am not tearful. I can honestly say I do not get much of a conversation and finds it difficult with words like he says 'I have put something on the desk when he means worktop. Sometimes goes the wrong way, like he goes out of the living room in the wrong direction when intending to go to the kitchen. He does not have any interest in TV and just wants to sleep. He does not want to get up in the morning. I have to give him his pills.

		when asked to help. I have to keep him out of the kitchen.	
HA **CONTROL**	09	It has been frustrating in the past week. He cannot remember anything and he asks me repeatedly. I have to write things down so he stops asking me. He will take things out of cupboards but cannot remember which cupboard to put things back. I get angry but it is not his fault so I got to stop myself. I love him so much as I hate to see him like this. He is not so nice when we are here on our own but cheers up when someone is around. He is a bit snappy at times and shouts at me. He is still driving but only to familiar areas.	Still frustrating. We argue quite a bit because he keeps asking the same thing. I write things down for him now, like the time of the day. Every day is a hunt day, looking for keys, looking for remote. He cannot keep anything in one place keeps on the moving things. I must admit it is hard. Bless his heart he cannot help it. With me not being well, it is hard, he cannot appreciate it and keeps saying go to the hospital, though I remind him I have already been. He used to be a very caring person. Went to a wedding and a fair, which went well and did not need anyone to keep an eye on him.
AD **CONTROL**	10	He has been normal this past week. He often puts things down and had to hunt. He does forget things and I have to remind him. I do not have to help him at all. Sleeps a lot and only has to sit in a chair and nods off. It is just frustrating having to tell him things over and over again.	A couple of awkward moods. They were something trivial. There have been no difficulties over the last week. Doing some work in the garden with no supervision.
JC **DIARY**	11	Washing is a definite problem also to day for instance brushing her teeth. She had toothbrush in her hand and ended up using it to brush her hair smearing toothpaste on her hair, when I had turned away while helping her wash. She has the fear of water and this makes it difficult for her to have a bath. She also smears faeces and on one occasion smeared faeces on the dogs. Needs to be watched most of the time. Since she broke her hip it is rare for her to get up unaided. She does not get out of bed anymore since the hip operation and she now sleeps better. She does not like changing her clothes. At times has difficulty swallowing or cannot remember what to do with her cutlery.	It has been pretty normal but the issues of continence has become more often. She puts her hands in her pants and throws her faeces or gives it to the dog. She defecated on me once. She cannot remember where anything is or what things are for. She cannot go to the toilet anymore. Uses things like combs inappropriately.
EH **CONTROL**	12	The only problem she forgets what she is doing. For example, she made two cups of tea instead of one, forgetting	She had a bad day on Thursday. She had gone to her granddaughter's sports day and

		she had already made one for herself. She is definitely not eating properly. This causes a few arguments. Her youngest daughter makes sandwiches and took a long time to finish them as I have to encourage her to eat. Sometimes gets dressed to go out when there were no plans to go out. She loves Irish Club and has been going for years. She enjoys whiskey and water.	went home but forgot she had been when it was time to collect her with me. This was only bad day in the week. The rest of week was fine. She is fairly good though has the occasionally slip. Sometimes I have to tell her not to drink too much decaffeinated tea as she has forgotten she has had a drink. I tell her that but it does not register with her.
IR **DIARY**	13	Have problems getting him up and dressed. Getting him to realize he has to get a move on is a bit of challenge. I have to do his buttons up and change his socks. Mainly need to get him to wash. I always have to tell him to wash his hands before his meals and this causes an argument. I feel right heel tell tales on him. I do the dinner and have to call him repeatedly to come and eat. It is like talking over his head as he does not understand what I am talking about. If I keep on to him to hurry up, he shouts at me to shut up. He has never been like this all his life. He had another fall and has bruise on his forehead. I got him but could not hold him and he just went down. He is always cutting up paper and making squares, as he used to be a draughtsman. He is telling false tales up the bombings during the war that are not true. I get embarrassed by all these tales he tells people. He has always been a popular man and sociable.	Withdrew from study as going into respite care
DH **DIARY**	14	I have to find his misplaced keys. I often have to remind him about things like his bus pass. Sometimes gets a bit grumpy. He is so slow with everything. He misses buses and things. He has all these going on like cancer. I am a bit worried about my operation. I am worried leaving him on his own when I need to go into hospital for an operation. He does the cooking but I have to keep an eye on things to	Withdrew from study.

		remind him to switch the cooker off.	
PW **DIARY**	15	Since she has been taking the medication just for a couple of days there has been no change. While we are at home she often asks what to do. I have not noticed any change in her memory. There is nothing difference to what we 4vb had for long term. She forgets to do her clothes washing, but she gets dressed and washes herself. Spends a heck of a long time in the toilet because she has a stoma which she has to sort out. I have got so use to doing the medication as she cannot remember when to take.	Every day is the same routine. Basically she asked me what she needs to do when we come down in the morning. I get the breakfast and do the lot of it. I cannot leave her alone and we go out everywhere. She does not remember what to do and I have to tell her to do things. She asks me what to do. The only problem has been her memory.
GH **CONTROL**	16	The biggest problem he has when he cannot walk and he just stands. You do not know what to do. He has a problem with his speech in last three days and is not able to speak properly. Speaking so slurred and low He has no co-ordination with his hands and unable to put food into his mouth and I have had to feed him. This morning he said I ought to go as I am a burden to you. Last night he could not speak and was seeing things last night. He saw a paddle or oar in his room where there was none. I think it had to do something with rowing when he was young. He talks about his mum as if she was still alive. It is difficult to deal with all these changes which no one tells you about. He suddenly cannot talk properly and sleeps a lot. I have got to keep waking him up to keep him eating and drinking, as he has cancer of kidneys and needs to drink a lot. When people with dementia are diagnosed it will be helpful to know what to expect.	Withdrew from study.
CS **CONTROL**	17	He refused to go to the lavatory when going to the hospital when I asked him. We got to the bus stop and it was raining and when the bus came he said he was bursting to go to the toilet but she refused to let him go and would not get on the bus. A passer-by helped to put on the bus. On the bus he was	We have visitors from our daughter in law and grand-daughter. Both he and his carer's granddaughter got on very well and he was laughing. His mood lifted and watched TV. I asked him where he lived. At night he woke up to go to the toilet and confused. He did not understand a

		holding his penis on the bus ride. I think he was playing up and said he claimed his penis had burst when eh wet himself. Two or three times he tried to get off the bus. On return home he was furious with me and she had to change him. He calmed down when I showed him a letter from his sister with some photographs. The rest of the week has been uneventful apart from his urological problems trying to go to urinate but cannot. On one occasional I had to go to shopping in Tesco but he insisted he wanted to go. On the way he could not walk anymore so she had to ring for a taxi to bring us home. Last night he had horrendous night going to urinate repeatedly. I measured about 700 ml This morning I was talking to him about his sister, when he asked if I wanted to go and see his father and mother and I replied I cannot as they are dead. He then believed that we had broken into the house which is the one here where we both live. He had done this before believing it as not our house. Often pacing up and down today believing he needed to get out of the house which was not his own.	word they say. He felt jittery four days ago. I kept notes and he was quite disturbed by my writing and I explained to him. He is very gracious. On one day he came through to the kitchen but could not remember what he wanted, then came back and said I sometimes feel like crying. He was very emotional.
KG **CONTROL**	18	She was a bit anxious about the visit today. Every day she asks questions about when a family member is visiting several times. Spends most of the time watching TV. She asks questions over and over again. She is very good with her personal hygiene. I have taken over the cooking. Nothing outstanding comes to mind. She was a bit anxious going to the clinic last week	Overall it has been pretty average. There were a few highlights. Our daughter came over and took her to Hitchin Did a bit of shopping and enjoyed herself. That was good. Yesterday we got the scrabble out and she was a bit slow initially and gradually she got a bit better and won. We used to play it all the time and we are going to start playing more. It was good to see her play well. She still asks questions repeatedly and I get a bit irritated and that is all.
AF **DIARY**	19	It is the restlessness that bothers him most. He moves about a lot. We do have odd good nights. Otherwise he is in and out of bed at night, sometimes	It has been quite usual. The day centre is shut for two weeks so he is home all the time. He had a

		going to the kitchen to eat. His main interests seem to be food and drink. Sometimes he comes up to me saying I do not know what to do and I do not know what to do either. Always very tired when comes back from day centre, sitting a chair and going off to sleep. People from North Herts home visited and it was very encouraging that we told about flexi-care though there is a long wait.	dizzy spell at night on new medication so had to stop it. He still gets up at night but no more problems than usual. I worry if I am doing everything right because you believe you can do more. My sister visited yesterday and she took me to see my other sister who is quite poorly. My nephew stayed with my husband at the time with no problems.
BC **DIARY**	20	No real problems apart from the memory. She asks me the same question over and over again. I do not have to help her in any way. She does all the house chores and her own personal care. She helps in the garden and knows the names of all the flowers. Our days are much the same and she gets the breakfast. We do shopping for ourselves and a neighbour. She has given up driving now. She remembers lots of things but short term she forgets like attending a funeral last week.	The last week has been fine. She has the same problem, she keeps repeating herself. She asks you the same question again. She does not have nasty temper or is violent. She carries out all her household chores as normal.
TS **CONTROL**	21	Things have been awful. This week, one morning he said he did not sleep because of the bedclothes claiming he was cold. I do not really know. Face flannels disappear and do not where they are going to. I cannot get him to bath. I walk on cotton wool just to keep the peace around me. In the past I had tried to divorce him and he threatened to cut his wrist and commit suicide. Toilet paper goes so quick and do not know what he is doing with it. This morning he reckoned there were two other people in bed. I tried too explaining to him that when you have dementia your mind goes back to your childhood. I explained to him this experience may be due to his childhood when he had to share a bed with his two brothers.	It has not been a good week. He took the gate to bits and it will not close anymore. He just will not listen. He also took the lawn mower apart and could not find the bits he took off, so I had to go and buy a new one. He told me off about speaking sharply to him. Then he needed a dentist and when I offered to ring for him he said no one day and agreed this next day. He refused to let me put the Rivastigmine patch in the morning. He told me off for waking him up. He also wet himself during the day time.
RF **DIARY**	22	Having to repeat things time and again and it is difficult to keep my cool. I can't help showing my inpatient. I do	It is a constant forgetting what we have just done and about to do and future planning though he always

		not think I am too bad. This upsets him. He constantly asks questions over and over again. It is difficult to carrying out a normal conversation like things in the news he forgets quite quickly and cannot converse. Our conversations are now much less than they used to be. He cannot follow a film through as he forgets likewise in a TV serials. These make conversations much less. This morning a neighbour rang from the Isle of Wight who died but he could not remember him so could not discuss about the deceased person with him as he has forgotten. We had our 50th wedding anniversary and had a big party which he has totally forgotten about so cannot refer back to and it is difficult to carry on life as one would like.	wants to know what we are going to. He often gets the diary down and I dread that as he wants to know when things are about to happen. He constantly forgets things like where he put his glasses and sticks. It is difficult to carry on conversations with him. We spent the weekend with our daughter and he has forgotten we went so won't talk about it. He often refers about his age, for example one evening he was tired and got tow and just said I know my mind is going and sometimes worry what will happen to me as I do not want to end at home. I can change the subject when he feels this way and he will be fine again. Often refers to his age and why he cannot do what he used to do so I have to distract him with other things. He feels he is losing control.
CC **CONTROL**	23	Keeping asking her to take her tablets. She forgets to take her tablets. Sometimes she said yes and other times she refuses to do it saying she is not ready. During the day she rings her son at any time of the day. She keeps saying she has a pension book though she does not have it. Believes her children have taken it and taken her money. She rings the children repeatedly. I help her clean the house but I have stopped doing it because she accuses me of taking her tings. We always take her shopping but sometimes for gets things and claims to go to the shop herself for things. Sometimes she goes out without telling us and we finds evidence she has been out with her shoes and clothes left in the hallway, but she denies it.. She went to Morrison shopping supermarket and could not find her way home and saw a family member saw her and she said she did not know the way home. Often panics quickly if a letter for example comes through the	She was complaining she was cold when you left and refused to eat. She insisted she had eaten. Now she has been mixing up the rubbish as she puts them in the wrong bins. She convinced that it is people from outside who change the rubbish. This morning she felt it was Sunday instead of Tuesday. She repeatedly she asked what day it is. Then she thought it was Friday. She does not know what day it is. Last Thursday she went to pick up her pension but later rang her daughter to go up and pick up her pension again. Repeatedly asking to collect her pension despite keeping a calendar with the dates her pension is due being kept on the wall. Later felt the calendar had been tampered claiming the month of October was missing which was not. On Thursday claimed she had lost her debit card and became agitated and I was scared and trembling as I know she

		letter box and rings the children to come home quickly even if the letters are not important. Every day she forgets when she goes to the bank to get money though it was agreed she goes every two weeks. She no longer likes going out to visit family or go to church. Yesterday the children had gone to work and returned home but she was not at home. Discovered she had decided to go out to the nursing home.	was about to accuse me of taking it which she did. I asked her to go up to check in her bedroom and asked her to try and have some trust in her children. However she continued to accuse me but encouraged her to check in her bedroom where she found it. On Sunday her brother-in-law came visiting and accused the children of refusing to take her to collect her pension and became quite agitated. Her brother in law try to reassure her and showed him his debit card as the means to get money from the bank then next she accused her brother in law that this was his card and not hers despite being in the name of her brother. It took some time to calm her down. She does nothing at home all day.
MS **CONTROL**	24	I have to dig deeper into my reserves. She seems to have a problem with depression. She sleeps a lot and wakes up crying. I ask why and she does not know why she is crying. I have to get on with household chores. We go out every day on the advice of the doctor. We eat out most days and on return she wants to go to bed sometimes quite early and then come downstairs a few hours later saying she wants to go out again thinks it is morning. She wants to keep me in her sight all the time especially when I go into the garden.	One of the biggest problems is having to say things twice. Otherwise nothing untoward. She still sleeps a lot for 12 – 14 hours.
GB **DIARY**	25	His mood changes from very nice and chatting great then in a second it changes. When we are out he is not like that. It is only with me he gets angry. He deserves the best as he is just a good man. He can go back vividly from the time we are young and talks as if both his mother and mother in law are still alive when they are not.	He has been very good. More calm but still have the problem shaving him as he complains about his chin and skin being too sensitive. We have had no outburst and I have been taking him for walks and talking about holidays. On holiday he kept saying he was going home. A few times he was sad and wanted to go and see his mum. Been talking about his mum a lot lately.
AF **CONTROL**	26	Things are very bad. He is going downhill. He needs help to put his proper clothes on. He has had bad	He has been quite difficult last week. He has been very bad tempered and generally hard work.

