

# **Effectiveness of Recovery-Focused Mental Health Care of Older people with Memory problems**

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## **Structured Abstract**

**Introduction** Dementia is a syndrome due to disease of the brain, usually of a chronic nature, in which there is disturbance of multiple higher cortical functions including Memory, Comprehension, Thinking, Judgment, Orientation, language and communication skills and abstract thinking. It is one of the most challenging disorders both in terms of prevalence and economic burden. There are currently approximately 800,000 people with dementia in UK and national cost is 17 billion per year. It is estimated that in next thirty years, number of people with dementia will increase to 1.4 million and the national cost will be over 50 billion. The exceptional advances in modern medicine in terms of prolonging life expectancy do not necessarily improve the care delivered to people with dementia. Dementia is a progressive condition where clinical recovery is not possible despite the discovery of cognition enhancing drugs. This belief leads to low expectations that tend to erode hope and foster indignity. Advances in treatment of Alzheimer's disease have, however, stimulated new thinking and methods of service delivery. At certain stage of their illness, if not from the very beginning, personal, and social recovery becomes more meaningful for service users than their clinical recovery.

**Objective** To investigate whether recovery-orientated psychiatric assessment and therapeutic intervention enhances the wellbeing of people with memory problems and their family carers.

**Method** This study was a preliminary randomised control study. Patients were randomly allocated to recovery focus group or treatment as usual group acting as the control. Participants in the recovery focus group received a recovery-focused pre-diagnostic wellbeing assessment and counselling, diagnostic consultation with written feedback and post-diagnostic support over a period of six months. Participants in both groups were assessed using the WHO Wellbeing Index (WHO-5) as the primary outcome measure. The Mini Mental State Examination, Cornell Scale for Depression in Dementia, EuroQol-5D and Zarit Burden Interview were used as secondary outcome measures. Written records of the narrative accounts of participants in the recovery focus group were also obtained.

**Results** 48 patients with early dementia were recruited and agreed to take part in the study. Out of these, 34 patients completed the study, of which 17 patients were in the recovery focus group and 17 patients were in the treatment as usual group (control). There was a significant difference between the groups in terms of greater improvement in wellbeing as rated by the WHO – 5 Wellbeing Index in the recovery focus group compared to the control group. The secondary outcome measures in the areas of cognition, quality of life and caregiver burden showed no differences between the groups. However, case histories from the recovery focus group identified the main areas of improvement in improved mood, increased social interaction, reduction in carer strain and / or burden and improved self-worth and / or confidence.

**Conclusions** This study shows that recovery focused care can enhance the wellbeing of people with mild to moderate dementia. The additional benefits perceived by the patients and their relatives /carers include improvement in mood symptoms, social interaction and confidence as well as reduction in carer burden and strain.

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## **Statement of originality**

This thesis represents original work that I carried out at Logandene Care Unit, Hemel Hempstead of the Hertfordshire Partnership NHS Foundation Trust.

## **Ethical considerations**

Ethical approval was obtained from Hertfordshire Research and Ethics Committee East of England. The consent of all patients who were involved in the study was obtained. The participants were given verbal explanations about what the study involved and how, if any it would affect their care and that any time they could withdraw from the study. This information was substantiated by the provision of patient information sheet, which was designed into two parts; Part 1 was the simple explanation of the study and a more detailed explanation in part 2.

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# 1.Introduction

## 1.1 Background information on Dementia

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions including memory, comprehension, thinking, judgement, orientation, language and communication skills and abstract thinking. It is one of the most challenging disorders both in terms of prevalence and economic burden. There are currently approximately 800,000 people with dementia in UK and national cost is 17 billion per year (Lakey et al 2012). It is estimated that in next thirty years, number of people with dementia will increase to 1.4 million and the national cost will be over 50 billion. The exceptional advances in modern medicine in terms of prolonging life expectancy do not necessarily improve the care delivered to people with dementia.

In the 10<sup>th</sup> Revision of the International Classification of Disease (ICD- 10), in the section on organic and symptomatic mental disorders coded (F00 - F09), dementia is classified into the following categories:

1. Dementia in Alzheimer's disease.
2. Vascular dementia.
3. Dementia in disease classified elsewhere.
4. Unspecified dementia.
5. Organic amnestic syndrome other than induced by alcohol and drugs.
6. Delirium, other than induced by alcohol and drugs.
7. Other mental disorders due to brain damage and dysfunction and to physical disease.
8. Personality and behaviour disorders due to brain disease, damage and dysfunction.

## 9. Unspecified organic or symptomatic mental disorder.

In terms of epidemiology in later life, Alzheimer's and vascular dementia are the most predominant types of dementia (Jorm, 2002). The other dementias include Lewy body dementia, frontal-temporal lobe dementia and alcohol dementia.

There are several theories regarding the etiology of Alzheimer's disease and the most common one includes decrease in neurotransmitters Acetylcholine, changes in protein synthesis of Beta amyloid and Tau responsible for forming plaques and neurofibrillary tangles. The pathophysiological changes caused by Alzheimer's disease include diminished blood flow, neurofibrillary tangles, neuritic plaques, degeneration of hippocampus, cerebral cortex, hypothalamus, and brain stem. The Genetic theories include ApoE4 on chromosome 19 linked to late-onset Alzheimer's disease and Chromosome 21 responsible for early-onset Alzheimer's disease. Other theories suggest a dramatic decline in glucose metabolism and too much calcium leading to neuronal death in Alzheimer's patients. Environmental Aluminum trace and Zinc is detected in brains on autopsies. Food borne poisons-like amino acids found in legumes in Africa and India have also been suggested as a cause for neurological damage. Viral infections are suspected to remain hidden in body and attack brain cells years later (NIH-1995). Head trauma is believed to lead to an increase in the concentration of B-amyloid protein and hence associated with AD. It is also proposed that the individuals with low level of education are less able to compensate for cognitive deficits.

Clinical features of Dementia due to Alzheimer's disease include memory Impairment with at least one disturbance in other cognitive functions including Aphasia (loss of the ability to use symbols to communicate orally or in writing), Apraxia (inability to initiate complex



learned motor movement or unable to perform activity on command), Agnosia (inability to recognize familiar objects by sight, touch, taste, smell or sound) and Frontal-Executive dysfunction (Inflexibility in thinking, difficulties in problem solving and correctly sequencing behaviour, proverb interpretation and verbal fluency). Other cognitive deficits include impairment in reading (Dyslexia), impairment in writing (Dysgraphia), inability to calculate (Acalculia) and Right–Left disorientation. The non-cognitive symptoms include mood and behavioural changes, lethargy, withdrawal, sleep disturbances, restlessness, destroying property, and verbal disruption, sexually inappropriate behaviour along with urinary and faecal incontinence.

Alzheimer's disease is divided into four physical stages of mild, moderate, severe and terminal stage based on the progression of symptoms. The symptoms of mild stage are memory loss, disorientation about place, loss of spontaneity, loss of Initiative and mood/personality changes. Patients take longer to perform routine chores and have trouble in handling money and paying bills. The next stage entails moderate impairments in language, motor ability, and object recognition, increasing memory loss and disorientation, problems in recognizing family members and close friends, repetitive statements and/or movements, restlessness especially in late afternoon and at night. They can also experience occasional muscle twitches or jerking, problems in organizing thoughts and in reading and writing. People may become suspicious, irritable, and fidgety, teary or silly. Severe stage symptoms include weight loss even with good diet. There is little capacity for self-care and person can not communicate with words. They may put everything in mouth or touch everything. They can not control bladder or bowel and may have difficulty with swallowing. They can also have seizures, skin breakdown and

infections. During the terminal stage there is loss of ability to ambulate, sit, smile, hold up head and to swallow.

Currently available classification system (ICD-10) only provides brief information about Mild cognitive disorder with an understanding that the boundaries of this disorder are still to be firmly established. However, Mild Cognitive Impairment (MCI) has become a part of everyday clinical practice in psychiatry after it was first introduced by Petersen et al., in 1999 (Rodda, Gandhi, Mukadam and Walker, 2013). Petersen defined MCI as a set of five criteria including the memory complaint preferably corroborated by an informant, normal activities of daily living, normal general cognitive function, and abnormal memory for age and absence of dementia. These criteria soon evolved and resulted in the description of subtypes of MCI as amnesic and non amnesic, as it became apparent that people with MCI can present with memory impairment and /or impairment in other cognitive domains. The amnesic subtype is predictive of Alzheimer's disease (Peterson, 1999; Bennett et al., 2002; Lopez et al., 2003) with an annual conversion rate of 10%-15% compared with 1%-2% in the general population. It is recognised that criteria for MCI are continuing to evolve over time and working group of the European Consortium in Italy in 2005 incorporated the further developments to help in identification of MCI. The criteria for MCI, according to the consortium includes cognitive complaints from the patients or their families, report of a relative decline in cognitive function during the past year by the patient or the informant, impairment in memory or other cognitive domain evident on cognitive testing, absence of major repercussions on daily life and absence of dementia (Porter et al., 2006).

Traditionally, the management of Alzheimer's disease involves thorough clinical assessment and some diagnostic tests to rule out presence of other reversible causes for declining cognition. The role of detailed history, collateral information, mental state examination, risk assessment, cognitive examination is crucial to reach a working diagnosis and guide further investigations including Neurological Exam, Blood investigations and brain Imaging like CT or MRI scan. Out of various scales used to assess the severity of dementia, the Mini-Mental State Examination (Folstein et al., 1975) is the one that is most often used in clinical practice. It has scores ranging from 0 - 30 and often used to rate severity of cognitive impairment with scores of 20 – 24 rated mild; 10 – 19 rated moderate and below 10 rated severe. The inability of one single scale being used to rate dementia and the associated problems has led to array of scales used to rate cognitive function, behaviour and psychological problems, quality of life and needs in dementia. Examples of such scales include:

1. Scales to measure cognition: Alzheimer's disease Assessment Scale (Rosen et al., 1984); Addenbrooke's Cognitive Examination –Revised (Mioshi et al., 2006); Clinical Dementia Rating Scale (Morris, 1993).
2. Scales to measure non-cognitive aspects of dementia: BEHAVE-AD (Reisburg et al., 1987); Neuropsychiatric Inventory (Cummings et al., 1994).
3. Measures of caregiver burden and stress: Screen for Caregiver Burden (Vitaliano et al., 1991); Burden Interview (Zarit et al., 1980).
4. Quality of life measures like Quality of Life in Dementia (Blau 1977); EuroQol (The EuroQol Group 1990).

The medical model of dementia care follows the diagnosis and management based on National Institute for Health and Clinical Excellence guidance [National Institute for Health and Clinical Excellence 2011]. In the guidance, clinical cognitive assessment in those with suspected dementia should include examination of attention and concentration, orientation, short and long-term memory, praxis, language and executive function. Although, as part of this assessment, the Mini Mental State Examination (MMSE) is the frequently used instrument, a number of alternatives are now available, such as the 6-item Cognitive Impairment Test (6-CIT), the General Practitioner Assessment of Cognition (GPCOG) and the 7-MinuteScreen. However, those interpreting the scores of such tests should take full account of other factors known to affect performance, including educational level, skills, prior level of functioning and attainment, language, and any sensory impairments, psychiatric illness or physical/neurological problems. Formal neuropsychological testing should form part of the assessment in cases of mild or questionable dementia. At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical co morbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions.

A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include: routine haematology, biochemistry tests (including electrolytes, calcium, glucose, and renal and liver function), thyroid function tests, serum vitamin B12 and folate levels. Testing for syphilis serology or HIV should not be routinely undertaken in the investigation of people with suspected dementia. These tests should be considered only in those with histories suggesting they are at risk or if the clinical picture dictates the requirement for the tests. A midstream urine test should always be carried out

if delirium is a possibility. Clinical presentation should determine whether investigations such as chest X-ray or electrocardiogram are needed. Cerebrospinal fluid examination should not be performed as a routine investigation for dementia. A diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria.

Approach to care in the medical model is based on pharmacological interventions for the cognitive symptoms of Alzheimer's disease as per the National Institute for Health and Clinical Excellence (NICE) guidance. The three acetyl cholinesterase (AChE) inhibitors (Donepezil, Galantamine and Rivastigmine) are recommended as options for managing mild to moderate Alzheimer's disease under all of the conditions specified in National Institute for Health and Clinical Excellence( 2011). Memantine is recommended as an option for managing Alzheimer's disease for people with moderate Alzheimer's disease who are intolerant of or have a contraindication to acetyl cholinesterase inhibitors or severe Alzheimer's disease. The National Institute for Health and Clinical Excellence recommends that people with dementia who develop behavioural and psychological symptoms that cause them significant distress should be offered an assessment at an early opportunity to establish likely factors that may generate, aggravate or improve such behaviour.

The recent advances in neuroimaging, cerebrospinal fluid assays and other biomarkers now provide the ability to detect the evidence of Alzheimer's disease pathophysiological process in vivo( Sperling & Johnson.,2013 ) , but we are still a long way to come up with an new and alternative pharmacological agent for its treatment and cure.

## 1.2 Caring in dementia

A report by the World Health Organisation (WHO) and the Alzheimer Disease Association International (ADI) suggested a crude estimated prevalence of dementia of 4.7% among people 60 years and above (WHO 2012). This indicates that 35.6 million people are living with dementia. The total number of people with dementia is projected to increase every 20 years. That is, to 65.7million people by 2030 and up to 115.4 million by 2050. Much of the increase is attributable to the rising numbers of people with dementia living in low and middle income countries. According to Dementia UK report 2010, dementia had the lowest healthcare costs of 1.2 billion, compared to £ 4.0 billion for cancer, £ 2.2 billion for coronary heart disease(CHD) and £ 1.6 billion for stroke. However, the costs placed on the social care system (£9.1 billion), far outweighed the social care costs of cancer, coronary heart disease (CHD) and stroke. Combining the costs to the UK health and social services, dementia cost £ 10.3 billion in 2008, compared to £ 4.5 billion for cancer, £ 2.7 billion for stroke and £ 2.3 billion for coronary heart disease. Using UK prevalence estimates for these four diseases, the health and social care costs per person with the disease were evaluated at £ 12,521 for dementia, £ 2,559 for stroke, £ 2,283 for cancer, and £ 1,019 for CHD. For dementia, 55% of total costs were attributable to informal care, 40% to social care and 5% to health care. Productivity losses for this disease were almost negligible. In contrast, for cancer half of all total costs of the disease were due to productivity losses (mainly mortality losses), with informal and social care only accounting for 16% of total costs. For both stroke and CHD, total costs were more evenly distributed across the different categories of cost. Stroke was the only disease for which health and social care costs accounted for over 50% of total costs.

In United States, of the estimated 5.3 million Americans with Alzheimer's disease and related dementias, over 80% are cared for by family members (Alzheimer's Study Group 2009; Gaugler et al., 2002; Zhu et al., 2006). Most carers are older people who may experience social isolation, poor health and unsatisfactory accommodation (Gilleard 1998). Carer studies have reported more psychiatric morbidity amongst carers of people with dementia (Pruchno & Potashnik 1989) and greater carer strain (Eagles et al., 1987, O'Connor et al., 1990). Factors associated with carer stress include behaviour problems, poor communication, formal relationship, home environment and premorbid closeness (Gilleard, 1998).

### **1.3 Models of care in dementia**

Most people with dementia are cared for by informal carers like friends and family members in their own homes. Other modes of care or support may be required when care at home is unavailable, inadequate or leading to carer stress. These may include day care, respite care; home care support and various forms of institutionalisation ranging from sheltered or supported accommodation, residential or nursing home care or long term hospital care like placements in the National Health Service funded continuing care units. The medical model of dementia describes the definition of dementia and the different types based on disease classification systems like the international classification of diseases using the World Health Organisation International Classification of Disease -10 (National Collaborating Centre for Mental Health, 2006; 2007). The diagnosis and management is based on National Institute for Health and Clinical Excellence guidance [National Institute for Health and Clinical Excellence 2011].