		tempers and I had a bad week with him. I do not know whether this is down to infection or Alzheimer's.	He has been very confused and generally difficult. For example this morning I was cleaning the windows and he kept moving the furniture when I told him to leave them he threw a wobbly and lost his temper. He shouted at me. He does not seem to like changes in the house and could not seem to cope with me cleaning the windows.
CR **CONTROL**	27	She is confused especially in the morning like where is the bathroom and are we upstairs or downstairs. It can be a little difficult at times because I have a urinary catheter and have a night drainage bag and have to detach myself to help her. She is asthmatic and often needs a nebuliser. She often misplaces things like knitting needles. If I say can you pick up something she will feel for the thing before she identifies it as if she is a blind person.	It has been quiet and fairly good. I took out for a walk on Saturday while I was on my mobility scooter. There have been no problems or difficulties in the past week. The care nurse she had a sore on her elbow and a community nurse came in to dress it. A lady also came in to day to cut her toenails. The home help has also been in.
RC **DIARY**	28	There has been just one thing, goes to bed with all his clothes on. I have to remind him to take his clothes off. He showers and dresses himself. He cannot make a cup of tea so have to make the cups of tea for him and cook. He goes to the day centre twice a week. He is not allowed to go out as he has got lost in the past so I have to lock him in when I go to work doing a little part time.	It has not been too bad. A few verbal abuses but nothing serious.
JR **DIARY**	29	He started to become obsessive about the lawn going to pick up leaves on the lawn or moving books because they were not tidy. He has become obsessive about tidiness. He keeps asking things over and over again. I have to plan for him as he asks me what I am going to do tomorrow. If I do not have an agenda for him tomorrow he becomes anxious and makes me anxious. We can never sit down and relax as he wants me to sit with me. If I am watching TV he graves for attention so disturbs me from watching the TV programme. I	Keeping the diary makes you concentrate. The problems come into three, forgetfulness, possessive behaviour and believing things that are not right. He has not been too bad. There was one day he had soup that was too hot and he claimed it had burnt him. I gave him a throat sweet, and later claimed it had caused him a rash. Often misplaces things and claims that I have moved them. Last week an example of possessive behaviour was he got angry when I was talking to a friend on the

		find it difficult to relax and I do not know what the answer is as he is not going to get better. I have signed up for cognitive behaviour therapy to stop getting anxious. At certain times of the day I get tired and get snappy and he responds angrily.	phone. He shouted that I should put the phone down and turned the TV up load. I feel I am getting quite upset. I think he is going to continue behave like a child if he does not get his own way. When he has got over it he is back to normal while I remain quite upset.
RB **CONTROL**	30	She needs to be reminded what she has to do on a certain day. I have to put this up on the calendar. She forgets cooking. She is able to go out. We went to Cambridge and that went all right. She forgets often and is better than she was in that she gets less anxious than she used to.	Things have been okay. We went shopping in Sainsbury yesterday. She got uptight and lost it a bit when I left her on her own. She is alright in Waitrose which she knows whereas she does not the local Sainsbury very well. She sought of lost her bearings until I came back. We are not going too many places anymore though we went to Cambridge last week and she was all right. She was able to leave to go about on her own because she knows Cambridge. However on her own in somewhere new she will find it difficult.
EW **CONTROL**	31	She gets concerned when we are going somewhere. She cannot remember things and needs to be reminded. Sometimes gets the days confused or when we are going somewhere. Sometimes drifts into the past and talks about her father as if he is still alive.	She has not been too bad. She gets muddled up about things. She woke up the other night asked me to check if Dad was all right. She tells things which are not quite true. Sometimes she does not want to go to bed and this can be quite tiring.
JS **DIARY**	32	Her memory is poor. She got a frozen sweet out for dinner and she had already brought out something for dinner. Often forgets where things are. I have to do her tablets as she forgets to take them. No other problems I can think of. She gives me the shopping list to right down as she no longer wants to do it.	Sometimes she has had a few tears telling people what she has got. On Saturday she wanted to change the bed sheets but could not find them in the airing cupboard. She is getting mixed up with the cooking not knowing what she has to put in the oven. This is all new to me I am not used to this. She went out to the traction engine show on Saturday and seemed to enjoy it.
JM **CONTROL**	33	Terrible. She calls me all the time rather than the carer. Calls me for anything she wants done. If I say let the carer do it she says that is it you do anything for me. She sits in the chair and talks about there are someone else in the room or that carer has her son	She has been a little bit worse. She said there were two blokes in the other room. She believed her husband was in the other room. She imagined her son and grandson were sleeping in the house. She has been up several times at night. She

		with her which is not true. She has been getting confused believing her grandson was going to stay. Sometimes mixes up the names of her son with her grandson. I find it very frustrating and sometimes have to walk out of the room or I will lose my temper.	has had difficulty walking since taking sleeping tablets. She has physically difficult to move about. She was due to go out and changed clothes four times as she was undecided about what to wear. She has a blank look and at times appears not to be able to understand what is going on. She has been crying a lot and said you might as well put me in a box as no one cares.
GW **DIARY**	34	He was a bit confused and forgetful. Always gets confused about what day it is. Otherwise he was all right.	It was not too bad. On Wednesday he thought it was Sunday and asked who was going to pick us up for church and I explained to him that it was Wednesday but sometime later he asked me again. On Thursday we had a blocked toilet and it took me all day to unblock it. He was going to feed the cat and needed a new box of food. Instead of opening a pack in the cat bowl, he poured the cat food on the floor.
NL **DIARY**	35	Mostly he does not know what he is doing and keeps calling me. He calls in such a way that I think it is an emergency but it may be there is a simply a pigeon on the roof. He keeps asking me what he shall be doing now. One of the problems is his incontinence especially when he has a tummy upset. I have to be aware whenever he goes to the toilet. There is a lot of washing to do when he goes to the toilet. I am able to do things when he sleeps. He helps to make salad so still helps where he can. I help him with his bathing and washing. I have to encourage him to do things like shaving. He is not always cooperative and sometimes he will not let me wash him, so I have to go with the flow. If we have the TV on he keeps asking what his or her name referring to the actors. His hearing is a big problem. Often he does hear me but hears other people. Sometimes he has diarrhoea and that was horrible and also had nose bleeds leading to a lot of	He got me up at night a number of times though I told him not to. On one night he was changing his clothes and had tears in his eyes saying I do not know him things have got like this. He got me up every night after that. Sometimes he has just been confused. He has taken to wearing a dressing gown his daughter gave him, despite I telling him he will get hot and he did not take it off but went to bed wearing it then later woke me up at night saying he was hot. I also had a fall when I was taking the rubbish out. I could not get up but could not call him to help me, so I managed to get up myself unaided with difficulty. A lot of it is the inconvenience with the amount of work I need to do and care for him. It is very busy as I am elderly myself.

		clearing and washing to do. I am able to leave him for a while to go out.	
AC **CONTROL**	36	The hallucinations are getting worse. Other than that he has been the same being quiet and gentle. He really does believe that things are real. He has had them all morning and keeps saying he has something in his hair and brushing it all morning to keep them off. He keeps falling about as well. He fell yesterday.	He is still getting the hallucinations and sometimes they frighten him. This morning he said he did not feel very well. He had a bad night. He keeps getting like a gas smell. He is still putting the patches on and his memory is the same. Last Saturday we went shopping and he went round the shops more confident without falling.
JP **DIARY**	37	He has been up and down. Yesterday I was doing the housework and was cleaning the floor and he got angry when I asked him not to come in to a room. He says he is okay but he is not at all. He sits out in the patio all day and shouts at me to get him something to eat then sits out again all day. I do not know what he is going to do during the winter. I keep a dairy anyway.	Not too bad. Saturday he was a bit off as I had to get him up earlier to get his flu injection. I had to some shopping as well and he turned a bit ratty with me but I decided to get on with it and ignore him. He still gets up early at 8.30 and has his breakfast and sits out in the garden all day. He just does do anything most times except make me an occasional coffee and help with the potatoes.
AM **DIARY**	38	There are things that he forgets. He drives wonderfully as he worked as a lorry driver. He is always losing things. He gets obsessed with things like how much money he has in the bank. The fishpond had gone green due to the trees were cut. He went around asking people for the reason for the change of colour.	He has been pushing me on occasions. He has been fine. He went to a funeral yesterday and visited family with no problems. He has been helpful in the house.
YB **DIARY**	39	The major problem she is going through the time reversal. She goes to bed and an hour later she is up waiting for the district nurse. The other morning I left her watching TV and the next minute she had gone to bed. Time is a real problem. She finds it difficult to say what things are. Sometimes it is difficult to understand and she gets upset believe we are being difficult in not understanding. Very frustrated in trying to make her understood and mixes up her daughters.	The major difficulty is she has been getting up in the middle night and getting up dressed and not wanting to go back to bed. She tends to sleep on the day. She is also not remembering dates, times, places and names. She has been hearing things that I have not heard like believing someone was at the front door when there was no one there.
DG **CONTROL**	40	She is forever asking me what to do. Things sometimes get put away by my wife in different ways. I am not sure if this is down to me being oversensitive	She is still quite anxious. Needs reassurance. She repeats things we talked about. Still goes badminton and bowling. Just the odd things

		so may be down to me. She repeats something we have already talked about and repeats things like ‘we are going out Friday night’. I can see terrible times ahead.	but might be being over meticulous but some things are not put in the right place but I may just be oversensitive.
SE **CONTROL**	41	I felt a bit under pressure looking after her. We have come head to head a couple of times as Mum always knows best. Sometimes unhappy with my cooking. She has been losing things like her lower dentures. Puts food in the wrong place like vegetables in the freezer. She gets a bit down sometimes and as temper tantrums. She is completely out of character and this has changed her personality.	It has been pretty good. We have had a couple of lost things but no real problems. I think her memory is getting worse quite quickly but it means she is getting more compliant
JL **DIARY**	42	Not too bad. Last night he got up in the night. I had to take him to the bathroom as he was completely confused. Other times he has not been too bad. I usually do everything for him. I do his meals and may be do too much for him. I get up and get his clothes out every day. He sometimes forgets to puts his pants on or the puts his jumper on the wrong way. Been plodding along like you have to. He is quite a placid man and does not lose his temper very often.	Not too bad. He was up one night and did not want to go to bed but I persuaded him. There was one day he was looking for a cat. In general he was not too bad and I have just got used to him.
MB **CONTROL**	43	We have just back from holiday. On holiday he was absolutely okay. When we are back in a routine he gets frustrated over things he used to do but cannot. Sometimes it appears he is not with me. We seem to be able to cope at the moment.	There have been no problems. It has been a pretty good week.
JD **CONTROL**	44	I have to be with him all the time. He gets up at night to go toilet but ends up not remembering what to do. In general he is fine in his own surroundings	There has been nothing more than usual. Sometimes if you try and hurry him that’s the worst thing. He gets agitated when I do that. He did not go to his club this week as we had a funeral of family relative who had lived to 103 yrs.
AN **DIARY**	45	On Thursday, it got to a peak I did not know what to do for her. I do not know what upset her or did wrong. We were on holiday, I told my son I feel like going home as she was quite difficult. She had a bad night and did not sleep.	There only bothering her are her legs. She is going to get her eyes done in Pinehill. She is not sure if the pain in her head is due to her eyes or legs. There have been no problems of note in the past week.

		Whether I said something I do not know. She was bit off handed the next day. She was abrupt and refused to go out initially, but later changed her mind. She has also been quite upset following a difficult consultant with her GP	She is due to have her bloods taken to check her thyroid.
KB **DIARY**	46	He has had an ulcer on his leg so I have been taking him to the surgery once a week. Yesterday he had a letter for an appointment for a scan of the bladder. The last time we saw the GP he did not mention this but did say she will refer him to the dermatologist. We tried to contact the GP about the scan request but were unsuccessful. Apart from that he is out every day and he enjoys that. We have carers twice a day with the morning one helps to shower and the evening one helps to change into his pyjamas. The morning carer is coming a bit too late as he likes to get up early. He does not sleep well as he gets up to pass water all the time as he takes water tablets.	He has been on a very even keel. There have no problems whatsoever. There was only one day he got a bit irritated with his favourite programme in the afternoon and could not watch it anymore. He got up and left the room and sat in the conservatory.
DJ **CONTROL**	47	He just forgets. He went down to the shop and was supposed to get 3 things but came back with two things this morning. He sometimes gets a little bit anxious, sometimes he gets on his high horse and at times he gets a bit tearful	No problems in the last week. He still seems a little bit agitated and makes funny movements with his hand. He asks the same questions over and over again and says the same things as well. I have just got used to it. He never knows what day it is and he always gets mixed up with his days.
LC **CONTROL**	48	He has been very cross and irritated. Often shouts. Perhaps I am a bit of the problem as I am not very patient. He wants his meals at certain times and has a set routine. He can remember certain things and other he cannot. He forgets things and asks over and over again.	This morning he did not remember when he had travelled to see his brother in law. My son asked where he went on holiday on Tuesday but he looked blank and said he did not know. He had to have his memory jogged to remember about his holiday. He gets a bit irate and cross at times and does not seem to understand things when I explain things to him. He also writes down times a

			go out and come back.
HT **DIARY**	49	He gets very moody. I will be quite honest he was so awkward last night I could have lost my temper. I cooked him a lovely dinner and he said he cannot eat all that in a loud voice. My son helps him with personal care. Physically he was incontinent in the bathroom once last week which I had to clean up. He is occasionally incontinent in bed once in every three weeks.	Five days pretty good and two dreadful. When he loses his temper he loses it completely; everything gets thrown including his stick. It is like throwing a red rag to a bull when he sees me. Then he goes to bed and has a good sleep then cannot remember what happened the day before. He has been out with the daughter in law, granddaughter and great granddaughter.
RM **DIARY**	50	He has not been sleeping properly at night since he came out of hospital. He has been very strange at night and always wants to get up and get dressed. He has been erratic in his speech and capability. It has been a very worrying time. My fear was that the distance he has moved in these nights is further away from me. Last night he called me a cow for the first time ever. His erratic behaviour means that he does not want to do what I ask him to like to rest and go back to sleep. He has been a bit more aggressive towards me and this has been very hurtful.	He has not been sleeping poorly and I have had to be awake with him all night until yesterday when he took the sleeping tablet you gave him. He has also been very incontinent and I have had to change his pads several times a day. He does not like me very much and he has expressed that I am not being kind to him by not letting him get up. Because he wets himself a lot he keeps asking if he is all right.
MW **DIARY**	51	Basically yesterday the bath was too warm for her when I ran it, but today when I ran the bath she found the same temperature she found it too cold. The biggest problem is time. We used to go shopping together but since March she has not been with me except when our son takes to the out of town shopping area.	This last week has been fine until yesterday and today. At approximately at 2 o'clock she had her arms moving in an uncontrollable manner. This was strange that this occurred when she was brightest. I have noted what we had for lunch. Yesterday for lunch we had lamb with mush room sauce and today pork sausage apples in it with apple sauce with roast potato and peas. After lunch she had the jumpy movements lasting a couple of minutes. She has been fine until recently when she has become a bit jumpy. Our daughter came to visit on Sunday and detected that something was wrong. She had a false recall about an experience she had when she was five years. This

			was in 1941 and she had to go to stay with an aunt in Birmingham when her mother when her mother went into hospital. She was very confused about the oft repeated fact that went with that time, which was quite disturbing being in was a long-time in her memory. There have three occasions of contrariness. We have a cruise booked for next year and she has changed her mind on whether to go or cancel the trip depending on if it is a good idea.
AE **CONTROL**	52	If I go out, I tend to wait till when he goes for his walks with a befriender. I have to switch off the mains of the cooker due to fear he may leave the cooker on.	We have had quite calm week. He has been happy as he has had his two walks a day because the weather has been fine. My son was home last weekend and that always perks him up. I have got use to the fact that his memory is not quite good and have to repeat things to him. This is different when you have other people in the house as the conversation is different.
LL **CONTROL**	53	Nothing new that has happened. It is just the same day in day out. We go out to the town. He had knee replacement and he took a while to start walking. So now he likes going out.	There has been nothing out of the ordinary. He is very easy to live with and placid. He is very calm and nothing has changed at all except his memory. He a t times when we go out use his stick to move things on the side walk on the ground. I do not know what to expect when it gets worse.
FR **CONTROL**	54	I have had no trouble in looking after her. She is still capable of doing day to day things. I have told her several times she cannot drink alcohol with the Aricept tablets. But several times this morning she said she wanted wine. I constantly have to tell her what day it is and the date. Every morning when she gets up she does not know what day it is. We are looking to going to the restaurant with our son over the weekend, but she keeps saying you should go to the restaurant now. She frequently follows me round the house and seems to need the confidence of	It has been okay. I have noticed several things my wife seems difficult to assimilate to understand. When I tell her things it does not appear to register. She seems happy enough in herself. She has become very clingy. She is not happy if I am not there for 5 minutes. If I go upstairs she follows likewise if I am doing some gardening. When she repairs some food she gets mixed up for example if we having cheese and biscuits she gets out sweet biscuits which are not suitable for cheese.