In essence, a psychiatric assessment provides knowledge and understanding about the patient, but it does not always give us a true perception of patients' feelings. Personal

values and needs require additional assessment skill variously described as rapport, empathy, intuition, sixth sense etc. That interaction does not take place at intellectual level. It is happening at 'feeling' or 'emotional' level. Although psychological perspective is a key part of the biopsychosocial triad underpinning good psychiatric intervention, this may not be enough. In dementia care, there is a need to recognise the fourth dimension – emotional/affective component of care and therapy. Usually the emotional repertoire of people with dementia remains intact. To access the individual at emotional level, the therapist has to develop special skills in what Rogers called 'unconditional positive regard' (McLeod, 2007) and Kitwood called 'Love' and 'empathy' (Kitwood, 1997).

#### **1.4 Person Centred Care in Dementia**

Person Centred Care (PCC) has its origins in the work of Carl Rogers and client centred counselling and psychotherapy. Professor Tom Kitwood was the first to use the term Person Centred Care. There is a huge acceptance of the person- centred approach in dementia care, initially developed by Kitwood (1997) and later described by Sabat (2002) and Brooker (2007). Kitwood (1997) challenged the dehumanising care practice in dementia and described the frame of reference as PERSON –with- dementia rather than person- with- DEMENTIA. He published his ideas in several articles and compiled them together in his best known book *Dementia Reconsidered*. He developed a theoretical framework of dementia and believed that dementia was an interplay between psychological, neurological, personal and social factors and expressed the configuration by  $D = P$  (Personality) + B (Biography) + H (Health) + NI (Neurological impairment) + SP (social I psychology). The configuration is unique to each individual and helps in developing the care tailored to that person. It is alluded to as the basis for the development of Person Centered Care (PCC).



Person Centered Care became the underpinning principle for Dementia care and service provision. Kitwood appears to have developed a firm theoretical ground for dementia care based on good communication and sound social contact. Person Centered Care affirms the complete value for all human beings irrespective of their age or cognitive ability. The emphasis is on recognising the individual uniqueness and accepting the differences in culture, gender, values and beliefs. Kitwood strongly opposed the view that diagnosis of the primary degenerative dementia is a death sentence that leaves the body behind. He recognised that people working in the care profession can become so conditioned by defining people they work with by their diagnostic group, problem type or service need that they are at risk of overlooking the person behind the label. For a person centred therapy to take place, it is not the patient who should be 'psychological minded', but the clinician who has to be 'heart minded'. To be able to provide dementia therapy at intuitive and emotional level the therapist has to have certain special skills and attributes.

To promote and maintain personhood, Kitwood (1997) used the term 'positive person work' to describe the following twelve different types of attributes for a therapist:

**1 Recognition** The caregiver brings an open and unprejudiced attitude, and meets the person with dementia in his or her uniqueness

**2 Negotiation** The caregiver sets aside all ready-made assumptions about what is to be done, and dares to ask, consult and listen

**3 Collaboration** A deliberate abstinence from the use of power, and hence from all forms of imposition and coercion

**4 Play** The caregiver is able to access a free, childlike, creative way of being

**5 Timalation** Forms of interaction in which the prime modality is sensuous or sensual, in which the caregiver is at ease with his or her sensuality

**.6 Celebrations** The caregiver is open to joy, and thankful for the gift of life

**7 Relaxation** The caregiver is free to stop active work, for a while, and even to stop planning to positively identify with the needs of people with dementia

**8 Validation** The caregiver goes beyond his or her own frame of reference in order to have an empathic understanding of the other

**9 Holding** Whatever distress the person with dementia is undergoing, the caregiver remains fully present, steady, assured and responsive

**10 Facilitation** Readiness to respond to the gesture which a person with dementia makes, sharing in the creation of meaning

**11 Creation** The creative action initiated by the person with dementia is seen and acknowledged as such

**12 Giving** The caregiver is humble enough to accept whatever gift of kindness or support a person with dementia bestows, and honest enough to recognise his or her own need.

Person Centered Care has continued to proliferate since its inception and has gained huge recognition both globally and within UK. The decision of Department of Health (2001) to make Person Centered Care for older people as Standard 2 of National Service framework was momentous. This led to significant changes and improvement in overall dementia care, but somehow along this process the original emphasis on authentic communication and changing care culture drifted and individualised care plan was loosely being interpreted as PCC.

The subsequent review by Dawn Brooker (2004) identified that the term Person Centered Care was not a straight forward concept and devised a contemporary definition with four essential elements (VIPS) and adopted Tom Kitwood's style of representing complex ideas

in equation form and expressed as PCC (person centred care) = V+I+P+S. V represents a Value base that asserts the absolute value of all human lives regardless of age or cognitive ability, 'I' suggests an individualised approach and recognising uniqueness, 'P' is to understand the world from the perspective of service user and, finally, 'S' is about providing a social environment that supports psychological needs. There is emphasis on practical application and care homes are provided with clear guidelines for implementation. Tom Kitwood and his colleague, Kathleen Bredin, first developed a structured tool called Dementia Care Mapping (DCM; 1980's) to improve the delivery of person centred care in dementia (Bradford Dementia Group 2005; Brooker 2005). It is based on a serious attempt to take the standpoint of the person with dementia using a combination of empathy and observational skill (Kitwood 1997a, p4). It is a well-defined observational tool (Bradford Dementia Group, 1997) used in formal care settings as an instrument for person centred care and as a tool in quality of life research. Dementia Care Mapping is based on experience of the care received by people with dementia, living in institutional settings like care homes. The tool is being constantly updated based on the feedback of its users. DCM provides a comprehensive evidence of impact of social psychology of dementia; displaying restoration of personhood by good care and fostering of vegetation through delivery of uncare.

A review of the literature on Dementia Care Mapping suggested that it has a role in practice. However, many care providers are not in a position to implement it due to cost and training implications. The NICE-SCSI Dementia recognises the principles of person centred care and recommends that the assessment of people with dementia should include the person's physical health, depression, possible undetected pain or discomfort, side effects of medication, individual biography, including religious beliefs and spiritual and

cultural identity, psychological factors, physical environmental factors and behavioural and functional analysis (National Collaborating Centre for Mental Health 2006; 2007). This should be followed by an individually tailored care plan which should be reviewed regularly. The guideline also acknowledges that just one intervention is often not enough because people with dementia do not only experience cognitive impairment, but also physical, emotional and social concerns. By combining interventions, professionals are more likely to succeed in promoting the independence of an individual than the use of one intervention alone.

Person Centred Care provided an initial momentum and motivation for service reform but has not greatly influenced public attitudes towards dementia.

The review of the research literature about Dementia Care Mapping by Brooker (2005) appears to be modest. The advantage of being a valid, standardized and international instrument is not always translated into a huge improvement in quality of life of people with dementia. However, it has a unique advantage in promoting positive practice development and evaluation in dementia care.

The Caring for Aged Dementia Care Resident Study (CADRES) was a cluster randomised controlled trial in which 324 people living in residential care were randomly assigned to person-centred care, dementia-care mapping, or usual care (Chenoweth et al. 2009). Carers received training and support in either intervention or continued usual care. Although, there was an improvement in agitation measured with the Cohen-Mansfield Agitation Inventory (CMAI) in people in dementia care mapping group, it did not translate as an improvement in quality of life in care home residents. Outcome measures were

assessed before and directly after 4 months of intervention, and at 4 months of follow-up. The benefits in outcomes like agitation, depression, drug prescription did not continue beyond the duration of intervention and hence application of these measures in routine clinical practice becomes difficult.

In contrast, Fossey` et al., (2006) showed that staff trained in the delivery of person centred care and skills development lead to a reduction in the use of antipsychotic medication in dementia care homes for managing behavioural symptoms. Moreover, the reduction in antipsychotic medication use in dementia was sustained for up to 12 months in their study and the levels of agitation and episodes of aggressive behavior did not increase.

## **1.5 Recovery Approaches in Dementia**

Person centered care outlined in the previous section does emphasise the importance of patient and carers emotions and wellbeing, which is an important step forward from purely medical model. However, it is not available to all patients and care givers and in addition, it considers the person as the passive recipient of the care.

The aim of the present thesis was to instigate a new approach in care of dementia using principles of recovery approach. Recovery is a concept that has been introduced principally by people who have recovered from mental health experiences and has evolved significantly around the developed world (National Institute for Mental Health in England 2005). Actively considering recovery and wellbeing based practice could provide a platform for change in normally held pessimistic attitudes by public and professionals about dementia. Recovery is not just about what services do to or for the people. It is

usually thought of as broadly equivalent to 'cure', a return to how things were before the injury occurred or the illness began. Recovery, according to the National Institute for Mental Health in England, is what people experience themselves as they become empowered to manage their lives in a manner that allows them to achieve a fulfilling, meaningful life and a contributing positive sense of belonging in their communities. One of the guiding principles of the National Institute for Mental Health in England is that 'users of service with the support of clinicians, practitioners and other supporters should develop a recovery management or wellness recovery action plan (Department of Health: London, 2005). This plan focuses on wellness, the treatments and support that will facilitate recovery and the resources that will support the recovery process. People with memory problems may accept these problems as part of normal ageing and continue to live a life lived by the majority of older people in a particular society. In early stages of dementia, people are usually aware of their difficulties in their day to day life. They express those experiences in various ways. It is only when their dementia progresses they become oblivious to their condition, surrounding and people around them. They may not be able to communicate their predicament in words, but that does not mean they do not communicate at all. The recovery goals of people with mild to moderate dementia are obviously different from those with severe dementia, but both groups of people have potential to recover in their own unique way.

The apparent lack of evidence that the professionals assess and address the recovery and wellbeing needs of people with dementia is the main driver for this research. People with dementia generally want to stay in their own homes, as do their carers, and their quality of life is higher at home than in a care home. Services that enable early intervention have positive effects on the quality of life of family carers. Professionals often assess carers' needs, but not their quality of life. The general needs of older people with mental

health problems are similar to other people, for example, in terms of need for shelter, food, money and companionship (Department of Health 1997). However, in addition, they are more susceptible to physical disorders like heart disease, stroke, cancer, osteoporosis and arthritis. These associated problems lead to difficulty with mobility and activities of daily living such as eating, washing and dressing and concordance with the medication. As a group, older people become more dependent on others and services to meet their needs, although many individuals remain independent. The mental health problems of ageing are similar to the younger population but, in addition, age related disorders like dementia are much more common, which results in increased dependency from worsening cognitive impairment. When mental health and physical problems coexist, as frequently is the case in the elderly, they may become more difficult to diagnose and manage.

Recovery and wellbeing approach provides a different paradigm that helps patients think and plan beyond their quality of life. In 2010, when the present study was in progress, Adams published a paper relating to the use of recovery approach and the people with dementia, particularly their nursing care. He proposed that the recovery approach shares many ideas with person-centered approaches to dementia care in relation to wellbeing, social inclusion, self-management and hope. Experiences of participants and recovery nurse in our study are in keeping with Adams's ideas and represent progressive nursing practice to promote wellbeing and maintain people with dementia in community settings.

## **1.6 Review of other psychosocial interventions for Dementia patients and/or their care givers**

There is a growing body of evidence emerging from robust randomized trials showing that non-pharmacological (psychosocial and environmental) interventions promote well-being of people with dementia and family caregivers (Gitlin, 2012). Nevertheless, few families have access to these interventions and their use in real world contexts is limited. Systematic reviews, meta-analyses and Cochrane reports over the past 15 years were reviewed to identify promising psycho-social-environmental interventions enhancing patient/family caregiver well-being. The findings suggest that varied multi-component tailored interventions benefit patients and reduce neuropsychiatric behaviors, minimize functional dependence, improve quality of life, and address depression and disengagement (Resources for Enhancing Alzheimer's Caregiver Health- the REACH multisite initiative at 6 months follow up. 2003). For caregivers, interventions decrease depression, burden and upset, and enhance their ability to deal with neuropsychiatric symptoms of dementia (Project CARE, 2006). The limitations include lack of interventions for different disease stages and etiologies, common clinical concerns (fall risk, physical health, and co morbidities), those living alone, and diverse caregivers with multiple care demands and financial strain. Few programs are integrated or sustained in practice settings of dementia care.

The effects of psychosocial intervention to family caregivers of patients with memory impairment were examined in a study by Yamada et al (2011). It was a randomized controlled trial with ad hoc (consecutive) recruitment, assessing effectiveness of caregiver



intervention. The data of outcome variables were designed to be taken from each participant right after entering the study and three times every 6 months thereafter during one and half years of the study. The results presented were from the interim analysis of the 6 month intervention. Patients and their caregivers were recruited by the physician after diagnosis of dementia and cognitive impairment. Thirty seven pairs of participants (patients and their family) were randomly allocated into two groups; the intervention group (n=19) receiving 6-month psycho-social intervention in addition to usual follow-up, and the control group (n=18) with usual follow up. Psycho-social intervention consisted of 1) once a month group meetings among caregivers, social workers and other staffs, and 2) telephone access to standby staff on three afternoons a month. Participants were interviewed on Activities of Daily Living (ADL), Instrumental Activities of Daily living (IADL), and depressive symptoms with CES-D (Centre for Epidemiologic Studies Depression Scale), Neuropsychiatric Inventory (NPI), Self-efficacy, ZBI (Zarit Burden interview Revised), and Caregivers Appraisal scale by principal investigator. Results showed that at baseline, there were no statistically significant differences in characteristics between the two groups on all measures taken, except for self-efficacy of caregivers which was significantly higher in the control group than that in the intervention group. After 6 months, instrumental daily activities (I-ADL) of patients as well as self-efficacy of caregivers declined in the intervention group. However, caregiver's feelings of burden (ZBI) became slightly lessened without significance. There was no significant difference in any outcome variables between intervention and control groups.

The Care of Persons with Dementia in their Environments (COPE) randomized trial was based on the idea that optimal treatment to postpone functional decline in patients with dementia is not established and the objective was to test a non-pharmacologic intervention realigning environmental demands with patient's capabilities (Gitlin et al., 2010). The study

design was a prospective 2-group randomized trial involving patients with dementia and family caregivers (community-living dyads) recruited from March 2006 through June 2008 in Pennsylvania. The interventions included up to 12 home or telephone contacts over 4 months by health professionals who assessed patient capabilities and deficits; obtained blood and urine samples, and trained families in home safety, simplifying tasks, and stress reduction. Control group caregivers received 3 telephone calls and educational materials. Functional dependence, quality of life, frequency of agitated behaviors, and engagement for patients and well-being, confidence using activities, and perceived benefits for caregivers at 4 months were the main outcome measures. Of 284 dyads screened, 270 (95%) were eligible and 237 (88%) randomized. Data were collected from 209 dyads (88%) at 4 months and 173 (73%) at 9 months. The COPE patients had less functional dependence and less dependence in instrumental activities of daily living at 4 months and also improved engagement compared with controls. The COPE caregivers improved in their well-being and confidence using activities. In this study, it was concluded that, non-pharmacologic biobehavioral environmental interventions resulted in better outcomes for COPE dyads at 4 months but not at 9 months for patients in comparison to control group caregivers. The COPE caregivers perceived greater benefits. This suggests that non-pharmacological interventions may have beneficial effects on both patients with dementia and their carers.

The Domus Project was a community care project for dementia developed with particular attention to the need for people to feel in control of their lives (Murphy et al., 1994). The evaluation of the project revealed that compared to more traditional setting, there was more interaction, decrease in depression and lower rates of general decline.

Lai et al. (2004) carried out a randomized controlled trial of a specific reminiscence approach to promote the well-being of nursing home residents with dementia. The study was based on the background that to date, no firm conclusions had been reached regarding the effectiveness of reminiscence for dementia and researchers had emphasized that there is an urgent need for more systematic research in the area. A single-blinded, parallel-groups (one intervention, one comparison, and one no-intervention group) randomized controlled trial (RCT) was adopted to investigate whether a specific reminiscence program leads to higher levels of psychosocial well-being in nursing home residents with dementia. The intervention adopted a life-story approach, while the comparison group provided friendly discussions to control for any changes in outcome as a result of social contacts and attention. The Social Engagement Scale (SES) and Well-being/Ill-being Scale (WIB) were the outcome measures used. The outcomes of the groups were examined with reference to the baseline (T0), immediately (T1), and six weeks (T2) after intervention. The final sample had 101 subjects (control group: n = 30; comparison group: n = 35; intervention group: n = 36). Using multivariate analysis with repeated measures, no significant differences in outcome were found between groups at either T1 or T2. Wilcoxon signed rank tests were performed for each group comparing outcomes between T1 and T0, T2 and T1, and T2 and T0. Significant differences were observed in the intervention group when comparing T1 and T0 WIB ( $p = .014$ ), but not for the other groups.

The study concluded that the intervention did not lead to significant differences between the three groups over time, but there was a significant improvement in psychosocial well-being for the intervention group. This study involved nursing home residents with dementia, likely to be more impaired compared those patients in our study. However, the study findings still indicate initial improvement in psychosocial well being. Some of the

previous randomized clinical trials have focused on the non-pharmacological intervention with either depression (Teri et al., 1997) or behavioural disturbances (Teri et al., 2005) associated with dementia. Teri et al. (1997) used two active behavioral treatments, one aimed at the patients and other at the caregivers. The emphasis was directed towards increasing pleasant events for the patients and training the carers in problem solving strategies. These treatments were compared with treatment as usual and waiting list controls. There was an improvement in patients as well as carers depressive symptoms in behavioral treatment arms as compared to control arms and the benefits were maintained at six monthly follow up. This highlights the relevance of non-pharmacological interventions in patients with dementia who may have mood disturbances such as depression.

Despite the lack of research on this topic, available evidence indicates that some of the psychosocial interventions may be beneficial. However, due to the wider lack of availability of such interventions, it is extremely challenging to demonstrate the benefits on day to day clinical practice. In addition, the above measures and interventions provide little information about the therapeutic benefits of interaction between clinicians, patients and their caregivers on the overall wellbeing of the patients. This is in contrast to recovery approaches, which enables practitioners to be in tune with changing realities of the dementia patients, develop a better understanding of carers feelings and support and facilitate an improvement in their wellbeing.

## 1.7 Possible role of the recovery based approach in memory problems due to early dementia

Dementia is a progressive condition where clinical recovery is not possible despite the discovery of cognition enhancing drugs. This belief leads to low expectations that tend to erode hope and foster indignity. Advances in treatment of Alzheimer's disease have, however, stimulated new thinking and method of service delivery. At certain stage of their illness, if not from the very beginning, personal, and social recovery becomes more meaningful for service users than their clinical recovery.

Dementia is preceded by a period of cognitive impairment and disability gradually progressing to dependence and death and application of recovery may seem to have little significance or even controversial. In order to implement the Recovery-focused approach for people with dementia, the definition of 'recovery' would require further modification. Instead of empowering older people with dementia to manage their lives, we felt that 'recovery from dementia' may be defined as 'a process of improving levels of wellbeing by developing a meaningful and satisfying life as defined by the person who may be able to control and manage their lives regardless of their cognitive impairment'. Recovery is essentially about values that promote health and wellbeing. There is huge emphasis on personal resourcefulness which may appear problematic in dementia care, as it is expected that certain personal resources like capacity to learn will inevitably diminish over time. However, professionals need to be mindful that not all resources diminish and preserved resources need to be identified to help people recover.

The recovery approach seems to pose a huge challenge to traditional methods of psychiatric treatment including drugs and psychotherapy and monitoring the response by

changing symptoms. The Royal College of Psychiatrists (2008) made a commitment to include recovery approach in training of psychiatrist in the Fair Deal Campaign with no distinct mention of its application to old age and dementia care. Amidst some evidence of support, there is uncertainty and unease among old age psychiatrists to the significance of recovery approach. There are concerns that recovery may construct unrealistic expectations among patients, carers and their relatives. The National Dementia Strategy (Department of Health, 2009) proposed historical transformational changes in the ways people with dementia and their carers are looked after in United Kingdom. The National Dementia Strategy endorses recovery and focus has moved from drugs and home care package to quality of life and well being of affected individuals. Recovery may mean the need to spend more time in direct contact with individual service users. Work force will require further training to change their style and attitude and move away from being expert to patient relationship to being a collaborator in patient's journey.

Early diagnosis and quality treatment are the key components of the National Dementia Strategy in the UK (Department of Health). Having a diagnosis of Mild Cognitive Impairment (MCI) or dementia is only the start of the process, and people are often left with a diagnosis but little support during the early stages of their illness. This requires responding to the need of the person for information about their condition and their role in its management. This is similar to the new discipline of the 'recovery-orientated psychiatric practice' (Sainsbury Centre for Mental Health) in general adult psychiatry where recovery has traditionally been regarded as predominantly about symptom alleviation. Recent research supports a holistic perspective that incorporates personal factors as well as symptoms (Hill et al., 2010). Old age psychiatric services have been built on a foundation of person-centred care in the early 1990s (Kitwood,1997), adopted by the National Service

Framework for Older People (Department of Health,2001) and re-emphasised by the National Institute for Health and Clinical Excellence dementia guidance in 2006 (National Collaborating Centre for Mental Health, 2006). However, person-centred care lacks clarity regarding the nature of the term and evidence base (James, 2007). Professionals have difficulty choosing from the overlapping concepts and measures of quality of life, wellbeing, recovery and person-centred care. Slade (2010), drawing evidence from positive psychology, puts 'wellbeing' at the heart of 'recovery' of the person.

The management of Mild Cognitive Impairment has not changed and until now remains as regular reviews in outpatient clinics at variable intervals of six to twelve months.

The working practices leading to the research idea for this study and its further development in 2008 were slightly different than the current set up of services. There were no designated memory services and NICE guidance did not approve the treatment with the cholinesterase inhibitors for people with mild Alzheimer's dementia. Apart from suggesting further review in six months to a year, patients were left with no support in the interim. This led to unsatisfactory outcomes during the review in the clinics and provided a platform to look into alternative ways to address this professional and patient disappointment.

Nationally, other initiatives were slowly gaining momentum such as the Fair Deal Campaign from Royal College of Psychiatrists and the National Dementia Strategy. Fair deal manifesto called for necessary shift of emphasis from being clinically and profession centred to being person centred and to seek the applicability of the recovery approach across all mental health specialities emphasising recovery of patients with mental health problems. The National Dementia Strategy, with its seventeen recommendations

encompassed the whole journey of the patient from the detection of dementia to end of life care, was just beginning.

The old age services are traditionally very familiar with the concepts of person centred care in Dementia in institutional settings including care homes. We were well aware that the services across the country had been built on a foundation of person-centred care after its introduction by Tom Kitwood in 1997 and later adopted by the National Service Framework for Older People (Department of Health, 2001) and re-emphasised by the National Institute for Health and Clinical Excellence dementia guidance in 2006 (National Collaborating Centre for mental Health, 2006). Person centred care is based on the background of humane movement of value based practice and recognises, respects and responds to the integrity of the person regardless of the difficulties and disorder with which they are struggling. However, person-centred care lacks clarity regarding the nature of the term and evidence base (James, 2007). The application of person centred care to Mild Cognitive Impairment and early Dementia did not appear suitable, as the emphasis is mainly on good care and patient is mainly receptive with no active participation.

Our inpatient old age services locally were already practising story book and person centred care initiatives and finding it beneficial. There was also extensive piece of research based on recovery concepts being conducted in general adult services within our Trust, but to consider such initiatives in Dementia appeared awkward and uncomfortable. The old age psychiatry staff had concerns about the risks of actually making things worse by possible misunderstanding of the recovery concept in Dementia and considered it unhelpful to incorporate it in clinical practice without further qualification and evaluation.



Our community team for older people services worked together, debated, discussed and educated ourselves with the concept of recovery, wellbeing and person centred care and hoped to develop a model of care for Mild Cognitive Impairment and early dementia based on recovery and wellbeing principles. We arranged several workshops, attended and presented by professionals from different disciplines, including director of adult recovery services, occupational therapist and spiritual leader within the Trust. It was identified that professionals had difficulty in choosing from the overlapping concepts and measures of quality of life, wellbeing, recovery and person-centred care and the idea was to develop a recovery care plan, based on concepts of well-being, with less emphasis on theoretical background.

We believed that actively considering recovery and wellbeing based practice could provide a platform for change in normally held pessimistic attitudes by public and professionals about Dementia.

The National Institute for Health and Clinical Excellence (NICE) had produced a public health guidance 'Mental wellbeing and older people' to promote the mental wellbeing of older people (National Institute for Health and Clinical Excellence, 2008). It asserted that a decline in mental wellbeing should not be viewed as a natural and inevitable part of ageing. Although the NICE's definition considered wellbeing of the most vulnerable and disadvantaged older people includes only those with physical or learning disabilities, those on very low income or living in social and rural isolation, and did not mention people with memory problems and dementia, we believed that the latter group fulfilled all the above criteria and hence their wellbeing deserved improvement too. While a few instruments are available to measure wellbeing of working adults, suitable instruments are lacking for older

people with memory problems. We identified the five-item World Health Organisation (WHO) Wellbeing Index (Heun et al., 1999) as the best available instrument to assess and monitor wellbeing in older people throughout the present intervention study. The scale had an adequate internal and external validity to be used in elderly people with low scores indicating low wellbeing related to psychiatric disorders or independently to poor living condition.

To deliver a recovery-focused intervention in the community, the members of the Specialist Mental Health Team for Older People (SMHTOP), including psychiatrists, nurses and occupational therapists were involved in the development of a new tool- the Mini Wellness State Examination (MWeSE – Appendix 1). The team members met weekly for an hour between November and December 2008 and agreed on the key domains and the questions related to the well-being of older people by adapting the World Health Organisation Well-being Index (Appendix 2) to measure five components of well-being – mental, physical, emotional, spiritual and financial. The six sub components within the mental well-being ( life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, sense of belonging and support) were adopted from the National Institute of Clinical Excellence (NICE) Public Health Guidance (2008). Together with the remaining four components (i.e. physical, emotional, spiritual and financial) ,the MWSE consisted of 10 questions. I prepared several presentations based on the available background literature and also invited several speakers to improve the understanding of the concepts of recovery. It was felt that mental well-being score on its own may not reflect the actual well-being of the patient and we added four more domains such as emotional, physical, spiritual and financial components to assess the total well-being.

The unique aspect of the Mini Wellness State Examination was that it enabled professionals to explore the possibilities of improving the scores on all the above 10 wellness domains, especially on the low-scoring domains. For example, if the client had scored only two on the 'self-esteem' domain, clients and carers would be asked more questions to describe the nature and degree of the self-esteem. They would be then encouraged to come up with ways and means to improve self-esteem. I went out together with the recovery nurse to test this tool on two to three patients even before developing the research protocol. It was not an easy task and our claims that we always check this became apparent, as it was difficult to add on the components of wellbeing and recovery to our usual ways of clinical assessment.

In the main intervention study, participants with MCI and early dementia were randomly assigned to intervention and control treatment as usual groups. At baseline all patients were assessed in terms of their well-being, cognitive state, mood and health state using the five-item World Health Organisation (WHO) Wellbeing Index (Heun et al. 1999), Mini Mental state Examination (Folstein et al. 1975; Anthony et al. 1982; Cockrell and Folstein 1988; Crumet al 1993), Cornell Scale for Depression in Dementia (Alexopoulos, et al. 1988) and Euro-QOL 5D (The Euro-Qol Group 1990) at baseline and six months later. In addition, at baseline participants in the treatment group completed Mini Wellness State Examination which was necessary to tailor individualised treatment sessions over the next 6 months.

In comparison, the control group was not assessed on this instrument and hence the problem areas were not identified, although the monthly sessions with the nurse did include addressing day to day problems, which were not directly related to the wellbeing

as assessed by MWSE. In other words, they received quite a lot of support like treatment group during the monthly sessions, but their interventions were not based on MWSE.

It was expected that by focussing on wellness, we might be able to offer specific interventions tailored to the needs of particular individuals in the recovery group. We predicted a significant improvement in the well-being of the recovery group compared to the treatment as usual group, as their wellness domains were not explored at baseline and not addressed during the six month period.

I wrote the research protocol after reviewing the available literature under the supervision of my Clinical supervisor Dr Arun Jha and Professor Tim Gale. The project commenced in November 2009 and I saw all the patients at the base line and at six months later. The participants in both groups completed same rating scales measuring cognition, mood, quality of life and carer burden. We as the main research team, met weekly to discuss the progress, difficulties and closely supported the recovery nurse in formulating the appropriate wellbeing based recovery plan for individual patients. The identity of the patients was not disclosed during these meetings and also my placement had changed to other old age team within the Trust and hence I was not involved in their direct clinical care.

## **2 Method**

### **2.1 Participants**

The catchment population included older people (aged 60 and above) living in the Hemel Hempstead borough of Dacorum Council, Hertfordshire, England, who were referred by their general Practitioners to our services for the assessment of their memory and other declining cognitive functions. The convenience sampling was used to achieve the required number in a relatively easy and inexpensive way by choosing the patients referred by their GP for memory assessment to the community mental health team of elderly people. A total of 60 patients were identified as being suitable of whom 48 patients agreed to take part in the study.

### **2.2 Participant inclusion criteria**

1. Age 60 years and above
2. Resident of Hertfordshire
3. Referral and assessment detect memory problems or mild to moderate dementia

### **2.3 Participant exclusion Criteria**

Following groups of patients were not to be included in the study:

1. Patients referred from the local District General Hospitals for liaison/consultation
2. Patients with acute physical or mental health problem requiring urgent medical intervention

3. Patients who in the view of the allocated clinician, lacked the mental capacity to participate in the study (Consent form – appendix 9)

## **2.4 Sociodemographic details of the participants**

Of the 48 patients who agreed to take part, 31 (64.6%) were females and 17 (35.4%) were males. Of those who agreed to take part, 25 were married and 23 were widowed. Of the 48 patients who were recruited and started the study, 34 patients completed the study six months later. The reasons for dropping out of the study included moving out of the area (2), becoming physically unwell and progression of dementia (4), deaths (3) and some participants in the recovery group did not wish to come back to complete the final assessment with the researcher (5).

Table 1 shows the distribution of patients in terms of their Sociodemographic data.

The age range was from 53 to 79 years with the mean age in the Recovery – Focus group as 78.47 years (SD= 8.00) and Treatment as Usual group 79 years (SD= 7.60). The modal age among patients who took part in the study was 85 (Figure 1).

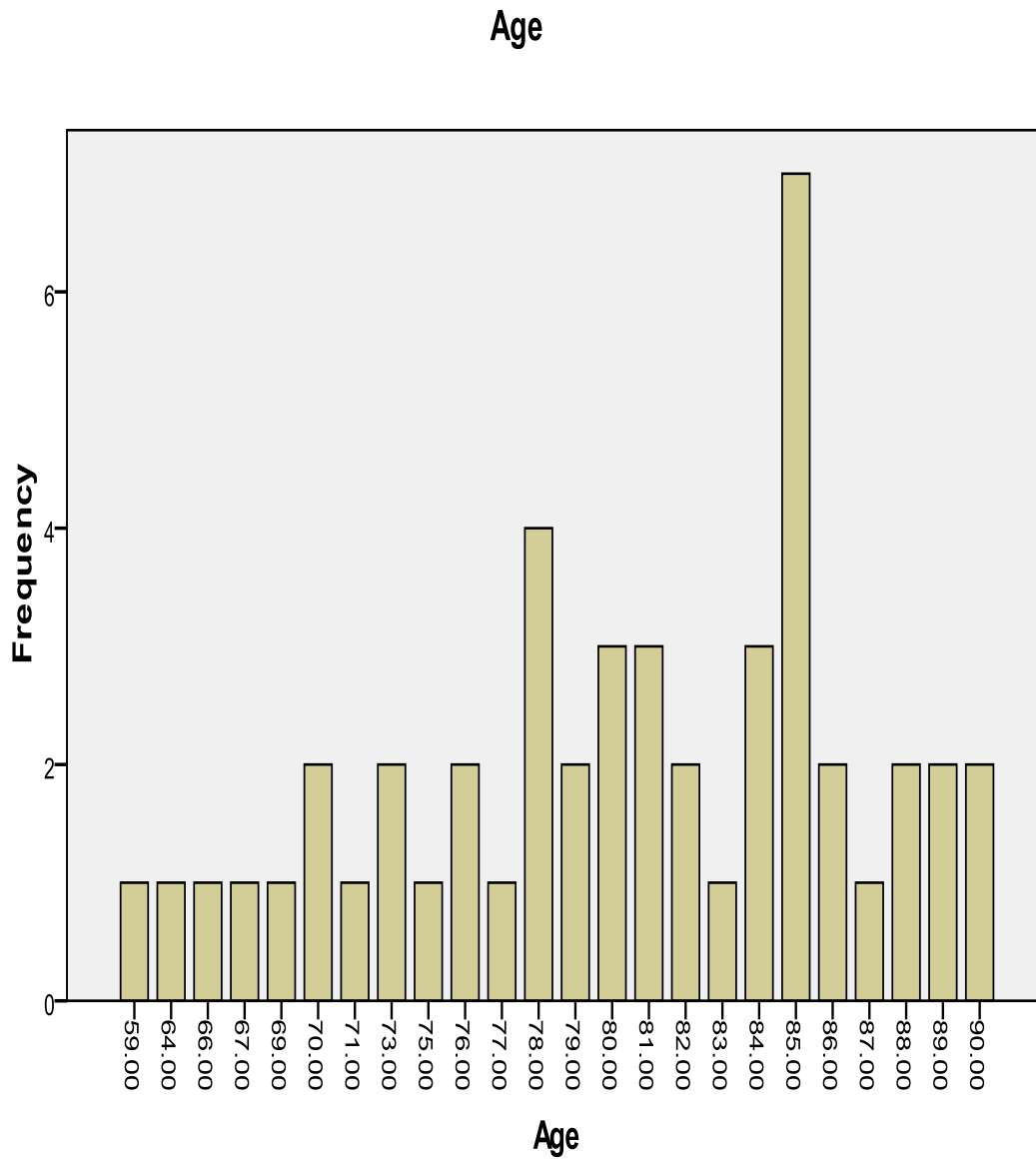
In both groups, Alzheimer's dementia was the most frequent type of dementia followed by vascular dementia (Table 2). The degree of dementia was mild to moderate with no associated significant behavioural and psychological symptoms. Most patients in both groups had a mild degree of cognitive impairment with their MMSE score above 24.