		my presence.	
BH **DIARY**	55	We had a challenge, last Friday he was very incontinent, wetting the chairs and bed, frequently taking his clothes last Friday. On Saturday morning he was defecating everywhere. He did not know what he was doing every day and taking his incontinent pads off. It became quite stressful as he repeatedly defecated on his bedclothes and his hands after changing the beddings. On Monday morning he was a lot better. We can tell when he is not right as he has that glazed vacant expression and gets quite shaky. Came back from the day centre where he was wet again due to incontinence. He is slower when walking sometime shuffling and sometimes does not look down to look on the way.	It has been a good week and he has not been incontinent of faeces. He has been okay. Still has some urinary problems, and puts his pyjamas o at the wrong time or puts his clothes on the wrong way. It is mainly the same problems, weeping in the bed or in the wrong place and changing his clothes dressed inappropriately.
LC **DIARY**	56	We have had the case of him believing he was staying in a hotel and needed to have it locked, so was quite repetitive insisting he needed the keys to his hotel room . He believes he had a business that burnt down. He also believes he has so many bank accounts. He spends all day sitting in a chair sometimes all night then falsely claimed he went to bed at night but he did not. He is at the day centre most days. He has no idea of time so ask for tea at 3 o'clock in the afternoon. On Monday when I came to pick him up from respite care he initially did not recognise me. He also does not recognise his daughter or granddaughter. Recently believed that he saved the Queen from some Bramble bushes where she had got stuck and talks about it often.	It has been more about asking the same thing all the time. He talks a load of rubbish like talking about buying a pen knife and giving it to the police. Sleeping wise it was a good night last night so did not get up to go to the day centre. He can sit for hours not speaking except crayoning. He got quite angry when his sister in law touched something he had been painting. On Saturday I took him to Wymondley, but he did not get out of the car but sat in while I went to see the author in a book signing ceremony. He can never remember that he has had his tea and says he is hungry just having his tea. He does not stop eating. Yesterday he got undressed to go to bed at 3 o'clock in the afternoon. I had to stop it. He is unable to say what time of day it is. He does not really know the day centre though he goes four days a week. He claims it is a café where he works and complained that he was not getting paid.
AM	57	We have had an exceptional rough week. Because we are old fashion we	She had been quite repetitive asking the same questions over and

CONTROL		withdraw a lump sum to go shopping but we misplaced it. On Tuesday we could not find the cheque book but later found it. The gas man came last week and we have to spend money on the heating. We are also getting the power of attorney sorted and the GP came round to help with it. I have to go to the Lister for an appointment. She is quite repetitive and asking the same questions over and over again. In all other things she is being quite rationale	over again. Such a shame as she is such a lovely person and we have been married 60 years. She got a bit agitated when the family came round in helping with the completion of the Power of Attorney documents. She generally gets wound up when there are people in the house.
JS **DIARY**	58	There is a toileting problem in that she does not know how to use the toilet anymore. She stands over the toilet and holds faeces in her hands. I have wanted to take her to the hairdressers but she has not wanted to go. She has been getting too tearful because no one comes to see her. She forgets names of people. She was tearful the other morning she could not find something which turned out to be her watch which she already had on. She does not like having a shower.	There have been no major upsets. I get her up in the morning, disconnect the stoma and gets her washed and dressed, and then get her breakfast. She usually sits on watches TV. Normally when we go shopping I leave her in the car and get the shopping. So does all the house work with support of a cleaning lady.
PO **CONTROL**	59	Our son was here last week and that has been very nice as he takes a load off it for me. He has had several arguments with his son and I just listened to see what would go on or try to calm it down. This morning he said he was going to get up at half past six to leave at quarter to eight for the hospital but did not leave till after nine as I cannot move him to do anything in hurry. The slowness is quite difficult to bear. On the other hand he did go out to get the paper yesterday and then came back and got some chocolates for me. He does go off on his own and I get really quite worried. He said it was only for shopping but it was more than that. He likes to go out in the car to the service station by the motor way.	He is still forgetful and won't even look on the calendar and forgets to look what he needs to do. At the moment he is even forgetful of what day it is and has to be reminded. It gets me particularly annoyed when we keep a calendar with a record of our activities. He has tidied his bedroom up and that has amazed me as he had previously spread papers all over his room. He has perked up after going to the day hospital.
SM **CONTROL**	60	I think that this last week she has been extremely good. There is kittle report in the last 7 days. No recollection of any problems.	There was just one occasion. I always do the laundry and put it into the washer and later the dryer. When I finish I put them in the basket and in the bedroom. I told her I finished but a few minutes

			later she asked me if I had finished the laundry so she had forgotten that I had brought the basket of washed clothes into the bedroom. Only other problem depressed her slightly in that someone downstairs said my wife had remarked that she had said the reason why another person went into hospital was probably she went in because she went in for a detoxification. The woman concerned became very angry and she had to go downstairs to apologize and the person's friend became abusive towards her. She decided to let it rest and forget it after she apologized. It was something about nothing but she was upset that the person friend had been abusive towards her. She got over it in the end.
EO **CONTROL**	61	I cannot really find anything specific. He went to see one of his brothers in Northampton and he was trying to describe the visit but had difficulty talking about the mobility chair and what he did or eat. Went down to watch the pictures and was trying to say it started at half-past 7 but it didn't as he was still at home at the start. So he is getting time confused.	Because I had a diagnosis I have been able to deal with him better because I know it is not his felt. He has been asking me a lot how his behaviour has been to day. He seems a little bit clumsy. He is very worried by driving concerns he has to report from the DVLA.
JG **CONTROL**	62	Not an awful lot of problems. We have had the work men in so had to go out which he did not like. I have to help him to dress most days. He does not do anything except walk to the toilet and back with his stick.	Just the usual not doing what he is told. He keeps scratching his head. He sleeps all day. He does not go to toilet when he goes to bed and hence he has accidents in bed (wets the bed).
FR **DIARY**	63	Last week he was getting up at 2 o'clock in the morning, getting shaved and dressed. Refused to get into bed and would ask who am I and I am not getting into bed with you. Every night he was getting dressed at 2.00 am. He would then sleep during the day. He cannot do any house work, urinates over the floor and fails to put the light on in the toilet. He keeps wanting to go out and when he goes out and returns	He has been much better. He still puts on the jacket. On Sunday night he opened the door saying the lady in the house wanting out despite there only being two of use here. He was bent on going out at bedtime which as unusually. The sleeping tablet is making him sleep better. He still does the repeating things and asks who is dead or alive. Still scratches the sofa

		home saying he wants to go out again. At 9 o'clock last night he was asking to go out. He is wetting the bed and incontinence nurse will change the incontinence pads to more absorbent ones.	repeatedly with his hands. He has been falling over a bit. One morning he was bent over in the toilet had to put him in bed for an hour after which he got better.
RB **CONTROL**	64	She was talking to my sister last week and the mobile phone cut off and she became angry it cut off. Could not remember what shops we went in. She thought her grandchild's boyfriend was a girl. She got the names of her grandchildren muddled up. Ashe her sister if Crossroads still on the telly. On Monday, I came in and she was moaning that I had gone on holiday and accused us of not taking care of her and my clothes being in her room. My sister asked if we had taken anywhere and she said no despite being offered to be taken out. She started crying on Monday because she has two sisters in a care home and one sister has not told them they are selling the house of her sister but this upset my mother and she started crying. She gets days muddled up. Telling more stories about the past when she was younger and relating more about the past than the present. She does not like one of my friends because she has a little boy and so my friends are staying away. She gets more aggressive and impatient.	She went to see her sister yesterday, both of them cried because she is in her home. She got a bit annoyed with her glasses falling down and hearing aid. She refused to go the hearing aid check but refused. She threw the hearing aid because it was not working. Yesterday she was a bit angry because of how long it took to see her sister in Luton by road. She got upset because she thought there was a shorter route and later she calmed down. Last week her warfarin went too high and this had to be stopped and got a bit annoyed about why it had gone up. Other than that she has been okay
IM **DIARY**	65	There are difficulties in that she sleeps a lot. Stays in bed till 11. And then sits in a chair and dozes off. So it means she does not go to bed till late. Sleep pattern is not very good. I have to give her 2 hours to get herself ready and this can be a bit stressful as one is keen to get to appointments on time. Basically she does nothing; I have to answer her correspondence, shopping, cooking, and keep the place tidy. She gets few phone calls because she has a speech problem and people cannot understand her. Socializing is out. She virtually does not talk and cannot have a conversation is out.	There are is general problem of asking repeatedly what day of week it is and what do we do today. I have to make sure she takes her pills. She is not really awake a lot of the time. She washes and dressed herself. She turns up downstairs at half past ten then sleeps in the chair.
CM	66	Today has been a bad day. I do not tell	He went wandering after going to

CONTROL		him what is coming up as he is poor with time. He has been aggressive and was not going to wait for the doctors coming today. Several nights this week it has been difficult to get him to bed. He gets in the landing and is never sure which bedroom to go to. Sometimes he wants to go the toilet and does not know where to go like the other time he went to the freezers. I cannot go shopping with him as he wanders off. It is impossible to have any conversation with him as nothing ever makes sense. He tends to think that people he sees in the street he knows them but he does not. Spends time at the window running a commentary of what the neighbours are doing. His whole personality has changed and used to be an easy going person who never put himself forward but now has to be the centre of attraction. He complains bitterly about taking tablets. The sad thing is he has lost the ability to do the most simple of things like making a cup tea. Everything seems to have gone.	the toilet while on a coach trip. I had to get our stuff off the bus and phoned the police and drove round Cricklewood and they got the police helicopter and police dogs out to look for him. My daughter arrived in the area and also joined the search. It was three o'clock in the morning he was found in Westminster. He was very tired and could not find out what happened. It was awful and a really cold miserable night and we did not know the area. He is not very well physically at the moment. I thought he had a urine infection and he had a urine sample taken. He has had diarrhoea which my daughter feels it might be the antibiotics. I think he has deteriorated and suddenly seems very fragile and frail. He gets very agitated at night and wants to go to every room to tidy up. He does not know which bed he sleeps in and often doesn't know which room the loo is in. His ankle seems to be swollen and GP is seeing him next Tuesday.
AS **DIARY**	67	We went out and sometimes he does not know where he is. Hopefully he will have cataracts done soon as he cannot see very well. Yesterday I have a mentor from Cross Roads and I came home and Alan and I went into town as lunch and Sainsbury. He had problems putting things into bags so I have pried his hands open. He gets tired and has to go to bed early. We went to our daughter's for dinner on Sunday. He saw the grandchildren and that went very well. On Saturday we went to Blue water and met with friends we had known for 50 years, the husband also had dementia. He got lost when he	Wednesday was extremely stressful, our fridge broke down and all the sockets stopped working. I tried to put the fuse box switch on. I called the handyman and he took the fuse out and the electricity came back on. Because the fridge was not working I had to get rid of some food. On Thursday we went to our friendship club and had a hilarious talk by an author. On Friday we met our daughter for lunch and did shopping. He could not get dressed. On Saturday, I went with a neighbour out and on return he was all upset. We had got

		went to the toilet. On Friday we went to the memory clinic and came home. He puts his clothes on from back to front I do not get upset or at least I try to. Sometimes he does not know which is his fork and knife. I try to shield him from people who look at him in public as if he should not be there. On Wednesday we went to Stotfold to Chequers with his club. People knew he had dementia and were fine with him. When we were leaving he tried to close the car door but his feet were outside he could not close it so I had to help him.	back late and he had forgotten I had gone on the train and not driving in the dark. Sunday was a quiet day. On Monday I saw my mentor and we went out for lunch. We went to Sainsbury and came home. Sometimes had his underpants on the wrong way or his pyjamas.
JF **CONTROL**	68	He sometimes forgets what day it is. He asked me are you doing so and so today and I tell him I do that on a Sunday and the day is Tuesday. Sometimes he goes to ask me something but cannot finish the sentence. He usually asks me to get his breakfast as he cannot make porridge. On the whole he does not do a lot and he does sleep a lot. If there is phone call he may not remember to tell me immediately but may remember later.	He still sleeps quite a lot. He is slowly deteriorating. We had some visitors for lunch and he was very quiet but was able to cope with it. He does not seem to want to go out and he does not seem to do much. He will not read a book and he use to read a lot. I bought a puzzle book and showed him how to do it and I have not seen the book since. He is very muddled and cannot use the phone. Someone rang when I was out and he could not remember who it was. On another occasion he said the phone rang and he could not get to the phone fast enough.
PW **CONTROL**	69	Sometimes he tidies my desk which he should not and in doing so he causes me to lose things. He cannot remember where he puts things. This also happens in the kitchen. He finds new imaginative places to put things. He does not remember where things are stored.	Thursday last week it was bit of a foggy day with his memory and as a consequence he was not too happy. On Saturday we spent most of the day at a Christmas fayre selling our jams and preserve. He had the challenge of giving change and coping serving people never without me there. He coped extremely well and just on 2 occasions he had to give change for £20 which proved a challenge and I had to help him. He has forgotten how to count upwards with money. In general he rose to the challenge. He has been so much happier on those tablets you prescribed.
PD	70	We had some friends in for dinner on	The problem with the memory she

DIARY		the weekend and we were talking about grandchildren. She asked the age of the grandchildren of our friends three times. This morning we were going shopping and asked how we were going to pay and I told by card and she asked again two hours later and had no recollection of asking. There is something every day.	keeps misplacing things which are often quite easy to find. A couple of times this week we have not found things. The occurrence is a lot more frequent. The other things I have noticed she gets more anxious when we have to do things partly due to her memory. She cannot get clear the sequence of events that are going to happen. She driven over to Cambridge to do her shopping and this made her quite anxious with her daughter. I used to live and work abroad, she used to travel a lot on her own before but there is no way she can do that now.
FM **DIARY**	71	No real problems. He sits there and read the paper and watches TV. He likes it when the twins come over. I have to tell him to have a shave or to have a bath and tell him what to do. I help him get dressed. He forgets the days and the months. My sister rings and tests him and he always says the same month February.	There have been no problems in the past week. He just gets up and has his breakfast after a wash and shave. We went to Baldock last night baby-sitting his grandchild.
KE **CONTROL**	72	He has been complaining about his tablets and feeling queasy because of not eating properly. He has been a lot better since being on the pills. He does not appear to be so agitated. He does not lose his temper as easily as he was before. He has still been sleeping during the day. He was trying to wire a new light but has not been able to do it yet which he used to be able to. He appears to be dragging his feet recently and he had an appointment with the GP who has arranged a hearing test appointment. Other than that he has been pretty good.	I tried to get him to cook dinner one evening but he could not remember what to do. I keep him busy by getting him jobs to do. I have got him a dog to keep him busy and active. The dog is good company for him.
EAS **CONTROL**	73	At times she gets very tearful and upset about taking pills whether she has taken them or not. She is forgetful about food and I have to decide on what we are going to have for a meal. She gets upset about her forgetfulness and what is to become of her. Wonders how she will cope if I was not there.	The normal sort of level of tearfulness. She was looking at something on the web and donepezil came up connecting it with dementia and this upset her for quite a while. She was very tearful and unwilling to be

			consoled. She worries about constipation and gets upset when she has not gone for a few days. She has tearful episodes from time to time. She gets anxious and worries from time to time.
MS **CONTROL**	74	He gets very snappy and he also falls asleep a lot during the day. He sits with his mouth open all time. He forgets and is repetitive saying I did not tell him something I had told him.	He has not been so aggressive and I think he is remembering a little bit better. No problems in the past week
JS **DIARY**	75	He does not always remember where he is. Keeps going back to where his mother lives. I try to reassure him by showing him the car and house is ours. Sometimes forgets where his clothes are, often in the mornings.	Been up and down Started off not too bad but had a phone call from the hospital. He had an appointment from hospital but it stressed him out. He also has nightmares saying he cannot go. So I had to cancel the appointment. Last night he was up all night head in hands. He goes to bed quite happy but night times are problems. Got up at 4 am fully dressed and when I asked where he was going I told. He still thinks he is not in Baldock where he lives. He also hallucinated when he was on diazepam, pointing to someone in the corner.
PO **CONTROL**	76	Nothing to do with him. It is just usual things he has a wash in the morning and puts the towel on the radiator instead of folding them up and put them away. He is having trouble with doors asking him to leave doors open but keeps closing them or opposite he leaves doors open when they should be closed. Generally he is very good other than being forgetful with a lot of things. I have started to have to deal with his tablets as he sometimes forgets	He has been very good. He has been doing the jigsaw puzzle. He was able to complete a very difficult bit and he was really chuffed that he could do a part of it. I do get very tired and have down days but he has been good. He has been enjoying himself watching cricket on TV and going for his walks.

		to take them.	
BH **DIARY**	77	There have been domestic problems. We have just got a new washing machine which has lots of different programmes and she is struggling with that. Most of the problems is me not being gentle as I should be when she repeats things and she ends up chastising him.	There have been no real problems at all.
MM **DIARY**	78	Tends to start doing something then does not finish before she goes on to something else. Often have to remind her about what she was doing before that she had not finished. Her concentration is not too brilliant. She sleeps quite a bit up to three or four times in the afternoon	There have been no problems but she still forgets things. Her mind tends to wander and does half a job but not finishing it unless I remind her. I wear a bit thin as I get tired and annoyed. Apart from that there is not a problem. I am the problem as I am so annoyed for having a go at her for not remembering.
ROD **CONTROL**	79	He has forgotten he had a meal or forgetting people he has seen many times. He has been falling off the toilet which has been a worry as he sleeps off in the toilet.	Today has not been a good day as I think he has had a cold. He said the tablets are helping. He went to mass for the first time in weeks and hoping to go next Sunday. He cannot remember things from yesterday. He has not fallen off the toilet anymore. He is a bit dithery and is quite conscious of what is happening to him.
CF **CONTROL**	80	There is mental tiredness from being asked the same questions over and over again. You got keep the calendars up to date. There was one day she complained about a pain in the head which felt heavy inside. Her memory goes for a while like not remembering names then come back again but not 100%.	She has been hallucinating and having the shakes on the higher dose of Rivastigmine patches for her memory and has some redness on her skin. She has complained about her memory has gone and was really confused but this seems to come back and she is more confident now. For a couple of days she had felt a bit nauseated.
GS	81	Sometimes if you say to him he can	There have been no problems in

DIARY		remember things and at other times he cannot. His walking is bit unsteady and notice he shakes a bit. Just need to help with his clothing and I have a carer he helps in the mornings	the past week.
GM **DIARY**	82	He gets up and said have I got to get up as he has no idea of time. In the evening he cannot remember often what he has done. When he goes to bed he comes down stairs looking for the bed. Cannot remember whether he closed the gates behind the dogs or not. Sometimes he wears underpants over the tenant pants wearing them the wrong way. The other night he could not remember what to wear going to bed.	He has total control over the TV remote control and gets very frustrated when I can very angry. I later found out and he was alright. The letter from clinic arrived said he was very aggressive and he became very angry and shouting at me. He also became upset about the diary for a while and I had to explain to him the benefits of it. On one occasion he left his soiled pants on the floor and dogs got it and this made me very angry.
DA **CONTROL**	83	She is very difficult with appointments. She missed one of hair dressing appointments and remembered it the next day. She mixes up the days. She has a lot of mood changes and sometimes is extremely irritable.	She has not been too bad. We had one or two sessions where we had argument about the television. I asked her what she wants to watch but she could not say and got angry I did not want to make the decision on what programme she should watch though I did not want to watch the television. Constantly looking for things she has lost like her door keys.
VEB **DIARY**	84	She totally forgot a TV programme she had been watching. Unable to pick up threads of conversations or TV programmes. On one occasion forgot how to switch on the television upstairs. At times does not pick up the phone as she has forgotten how to operate it.	We have a couple of problems regarding her recollection of my dad. We were just staying in the kitchen and she said ‘your dad punched me in the chin recently’ though he has been dead many years ago and was not true. Few days later she was telling my granddaughter what a lovely man she was married to.

APPENDIX 14: UH Protocol number for REC (NHS) approved study

From: hhsecda, uh [mailto:tv13xaa@herts.ac.uk]

Sent: 23 August 2016 10:10

To: 'dilinijayalath@aol.com'

Cc: Ashaye Kunle Dr (RWR) Hertfordshire Partnership University FT; Lee, Kathy

Subject: UH Protocol number for REC (NHS) approved study - M Jayalath 9213615 **Importance: High**

Dear Mestiyage,

Thank you for arranging for your supervisor to forward evidence of REC (NHS) approval covering your study entitled *Reverse Journey in Dementia: A clinician's research journey leading to the development of carers' diaries.*

The Chairman has considered and accepted the submitted paperwork. Please quote UH protocol number HSK/PGR/NHS/02469 on any submission paperwork, including your Application for Approval of Examination Arrangements Form. It is recommended that you retain a copy of this email with your ethics protocol paperwork.

Kind regards,

Lesley Powell

Academic Services Officer (Ethics)

Academic Services

MacLaurin Building, de Havilland Campus, University of Hertfordshire

Ext – 1254

Ethics Approval StudyNet Site available here:

http://www.studynet2.herts.ac.uk/ptl/common/ethics.nsf/Homepage?ReadForm

ECDA email addresses:

Health & Human Sciences – hhsecda@herts.ac.uk

Science & Technology – stecda@herts.ac.uk

Social Sciences, Arts & Humanities – ssahecda@herts.ac.uk

APPENDIX 15: Ethics committee approval letter copy from NRES Committee East of England – Cambridge East

NRES Committee East of England - Cambridge East

The Old Chapel

Royal Standard Place

Nottingham NG1 6FS

Telephone: 0115 8839425

27 February 2014

Dr Kunle Ashaye

Hertfordshire Partnership University NHS Foundation Trust

Coreys Mill Lane

Stevenage SG1 4AB

Dear Dr Ashaye,

Study title: Use of Carers' Diaries in Dementia

REC reference: 14/EE/0008

IRAS project ID: 138812

Thank you for your letter of 08 February 2014, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Committee Lead and Second Reviewer.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so.

Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager - Liza Selway on 01154 8839425.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Advisory note:

The committee advise you to produce a simplified or summary version of both the Participant Information Sheet (for persons with Dementia and for their carers) as the current versions still require a high reading age. This can be submitted as a NOSA for subsequent approval.

The committee suggest using simpler individual words, shorter sentences and using active rather than passive tenses as much as possible. E.g. change ‘pertaining to’ to ‘about’ your ‘care’, ‘centred around’ to ‘about’. The Committee suggested contacting your R&D Department to advise on readability.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Version Date

Covering Letter

29 November 2013

Covering Letter

08 February 2014

GP/Consultant Information Sheets 1

03 February 2014

Other: CV: Kunle Ashaye

Other: CV: Dilini Jayalath

Other: Lone Working Policy

23 October 2012

Participant Consent Form: Patient

2

18 October 2013

Participant Consent Form: Carer

2

18 October 2013

Participant Information Sheet: Carer

4

04 February 2014

Participant Information Sheet: Patient

4

04 February 2014

Protocol 6

16 November 2013

Questionnaire: EQ-5D-5L

Questionnaire: Neuropsychiatric Inventory Worksheet

REC application

138812/533573/1/468

26 November 2013

Response to Request for Further Information

08 February 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed

guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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We are pleased to welcome researchers and R & D staff at our NRES committee members’

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With the Committee’s best wishes for the success of this project.

Yours sincerely

Dr Niki Bannister

Chair

Email: NRESCommittee.EastofEngland-CambridgeEast@nhs.net

Enclosures: “After ethical review – guidance for researchers” SL-AR2

Copy to: Tim Gale, Hertfordshire Partnership

Appendix 16

Peer reviewed publications of my research journey in dementia

1. Balalle, C., Jayalath D, Shankar K, Ashaye K. (2010) Prevalence & management of behavioural & psychiatric symptoms on a continuing care unit for patients with dementia. *International Journal of Psychiatry in Medicine*, 40 (4): 425 – 438.

2. Jayalath D, Shankar K, Ashaye K. (2013) A follow-up study of patients with dementia in an NHS Continuing Care Unit. *The Psychiatrist.* **37**: 11 – 14.
3. Russell M, Sundararaman S, Jayalath D, Anwar R, Ashaye K. (2014) Reasons for admission to an Inpatient Dementia Ward. *Hertfordshire Journal of Medicine,* 9 (1): 5 – 9.
4. Jayalath D, Ashaye K, Kvavilashvili (2016) Carers' diaries in dementia: Is there a role in clinical practice? *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. DOI: http://dx.doi.org/10.1016/j.dadm.2016.03.003

Publication 1:

Prevalence and Management of Behavioural and Psychiatric Symptoms on a Continuing Care Unit for Patients with Dementia

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3. Kuttalingham Shankar, MB BS, MSc, MRCPsych
4. Kunle Ashaye, MB BS, MD, MRCPsych

International Journal of Psychiatry in Medicine **December 2010** vol. 40 no. 4: **425-438.**

Abstract

Objectives: With the increasing concerns over the safety of some pharmacological interventions or lack of sufficient evidence of effectiveness in managing neuropsychiatric symptoms in dementia, there is a constant need to review how such patients are managed. This study looks at the prevalence and management of behavioural and psychiatric symptoms amongst patients with dementia in a National Health Service (NHS) continuing care unit.

Method: In this study, a survey of all 50 patients admitted to a long stay NHS-funded dementia care unit was carried out. The socio-demographic details along with severity of dementia, neuropsychiatric symptoms, and medication were obtained on all the patients.

Findings: All 50 patients were prescribed some form of medication for either physical and/or mental health reasons. Only five (10%) patients were not prescribed any form of psychotropic medication. A lack of non-pharmacological treatment options for the treatment of neuropsychiatric symptoms was evident in the unit with only one occupational therapist available.

Conclusion: Effective management of severe behavioural and psychiatric symptoms in dementia is challenging even in a NHS continuing care dementia unit due to the absence of clear benefit from pharmacological interventions and lack of resources for optimum non-pharmacological interventions.

INTRODUCTION

With the increasing life expectancy, prevalence of dementia is on the increase, Alzheimer’s disease being the leading cause. According to the Department of Health (Living with the dementia—National Dementia Strategy 2009), the prevalence of dementia in the United Kingdom in 2008 is about 700,000 and this is expected to increase up to 1.4 million in 30 years. The cost of looking after people with dementia will also increase from £17 (US$27) billion at present to over £50 (US$80) billion in 2038. Dementia is a progressive disease where the person would become more cognitively and functionally impaired with time [1]. Toward the latter part of the disease most of these patients would need 24-hour care in a structured environment such as dementia residential or nursing homes. Alongside the decline of cognitive and daily living functions, most people with dementia also develop behavioural and psychological symptoms such as depression, psychosis, aggression, and wandering which complicate care [2-7]. The course of some neuropsychiatric symptoms can show distinct patterns during the progression of the disease; some changes tend to occur earlier than others, however, most symptoms can occur at almost any time in the course of dementia. This is also a significant contributory factor to the carer’s distress and acceleration of institutionalisation [8, 9]. Beeri and colleagues found that approximately 30% of the total annual cost of Alzheimer’s disease is invested in the direct management of behavioural and psychological symptoms in dementia (BPSD) in a U.S. study [10]. BPSD is increasingly recognised as a major component of dementia with considerable adverse impact on patients, care givers, and health and social care costs. However, effective intervention in managing BPSD is still to be found.

In England, patients with severe BPSD often end up in National Health Service (NHS)-funded care as they present with symptoms too difficult to manage in Social Services’-funded residential or nursing home placements. With the increasing concerns over the safety of some pharmacological interventions or lack of sufficient evidence of effectiveness in managing neuropsychiatric symptoms in dementia [11], there is a constant need to review how such patients are managed.

The prevalence, course, and severity of BPSD and its impact on carers have been investigated in many settings including in general populations, care homes, inpatient units, etc. [3, 7, 12]. However, there is very limited data available regarding BPSD and its management in patients in NHS continuing care settings in England.

METHOD

In this study, a survey of all 50 patients admitted to a long stay NHS-funded dementia care unit was carried out. The survey was carried out in a 50-bed unit consisting of two purpose built bungalows for patients with challenging behaviour in dementia based in Stevenage, a town about 30 miles north of London. The unit is staffed with qualified and unqualified nurses, general practitioners, old age psychiatrists, and one occupational therapist. The unit has a higher proportion of nursing staff when compared to local homes. Of the 53 members of nursing staff in both courts, 19 were qualified nurses and 34 were healthcare assistants. The staff: patient ratio during the day shift is about 3.5 to 1 and during night shift 7 to 1. Generally there are two qualified nursing staff during each shift. Though this is a higher staff:patient ratio when compared to local nursing homes, the staff still find it difficult to manage at times when one or more patients become agitated, which is a frequent occurrence in this unit, as at such times up to four staff could get involved in managing just one patient. There is one full-time occupational therapist (OT) covering both units. However, as the OT rotates every 6 months, there can be gaps without an OT in between their placements, which, at times can be up to 2 months. OT carries out activities 2 days a week in each unit which comprise of small group activities in the mornings and large group activities in the afternoon. Activities include games (ball passing, dominos, musical bingos), hand massaging, music, and dancing. There are time-tabled activity schedules for the whole week even in the absence of the OT, to be carried out by the other nursing staff. However, such activities in the absence of the OT are rarely done due to the staff shortage. Though there is a multi-sensory room on the premises, this again is used infrequently due to staff shortage. There is a once-a-week movie session over the weekends. Apart from above, staff spends one-to-one time with patients as time allows.