Twenty seven of the study participants who completed the study still lived in their own homes and three had moved into residential care homes at the time of follow-up six months later (Figure 4).

**Table 1: Mean age and Sociodemographic data of the patients who were randomly allocated to the Recovery – Focused Care (intervention) and Treatment As Usual Group (control)**

	<b>Recovery - Focused Care group (intervention group)</b>	<b>Treatment As Usual group (control group)</b>
<b>Participants</b>	24	24
<b>Mean age in years (±SD)</b>	78.47 (±8)	79 (±7.6)
<b>Male</b>	7	10
<b>Married</b>	13	12

Figure 1: Age distribution of the 48 patients who participated in the study





**Table 2: Distribution of ICD 10 diagnoses of dementia and severity of cognitive impairment amongst patients allocated to the intervention and control groups**

	<b>Recovery - Focused Care group (intervention group) – 24patients</b>	<b>Treatment As Usual group (control group) – 24 patients</b>
<b>ICD-10 diagnoses:</b>		
Mild cognitive disorder	8	11
Dementia in Alzheimer's disease	9	8
Vascular dementia	4	3
Other dementias	3	2
<b>Degree of cognitive impairment:</b>		
Mild Cognitive Impairment (MMSE >24 and up to 28)	11	10
Mild dementia (MMSE 20–24)	6	7
Moderate dementia (MMSE < 20)	7	7

## **2.5 Study design and sample size calculation**

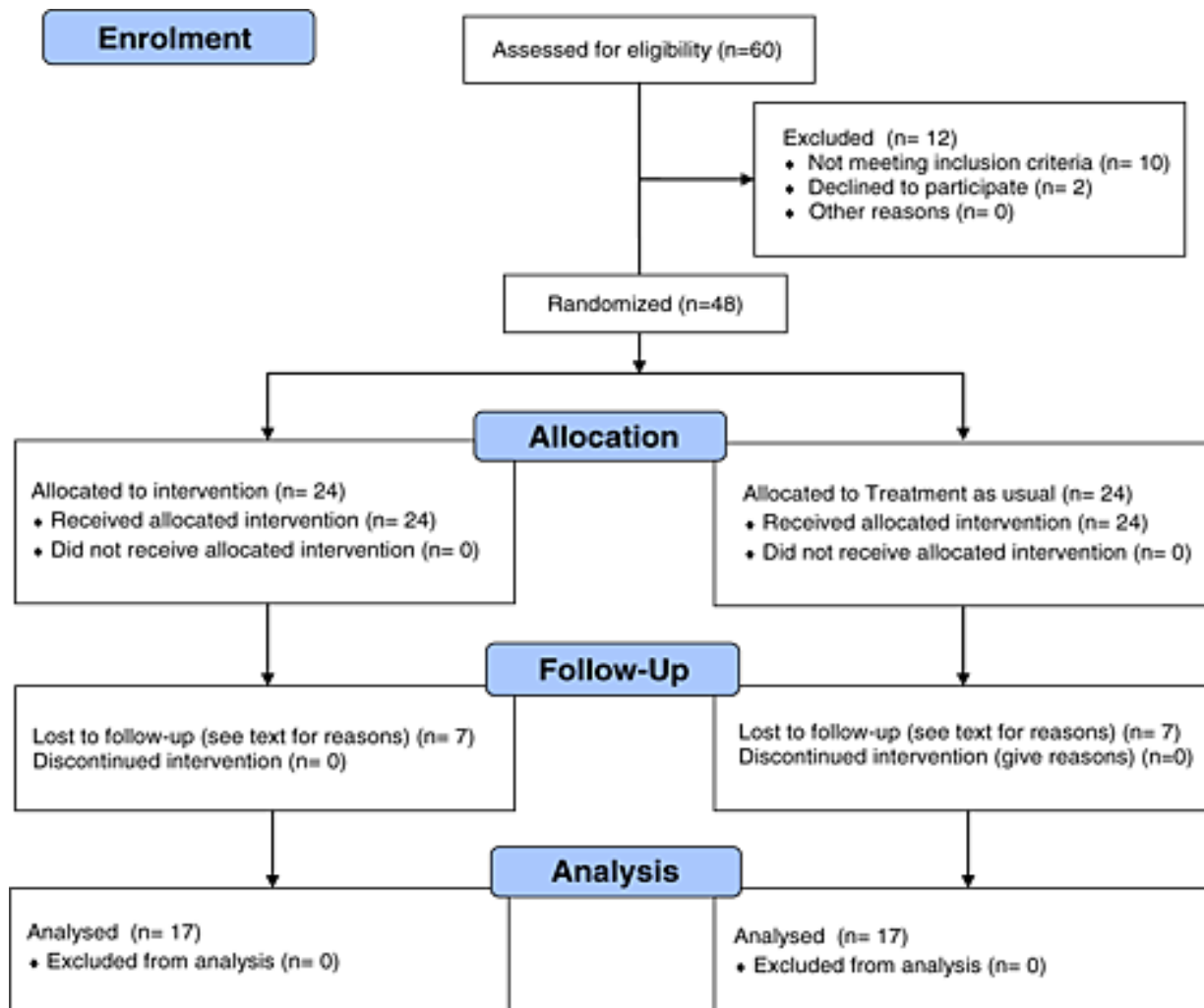
The design of the study was a randomised controlled single blind study in which every new referral to the Specialist Mental Health Team for Older People (SMHTOP) was randomised to receive either a recovery-focused care (RFC) or Treatment as usual (TAU) care.

Their well-being, cognitive state, mood and health state were rated blindly using the five-item World Health Organisation (WHO) Wellbeing Index (Heun et al. 1999), Mini Mental state Examination (Folstein et al. 1975; Anthony et al. 1982; Cockrell and Folstein 1988; Crumet al 1993), Cornell Scale for Depression in Dementia (Alexopoulos, et al. 1988) and Euro-QOL 5D (The EuroQol Group 1990) at baseline and six months later. In addition, participants in the treatment group completed Mini Wellness State Examination which was necessary to tailor individualised treatment sessions over the next 6 months. Treatment as usual participants did not complete this assessment (see figure 3).

Patient's spouse or children or carer, accompanying them during their initial review with the researcher, were requested to complete the Zarrit Burden interview and their participation was completely voluntary. Ethics committee did not advise to obtain a separate consent form from carers.

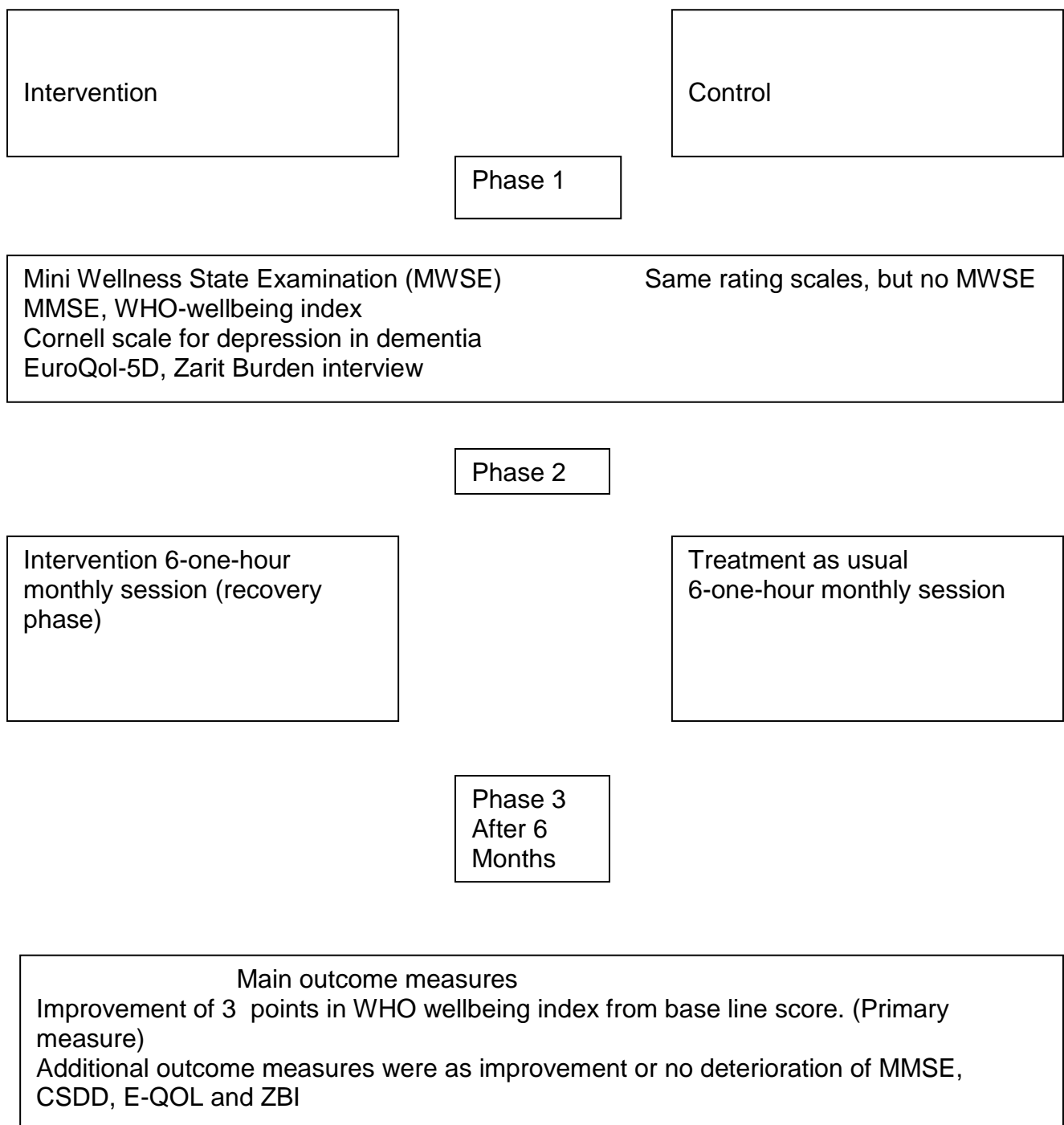
The mean expected change between control and recovery groups was calculated to be 3 points on the five-item World Health Organisation WHO Wellbeing Index (Heun et al. 1999). The assumption of a pooled standard deviation of 3 points was based on the estimates of score dispersal in patients referred to the Specialist Mental Health Team for Older People in Hemel Hempstead (i.e. range 8 - 16 points). This gives a minimum sample size per group of 25, with an alpha level of 5% and power of 90%.

Figure 2: Flowchart of enrolment, allocation and follow-up of participants



(Adapted from CONSORT, [www.consort-statement.org](http://www.consort-statement.org))

**Figure 3: Study Design and the Procedure**



## **2.6 Study materials and measures used**

**1 Mini Wellness State Examination (MWSE)** This new 10 item scale was developed specifically to assess and deliver the recovery and wellbeing intervention (see below). For the definition of wellbeing, we used the NICE guidance on the wellbeing of older people (National Institute for Clinical Excellence), which defines 'mental wellbeing' consisting of six components: life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, and a sense of belonging and support. To create a tool that would facilitate recovery action planning, based on the person's holistic wellbeing, we added physical, financial, emotional and spiritual domains to the NICE mental wellbeing framework, resulting in 10 domains or items.

Each item in the Mini Wellness State Examination is a statement, which the patient was asked to endorse using a 4-point scale (Appendix). For example, 'I have been feeling cheerful and in good spirits' (emotional), 'Health wise, I feel quite fit and able to do things myself' (physical), or 'I have come to understand the meaning of life (spiritual). The assessment started with an opening sentence 'we would like to know about the current state of your wellbeing. Please indicate for each of the following 10 statements which are closest to how you have been over the last few weeks. The response options ranged from 4 (all the time) to 0 (at no time). The total score ranges from 0 to 40, 0 representing the worst and 40 the best possible state of wellbeing for the person at a given point of time. It is worth noting that the Mini Wellness State Examination is a tool for identifying needs to be targeted in the intervention and not a research measure.

## **2 The World Health Organisation WHO Wellbeing Index (Heun et al 1999)**

This 5- item scale was the primary outcome measure in the present study. It assesses participants emotional and physical well-being. The range of possible scores is 0–25 (five questions on a 6-point Likert scale scored 0–5), with higher score indicating greater wellbeing. All scores were multiplied by 4 to give a percentage score, which is often recommended as the best way of monitoring change in an individual patient. The wellbeing scale has been proposed for widespread application including both patients and the general population (Huen R., Burkart M., Maier W., Bech P., 1999). The scale has an adequate internal and external validity in the elderly general population. Low scores indicating decreased well being might be related to the presence of a psychiatric disorder or independently to poor living conditions. Wellbeing scale might also be used to detect those with reduced subjective quality of life and thus increased need of psychological and social support. The scale appears to be more adequate for identifying subjects with low subjective well-being than comparing wellbeing in different populations.

**3 The Mini Mental State Examination (MMSE)** (Folstein et al., 1975) is a widely used method for assessing cognitive functions. As a clinical instrument, the MMSE has been used to detect impairment, follow the course of an illness, and monitor response to treatment. The MMSE has also been used as a research tool to screen for cognitive disorders in epidemiological studies and follow cognitive changes in clinical trials. The Mini Mental State Examination (MMSE) is a tool that can be used to systematically and thoroughly assess mental status. It is an 11-question measure that tests five areas of cognitive function: orientation, registration, attention and calculation, recall, and language. The maximum score is 30 and people scoring between 23 and 10 are considered having mild to moderate degree of dementia, and those scoring 24 or above as having suspected

dementia or a mild cognitive disorder diagnosis using ICD-10 criteria (World Health Organisation,). The MMSE takes only 5-10 minutes to administer and is therefore practical to use repeatedly and routinely. MMSE has a test/re-test reliability of 0.89 and inter-rater reliability of 0.83.

**4 The Cornell Scale for Depression in Dementia (CSDD)** is a 19-item depression scale designed to measure the severity of depression in people with dementia. The items of the scale were chosen following literature review on the phenomenology of depression in demented (Roth 1955; Mohs et al., 1983; Greenwald et al., 1986) and non demented patients (Nelson & Charney, 1981) and obtaining information from the experts in the field. Items were constructed in a way to help elicit symptoms by observation and complex symptoms of depression, phobias and obsessions are not included in the scale. The severity of each symptom is as absent, mild or intermittent or severe. The scale is administered by clinicians who are familiar with the depression phenomenon and requires a minimal training. The scale can be administered in two steps and involves getting the information from the caregiver and from the patient as long as they are able to communicate their basic needs. The participants in the study had mild dementia and were well able to complete the questionnaire.