When patients are first placed, a person-centred care plan is developed and this is reviewed every 6 months. The psychiatrist reviews the medication of each patient once every 3 months with the pharmacist and again at 6 monthly intervals during CPA (Care Program Approach) reviews. In addition, patients are reviewed whenever needed by the staff psychiatrist or the general practitioner if there is sudden deterioration of patients' mental or physical health condition. The review of medication is done according to the clinical presentation. Psychotropic drugs are gradually withdrawn if there is no improvement and also when the patient has been settled for a period of time. There are no regular scales used to monitor symptoms. There is no specific local policy outlining the use of psychotropic medication in BPSD, however, NICE (National Institute for Health & Clinical Excellence) guidelines on Dementia (13) is generally followed.

All 50 patients were assessed using a proforma to collect socio-demographic details. These were obtained from patients' medical notes. The ICD 10 diagnostic criteria and DLB Consortium 2005 Clinical Diagnostic Criteria (14) were used to classify type of dementia and associated psychiatric disorders. The neuropsychiatric symptoms were rated using the Neuropsychiatric Inventory (NPI) [15]. The NPI is a relatively brief interview with a carer, rating 12 behavioural areas in dementia. It is scored from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed. Both the severity and frequency of each symptom are rated on a 3- (1-3) and 4-point (1-4) Likert scale, respectively. For the purpose of this study, clinically relevant neuropsychiatric symptoms measured on the NPI were defined by F × S score for each individual symptom = or > 4 [16, 17]. The severity of the dementing illness was rated using the Clinical Dementia Rating Scale [18, 19]. The Clinical Dementia Rating (CDR) covers six domains consisting of memory, orientation, judgment, and problem solving; community affairs; home and hobbies; and personal care. Each domain is rated 0 (*healthy*); 0.5 (*questionable*); 1 (*mild*); 2 (*moderate*), and 3 (*severe*). Composite scores give a global measure of dementia. The Mini-Mental State Examination [20] was not carried out for the purpose of the study, as the majority of the patients were severely cognitively impaired and would have been unable to complete the assessment.

All assessments were carried out by an experienced staff psychiatrist (DJ) with a trained nurse staff member who was familiar with the patients. The data collected was analysed using the SPSS v 14 to carry out both descriptive and analytical statistics such as *t*-tests, chi-squared tests, and analysis of variance with level of significance set at $p < 0.05$.

RESULTS

There were 50 patients consisting of 26 males and 24 female patients. Their mean age was 79.6 (standard deviation – 8.0) years and there was no significant difference between the ages of female and male patients. The duration of dementing illness ranged from 1 to 24 years with a mean duration of 5.7 (*SD* = 3.6) years. There was no significant difference between male and female patients. The prevalence of different types of dementia is shown in Table 1.

Table 1: Prevalence of Different Types of Dementia (**(Table available in original text on line)**

Fifteen patients (30%) had other psychiatric diagnoses made in the past aside from dementia, which included six patients with depression, four with epilepsy, two with anxiety disorder, two with alcohol dependence, and one with a diagnosis of schizophrenia. The composite CDR scores showed that 39 patients (78%) had severe dementia; 10 patients (20%) had moderate dementia and one patient had mild dementia. Agitation, irritability, apathy, and aberrant motor behaviour were the most frequent neuropsychiatric symptoms identified using the NPI (see Table 2). Seventy-four percent of patients exhibited at least one neuropsychiatric symptom to significant severity. The staff members (professional carers) rated agitation and irritability as the neuropsychiatric symptoms they found most distressing (see Table 2 and Figure 1).

All 50 patients were prescribed some form of medication for either physical and/or mental health reasons. Only five (10%) patients were not prescribed any form of psychotropic medication. Psychotropic medication prescribed included antipsychotics, antidepressants, anti-epileptics/mood stabilisers, and benzodiazepines (see Table 3). The most frequently prescribed medications were Trazodone (antidepressant) and Quetiapine (antipsychotic). Benzodiazepines were most frequently prescribed in the form of Temazepam for night-time sedation or Lorazepam as required for increased agitation or irritability. More than half of the patients (54%) were on combination of psychotropic medications excluding tranquilisers and night-time sedation.

There was no significant difference in total NPI scores between patients who were and were not prescribed PRN benzodiazepines (see Table 4). There were no significant differences in the CDR between gender and patients prescribed or not prescribed antidepressant or antipsychotic medication using chi-squared analysis (see Table 5). Using the analysis of variance, there were no significant differences ($p > 0.05$) between patients on or not prescribed antipsychotics and also between those on or not prescribed antidepressants in terms of total NPI scores (see Table 6). Similarly, there were no significant differences in terms of age, duration of illness, and NPI scores between male and female patients.

Tables 2 – 6 and Figure 1 (**available in original text on line)**

DISCUSSION

Summary of Results and Comparisons with Previous Studies

Continuing care setting in England generally caters to patients with severe dementia and added behavioural and psychiatric symptoms. We found a high prevalence of BPSD in this group (74%) indicating that these symptoms present any time despite the stages of dementia. The most frequent neuropsychiatric symptoms were agitation, irritability, apathy, aberrant motor behaviour, and night-time behaviour. This is a similar finding to the symptoms of final phase of dementia in other settings [12]. However, the professional carers rated agitation and irritability as the most distressing neuropsychiatric symptoms for them, whereas Wood and colleagues found apathy and agitation to be the most distress-causing symptoms for carers in care home settings [8]. In community-based studies involving spousal carers, apathy was found to be one of the most distressing symptoms for the carers of patients with Alzheimer’s dementia as well as in Fronto-temporal dementia [21]. However, in our study the carers didn’t find apathy as a high distress-causing symptom. The reason for this could possibly be that paid carers find such patients less active and demanding of their time.

We also found marked differences in BPSD in male and female patients and the way they were treated. In this study more than half of male patients exhibited significant agitation, whereas only about one-third of female patients had similar symptoms. Generally the male patients scored higher scores for agitation and they were on more antipsychotic medication and combination of medication than the female patients, whereas female patients with significant agitation were treated with more antidepressants; however, these differences did not reach a statistical significance. Further studies of larger scale will be needed to confirm the difference in symptomatology and treatment in male vs. female patients with dementia because if there is a genuine difference in the symptoms of males and females with dementia it would be useful in future management and care planning.

Another major finding in the study is the extent of the use of psychotropic medication in this patient group. Ninety percent of patients were on psychotropic medication though only 30% had recognisable psychiatric disorder which required such treatment. When observing the specific significant psychiatric symptoms (scoring = or >4), 16% had delusions, 12% had hallucinations, 8% had anxiety symptoms, and 6% had depressive symptoms. These did not necessarily correlate with the presence or absence of a previous psychiatric diagnosis. As the most frequent neuropsychiatric symptoms were agitation, irritability, apathy, aberrant motor behaviour, and night-time behaviour, it would appear that most patients were being prescribed psychotropic medication for these reasons.

It is a common practice to use antipsychotic and antidepressant medication in attempt of controlling BPSD in dementia despite controversial evidence of such treatment and recent recommendation from the ministerial review following the increasing concerns about the use of antipsychotic drugs in dementia [22].

A systematic review of the evidence for pharmacological treatment of BPSD by Sink and colleagues showed atypical antipsychotics having a modest effect, mainly Olanzapine and Risperidone, but complicated by increased risks of cerebrovascular accidents and antidepressants not showing significant efficacy other than as a treatment for depression [11, 23-25]. Despite this lack of strong evidence and possible adverse factors, our unit was still using a significant amount of psychotropic medication in an attempt to manage BPSD.

Comparing those patients on antidepressants and antipsychotics with those who were not, revealed no significant differences in terms of age, sex, or severity of dementia and neuropsychiatric symptoms. Whether this is because the patients who are already on psychotropic medications are gaining some benefit is a question which needs answering with further trials of discontinuation of treatment for longer periods. Previous studies of controlled antipsychotic discontinuation trials in nursing homes had revealed no overall deleterious effect on behaviour problems in dementia [26-28]. However, low baseline BPSD scores were found to be predictive of beneficial outcomes after antipsychotic medication is discontinued [29]. Ruths and colleagues found in an antipsychotic discontinuation study, that a month after the completion of the study, 50% of the patients whose antipsychotic medication had been stopped were placed back on antipsychotic medication [26]. When considering the severity of the BPSD in a continuing care population, they would probably need more frequent pharmacological interventions in order to reduce distress than for patients in ordinary care settings, especially when there is significant lack of non-pharmacological management options.

Anti-dementia medications were used only in 8% of the patients in this study. This could be due to the lack of beneficial effects of such medication in controlling severe BPSD. Acetyl-cholinesterase inhibitors were noted to have some beneficial effects, especially in mild to moderately severe dementia [30-32]. There are conflicting findings in the case of Memantine [33]. The patients who are admitted to NHS continuing care units usually undergo an assessment and treatment period in an acute mental health assessment unit for dementia prior to becoming eligible for continuing care. During such assessments, all the available options of medications are generally exhausted including Memantine before their placement. Anti-dementia medication is generally discontinued after several weeks if it proves non-beneficial. This may be the reason for less use of anti-dementia medication in this group.

Although there is one full-time Occupational Therapist covering both units (50 patients), for a majority of the week patients spend time without scheduled activities. Also, despite the availability of the multi-sensory room, this is used infrequently due to staff shortages. Most of the evidence for the nonpharmacological management options for BPSD in dementia is mainly effective in the short term [34-36]. When considering that NHS continuing care units receive patients with most severe BPDS who are not possible to manage in an ordinary dementia nursing home, it is not clear what benefits we could achieve with non-pharmacological interventions as the evidence of such interventions is not strong when managing severe BPSD in the long term or in severe dementia. Major limitation of our study is the small sample size which might have contributed to statistically insignificant results. Also, this study being a cross-sectional view, it does not allow us to compare how patients respond to commencement or discontinuation of psychotropic medication.

CONCLUSION

In the absence of clear evidence of benefits of pharmacological as well as some non-pharmacological management of severe BPSD in dementia, it is a challenge to treat patients with severe symptoms even in a highly specialised unit such as NHS continuing care settings. Care provision by more specialist staff seems essential. There is an increasing need to further explore and provide potentially less harmful alternative options such as music therapy, occupational therapy, aromatherapy, and environmental modifications of units caring for people with severe BPSD in dementia. Until then careful use of psychotropic medication including anti-dementia drugs may be necessary when neuropsychiatric symptoms re-emerge or worsen upon discontinuation of such treatment, where adequate behavioural treatment options and environmental modifications are unavailable or difficult to achieve or make no difference.

There are no recent statistics about how many patients with dementia in England eventually reside in hospital continuing care units due to severe BPSD; however, the number is likely to increase in the future with increasing numbers of people with dementia leading to further burden on existing resources including families, health and social care service. A better understanding of the efficacy and safety of various pharmacological and non-pharmacological options in treating patients with severe BPSD would enable them to be cared for in the community as long as possible before considering continuing hospital care.

REFERENCES (available in original text on line)

Publication 2:

Two-year follow-up study of patients with dementia in an NHS continuing care unit

Dilini Jayalath, Kuttalingam Shankar, Kunle Ashaye

The Psychiatrist Online Jan 2013, 37 (1) 11-14.

Abstract

Aims and method This is a longitudinal, observational prospective study carried out in a 50-bedded dementia care unit. Fifty patients who had been assessed in 2009 as part of an earlier study were reassessed 2 years later.

Results All patients had a diagnosis of dementia, with Alzheimer's dementia being the most common. By 2011, 23 (46%) patients reviewed in 2009 were deceased. We found that there was a reduction in psychotic symptoms in patients 2 years later despite none of them being on antipsychotics. The most common problems on follow-up were apathy, agitation and aggression, irritability and anxiety.

Clinical implications Our findings support the view of the need to regularly review patients with dementia who have psychotic symptoms that require antipsychotics, as long-term treatment may not be required or beneficial in light of known adverse side-effects.

Patients with dementia who have challenging behavioural problems often end up in long-stay in-patient units as they present with behavioural problems too difficult to manage at home with informal care offered by spouses and family members. These individuals often require pharmacological interventions to help alleviate symptoms when non-pharmacological interventions fail. With increasing concerns over the safety of some pharmacological interventions or lack of sufficient evidence of effectiveness in managing neuropsychiatric symptoms in dementia, there is a constant need to review how such patients are managed. A study in 2008 found that a large group of patients who were on long-term antipsychotic medication did well on discontinuation.[1] The study findings put into question the value of long-term use of antipsychotics in dementia. In a different study looking at patients in the final phase of dementia, there was a high prevalence of apathy, agitation and behavioural problems such as strange noises, grabbing, performing repetitious mannerism, spitting, hitting, screaming and pushing.[2] These clinical features may not respond to long-term psychotropic use without looking at possible aetiological factors for such behaviour. Professional caregivers found apathy and agitation as the most distressing psychiatric symptoms in patients with Alzheimer's dementia.[3] These symptoms may be difficult to distinguish from depressive symptoms in severe dementia.

In 2009, we carried out a survey of all 50 patients admitted to an in-patient continuing care unit for patients with severe behavioural and psychiatric symptoms in dementia.[4] Only 5 (10%) patients in the survey were not on any form of psychotropic medication and the authors noted the lack of non-pharmacological options. In this follow-up study of those 50 patients, 2 years later, the outcome of care, neuropsychiatric symptoms and medication were reviewed. The study was carried out in a 50-bedded unit consisting of two purpose-built bungalows in a town about 30 miles north of London. The unit is staffed with qualified and unqualified nurses, general practitioners, old age psychiatrists and one occupational therapist. In the intervening 2 years, improved access to occupational therapy along with structural improvement to the unit took place. The unit won a successful grant bid from the Kings Fund, to improve the entrance and communal areas in one of the bungalows, Elizabeth Court. Some walls were changed to glass so that from the reception area one can see directly out into the natural landscape creating more natural lighting and space. With support from the local carers group, a multisensory room was also provided. Around the time of the redesign, two activity workers were appointed to support the occupational therapist. As a result of the increased concern about the use of antipsychotic medication in dementia to treat behavioural problems, decisions had been taken locally to review and discontinue the use of antipsychotics where possible. The aim of this study was to assess, 2 years after the initial study, the effects that changes in prescribing practices, staffing and structural design had on patients in a continuing care dementia unit.

Method

This is a longitudinal, observational, prospective study involving patients in a long-stay in-patient dementia care unit using a proforma to collect sociodemographic details obtained from patients' medical notes. The ICD-10 diagnostic criteria were used to classify type of dementia.[5]

The neuropsychiatric symptoms were rated using the Neuropsychiatric Inventory (NPI).[6] The NPI is a relatively brief interview with a carer, rating 12 behavioural areas in dementia. It is scored from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed. Both the severity and frequency of each symptom are rated on a three- (one to three) and four-point (one to four) Likert scale respectively. For the purpose of this study, clinically relevant neuropsychiatric symptoms measured on the NPI were defined by a F×S score for each individual symptom $\geqslant 4$ as used in other studies.[7]

The severity of the dementia was rated using the Clinical Dementia Rating (CDR) scale.[8] The CDR covers six domains consisting of memory; orientation; judgment and problem-solving; community affairs; home and hobbies; and personal care. Each domain is rated 0 - healthy; 0.5 - questionable; 1 - mild; 2 - moderate and 3 - severe. Total scores give a global measure of dementia.

The initial assessments in 2009 and 2 years later were carried out by the same specialty doctor (D.J.) who had over 8 years' experience in psychiatry and a trained nurse staff member who was familiar with the patients. The data collected were analysed using the Statistical Package for the Social Sciences (SPSS) for Windows version 14 to carry out both descriptive and analytical statistics for chi-squared tests, one-tailed *t*-tests and one-way analysis of variance, with level of significance set at $P<0.05$.

Results

In our previous study conducted in 2009, there were 50 patients in the unit consisting of 26 males and 24 female patients. In 2011, there were 48 patients in the unit as 2 patients had recently been transferred to a nursing home. Of the 48 current patients in the unit, 25 patients were part of the initial study in 2009 and the remaining 23 were new patients. By 2011, 23 of the 50 patients reviewed in 2009 were deceased. There were no significant differences between the patients in the unit in 2009 and 2011 in terms of their ages, gender distribution and duration of dementia (**Table 1**). In 2009, using the CDR scale scores, there were 39 patients (78%) who were rated severe compared with 38 patients (79.2%) rated severe in 2011. The rest of the patients had a rating of moderate dementia in both 2009 and 2011.

Table 1 : **Sociodemographic data of patients in the continuing care unit in 2009 and 2011**

	2009	**2011**
Patients, *n*	**50**	**48**
Age, years: mean (s.d.)	**79.76 (8.02)**	**78.97 (7.81)**
Male, *n* (%)	**26 (52)**	**25 (52.1)**
Duration of illness, years: mean (s.d.)	**5.67 (3.57)**	**5.44 (3.64)**

Among the 50 patients in the initial study (2009), all patients had a diagnosis of dementia. Alzheimer's dementia was the most frequent form of dementia diagnosed (*n* = 31, 62%), followed by vascular dementia (*n* = 6, 12%) and then dementia with Lewy bodies (*n* = 4, 8%) and Frontotemporal lobe dementia (*n* = 4, 8%). Similarly in 2011, all 48 patients had a diagnosis of dementia, with 33 patients (68.8%) diagnosed with Alzheimer's dementia, 5 patients (10.4%) diagnosed with vascular dementia and 5 patients with Frontotemporal dementia.

The number of patients prescribed antipsychotic medication had reduced from 32 (64%) in 2009 to none in 2011. There were no significant differences between the mean ages, duration of diagnosis, CDR score and initial total NPI scores of those patients who were deceased at the follow-up compared with those who were still alive (Table 2). In comparing the proportion of patients on antipsychotic medication with those who were not at the time of the initial assessment in 2009, analysis using the chi-squared test revealed no significant difference in their outcome in terms of survivability.

Table 2: Initial assessment data (2009) of patients, by survival status in 2011

	Deceased by time of follow-up in 2011	**Alive at time of follow-up in 2011**	***P***
Patients in 2009, *n*	**23**	**25**	
Age in 2009, years: mean (s.d.)	**82.3 (7.66)**	**78.8 (6.63)**	**0.09**[a]
Duration of diagnosis in 2009, years: mean (s.d.)	**6.04 (2.63)**	**5.28 (4.36)**	**0.46**[a]
Total Neuropsychiatric Inventory score in 2009, mean	**15.5**	**15.2**	**0.95**[a]
Patients with Clinical Dementia Rating severe rating in 2009, *n* (%)	**19 (82.6)**	**18 (72)**	**0.52**[b]
On antipsychotics in 2009, *n* (%)	**12 (52.2)**	**19 (76)**	**0.21**[b]

- ↵[a.] ***t*-test.**
- [b.] **χ^2.**

In terms of individual items on the NPI, the most frequent problems identified at the time of initial assessment were agitation and aggression (*n* = 21, 42%) and irritability (*n* = 14, 28%) (Table 3). On follow-up, among the 25 patients who were still alive in 2011 that had been assessed in 2009, there was an increase in the prevalence of apathy (*n* =20, 80%) and anxiety (*n* = 5, 20%). The most common problems on follow-up were apathy, agitation and aggression, irritability and anxiety. Despite antipsychotics no longer being prescribed, there were no patients who were reported to be experiencing hallucinations or delusions.

Table 3: Prevalence of behavioural and psychological problems identified by using the Neuropsychiatric Inventory among patients assessed in 2009 and on follow-up in 2011

	***n* (%)**	
Neuropsychiatric Inventory items	**Patients at onset (*n*=50)**	**Patients still alive at follow-up (*n*=25)**
Hallucinations	**8 (16)**	**0**
Delusions	**6 (12)**	**0**
Irritability	**14 (28)**	**8 (32)**
Agitation and aggression	**21 (42)**	**9 (36)**
Depression and dysphoria	**3 (6)**	**2 (8)**
Anxiety	**4 (8)**	**5 (20)**
Elation and euphoria	**2 (4)**	**0**
Apathy	**13 (26)**	**20 (80)**
Disinhibition	**2 (4)**	**0**
Aberrant motor behaviour	**10 (20)**	**4 (16)**
Night-time behaviour	**8 (16)**	**1 (4)**
Appetite problems	**8 (16)**	**7 (28)**

There was a general reduction in the proportion of patients on psychotropic medication. The number of patients prescribed antipsychotic medication was reduced from 32 (64%) in 2009 to none in 2011, antidepressants were prescribed to 33 patients (66%) in 2009 and 28 (58.3%) in 2011 and benzodiazepines were prescribed in 26 patients (52%) in 2009 and 21 patients (43.8%) in 2011.

The most frequent drugs prescribed regularly in 2009 were quetiapine in 22 patients (44%), trazodone in 19 patients (38%) and citalopram in 8 patients (16%). In 2011, the most frequent drugs prescribed regularly were trazodone in 15 patients (31.3%) and citalopram in 6 patients (12.5%). Lorazepam was the most frequent benzodiazepine prescribed in both 2009 and 2011. It was mainly prescribed as required, to be administered for episodes of increased aggression and agitation.

There was an increase in the use of Memantine from 1 patient (2%) in 2009 to 4 patients (8.3%) in 2011 and a slight increase in use of cholinesterase inhibitors from 3 (6%) in 2009 to 4 patients (8.3%) in 2011.

Discussion

Main findings

This study reviewed aspects of the outcome of care for 50 patients in a National Health Service continuing care unit diagnosed with dementia who had been assessed in an earlier study in 2009. Of the 50 patients assessed in 2009, nearly half were deceased 2 years later. There was no apparent relationship in outcome in terms of mortality, with respect to age, gender, duration of diagnosis and severity of neuropsychological problems (see **Table 2**). It has been reported that the features at diagnosis that are significantly associated with reduced survival are increased severity of cognitive impairment, decreased functional level, a history of falls, physical examination findings of frontal release signs and abnormal gait.[9]

There is evidence that some atypical antipsychotic drugs confer benefit in the treatment of aggression in people with Alzheimer's disease over a period of up to 12 weeks.[10] These benefits have to be considered in the context of significant adverse events, including extrapyramidal symptoms, accelerated cognitive decline, stroke and death.[11] In our study, all patients who were alive at the time of follow-up in 2011 were no longer on antipsychotic medication. When comparing outcome between those who had been on antipsychotic medication and those who had not, no differences were found. It was also noted that none of the patients in 2009 who had delusions or hallucinations were observed to experience either problem in 2011 despite no longer being on antipsychotic medication. This would support the view of the need to review patients with dementia on a regular basis who have psychotic symptoms that require antipsychotics. Long-term treatment with these drugs may not be required or beneficial in light of known adverse side-effects.

Looking at individual neuropsychological problems in our study, the most frequent symptoms identified at the onset were agitation and aggression and irritability. At follow-up, the most common neuropsychological problems were apathy, agitation and aggression, irritability, anxiety and appetite problems. Our findings are similar to a larger study involving nursing home residents with dementia, where apathy tended to increase and agitated behaviour were particularly persistent.[12] It has been observed that aggression, agitation and psychosis are more frequent in moderate/severe stages, and they occur within a context of symptoms that indicate a greater Frontotemporal lobe involvement of Alzheimer's dementia pathology.[13] We are unable to ascertain whether this is the case in our study, as this was not the focus of the study.

Implications

Given the safety concerns related to pharmacological therapies, non-pharmacological interventions are recommended as first-line therapies despite a lack of strong, consistent evidence, the modest benefits and questions about lasting benefit.[14] There is evidence to suggest that behavioural treatment of depression is effective,[15] music therapy may alleviate agitation and apathy[16] and controlled multisensory stimulation, also known as Snoezelen, might help with apathy, and psychomotor therapy might alleviate agitation.[17] At the time this study was carried out, improved access to occupational therapy activities along with the structural redesign of the reception and activity areas in one of the bungalows of the unit took place as described earlier. The impact of these changes could not be evaluated to find out whether they have contributed towards the successful reduction of antipsychotic use.

Despite the evidence of potential harmful side-effects, antipsychotic medication may be required in severe cases of behavioural and psychological problems in dementia. Medication such as atypical antipsychotics, antidepressants, benzodiazepines, Memantine and cholinesterase inhibitors have all shown some, but not always conclusive, benefits in the treatment of neuropsychological symptoms in severe dementia. The potential for harmful side-effects means that such pharmacological approaches require careful monitoring and periodic reassessment to determine whether continued treatment is necessary. In our study, an experienced psychiatrist supported by a senior pharmacist carried out 3-monthly reviews of medication for all patients on psychotropic medication for neuropsychological symptoms to decide on the need for continued use.

Acknowledgments

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Publication 3:

Reasons for Admission to an Inpatient Dementia Ward

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Abstract

Background: As dementia progresses, patients require increasing levels of support in the community. If inadequate community support exists or a patient's symptoms are too challenging to manage in the community, admission to an inpatient dementia assessment unit may be required. Admission removes patients from their usual environment, with a subsequent loss of independence, and can expose patients to aggressive and violent behaviour from other service users. Admissions are costly for the National Health Service and frequently create a travel burden for friends and relatives.

Aims: To analyse the reasons for admission to a dementia assessment ward and identify strategies that reduce the need for admission.

Methods: We reviewed the notes of all patients admitted to a 14-bedded inpatient dementia assessment ward over a 3-year period. The primary reason for admission was recorded for each patient, in addition to carer-related concerns and demographic data.

Results: 114 patients were admitted to the ward between January 2010 and December 2012. Aggressive and/or violent behaviour was, by far, the most frequently documented reason for admission. Prior to admission, most patients were living at home, with the vast majority of carers reporting that they felt unable to cope. Following admission, a minority of patients were discharged home, with most patients being discharged to residential homes, nursing homes or continuing care wards.

Conclusions: Patient aggression was the most frequently identified reason for admission to a dementia assessment ward and most carers felt unable to cope in their pre-admission setting. To avoid admission, there is a need to identify those patients who are at risk of admission due to aggression and utilise pharmacological and non-pharmacological therapies via outreach teams or day treatment units.

Background

Dementia refers to a syndrome of progressive deterioration in higher cortical functioning in the absence of altered consciousness.[1] Clinical features include impairment of short- and long-term memory, disruption of language skills, impaired reasoning and judgment, and behavioural and psychological manifestations such as aggression, disinhibition, wandering, sleep disturbance, depression and psychotic symptoms. Behavioural and psychological symptoms of dementia are frequently implicated as a cause of carer distress and as a primary reason for admission to inpatient dementia units, and have been associated with a poorer prognosis.[2,3,4]

As dementia progresses, patients require increasing levels of support and care in the community. If inadequate community support is in place or a patient's symptoms are too challenging to manage in the community, admission to an inpatient dementia assessment ward may be required.

Admission to an inpatient dementia ward has several downsides:

1) Patients are taken out of their usual environment with a consequent loss of independence. A new environment may result in increased confusion and disorientation for the patient. Moreover, there may be an increased travel burden for relatives and friends.

2) Whilst on inpatient dementia wards, patients may be exposed to aggressive and violent behaviour from other service users and may suffer harm as a result.

3) Admissions to hospital are expensive and consume resources that could be diverted to increased community support and therapy for patients with dementia.

4) Demand for inpatient elderly psychiatry beds often outstrips supply, resulting in long waits for beds and/or inappropriate admissions to adult psychiatric units.

Should a patient require admission to an inpatient dementia unit, it is essential that there is accurate documentation of the reasons for admission in order for these reasons to be addressed and re-admission prevented. Current NICE guidance recommends:

"Admission to an inpatient unit should have a clear objective that is shared from the outset with the person with dementia, the carer and the multidisciplinary team. When the objective has been achieved, there should be an efficient discharge process, supported by community resources."[5]

For example, clear documentation of patient aggression as the primary reason for admission would permit trials of pharmacological and non-pharmacological therapies aimed at managing dementia-associated aggression, such as Memantine and multisensory therapy, respectively.

On a population scale, analysis of the reasons for admission to inpatient dementia units helps to target public health interventions aimed at reducing the need for admission. This is particularly important given the current demands on NHS funding and the predicted rise in dementia prevalence from 800,000 people currently to 1.7 million people by 2051.[6] Examples of strategies that could be used to prevent admission include referral to day treatment units and increased utilisation of community outreach teams. Brodaty *et al.* report that with adequate community-based outreach, crisis and home treatment teams, fewer than 1% of patients with dementia should require admission to an inpatient unit for treatment.[3]

Our aim was to analyse the reasons for admission to one of our Trust's inpatient dementia assessment wards and, using this information, identify strategies that might reduce the need for admission.

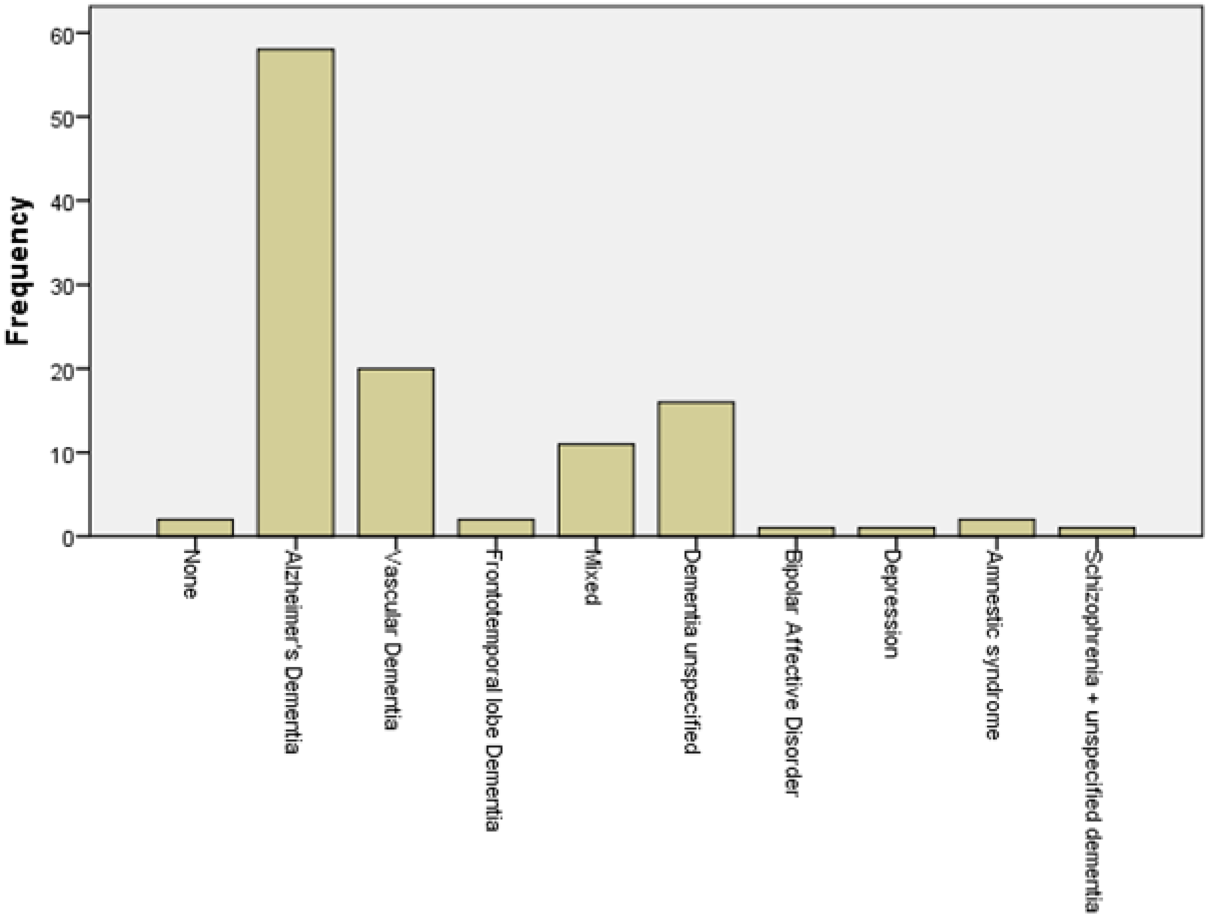
Methodology

We reviewed the medical records of all patients admitted to a 14-bedded inpatient dementia ward over a 3-year period. The primary reason(s) for admission were recorded, along with carer-related issues and concerns. For each patient we also recorded the following information (where available): age, sex, diagnosis, severity of diagnosis, abode before admission, relationship of carer(s) to the patient, presence of homecare packages prior to admission, length of admission, interventions used during admission and the place of care on discharge.