**5 The Euro-Qol 5D** health questionnaire measures health related quality of life and has been validated in a number of European countries, including the UK (Wolfgang Greiner et al., 2003). The scale is primarily designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face-to-face interviews. It is cognitively simple, taking only a few minutes to complete. There are two core components to the instrument: a description of the respondent's own health using a health state

classification system and also rating on a visual analogue thermometer scale. There are five dimensions to the health state classification including mobility, self-care, usual activities, pain/discomfort, anxiety/depression and each dimension having 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. The respondent is asked to indicate his/her health state by ticking in the box against the most appropriate statement in each of the five dimensions. This decision results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health status.

The Visual Analogue Scale (VAS) records the respondent's response on a vertical scale with endpoints labelled `the best health you can imagine` and `the worst health you can imagine`

The instrument plays a role of linking cross-national data in the field of health status measurement. The EQ-5D was scored by using above five items, as well as visual analogue measure in both the groups at the baseline and after six months.

**6 The revised 22-item Zarit Burden Interview (ZBI)** assesses the caregiver's perceived care burden. It is a valid and reliable instrument for measuring the burden of caregivers (Boon & Kheng Seng et al., 2010). ZBI provides a comprehensive assessment of both subjective and objective burden and is commonly used rating scale to measure the carer burden in much culturally or ethnically diverse population. Each item on ZBI is assessed on a 5 –point Likert scale, ranging from 0=never to 4 =nearly always. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The focus of the questions is on caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and the patient.



## **2.7 Procedure**

### **Initial assessment and randomisation (all participants)**

On referral, every patient was allocated to a Specialist Mental Health Team for Older People member for initial psychiatric assessment. The routine cognitive tests included the Mini Mental State Examination (MMSE), clock drawing test on a pre-drawn circle and verbal fluency test. The patients' General Practitioners were requested to arrange necessary blood tests and an electrocardiogram. A computerized tomography head scan was requested for borderline and atypical cases.

Following the initial assessment, every eligible patient was subjected to a randomisation procedure. A computer-generated randomisation list was used to allocate participants to the recovery focused care group (intervention group) or the treatment as usual group (control group). Using the randomisation list, the team secretary allocated cases in the intervention group to a Recovery Nurse (CN) and control group cases to other nurses of the team. The clinical team members were blind to this procedure and the researcher (FJ), who carried out the assessments at baseline and after the 6-month study period, was not involved in participants' clinical care and was blind to which group the participants belonged to. Each assessment lasted for at least an hour.

The consent of all patients who were involved in the study was obtained. The participants were given verbal explanations about what the study involved and how it would affect their care and that they could withdraw from the study. This information was substantiated by the provision of patient information sheet, which was designed into two parts: Part 1 was the simple explanation of the study and part 2 provided more detailed explanation.

The researcher established the capacity of the patient to go ahead with the study informally and addressed any issues raised by the family or the carer prior to completing the baseline questionnaire.

## **2.8 The Wellbeing-based recovery-orientated interventions**

The assessment process and the interventions offered to the recovery group are outlined below;

### 2.8.2 Two phases of the intervention

The intervention was offered in two phases: clinical phase and a post-diagnostic recovery phase. The clinical phase used a tripartite model consisting of three components: (a) pre-diagnostic counselling and wellbeing assessment; (b) therapeutic diagnostic consultation; and (c) written feedback. The post-diagnostic recovery phase included monthly home visits by the recovery nurse for at least 6 months. All participants in the recovery group were aware that they were on a recovery programme, as they all had an information sheet and consented to participate.

### 2.8.3 Pre-diagnostic counselling and wellbeing assessment

Following the initial psychiatric assessment, the research nurse carried out a wellbeing assessment using the Mini Wellness State Examination, preferably in the presence of family members. The clinician would rate the individual on each of the 10 wellbeing items including life satisfaction, optimism self-esteem; Mastery and feeling in control, having a purpose in life, sense of belonging and support, emotional state, physical condition, financial situation and spiritual wellbeing and explore ways and means to improving the score. For instance, if the score on the domain of self-esteem was 2, the clinician would

explore with the individual and their family potential activities or strategies that the individual may like to undertake to enhance their self-esteem. A similar exercise would be repeated for each item requiring improvement. Finally, all those action plans would be summarised and incorporated in the individual's recovery care plan to be implemented during the post-diagnostic recovery phase.

#### 2.8.4 Therapeutic diagnostic assessment

Patients, along with a family member, were invited to the diagnostic clinic for an hour-long consultation. The psychiatrist carried out a brief assessment to confirm the findings of the initial assessment, avoiding a more traditional information-gathering approach to avoid limitation of interaction with the patient. The patient's concerns relating to test results, especially computerised tomography brain scan, were also addressed. A more collaborative approach was adopted by focusing on the patient's subjective experience and their strengths or areas of intact functioning, which families could use to facilitate optimal functioning. Given that persons experiencing cognitive change are at risk of viewing themselves negatively, attempts were made to reframe their self-concept, for instance, by explaining that changes are due to an identifiable disorder rather than personal failings or undesirable personality traits. Towards the end, patients and their family were individually invited to ask any remaining questions to which answers were given, checking for their satisfaction with the responses.

#### 2.8.5 Diagnosis and feedback

Patients and their family were sensitively given the diagnosis and prognosis along with a treatment plan including drugs for dementia, if eligible. They were encouraged to ask questions or clarify queries related to the diagnosis and treatment. The presence of family

or friends allowed the clinician to assist with difference of opinion, respond to individual questions and facilitate the patient–family interaction.

To supplement the feedback session, the patient was sent an individualised letter outlining the outcome of the assessment, diagnosis and a collaborative treatment plan, and a summary of discussion of their key questions and queries was posted to them with a copy of the letter sent to their general practitioners.

#### 2.8.6 Recovery phase

During this phase, every participant was offered post-diagnostic counselling and support at the monthly visits lasting at least an hour for 6 months. Instead of adopting any particular model, a common sense ‘here and now’ approach was used for counselling. The first visit was mainly to discuss any unresolved issue overlooked at the diagnostic clinic. They were assisted to alleviate anxiety regarding diagnosis and treatment plan. The visit also provided an opportunity where the nurse would enquire into any changes that had occurred since the previous assessment sessions, re-establish rapport and modify interpretations if necessary. During subsequent visits, individuals were encouraged and assisted to work on the wellbeing-based recovery care plan. A recovery-focused approach was adopted primarily to assist the patient in feeling understood, seen and listened to by the visiting nurse, and to provide the patient with information and understanding to allow improved insight, acceptance and the ability to move forward with his or her life. Throughout the recovery phase, instead of focusing on their illness, individuals were encouraged to think in terms of their roles as a wife, mother, funny granny, caring brother or sister, and sensitive and loving person.

The interventions in the wellbeing based recovery care plan were generated from the domains of the Mini Wellness State Examination (Table 3)

**Table 3: Wellbeing-based recovery care interventions generated from the domains of the Mini Wellness State Examination**

<b>Domains of the Mini Wellness State Examination</b>	<b>Interventions offered for the Mini Wellness State Examination item scores &lt; 2</b>
<i>Life satisfaction</i>	1:1 supportive psychotherapy sessions, Day hospital care
<i>Optimism</i>	1:1 psychological treatment
<i>Self-esteem</i>	OT activities like exercise bikes
<i>Mastery &amp; Feeling in control</i>	Day hospital care, 1:1 psychotherapy sessions. Telecare, Diaries, organised bus passes
<i>Having a purpose in life</i>	Coffee mornings, Organising joint activities such holidays for couples ,fostering and supporting the intact abilities and skills
<i>Sense of belonging and support</i>	Developed life stories ,well planned and structured family visits in care home setting
<i>Emotional state</i>	Antidepressants, 1:1 individual sessions focussing on education and problem solving
<i>Physical condition</i>	Physiotherapy, provision of diet plans and liaison with the dieticians, advice on other life style matters like exercise, smoking cessation, alcohol intake
<i>Financial situation</i>	Organise bus passes, personal grant to purchase items like exercise bikes, Television , clothing items and holidays
<i>Spirituality</i>	Encourage and facilitate recovery sessions without any disruption to people's routine like church attendance

## **2.9 Treatment as Usual group (control)**

After being randomised into this group participants had the base line five-item World Health Organisation WHO Wellbeing Index (WHO-5), Mini Mental state Examination (MMSE), Cornell Scale for Depression in Dementia (CSDD) and Zarrit Burden interview (ZBI). The MWSE was not used for the control group and the team members were advised to avoid initiating conversation regarding their quality of life and wellbeing unless raised by them. They were seen 6 times and at the end completed the outcome measures.

Dementia care in our Trust was similar as in other places within the National Health Service including memory clinics, day hospitals, community nursing support and inpatients care for assessments, treatment and long term care for those persons with challenging behaviour problems. An integral part of dementia care involves the social care often funded through social services to provide home care, day care and adaptations to homes to make them safer for persons with dementia. Despite the care through the National Health Service and Social Services, the majority of the care is provided by informal carers, mainly family members such as spouses, children, siblings, and friends or neighbours. Bringing all the different levels of care provided together in England often involves the Care Programme Approach and needs led or problem led care. The Care Programme Approach required all patients under the care of specialist mental health must have a key worker responsible for making sure all their health and social needs are met (Hope & Pitt 1998). A problem orientated approach in dementia is used in current practice and at the time of this study involves the following steps:

1. Identifying problems which might need addressing.
2. Identifying strengths of the patient and the support system.
3. Establishing priorities for problem list.
4. Setting realistic goals.

5. Ensuring patients and carers are well informed of plans.
6. Assessing effectiveness of management plan and reassessing problems.

The problem orientated approach was in place in our specialist mental health services for older people at the time of this study. They were offered further outpatient appointments following the initial assessment, if felt necessary by the assessing team member or requested by the patient or their family. The needs led services was delivered based on Care programme approach (CPA). Those requiring anti-dementia drugs and other treatments like antidepressants or investigations or referral to psychological services, day hospital or other agencies were offered when appropriate. Each monthly hour-long contact consisted of general conversation around neutral topics, their progress with the current treatment plan, outcome of the investigations and other referrals, update on their physical health status or issues raised during the meeting by the individual and their family.

### **2.10 Outcome measures obtained after 6 months (all participants)**

Outcome of the interventions after 6 months in both the groups were on the following measures

- 1 Improvement of 3 points from the base line score on the five-item World Health Organisation (WHO) Wellbeing Index (Primary Measure).
- 2 Improvement or no deterioration of Mini Mental State Examination score.
- 3 Improvement or no deterioration of Cornell Scale for Depression in Dementia scale score.
- 4 Improvement or no deterioration of EURO-QOL scores.

## **2.11 Statistical analysis**

Statistical analysis involved the use the Statistical Package for Social Sciences version 17 (SPSS v.17). The mean values were compared using the independent t-tests and one-way analysis of variance. The level of significance was set at  $p < 0.05$ . Correlations of outcome measures were conducted using the Pearson's coefficients.



### 3. Results

Out of the 48 patients who agreed to take part and started the study, 34 patients completed the study six months later with 17 participants in the treatment and control groups, respectively.

#### 3.1 Analysis of the scores of the various outcome measures

The one-way analysis of variance was used to compare the means of the differences in the five outcome measures at onset and six months follow-up (Table 4). There was significant difference ( $p < 0.01$ ) between the differences in the mean scores at onset and follow-up in the five-item World Health Organisation (WHO) Wellbeing Index between the Recovery Focus Care and the treatment as usual (control) groups. There were no significant differences in the mean differences of the other four outcome measures.

**Table 4: Analysis of variance comparing the differences between initial and follow-up scores using the five outcome measures in the intervention and control groups**

<b>Outcome tools</b>	<b>Recovery Focus Care</b>	<b>Control</b>	<b>Level of Significance</b>
<b>WHO - 5 Wellbeing Index</b>	23.31 (13.99)	1.71 (19.66)	$p < 0.01$ *
<b>Mini-Mental State Examination</b>	0.23 (3.21)	-2.88 (8.59)	$p = 0.17$
<b>Cornell Scale for</b>			

<b>Depression in Dementia</b>	-3.94 (6.53)	-4.65 (9.8)	p = 0.81
<b>Euro-QOL 5D</b>	3.18 (12.54)	-5.00 (15.51)	p = 0.1
<b>Zarit (Caregiver) Burden Interview</b>	-6.6 (25.05)	0.82 (16.64)	p = 0.4

p – level of significance. \* = p < 0.05. Standard deviation – ( )

The one-way analysis of variance was used to compare mean outcome scores at the onset and at follow-up of the 34 study participants who completed the study (Table 5). It revealed there were significant differences in the baseline scores between participants in the recovery focused care group and control for the WHO - 5 Wellbeing Index and Mini-Mental State Examination. There were no significant differences for the other outcome scales between the recovery focused care group and control at either the onset or follow-up assessments.

In Table 5, the onset and follow-up outcome mean scores were compared for both the recovery focus group and control. There were significant differences seen in the recovery focus group in the WHO wellbeing scale and the Cornell scale for depression in dementia. There were no significant differences between initial and follow-up in any of the other outcomes scales used.

**Table 5: Analysis of variance comparing the mean scores in the five outcome measures at onset and follow-up between the intervention and control groups for the 17 participants in each group**

	<b>Recovery Focus Care</b>	<b>Control</b>	<b>Level of Significance</b>
<b>WHO - 5 Wellbeing</b>			
Initial	37.00 (18.51)	52.47 (13.41)	p < 0.01*
Follow-up	61.37 (10.85)	54.18 (17.61)	p = 0.171
<b>Mini-Mental State Exam</b>			
Initial	19.76 (7.39)	24.88 (6.72)	p = 0.43*
Follow-up	20.00 (7.04)	22.00 (6.3)	p = 0.39
<b>Cornell Scale for DD</b>			
Initial	7.71 (6.53)	9.47 (11.36)	p = 0.58
Follow-up	4.00 (1.79)	4.82 (2.24)	p = 0.254
<b>Euro-QOL 5D</b>			
Initial	58.23 (14.02)	67.94 (14.26)	p = 0.054
Follow-up	61.41 (16.55)	62.94 (15.11)	p = 0.78
<b>Zarit Burden Interview</b>			
Initial	39.59 (19.73)	26.53 (17.61)	p = 0.059
Follow-up	31.47 (14.99)	31.3 (21.26)	p = 0.96

p – level of significance. \* = p < 0.05. Standard deviation – ( )

**Table 6: Paired t tests comparing the mean scores in the five outcome measures at the onset and follow-up for the 34 patients who completed study in both the recovery focus (17) and control groups (17)**

<b>Outcome tools</b>	<b>Recovery Focus Care Group</b>	<b>Control</b>
<b>WHO - 5 Wellbeing</b>		
Initial	38.06 (18.57)	52.47 (13.41)
Follow-up	61.37 (10.85)	54.18 (17.61)
	p < 0.01*	p = 0.72
<b>Mini-mental State Exam</b>		
Initial	19.76 ( 7.4)	24.88 (6.7)
Follow-up	20 (7.1)	22 (6.29)
	p = 0.77	p = 0.18
<b>Cornell Scale DD</b>		
Initial	7.94 (6.67)	9.47 (11.36)
Follow-up	4.00 (1.79)	4.82 (2.24)
	p = 0.029*	p = .068
<b>Euroquol-5D</b>		
Initial	58.23 (14.02)	67.94 (14.26)
Follow-up	61.41 (16.55)	62.94 (15.11)
	p = 0.31	p = 0.20
<b>Zarit Burden Interview</b>		
Initial	38.07 (18.99)	30.18 (18.38)
Follow-up	31.47 (14.99)	31.00 (22.29)
	p = 0.32	p = 0.87