Results

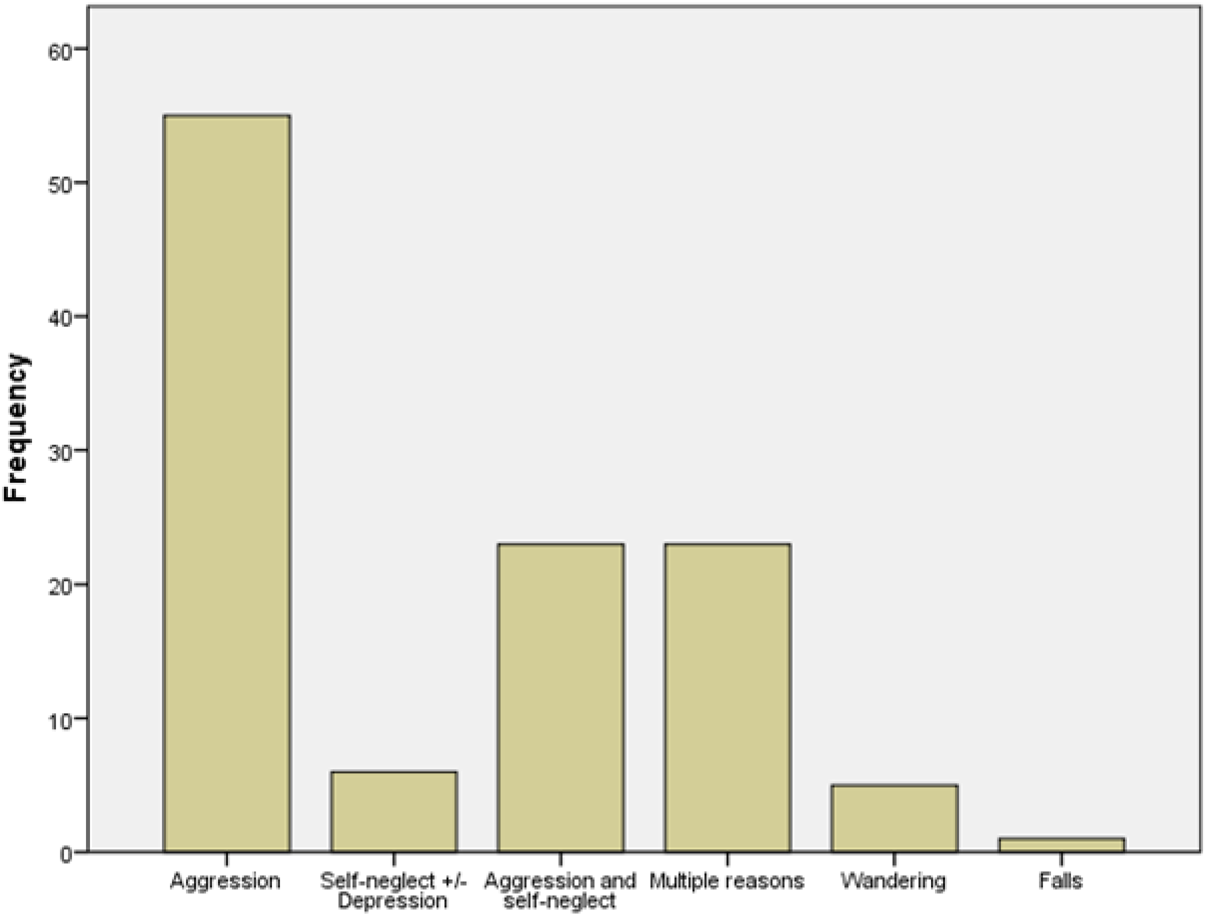
114 patients were admitted to the ward from January 2010 to December 2012. The mean patient age was 80 and the ratio of male-to-female admissions was 50:50. The average length of stay on the ward was 118 days. 10 patients died during admission (8.8%), comparable to the mortality rate of 8.2% seen in another study analysing the mortality rates of patients admitted to psychogeriatric units.[7] The diagnoses of patients admitted to the ward are displayed in figure 1. The most common diagnosis was Alzheimer's disease, followed by vascular dementia. The majority of patients admitted to the ward had severe dementia. There were no cases of mild dementia in patients admitted to the ward.

Figure 1: Distribution of diagnoses amongst the 114 patients admitted to the dementia assessment ward (2010 – 2012)



A reason for admission was clearly documented in the notes of 113 out of 114 patients. The primary reasons for admission are displayed in figure 2. Aggressive and/or violent behaviour was the most frequently documented reason for admission, followed by aggression and self-neglect together. In 23 cases, multiple reasons for admission were documented in the patient notes, which included problems such as aggression, violence, wandering, incontinence and falls. While on the ward, pharmacological therapies and non-pharmacological therapies were utilised in 99% and 88% of admissions, respectively.

Figure 2: Frequency of documented reasons for admission to the dementia assessment ward



107 (93.9%) patients were identified as having carers pre-admission. Spouses were documented as being the primary carers most frequently, followed by professional carers and the children of patients. Of note, 64% of patients living at home pre-admission did not have a professional care package in place. 105 out of the 107 patients with carers had carer-related issues documented in the patient notes. In 96% of cases, the primary issue was that the carer(s) felt unable to cope with the patient in their pre-admission setting. The majority of patients were living at home, with or without a resident carer, prior to admission (figure 3). In contrast, only a minority of patients were discharged home from the ward, with most patients being discharged to residential homes, nursing homes or continuing care wards (figure 4).

Figure 3: Patients' abode before admission

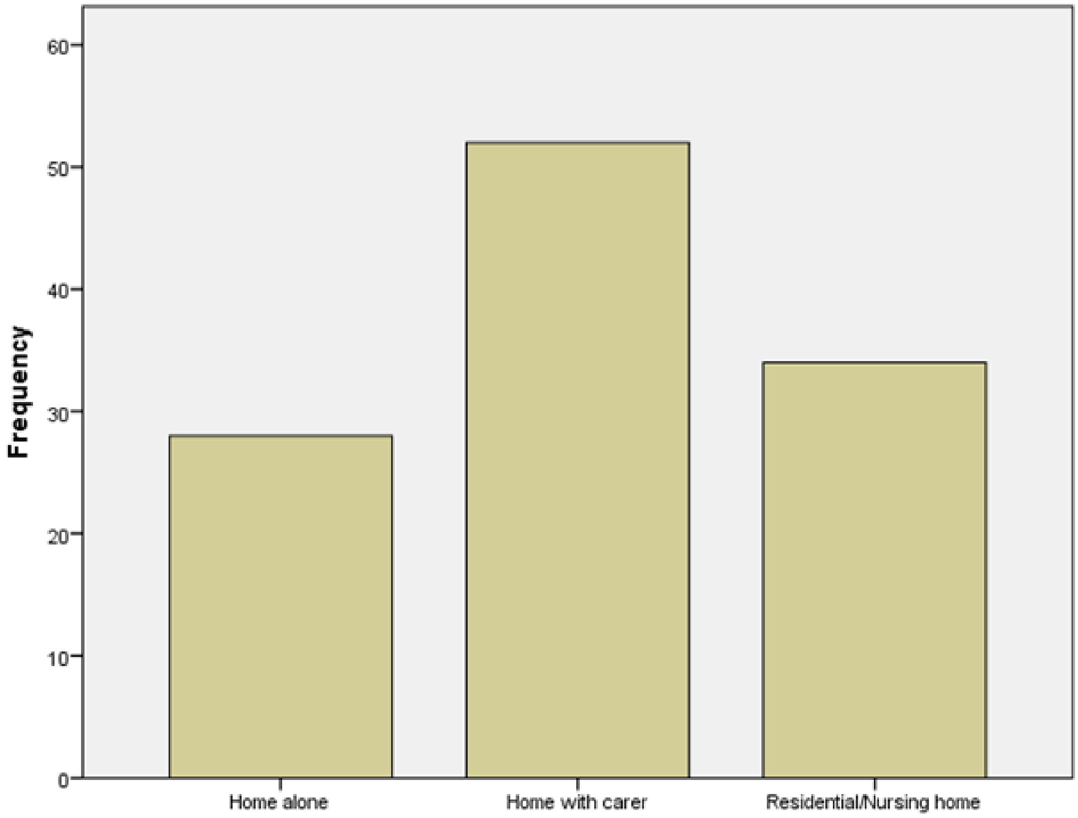
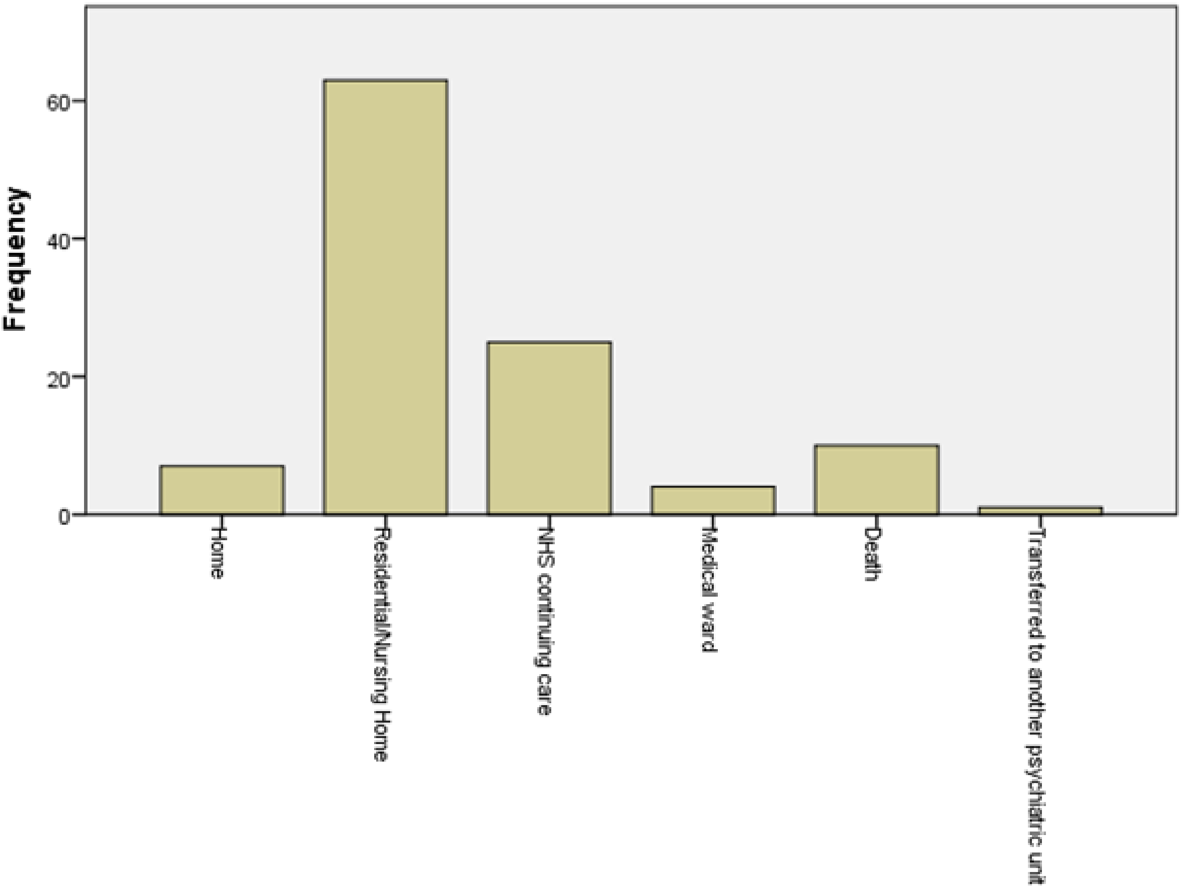


Figure 4: Patients' abode on discharge from the dementia inpatient ward



Discussion and conclusion

Aggressive and/or violent behaviour was, by far, the most frequently identified reason for admission to an inpatient dementia ward. Multiple therapies exist to help manage behavioural symptoms of dementia and we demonstrated that both pharmacological and non-pharmacological interventions were utilised in the vast majority of patients admitted to the ward.

If we are to reduce the number of hospital admissions, it is critical that we identify those patients in the community who are at risk of admission due to aggressive and violent behaviour. Use of pharmacological and non-pharmacological therapies in the community, for example via outreach teams or day treatment units, could help to reduce the need for admission.

We also identified that most carers felt unable to cope with the patients in their pre-admission setting. If admission is to be avoided, it is critically important that we identify those carers who are struggling in the community and offer them support. Prompt assistance, in the form of additional care, respite placements and psychological support, could avert the need for admission. Similarly, we note that post-admission the vast majority of patients were discharged to long-term care facilities (either residential/nursing homes or NHS continuing care wards), whereas pre-admission most patients were living at home. This may suggest that many patients and carers were "teetering on the brink" in the community prior to admission and that it took an admission to hospital to appropriately address the patients' care needs. It follows that a proportion of these admissions might have been averted if there had been a timely review of care requirements in the community.

It is also worth noting that a significant proportion of patients were admitted to hospital from residential or nursing homes, with the majority of homes reporting that they were unable to cope with the patients' behavioural symptoms. Another potential strategy to help reduce admission rates might therefore be to train care home staff in the use of non-pharmacological therapies, such as multisensory therapy and animal-assisted therapy, to help manage patients with behavioural and psychological symptoms of dementia.

Key points

1) Aggressive and/or violent behaviour is the most frequent reason for admission to inpatient dementia units.
2) There must be a concerted effort to identify those patients who are at risk of admission due to aggression and to utilise pharmacological and non-pharmacological therapies via outreach teams and day treatment units.
3) Carers of patients with dementia should have their needs assessed on a regular basis and additional support offered in a timely manner.