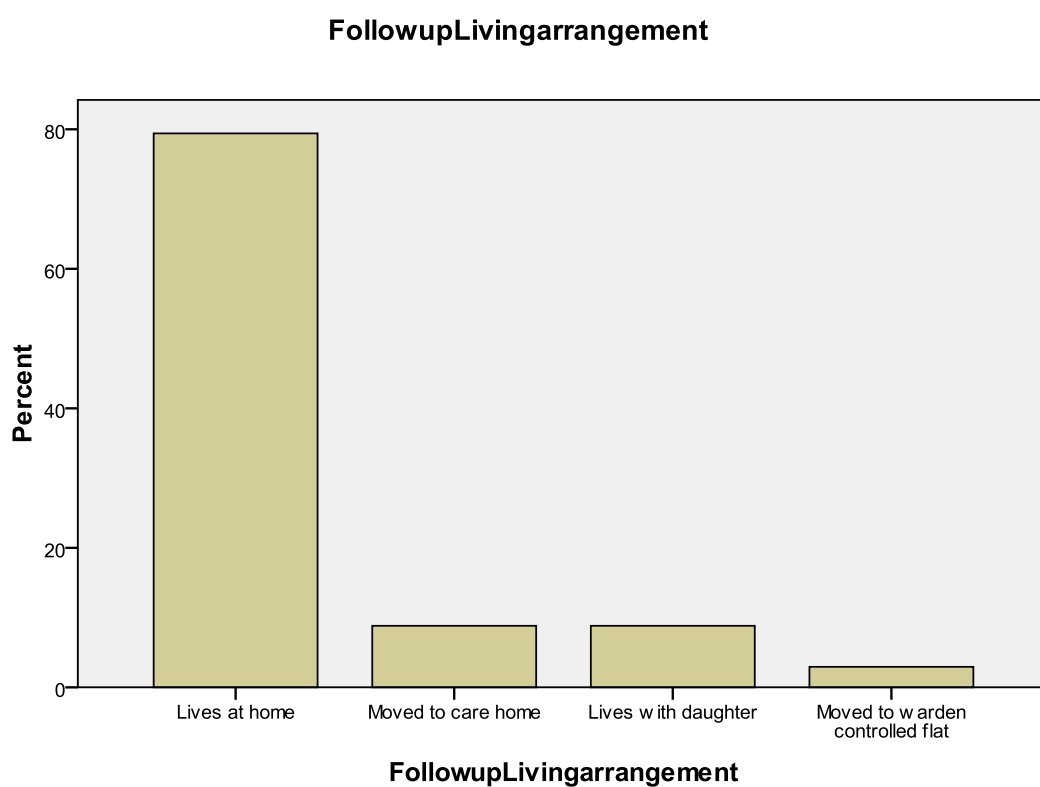
p – level of significance. \* = p < 0.05. Standard deviation – ( )

There was significant ( $p < 0.05$ ), moderately positive correlation between the initial total scores on the World Health Organisation WHO Wellbeing Index (WHO- 5) and the Euro-QoL-5D (Table 7). Both the Cornell Scale for Depression in Dementia and Zarit (Caregiver) Burden Interview had moderate negative correlations with the World Health Organisation WHO Wellbeing Index ( $p < 0.05$ ).

**Table 7: Pearson correlation coefficient between the initial World Health Organisation WHO Wellbeing Index (WHO- 5) and the four other outcome measures**

	<b>Pearson's Correlation Coefficient of initial WHO- 5 Index</b>	<b>Level of significance</b>
<b>Initial Mini-Mental State Examination</b>	- 0. 089	$p = 0.548$
<b>Initial Cornell Scale for Depression in Dementia</b>	-0.37	$p = 0.01^*$
<b>Initial Euro-QOL 5D</b>	0.301	$p = 0.038^*$
<b>Initial Zarit (Caregiver) Burden Interview</b>	-0.346 <sup>*</sup>	$p = 0.020^*$

**Figure 4: Living arrangements at six months follow-up of the 34 study participants who completed the study**



The assessments of patients in the recovery focus care group also involved recording case histories specific to well being domains from patients and carers alongside the observations made in the assessments. This relevant information was obtained from 23 participants (instead of 24, as one patient was lost to follow up due to change in recovery nurse) recruited to the recovery focus care group. The detailed case histories can be found in the latter part of this chapter. A number of problems were identified in session 1 which formed part of the initial assessments in the group (Table 8).

The summary of the sessions in the recovery focus care group revealed a number of positive experiences and outcomes (Table 9).

Table 8: Wellbeing domains requiring improvement as identified from case histories of the Recovery Focus Care Group’s during Session 1 (initial assessments)

<b>Problems</b>	<b>Patient descriptions</b>
Memory loss	Awareness of memory difficulties and /or memory loss leading to problems like missing appointments (1, 4, 9, 12, 16, 23)
Feeling lost and disorientation	Overwhelmed by changes in living circumstances and by being in unfamiliar surroundings, unsure about finding their way round in care home setting, at day centres and on holidays (1,2,6,8,9,18,19)
Self worth and esteem	Wished to maintain their personality and improve confidence (1, 3, 4, 7, 8, 9, 10, 13, 16,17, 21, 22, 23)
Anxious about the future	Unsettled & worried / Worried about what would happen if partner became unwell / Apprehension about inability to attend daughter’s wedding. (2, 3, 8, 9, 18, 20)
Social isolation	Loss of spouse (5) Poor mobility meant difficulty (5); Warden felt structure to her day might help as it was felt she was socially isolated (9).
Low mood	Felt low due comments of family member / loss of abilities (9, 12, 15, 16).
Carers burden concerns	Concerned about impact on spouse (10, 21, 22); Wanted to show appreciation to spouse for caring (13)
Mobility	Upset about poor mobility to get about (5, 22); Limitations of mobility due to generalised weakness and postural instability (11, 15, 19, 21, 23).
Sensory deficits and overall health decline	Frustrated due to new deficits like difficulty to express themselves due to speech problems (7), poor tolerance to noise (12) and decreased vision (8).



Key: ( ) - Patient no. in the Recovery Model and Wellbeing Group

Table 9: Positive experiences from the Recovery Focus Care Group's Sessions

Positive Experiences	Patient descriptions
Coming to terms with memory impairment	Reminiscence activities including life story work(2,4),sharing fond memories(3,5,8) made it easier to accept memory impairment and focus on intact abilities.
Self worth / confidence	Felt more valued and listened to (1); Improved confidence in decision making and able to go out more (2, 3, 17, 21); Maintain independence (8, 10);
Personal care	Developed more independence in doing personal care (1) and supported to maintain independence (9)
Mood	Mood improved with help provided to maintain hobbies and other activities (1, 3, 6, 10, 14, 15, 16, 17, 20, 23)
Social interaction	Improved interactions with family members (1,3,8). Helped to maintain & improve social interaction (1, 2, 5, 9, 10, 12, 16, 18, 21, 22)
Mobility	Received physiotherapy and aids to improve mobility (1,11,15,19,22,23); provision of taxi vouchers to enable couple to go out (6)
Responding to new health challenges	Combination of creative ideas and use of assisted technology(7,8,12)
Reducing Carer Strain	Improved relationship with family members (2, 3, 10, 11, 12, 15, 16, 18, 21)

Key: ( ) - Patient no. in the Recovery Model and Wellbeing Group

### **3.2 Case histories from the Recovery Focus Care Group**

The summary of the sessions captured the experiences of the patients going through the journey of recovery process supported by their carers and empowered by their recovery nurse. Below are the written records of the case histories referred to in Tables 9 and 10. I was able to obtain the case histories from 23 patients, even though only 17 patients are included in the final analysis. There were four patients in the recovery group, who refused to attend final assessment, as they were satisfied with the information and support provided by the Recovery nurse. One patients in the recovery group moved out of the area, one was lost to follow up due to the sudden change of the recovery nurse and her work being carried out by another recovery nurse and one patient was physically unwell to attend the final assessment with the researcher.

#### **PATIENT 1 (completed all the six sessions and final assessment with the researcher)**

Session 1: Mrs P was so keen to maintain her social persona of being a “fun Gran” who makes cakes and not the boring Gran who sits in the corner .She was acutely aware of her decrements due to her short term memory impairment. The focus of the recovery intervention was to help her to focus on her healthy self and enable to create a worthy self in which she could take pride. She was assisted in order to continue with her ability to make cakes, which she perceived as a way of bringing the family back to what was normal for them. She was reluctant to adopt a patient- carer role model despite her diagnosis. She retained her cake making ability and just required some support to regain her self esteem

and confidence which was low as indicated by her initial Mini Wellness State Examination score.

Session 2: She felt the carers took over with regards to personal care and did not interact with her and felt rushed. This is not uncommon and what is referred to as “malignant social psychology” by Tom Kitwood in the context of dementia. There is a tendency for the healthy individuals to consider people with dementia to be dysfunctional. The wellbeing based personalised care plan was based on her strengths and retained skills. Her ability to wash her face and preference of warm water over hot water allowed her to look forward to personal care rather than dread it. She had confirmed that personal care had previously impacted on her mood and affecting her overall mental wellbeing

Session 3: The placement in a new environment could be a daunting experience and time for increased confusion and isolation. She was assisted with her orientation during her move into her new accommodation in a residential home. She was introduced to the staff and residents and toured around the building. The explanation around activities, activity and quiet rooms made her feel comfortable.

Session 4: She had a 12 month old grandson who always seemed to cry when he visited her in the residential homes which led to shorter visits by family members. Following discussion, recovery nurse accompanied her on her wheel chair to Tesco to buy some toys for her grandson to entertain him and allow her relatives to stay longer for a more enjoyable and quality visit.

Session 5: She was a keen murder mystery reader. However, she was finding the books difficult to follow as the print was small and was unable to sustain her attention and often get lost throughout the story. The recovery nurse contacted the talking library, but they

were reluctant at first to supply their service to someone who is not blind. However, following some dialogue, Mrs P was able to consent for a pilot project to see whether library services could meet a broader variety of client group.

Session 6: Mrs P had a fall, and had lost her confidence in walking. She detested being rushed and eventually her mobility deteriorated where she required the use of a hoist which lowered her emotional state score using the Mini Wellness State Examination. This was communicated to her Physiotherapist, Occupational Therapist and General Practitioner and it was agreed that her home support grant could be used to purchase a mini exercise bike to build up muscle tone in her legs. The Recovery Nurse discussed this with the care home, who devised a care plan to use the mini exercise bike twice a day to build muscle tone. Mrs P and her husband consented to this plan and two months later she was walking around the residential home with a Zimmer frame. Both of them were very thankful for the project and for listening to what was important to her.

## **PATIENT 2 (completed all the six sessions and final assessment with researcher)**

Session 1: Mrs L scored low on mastery and feeling in control, optimism and emotional component of the Mini Wellness State Examination. Mr L scored high on Zarit Burden interview. Both, her and her husband were worried about the future, with a lots of uncertainties, especially about the care arrangements should her husband become unwell. The Recovery Nurse discussed the need for a contingency plan and once completed, it reduced their anxiety levels and allowed them to relax.

Session 2: Mrs L enjoyed talking about her family and reminiscing as she was very proud of certain aspects of her life. The idea of completing life story work was discussed and she

engaged in this topic for the rest of the session. She was encouraged to choose herself things she would like to be a part of the book including photos and memorabilia.

Session 3: The life story work was completed and Mrs L enjoyed looking through and sharing her fond memories. The whole experience improved her life satisfaction and emotional state using the Mini Wellness State Examination to help generate appropriate interventions.

Session 4: Mrs L and her husband were becoming frustrated with their weekly food shopping trip to Tesco. Mr L reported feeling on the edge and irritable due to his wife's extreme slowness and indecisiveness while buying things and repeatedly purchasing the same items. The strain in the relationship due to daily chores was acknowledged by the couple and were receptive to any suggestions. It was agreed and arranged for Mrs L to complete a shopping list at home, the couple to visit Tesco together and Mrs L to complete the shopping, while her husband sits in the café reading a newspaper. They both tried this and reported it working well. The recovery plan, though simple made their trip to Tesco more enjoyable and improved her emotional state score on Mini Wellness State Examination and significantly changed the score of Zarit Burden interview for Mr L

Session 5: Mrs L felt socially isolated due to her forgetfulness and admitted that she was stopping herself from communal integration as she was embarrassed of mixing peoples names and by repeating herself. She had a fear of being stigmatized. Her feelings were validated, but she was empowered to make her decision about going together with Recovery Nurse to a local coffee morning group. It was explained to her that she was not alone, everyone had something they were worried about and attending this group would possibly allow her to realise it and accept for herself. When she arrived at the coffee morning, she met her old darts team and engaged in conversation with them immediately

reminiscing, she forgot that she was accompanied by the Recovery Nurse. She didn't require further support there and decided that she would go independently subsequently. She reported feeling comfortable and confident within this particular group.

Session 6: Mrs L and her husband were keen to go on holiday but were worried about the practical limitations and the fear of increasing confusion and disorientation in unfamiliar surroundings. She was particularly adamant to go on holiday one last time due to intact insight that she might not be able to do so in the future due to worsening of symptoms. It was evident that her wellbeing would certainly improve by venturing on a trip. She requested some advice and support. It was explained by the Recovery Nurse that despite memory problem being only mild, she would be coming out of her comfort zone, routine and familiar surrounding. The possibility of becoming more muddled and distressed at times was highlighted. However, she was reassured that careful planning would minimise the perceived risks. Mr L was encouraged to go somewhere they used to go, try and book the same hotel and visit places they had been before in order to reduce her anxiety and allow them to have a holiday. Mrs L had already expressed that she enjoyed reminiscing. The couple agreed with this plan and went to Weymouth and stayed in the same hotel and re visited past places they enjoyed previously. When they returned, they had so much fun they booked to go again.

**PATIENT 3 (completed six sessions, but did not complete the final assessment with the researcher)**

Session 1: Mr B scored low on self esteem, confidence and was not very hopeful. The relationship with his wife was strained, as Mrs B wanted a break from her caring role once a week to go swimming. Mr B refused to attend a day centre as he felt they didn't meet his needs and wished to go somewhere where he felt more comfortable and less isolated. Following discussion with local services in the area and the Parkinson's association, the Recovery Nurse was directed to a Parkinson's exercise class at Sports Space gym for two hours. The group was free for over 65's. She attended with Mr B initially to address the issues of low self esteem and confidence. He gradually developed interest in attending the group and felt enabled and listened to. Mr B and his wife were able to continue with this care plan without the Recovery Nurse, as she went swimming at sports space while he attended his exercise class. This improved his overall quality of life and confidence.

Session 2: Mr B and his wife preferred to be socially isolated during the post diagnostic phase, as they were unsure about their family and friends' responses to his illness. However, they were keen to accept any support to overcome this difficulty. It was crucial that the right therapy was available to enable him to retain his relationships as well to preserve his dignity. The ongoing support from the Parkinson's group empowered him and wished to broaden their social group with people who were going through this process for support and advice. He was introduced to MIND memory support group and accompanied by Recovery Nurse during his first session for support and advice. Both Mr and Mrs B enjoyed this session. Mr B attended the group while his wife went line dancing with one of the family members of another person attending the group. The whole experience allowed them to ventilate to each other and discuss ideas and local support in the community.

Session 3: Mr B's sons were very keen for him to continue to go bowling, as this was a hobby they used to enjoy together and he had fond memories of this activity. His diagnosis made him nervous and he was very apprehensive that his shortcomings would render him liable to make a fool of himself. The whole session was based on psycho-education together with supportive psychotherapy to allow Mr B to appreciate his sons' efforts to maintain the quality of the family time together and not just the bowling experience. It was mutually agreed that he would go bowling together with Recovery Nurse to ascertain his current bowling skills and build his confidence. Mr B subsequently withdrew from going to bowling session with Recovery Nurse and perceived a sense of embarrassment by being accompanied by a young lady. It was agreed that other member of his MIND group can join him to the bowling session so they can practise together and the Recovery Nurse would stay around for support and reassurance. All the parties involved agreed and consented to this activity scheduling.

Session 4: Mr B was able to express himself very well during his MIND groups. He described himself inherently being very competitive and wished to work harmoniously with other members without getting overly excited and competitive. He had also noticed exacerbation of his Parkinson's symptoms by being in group sessions seeking some degree of competition like quiz. He felt increasingly embarrassed about it and requested Recovery Nurse to accompany him during one of these sessions. She escorted him to the next MIND session for support. Whilst he was playing pool, he became spirited, his hands started to shake and he started pacing with a large grin on his face, looking nervous and embarrassed. The Recovery Nurse assisted Mr B to come to a quiet area and asked him to close his eyes and practise mindful breathing which we had practised previously. He was able to relax, his breathing returned to the normal rate and his hand tremor reduced.



He was very thankful and pleased that he would be able to continue to attend group activities.

Session 5: Mr B was able to share this behavioural technique with the responsible staff to allow him to continue the group without ongoing support from Recovery Nurse. This arrangement worked so well that his wife learned the same technique to practice it at home. They both enjoyed simple, yet relaxing exercise and did not experience any negative effects.

Session 6: Mr B settled well into his new routine and his relationship with his wife improved significantly. He was able to establish some new social network and this renewed his long-lasting relationship with his sons. They were able to feel part of his father's life again. Mr B requested a reassessment of his memory which showed only minimal change. Mrs B and their family commended the positive outcome of recovery process and appreciated the collective effort in re-establishing their relationships.

#### **PATIENT 4 (did not complete all the six sessions)**

Session 1: Mrs H discussed her fears and goals, looking at solutions, ideas and support, as her she was still active in the community, driving and able bodied, attending various exercise and dance classes throughout the week. However her short term memory was making her late for appointments. We discussed the need for an electronic diary which beeps to remind her of her appointments which we discussed with the Occupational Therapist to provide.

Session 2: Mrs H said she has had a fascinating life and wanted to share all of her funny memories and experiences with others. It has always been her dream to write an autobiography. We discussed how to start the book and agreed to write heading for

different chapters of the book, and as she was talking I was writing, and put together a skeleton of the book which she was pleased with.

*Withdrew from Recovery trial as her move to Cornwall came quicker than she expected.*

**PATIENT 5 (completed all the six sessions and final assessment with the researcher):**

Session 1 Mrs D had become socially isolated following the death of her husband. She is a lady of immense strength and felt fulfilled by human contact. Her physical limitations of poor mobility required the use of Zimmer frame. She was unable to catch the local bus and to carry her shopping long distances. She scored low on mental and physical wellbeing. She resisted provision of the carer input from the local authority and was keen to stay independent. She took pride in her appearance and wished to decide herself about her own food and clothes. The recovery framework allowed the Practitioners to be more creative and look out for solutions. Recovery nurse applied to the council for taxi vouchers after discussing with Mrs D. She was able to maintain her independence, while recognising that carer input might be an option for the future.

Session 2: Mrs D enjoyed socialising and was a very good company. She was accepting her disabilities and showed gratitude towards intact abilities. It was identified that attendance to a day centre might be an opportunity for her to have a good quality interaction. The whole process of group setting and the transport arrangements were explained to Mrs D. She went through brochures of the local day centre and chose the one she felt was appropriate for her. She was accompanied by Recovery Nurse to pay an initial visit and later on was picked by the bus once a week. She was able to give a fragmented

account of her activities at the day centre during her subsequent recovery sessions and appeared reassured and understood by other people's company.

Session 3: Mrs D shared her fond memories with the recovery nurse about going to the garden centre with her husband during most of their married life at least once a week. She said that she used to fill her house with flowers and it always brightened her mood. She was unable to pursue this pleasant activity following the death of her husband about a year ago. She was appreciative of her family help every now and then, but aware that they lived far away and were unable to take to the garden centre often. I agreed to take her to the garden centre; she bought flowers for her neighbours as a thank you for helping her do odd jobs which made her feel empowered. Mrs D also joined the gardening club so she could choose what flowers gets delivered to her home.

Session 4: Mrs D was physically unwell and unable to go out; we reminisced as Mrs D enjoys talking about her late husband. We discussed her worries and concerns, putting in coping strategies and action plans.

Session 5: In this session called Mrs D to bring the visit forward as she has been looking forward to the Heather Club Christmas party but as she had to wait in for the district nurses to dress her legs she missed the transport. I agreed to take her and I stayed with her for a while to settle her in, as she was a little flustered as her routine had changed, after half an hour Mrs D had settled and enjoyed the Pantomime of Cinderella.

Session 6: Mrs D wanted her care package to be reviewed for our last visit to make sure she understood everything. I drew her up a time table so she could see how her weeks were planned out, to prevent her having to ask others on a daily basis.

**PATIENT 6 (completed all the sessions and the final assessment with the researcher)**

Session 1: RN discussed plans to work on the strengths displayed by the patient during the review. Both patient and her husband were very positive in their outlook and willing to accept a suggested plan.

Session 2: Recovery nurse attempted to build therapeutic relationship to gain trust due to sudden and unexpected change of recovery worker. Mrs H discussed what she was hoping to achieve and planned for next visit after gathering lots of ideas to follow up prior visit. The referral was made for taxi vouchers as her husband had to give up driving due to physical health limitations and she was struggling to carry the shopping and often forgot the bus times.

Session 3: Mrs H was intending to give up cooking due to her impaired memory, as she was burning things or under cooking their meals. Mr H disliked cooking which always led to arguments and resentment during meal times. They did not wish to try meals on wheels as they felt that they were for the older generation. Recovery nurse suggested going out to eat at the Harvester which was very near to their house. The benefit entailed enjoying their meal, having a happy hour and meals were working out cheaper. Mrs H felt nervous about going to new places as she felt disoriented in new surroundings. She was apprehensive that she would be unable to locate the toilets and perhaps unable to choose from the menu. Recovery Nurse agreed to take Mrs H for a visit and have a cup of tea, so she can become familiar with the menu and orientate herself with the toilets etc, which she enjoyed and described it as a positive experience.

Session 4: Mrs H reported being stressed in the evening, and used to enjoy watching her fish swimming to relax her. She had recently found her large aquarium too difficult to manage and sold it prematurely. She felt that she needed to bring it back or buy something similar to relax. We agreed with her husband to buy a small gold fish bowl which would be easier to manage and may have the same relaxing effect. The originally planned trip to go to the pet shop to purchase it was unfortunately cancelled due to snow, but Mrs H was agreeable to make this trip with her daughter next time.

Session 5: Mrs H reported feeling better with the arrival of new fish bowl. She brought to the attention of the Recovery Nurse that she was increasingly feeling less confident especially outdoors. She was worried about going to the shops as she experienced anticipatory anxiety about being unable to recall her pin number while making payments. Recovery Nurse accompanied Mrs H to the shops and tried mindful breathing before entering the shop. She also advised Mrs H to associate her pin number with known dates and worked well on that occasion. She felt that she would be able to persevere with this routine to regain her confidence and be able to shop independently again.

Session 6: Mrs H would talk intermittently about her daughter during the sessions and missed having her living at her home. She requested Recovery Nurse to organise a girly afternoon, and felt it would go a long way in improving her self esteem. She dyed her hair and painted her nails and reminisced about her family and felt relaxed. Recovery Nurse advised her to ask her daughter round once a month for a pampering evening and felt that this could be an opportunity to begin as a tradition for the family especially when the daughter realises that her mother enjoys it thoroughly and would wish to continue it .

**PATIENT 7 (completed all the sessions, but did not complete the final assessment with the researcher)**

Session 1: She scored low on almost all the domains of Mini Wellness State Examination, but was very willing to engage in the recovery programme and retain her independence. She had physical limitations and expressive dysphasia and this was affecting her confidence and self esteem.

Session 2: Mrs W wanted to be more independent with her shopping tasks and work around her limitations and deficits. She often forgot what she intended to buy once she reached the shop, and due to her expressive dysphasia she was unable to seek assistance. RN created a prompt sheet with pictures of various objects she would usually buy, such as toiletries, dairy, bread, coffee, tea, etc. She found using it extremely useful and she attached it to her shopping trolley and felt much more confident on her shopping trips.

Session 3: We looked at ways to enable J to become more independent and be less reliant on her son. He was visiting her twice a day. RN arranged a care package of carers in the morning, referred to the OT to enable her to access the garden independently by introducing grab rails and referred for a life line pendant alarm for emergencies.

Session 4: Mrs W was feeling very emotional on this day, as people came to her home selling poppies. She used to enjoy selling poppies with her late husband every year which brought back happy memories. She wished to use this time to reminisce about her husband talking about how they met and their time together.

Session 5: Mrs W was planning to relieve her son from having to cook for her every day, as their time together was very task orientated. She was hoping to spend quality time with

him and have time to talk and socialise. Recovery Nurse arranged for Mrs W to have meals on wheels, she talked her through the menus which she was pleased about.

Session 6: Mrs W was pleased to go through a weekly time table devised for her by Recovery Nurse. The aim was to remind her about the day's events each day to help her to orientate and facilitate her memory. She was also introduced to her new community worker following completion of the recovery project, as she still required some ongoing input from the services.

**PATIENT 8 (completed all the sessions and the final assessment with the researcher)**

Session 1: We spent our first visit building a therapeutic relationship, establishing her goals and working on low scores of physical, emotional and financial wellbeing. She informed the Recovery Nurse that she used to make her own clothes and was saddened not to continue to do so following deterioration of her vision. She mentioned about her apprehension of not being able to attend her daughter's wedding as she couldn't afford an outfit. The Recovery Nurse discussed the need for a home support grant to buy her a new outfit, which she agreed and by her own admission would not have been able to work out any solutions outside recovery setting for this lady.

Session 2: Following the home support grant, Mrs W was able to buy a new dress with support of her daughter. They had a day out and had lunch together which she found very rewarding and described it a fond memory to treasure amongst her fading abilities. She felt joyous about describing her experience of attending her daughter's wedding and how she

danced with her grandchildren all evening and expressed her gratitude to be able to do it with support grant.

Session 3: Mrs W's daughter had recently moved out, however, she was continuing with daily basis to prompt her mother to take medication. Mrs W refused carer input and was keen to remain independent with some limitations. She was active in the community with her religion and did not wish to wait in for carers. Occupational Therapy assessment was arranged to arrange for alarmed medication box which would beep to remind her to take medication to support her independence.

Session 4: Mrs W was becoming increasingly forgetful and worried about her response in new surroundings. She was due for outpatient review soon and asked the Recovery Nurse to accompany her. She was finding hard to concentrate and was preoccupied with sudden loss of her memory and unable to ask questions. The Recovery Nurse suggested relaxation techniques and supported her to write down all the questions in advance that she was hoping to ask and arranged to pick her up for her appointment.

Session 5: The Recovery Nurse picked up Mrs W and attended her Outpatients clinic appointment as agreed. Mrs W remembered her list as prepared during the previous review and appeared much relaxed throughout the appointment. Mrs W was very thankful for the time spent by the Recovery Nurse and was aware that she would perhaps not been able to provide this extra time outside recovery setting.

Session 6: Mrs W was referred by the Recovery Nurse to the Blind society for support and received in the post a large envelope with a brochure of products available, and some free samples such as a magnified ruler which is useful to read books, instructions and letters.



She was pleased with this and described it as “these aids are discreet and a life saver”, making my life more independent.

**PATIENT 9 (Completed all the sessions, but did not complete the final assessment with the researcher)**

Session1: Mrs J was low in mood during the first visit as she felt overwhelmed by her sister’s suggestions of moving into residential care. She wished to remain in her warden controlled flat. The Recovery Nurse elicited in great detail the benefits and limitations about her current residence and listened to her sister’s concerns. Her sister reported Mrs J not eating well enough and feeling bored throughout the day. The warden felt Mrs J was socially isolated and required some structure to her day. The Recovery Nurse arranged an action plan and care package of a day centre for 7 days a week and for the day centre to monitor her dietary intake and Mrs J and day centre manager agreed. Mrs J felt empowered by this plan and her sister and warden felt reassured.

Session 2: Mrs J reported that she was enjoying the day centre, and looked forward to the mornings to get ready to go to the day centre. However, she expressed continued feelings of boredom in the evenings maintaining her low mood. She felt helpless regularly in the evenings and kept calling her sister begging her to come round. We discussed past hobbies and ways to fill her afternoons and evenings and made a referral to the telephone club and befriender from age concern. She was willing to accept the offered suggestions and any other treatment plan.

Session 3: The Recovery Nurse met Mrs J just off the transport bus. She was tearful and in a hurry as she had become incontinent on the bus. The Recovery Nurse attended to her

care needs following consent and provided reassurance and education about the progression of her symptoms. Mrs J reported being too embarrassed to return to the day centre in case the incontinence recurred. The Recovery Nurse requested the General Practitioner to visit to rule out infection and introduced Mrs J to Conti knickers which are discreet pads within knickers to improve her confidence and prevent her social isolation. She was pleased about it and agreed to try.

Session 4: The care plan review meeting was arranged and her sister was invited to provide the progress feedback. It was established that Mrs J was managing better than previously, feeling more independent and active with resultant improvement in her quality of life. Mrs J's sister said that she was still receiving calls in the evening and comprehensive programme was mutually agreed to address this ongoing issue.

Session 5: The Recovery Nurse visited Mrs J at the day centre due to concerns regarding her diet. She did not perceive any problem with her food intake. She reported always being keen on small portions and has never had big meals. The manager at the day centre described her food intake low at the beginning of attendance, but gradually eating adequately now. The Recovery Nurse charted a food menu with Mrs J where she listed food she enjoyed and food she disliked. The personalised menu was not provided, but she was reassured that the staff would be made aware about her dislikes and the food would be substituted by adding something extra to encourage her to eat and she agreed to this arrangement.

Session 6: The Recovery Nurse persisted with her efforts to encourage Mrs J to attend the evening activities at the warden controlled flat. She drafted activity sheet for the week during the recovery sessions for her to choose her preferred options in order for her to

persevere with it on long term basis. Mrs J's preferences were passed on to carers in order for them to call her before it started to remind her to attend.

**PATIENT 10 (completed all the sessions and the final assessment with the researcher)**

Session 1: The session was longer than expected as Mr M was keen to discuss in detail about the limitations due to his memory problems and its impact on his wife. He said that he relies on his wife and wants to try and maintain the relationship of husband and wife rather than patient and carer.

Session 2: The Recovery Nurse made a referral for an attendance allowance so that he had an income to treat his wife and feel independent. She accompanied him to visit a tourist information centre and gather ideas to spend some quality time with his wife in the future.

Session 3: Mr M wished to pursue a hobby rather than focus on his illness. We arranged for him to go bowling with another service user from day hospital at his request and they both enjoyed themselves. He explored the facilities, spoke to the staff and came up with the idea of weekly bowling trip on Wednesdays due to concession prices. Both couples had arranged their wives to go shopping together at Tesco's next door while they entertained themselves. He was supported and empowered to make decisions for himself.

Session 4: Mr M was trying his best to support his wife, whom he found at times struggling and feeling helpless. Carer's assessment was completed and it was agreed with Mr M

that he would be referred to a day centre and his efforts were acknowledged and appreciated. He reported enjoying his attendance to day centre during subsequent visits.

Session 5: The Recovery Nurse escorted Mr M to the local community sports club with other service user and identified activities which he was keen to continue for the foreseeable future.

Session 6: Mrs M was pleased and reassured that her husband had been able to find a structure to occupy and enjoy his time. She reported to be coping well with new changes and was very appreciative of the support provided by the recovery nurse.

**PATIENT 11 (completed all the sessions and the final assessment with the researcher)**

Session 1: The Recovery Nurse spent the session in rebuilding a therapeutic relationship as it was interrupted due to change of worker. She charted her strengths and limitations, devised achievable goals, using small steps to reach their goals based on the weaker domains in MWSE.

Session 2: Mrs C enjoyed an interdependent relationship with her son, but was aware that demands from her side had been building up .She was amenable to the alternative suggestions and accepted the offer of the referral to the day centre as a long term measure and minimise the potential for carer distress in the future. She acknowledged that although her son was managing now, he may need a break to continue caring for her longer.

Session 3: Mrs C was quite sleepy throughout the visit and RN spent the sessions in assessing her son for a carer's assessment. He was given all the required information about his entitlements as a carer for his mother. He was able to reassure the RN that he is able to manage his mother's needs at the moment, but was glad to have the information for the future.

Session 4: Mrs C said that she was having trouble getting out of her chair and her son had developed lower back pain. RN arranged for a carers grant to pay for a recliner chair that would enable her to stand up to prevent carer breakdown. They were both pleased about it.