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Publication 4:

Carers’ diaries in dementia – Is there a role in clinical practice?

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ABSTRACT

INTRODUCTION – Carers' diaries have been used in very few instances in dementia to assist with gathering information about persons with dementia in the community. The main aim of this study was to compare problems identified using diaries kept by family carers for a week with carers' oral recollection of problems.

METHOD - Carers were randomly allocated into two groups, diary and control groups. In the diary group, carers received a diary and instructions on how to complete it for 7 days.

RESULTS - 78 carers completed the study. The frequency of problems identified in the carers diaries were greater than in the carers' narrative accounts at Day 1 and Day 8. The most common problems were behavioural and cognitive problems.

DISCUSSION – Carers' diaries may complement the assessment of dementia as they can provide more information on the problems faced by the persons with dementia.

Key words: Carers' diaries, assessments, dementia

1. INTRODUCTION

At the onset of presentation to dementia care services, initial assessments often involve taking a history from both persons with dementia and their carers who are often family members. It is not uncommon that the reason for presentation is based on observations of memory loss by family carers or carer distress or breakdown. What carers recollect at an initial assessment may be quite variable and they, along with their loved ones, may find it difficult to retain and recall all the problems in the initial assessments or follow-up appointments. Some carers attend clinic with written unstructured account of problems they face in caring to help provide information at the initial assessment. From the literature reviewed, there were very few studies on the use of carers' diaries in the assessment and management of dementia.

It has been reported that diaries can be used as a primary method of data collection with family caregivers and they found completing a diary both therapeutic and pleasurable [1]. Four types of diaries were described:

1. Meagre diaries - brief with only few lines recorded.

2. Reporting diaries - written like reports of daily timetables

3. Descriptive diaries - the type where family caregivers describe their daily tasks.

4. Reflective diaries - contained information about family caregivers' daily lives and emotions.

In a study examining the unstructured diaries of carers over the first six months following diagnosis of dementia, the two core themes found in the diaries were that the meaning of the onset of Alzheimer's disease has on the lives of carers and the restructuring of their lives [2]. In another diary study to examine relationship between caregiver-burden, leisure satisfaction and affect in dementia caregivers, a positive correlation between leisure satisfaction and positive affect amongst care givers was reported. Diary records capture rich source of data, but it has been suggested that solicited diary recording should be limited to one to two weeks in older adults as there will not be sufficient data if it is less than a week and for periods over two weeks the participants will get bored or tired of making entries which would make the data inadequate or unreliable [4].

There are drawbacks and limitations when people with dementia record their thoughts in written diaries. People with dementia became aware of their diminishing skills, frustrated and not sure what to record in their diaries [5]. Diary recording relies on participants to be self-motivated and inspired to notice and records their thoughts. Therefore, it has been suggested that this method should be in conjunction with other methods like interviews and also to include photo and audio diaries to help the researcher to understand the many facets of a person's life [6].

In a study using a diary method in conjunction with an interview to collect data from 14 family carers, the process of normalization was described, in which the family carers continuously defined and redefined their relationship with the persons with dementia as was normal for them [7]. The strategies taken up by family carers with the support of professional carers was said to be able to facilitate this process of normalization. The research also showed the diary method to be valuable as it provided a detailed account of factual, emotive, personal and sensitive events and emphasised the importance of it, when used in conjunction with interview data.

This present study aimed to examine a novel hypothesis that asking carers to record dementia patients' problems and symptoms as they occur in everyday life, may aside from recording more problems, have therapeutic effects on caregivers' mood and well-being by giving them better insight into the problems and how to cope or prevent them.

2. METHOD

2.1. Study Design

This was a mixed qualitative and quantitative, randomised controlled study in which experimental (diary group) and control participants completed various questionnaires assessing behaviour and psychological problems in people with dementia living with family carers, as well as the carers' health-related quality of life and mood. In addition, participants randomly allocated to the diary group were given a diary to complete of patient problems for one week (between Day 1 and Day 8) and the control group were not asked to keep a diary. The carers were randomly allocated to two groups, control and diary groups respectively.

2.2. Study Participants

The study participants were recruited from the local memory clinic. It involved carers of patients newly diagnosed and follow-up patients with Alzheimer's disease referred to the clinic. Both patients and carers were provided with information sheet about the study and invited to participate. Patients were informed that their medical records would be reviewed for information pertaining to the study, which would be kept anonymous, and that they would not be interviewed. If both patients and carers expressed an interest, follow-up visits at home were arranged for Day 1and Day 8. Informed consent was obtained on Day 1 with both patients and carers being reminded they could opt to withdraw from the study at any time and that would not impact on their treatment in the memory clinic.

Inclusion Criteria:

12 Carers over the age of 20 years who cared for a person diagnosed with dementia and resided with them at home.

13 Participation of only those persons where consent was obtained from both carer and the person with dementia being cared for.

Exclusion Criteria:

3. Any carer who did not give an informed consent.
4. Any carer who was unable to speak, read or write in English to fully participate in the study.

a. Assessment tools

The following assessment tools were used:

1. The **Clinical Dementia Rating Scale** includes six domains consisting of memory, orientation, judgement and problem solving; community affairs; home and hobbies; and personal care [8, 9]. Each domain is rated on a 5 point scale with the following scale points: 0 – healthy; 0.5 – questionable; 1 – mild; 2 – moderate and 3 – severe. Total scores give a global measure of dementia. It was used to evaluate the severity of dementia by carers in the person they cared for at the onset of study on Day 1.

2. The **Neuropsychiatry inventory (NPI)** is a relatively brief interview with a carer, rating 12 behavioural areas in dementia [10, 11]. It is scored from 1 to 144, which is the sum of the multiplication of severity (S) and frequency (F) scores of the 12 NPI symptoms independently assessed by a clinician, based on information provided by carers. Both the severity and frequency of each symptom are rated on a three (1 – 3) and four point (1 – 4) Likert scale, respectively. It was used by carers to rate severity of problems in persons with dementia and their own distress at Day 1 and 8.

3. The **EuroQol** is a measure of health related quality of life and is designed for self-completion by respondents and is ideally suited for postal surveys, in clinics and face to face interviews [12]. This measure was completed by the carers to rate their own quality of life at Days 1 and 8.

4. The **Hospital Anxiety and Depression Scale (HAD)** is a 14-item scale that is self-administered and used to assess for possible anxiety or depressive symptoms [13]. There are 7 items each, for depression and anxiety, respectively. This was completed by carers to rate severity of anxiety and depressive symptoms at Days 1 and 8.

5. The **6-CIT Dementia Test** is a brief and simple test of cognition [14]. It reportedly performs well as a screening instrument for dementia and is widely used in Primary Care and only takes approximately 2 minutes. It consists of six questions, with a total score of 28. Scores of 0 - 7 are considered normal and 8 or more as significant. It was used as a screening tool in carers on day 1 to identify if any of them had possible dementia.

6. A **proforma** was also developed collecting sociodemographic details of patients and their carers which was completed on Day 1 obtaining information from carers and the patients' medical records.

7. **The diary** was adapted for use in carers of patients with dementia from previous diary studies of autobiographical and intrusive memories involuntary and everyday memory failures in young and old participants [15, 16]. The diaries were semi-structured to allow free

flowing responses as well as ratings of severity of problems or distress using Likert scales. The diary was an A5 size booklet containing 7 questions per page, with participants in the diary group expected to record one problem or difficulty per page.

At Days 1 and 8, carers in both groups were asked to give verbal narrative account of the problems the person with dementia that they cared for had in the preceding week.

5. RESULTS

3.1. **Recruitment of participants**

Over the 1 year period of recruitment from 1 May 2014 to 30 April 2015, 97 couples were identified and approached to take part in the study following which 84 couples agreed and gave written informed consent to take part and were subsequently recruited. The participants on recruitment were randomly allocated into the diary and control groups. 41 participants in the control group and 39 participants in the diary group completed the 8th day assessments and / or diaries. The background variables of patients in the diary and control groups, in terms of age, gender, severity, and duration were not significantly different at day 1 (Table 1). Likewise, amongst the carers, there were also no significant differences in the background variables (Table 2).

3.2. **Outcomes in diary and control groups**

The problems identified in the narratives and diaries were coded and counted by two raters who came to a mutual agreement where there were any discrepancies. The problems identified were classified under Behaviour, Cognitive, Emotional, Psychiatric and Other Problems (Table 3).

Of the 39 carers randomly allocated to the diary group, 12 were male and 27 were female carers. The mean number of diary entries (pages) was 4.3 (S.D=3.97) pages. 8 (20.5%) carers made no entries claiming there were no problems to record. The maximum number of diary entries (pages) by a carer was 17 and the mean number of problems identified per diary page was 1.8. The mean number of diary pages completed by female carers was 5.2 pages (S.D = 4.1) of diary entries and by the male carers 2.3 pages (SD = 2.9) which was significantly different ($p < 0.05$) using the analysis of variance. The number of problems identified in the diary entries was significantly greater for all 5 groups compared to the narratives in the carer group (Table 4). However, there were no significant differences between the total number of problems in the diary and control groups in the carers' verbal narrative accounts at both Days 1and 8. There were no significant differences between diary and control groups' mean scores in the Neuro Psychiatry Inventory, EuroQol and Hospital Anxiety and Depression Scale at Days 8 and 28 (Table 5).

Table 1: Background variables for patients in the control and diary groups

	Control **(n= 41)**	**Diary** **(n = 39)**	**Statistical Test**	**P**
Mean Age in years	78.02 (5.24)	79.64 (6.09)	F = 1.626	0.206
Gender	M = 23 (56.1%) F = 18 (43.9%)	M = 25 (64.1%) F = 14 (35.9%)	λ = 0.534	0.308
Severity	Mild = 21 (51.2%) Moderate = 18 (43.9%) Severe = 2 (4.9%)	Mild = 14 (35.9%) Moderate = 24 (61.5%) Severe = 0	λ = 0.521	0.157
Duration of symptoms in years	3.33 (2.71)	3.38 (2.53)	F = 0.008	0.93
Mean total initial NPI score	18.58 (16.55)	23.59 (19.64)	F = 1.524	0.221

Key: F – Analysis of variance; λ – Chi-squared test

Table 2: Background variables for carers in the control and diary groups

	Control **N = 41**	**Diary** **N = 39**	**Statistical Test**	**P**
Mean Age	75.87 (7.76)	75.08 (7.97)	F = 0.208	0.65
Gender	M = 15 (36.6%) F = 26 (63.4%)	M = 12 (30.8%) F = 27 (69.2%)	λ = 0.302	0.377
Relation to patient	Spouse = 37 (90.2%) Child = 3 (7.3%) Carer = 1 (2.4%) Daughter in law = 0	Spouse = 36 (92.3%) Child = 2 (5.1%) Carer = 0 Daughter in law = 1 (2.6%)	λ = 2.165	0.539
Employment Status	In employment = 1 (2.4%) Retired = 34 (82.9%) Housework = 6 (14.6%) Gave up work to care = 0	In employment = 5 (12.8%) Retired = 29 (74.4%) Housework = 4 (10.3%) Gave up work to care = 1 (2.6%)	λ = 4.416	0.22
Six-CIT Score	1.83 (3.02)	2.2 (2.67)	F = 0.347	0.56
Mean total NPI Carer distress score	9.58 (8.66)	11.49 (10.12)	F = 0.813	0.37
HAD-Anxiety Score	6.88 (3.8)	6.72 (4.1)	F = 0.033	0.857
HAD-Depression score	4.37 (2.85)	4.74 (3.27)	F = 0.304	0.583
Euro-QoL score	71.19 (18.59)	72.72 (21.07)	F = 0.118	0.732

Key: F – Analysis of variance; λ – Chi-squared test

Table 3: Grouping of problems in dementia

Groups of problems or symptoms	**Symptoms**
Behavioural problems	Aggression, Violence
Cognitive problems	Memory difficulties such as forgetfulness repetitiveness
Emotional or affective symptoms	Anger, low mood, anxiety
Psychiatric problems	Hallucinations, delusions
Other problems	Eating problems, sleeping difficulties, apathy, incontinence

Table 4: Comparing number of problems in diary entries with the narrative accounts of carers in the diary group at Day 8 (paired t test)

Problems	**Diary entries (S.D)**	**Narratives (S.D)**	**Statistical test**	**P value**
Behaviour	2.77 (3.5)	0.31 (0.57)	T = - 4.659	< 0. 001*
Cognition	2.69 (3.66)	1.49 (1.29)	T = - 0.109	0.032*
Emotional	1.03 (2.19)	0.26 (0.5)	T = - 0.046	0.038*
Psychiatric	0.49 (1.02)	0.26 (0.55)	T = -2.042	0.048*
Others	0.87 (1.54(	0.31 (0.61)	T = - 2.042	0.021*
Total	7.82 (9.2)	2.62 (1.66)	T = -3.878	< 0.001*

Key: T – paired t-test. * - level of significance < 0.05

Table 5: Comparing the diary and control groups' mean scores in the Neuropsychiatry Inventory, EuroQoL and Hospital Anxiety and Depression Scale at Day 8 (analysis of variance)

	Diary	Control	Statistical test	P
NPI score	17.436(15.87)	14.95(17.3)	F = 0.447	0.506
NPI Carer Distress score	8.49(8.3)	7.17(8.39)	F = 0.498	0.48
EuroQoL score	74.87(19.56)	74.71(15.29)	F = 0.002	0.97
HAD – A score	6.51(3.57)	6.02(3.7)	F = 0.36	0.55
HAD – D score	4.56(2.41)	4.19(3.1)	F = 0.35	0.56

6. DISCUSSION

This is an original study that involves the use of carers' diaries in dementia with a mixed qualitative and quantitative design. It is a randomised control study comparing real-time recording of problems using carers' diaries with the retrospective information gathered in the usual clinical assessments in clinics or domiciliary visits of persons with dementia living at home. The findings revealed that the carers' diaries identified a greater number of problems compared to retrospective information gathered from carers with forgetfulness and behaviour problems being the two most common problems. Carers' diaries identified more problems in the areas of behaviour, cognition, emotional and psychiatric, as well as, problems grouped under others such as insomnia and incontinence. Despite identifying more problems, the use of the carers' diaries in dementia did not appear to make a difference in carers in terms of carer distress, carers' health related quality of life or their mood.

In contrast, earlier studies involving carers' diaries in dementia were mainly qualitative and involved the use of unstructured diaries in comparison to this study [1, 2, and 3]. They found that there were beneficial effects on carers affects and experience of caring. These earlier studies mainly focused on carers' problems and impact of caring whereas this current study investigated both carers and the person being cared for with dementia.

An incidental finding noted was that the male carers in this study tended to under report problems in their narratives and diary entries which became apparent when reports were compared with the Neuropsychiatry Inventory scores. This under reporting may have an impact on the usefulness of diaries and narrative accounts in male carers or the need to put this into consideration, when taking accounts from male carers. It may be that male carers tend to normalise things much more than female carers, or a reflection though not confirmed in this study or the literature, that female patients with dementia may be less demanding on family carers.

Our findings suggest that there may be a potential use of carers' diaries in the assessment of dementia, in that they may identify more problems compared to relying solely on the retrospective account of patients and carers in clinic. More research using carers' diaries in dementia covering longer period than a week may be required to ascertain other benefits.

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