Session 5: Mrs C was feeling sleepy on the day of the review. Her son was pleased to inform RN that they had received the money for the recliner chair and he was looking forward to buy it. He was thankful for the positive impact and improvement to their quality of life by his mother being a part of the recovery project. The son believed that he had sufficient information about his mother's condition and felt reassured about the future.

Session 6: Mrs C and her son felt content and they reiterated what was said on last visit, which included that they were currently managing well. They perceived good level of support and information gathering during the process of recovery and felt enabled to contact in the future for any change of circumstances.

**PATIENT 12 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mrs H felt low at the beginning of recovery visits focussing mainly on her deficits due to memory impairment and things she could not do. Using the Mental recovery interview and supportive psychotherapy techniques, she realised her life was not significantly different now. She started to talk more positively and expressed her wish to go to the theatre again with her daughter and build the relationship up from patient carer to mother daughter again. She was allowed to pursue this through a home support grant.

Session 2: Mrs H was keen to be part of a club and keep going despite having diagnosis of cognitive impairment. She was accepting her diagnosis well and pleased to have the opportunity to plan her future. We looked at her past and present hobbies and she decided to join a gardening club. RN assisted her in completing the documentation and she was looking forward to attend the allocated sessions.

Session 3: Mrs H requested her 3<sup>rd</sup> visit to be at a local pub to continue a tradition of hers and her late husband every year on his birthday. They used to look at all the large houses in the area and imagined having a happy and better life in those houses. Mrs H's daughter had carried on this tradition but was currently on holiday. The Recovery Nurse agreed to go in order to support her to continue with her tradition and routine. Mrs H was very thankful to be apart of the research and be able to receive personal support understanding that it would not have been available to her otherwise.

Session 4: Mrs H felt that her memory had deteriorated and requested a reassessment. She was pleased that her memory test hadn't changed. However, we looked at ways for Mrs H to cope more independently by using assisted technology including an orientation clock, calendar and diary. She was seen by the occupational therapist and informed about further ideas to maintain the functional level at her optimum level.

Session 5: Mrs H's daughter although satisfied with the input from the recover nurse maintained that her mother should be reassessed by the doctor. Mrs H was in agreement and requested the Recovery Nurse attended the meeting as well and together with her daughter felt supported, listened and empowered by her input.

Session 6: The Recovery Nurse reviewed Mrs H's care needs and ascertained her progress with her new aids which are attempting to keep her independence and reduce her daughter's anxieties. She appeared to be adjusting well by using the diary. It served as an authentic reminder about the previously asked questions and obtained answers and helped her repetitive questioning. She was writing down her conversations particularly while she was looking for clarifications. Once she attempted to call her daughter, she could see if she had already asked that questions to limit the frequency of calls on daily basis.

**PATIENT 13 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mr M wished to visit a garden centre to buy his wife some flowers as he used to buy her flowers every week. Mr M was also keen for RN to let his wife know how much he appreciated her, as she had taken on all of his responsibilities such as gardening and bills. He felt "useless" at times due to his memory impairment. He went to a day centre with the RN for a cup of tea to decide about continuing to go there with a view to give his wife a break once a week.

Session 2: Mr M attended another day centre as he didn't like the previous day centre as there were too many women there. A carer's assessment was completed for his wife.

Session 3: Mr M was not keen to attend a day centre without his wife as he had not been apart from her for nearly 60 years, and he did feel right socialising without her as she was his sole mate. Following discussion we agreed to try the Alzheimer's café as it was something they could attend together and his wife also received carer's support.

Session 4: Mrs M was physically unwell and the Recovery Nurse arranged for Mr M to go into respite care. She escorted him there and settled him in, ensuring he had pictures and home comforts to make his stay less distressing and unsettling.

Sessions 5 and 6: The sessions focussed mainly on improved communication between RN, his wife and care home staff in order for Mr M to be less anxious and worried at respite care. He was reoriented to the place and kept updated about his wife's health status by the Recovery Nurse. He was very thankful for her input and was hopeful to return back to his home shortly.

**PATIENT 14 (completed all the sessions and the final assessment with the researcher)**

Session 1: The Recovery Nurse discussed recovery ideas and ways to prevent carer breakdown to enable the family to care for longer. He was not very keen on the whole idea and hence his capacity to continue on the programme was revisited. He made an informed decision about carrying on and was pleased to know that he could change his mind should he wish to do it in the future.

Session 2: Mr B requested assistance with formal capacity assessment and arranging Lasting power of Attorney to his daughter to manage his finances as he was aware he



wasn't managing as well as he used to. We also discussed the requirement for a day centre again reassuring him and explaining what to expect. The Recovery Nurse offered to accompany him for a visit to see what it was like and he preferred to think about it.

Session 3: Mr B had agreed to visit the day centre, and requested for his wife and daughter to attend for support and advice which I agreed to and facilitated it through the manager of the day centre. We stayed for half an hour, however, Mr B did not want to attend as he didn't feel it was for him.

Session 4: Mr B was supported through the process of executing his Lasting Power of Attorney application to his daughter with regards to his property and RN arranged for all the appointments involved to complete this task. Mr B expressed his gratitude and informed the Recovery Nurse that his wellbeing would improve greatly by future planning.

Session 5: Mr B had swollen legs and was being treated by his GP. His usual routine was accompanying his wife to complete the weekly food shopping in town, but he felt too uncomfortable to walk and walk up the steps on the bus. Mrs B was worried to leave him on his own and wanted to keep their routine. The Recovery Nurse offered to drive them to the town which they agreed and were thankful for.

Session 6: The Recovery Nurse reviewed Mr B's care, going through his future care plan as they were worried of being abandoned. They were reassured that Mr B would continue to be followed up in memory clinic and they were introduced to their new key worker. RN gave them information for the future and suggested to go back to the initial letter from the diagnostic clinic. They perceived it as sense of security and something they could refer back to, as it explained very clearly the initial diagnosis, likely prognosis and usefulness of Advance Care Planning. The Recovery Nurse completed a contingency plan with Mr B

together with the family. He appreciated it and mentioned that he was much more relaxed than he was in beginning of whole process of recovery .

**PATIENT 15 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mr D was low in mood at start of visit and RN offered therapy session based on concepts of cognitive behaviour therapy and supportive psychotherapy. The session focussed mainly on coping strategies and embarking on activities which gave him pleasure. He reported feeling positive at the end of session as he felt listened to and enabled rather than listening only to his wife and putting in services to help him.

Session 2: The Recovery Nurse discussed MIND memory support group to build confidence and support as he was worried about driving to new places. The recovery care plan was discussed and he identified the need to plan bus routes for the future and get used to it, while he was still capable to do so. We agreed to go to MIND together by bus and spent time to increase his orientation, talk to people and complete relevant documentation.

Session 3: Mr D brought to the attention of the Recovery Nurse that his alarm clock gave him a headache and set his low mood off. He was provided education about the symptoms of depression and increased sensitivity to noise being the one of them. This was discussed with the Occupational Therapist who suggested a lamp alarm clock which wakes the person gradually by light and has been proved to assist mood and Mr D agreed to try.

Session 4: Mr D was unable to continue his spinning class at sports space gym as he found it difficult to climb on the bike. He was disappointed as this was a positive point to his week which he spent with his wife and looked forward to. We agreed to try for a home support grant to buy a mini exercise bike to continue with the routine in the safety of his own home, supervised by his wife.

Session 5: The Recovery Nurse assisted completing the attendance allowance form as it was previously rejected. She was able to add more relevant information together with the supporting nursing and General Practitioner's letters as evidence following consent.

Session 6: Mr D wanted more support for his wife as he watched her rushing around and felt guilty. I completed a carer's assessment and referred for extra benefits to assist paying for a house keeper and gardener to take pressure of his wife which they both agreed. He reported benefitting from therapy together with the antidepressants and was very appreciative of the support he and his wife received by being a part of the recovery programme.

**PATIENT 16 (completed all the sessions and the final assessment with the researcher)**

Session 1: We spent the first session talking about her limitations as a result of memory impairment and ways to enhance low scores of her self esteem and confidence and to deal with difficulties in a more positive way. She agreed for a referral to an occupational therapist for a functional assessment at home to enable her in the home and adapt the coping strategies to maintain independence.

Session 2: Mrs T requested the Recovery Nurse to accompany her during her outpatient appointment. She stated that it was suggested by her son, who seemed to believe that his mother (Mrs T) presented well in front of professionals and wanted the Recovery Nurse to talk on her behalf describing her needs and mood. The suggestion was agreed, but she was encouraged to speak for herself with the Recovery Nurse, mainly providing the support to reduce her anxiety.

Session 3: Mrs T was becoming more aware of her limitations of memory problems and regaining some insight after being commenced on Aricept. The response to medication was positive in some respects, but there was impact on her mood leading to anxiety symptoms. The referral to the day hospital was discussed with a view to obtain more comprehensive assessment of her needs, mood, memory and day to day functioning.

Session 4: Mrs T was nervous about her referral to day hospital, but felt reassured by reflecting on the benefits to her quality of life and independence.

Session 5: Mrs T was attending the day hospital and was pleased about her progress. She still lacked confidence at times and appeared ambivalent about making decisions. She was finding it difficult to come to terms with the fact that recovery sessions were limited. She demonstrated some degree of dependency and requested the Recovery Nurse to accompany her during Memory clinic appointment. She was experiencing anticipatory anxiety about the prospect of forgetting what to ask when she attended and what was said afterwards. The Recovery Nurse agreed to attend but suggested writing down the questions and writing the response afterwards to enhance her memory and she agreed to try it.

Session 6: Mrs T appeared more confident and stated that she did not seek for reassurance from her son as much. She was independently making cups of tea even though it took longer. She was thankful and was able to gauge the benefits to her mood, dignity and respect and was more positive at the end of recovery treatment.

**PATIENT 17 (completed all the sessions and the final assessment with the researcher**

Session 1: Mrs H was already attending a memory support group and felt positive about it. However, she was keen to attend another available group locally. She was provided information about the local resources at MIND. We looked through the information leaflets and she chose a confidence building group which I agreed to book for her to attend as requested.

Session 2: Referred for a home support grant to buy a recliner chair to maintain independence in the home, as she relied on her daughter to get her up out of their chair which was putting a strain on her back. She was also using the coffee table to elevate her legs and had caught her skin several times and a recliner chair could help prevent these problems.

Session 3: We discussed her mood symptoms as she was worried about putting a strain on her daughter who was her live in carer. The Recovery Nurse completed a carer's assessment. We agreed to use a carer's grant to buy a new mattress to make her stay

more comfortable as the mattress she had been sleeping on was forty years old and was her original mattress from when she was a child.

Session 4: The Recovery Nurse escorted Mrs H to the confidence building class. She remained focussed throughout the session but felt it wasn't for her. She realized that she had a lot more confidence than all of the people in the group there which improved her confidence and had a positive impact on her mood symptoms.

Session 5: She was worried about death and her will, as she was concerned her wishes would not be listened to due to her family dynamics. We agreed to write labels on her things she was most worried about with the names of her family members who she would like the items to go to. We also completed an end of life questionnaire, to make her wishes known, giving a copy to her and GP.

Session 6: The Recovery Nurse completed a Mini Mental State Examination and capacity assessment prior to attending the solicitors. Mrs H requested RN to accompany her to the solicitors, as she didn't want a family member there to bias her opinions and it was agreed that it was merely for support. She was very pleased after completing the necessary paperwork and reported being relieved and feeling the weight off her shoulders and felt that she would be able to sleep better at night.

**PATIENT 18 (completed all the sessions, but did not attend the final assessment with the researcher)**

Session 1: The Recovery Nurse visited Mrs B at her home and found her unsettled and worried, hallucinating and had not slept well for few nights. She had been calling the police

as she had a false belief there were intruders in her home and she didn't feel safe. She discussed the need for urgent respite care and was assisted with transport and reassured whilst being accompanied to the respite.

Sessions 2 and 3: The sessions focussed mainly on improving Mrs B's orientation to the place and allaying her anxiety. The Recovery Nurse made arrangements for the medication to be reviewed while she was at the respite care. She reported feeling reassured and listened to and there was an appreciable improvement in her quality of life. She felt calm and was able to enjoy her stay, was impressed with the care and food at the home. She responded positively to her new medication and her sleep pattern improved significantly. There were no evidence of hallucinations, she was cheerful in mood and she thanked the Recovery Nurse for being compassionate and providing care, time and support through the whole process.

Sessions 4 and 5: The sessions involved moving Mrs B from respite to an enablement bed and finally long term placement in a residential care. Throughout the whole process she was given the appropriate information and her wishes and preference were taken into account and no decisions were made for her. She was encouraged to discuss with her family and given the brochures about the local places available. She looked at care homes locally which were suitable for her needs and were also nearby to her family.

Session 6: Mrs B felt that her long term goal of being in care had been achieved in a residential home. She expressed her wish to rebuild the relationship between her daughter and granddaughter and believed that current environment would enable her to do so. She had previously felt like a burden on her family and was pleased to look at things in a different perspective. She was enjoying the company and was attending the activities at the care home.

**PATIENT 19 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mrs P was known to memory assessment service and had received the diagnosis of mild dementia just recently. She was able to gauge the exact benefits of the diagnostic clinic and post diagnostic support, having gone through the different process before.

Session 2: RN discussed her needs, recovery goals and ways to improve her wellbeing. The carer's assessment and benefits available to the couple enabled Mrs P to make her choices and preferences known and it was agreed that the carer's grant would be utilised to pay for a new television, to help orientate and entertain her.

Session 3: Mrs P was so pleased that her television had arrived. The actual benefits had outweighed her perceived uselessness. She was caring for her autistic grandson with assistance from her husband. They said the television has enabled them to catch up on their religious programmes and kids programmes which entertained her grandson so she had time to rest.

Sessions 4: Mrs P was feeling a bit down due to her physical health problems including poor mobility. The limitations were having a strain on her family as she was finding it difficult to go out. She was reassured to know that it was part of her physical health problem and advised to see her general practitioner. She was provided information leaflet about the basic exercise routine to help her to build muscle strength, while awaiting the outcome of the referral to a physiotherapist.

Session 5: Mrs P reported significant improvement in her symptoms by using the graded exercise programme suggested by GP and her husband had agreed to support her when



she was out with the aid of a walking stick. She felt confident with this plan and thanked RN for the advice.

Session 6: Mrs P reported that she was unable to spend as much time as she used to in her garden due to her physical health limitations. She was unable to manage lawn mower. RN agreed to arrange for a home support grant to pay for a gardener once a month to tackle the majority of the garden, leaving her with the decorations and small jobs in the garden. She was very thankful for this and felt that she would still be able to enjoy her gardening without getting physically exhausted.

**PATIENT 20 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mrs L wished to spend her recovery visits ventilating her anxiety as she believed that she had a lot of built up emotions that she wanted to get off her chest and feel listened to. She felt that expressing her emotions had helped her in the past and made her feel happier afterwards. The Recovery Nurse agreed with this and was satisfied that by Mrs L taking the ownership of the process and support her in achieving the recovery goals of improved hope and self esteem.

Sessions 2 and 3: Mrs L had a long term hobby of reading love stories, which she had given up recently. She wanted to restart it by reading to the RN and reminisce about the old days. She had identified that she had happiest memories from her past and wished to share those during the sessions. This was agreed and she felt that the process kept her occupied for longer and stopped her thinking about sad memories. Mrs L continued to enjoy reading her love stories and appeared happier and more positive. This was evident

by the feedback from the warden, who agreed that she did not appear upset every time she visited and engaged in conversation well.

Sessions 4 and 5: Mrs L requested RN to accompany her to the outpatient's appointment fourth time, as she was aware about her memory problems and didn't want to miss out on anything important. Despite the fact that it was explained to her that she would receive the copy of her recovery care plan, the Recovery Nurse ended up attending with her to prevent any negative impact on her improving mental state and perhaps prepare her better for the future events.

Session 6: The Recovery Nurse tried to engage Mrs L in leaving her flat to attend a coffee morning or visit a charity shop to buy more books. She declined as she preferred her home comforts and felt that availability of the books in the communal lounge was sufficient to keep her interested and going. Mrs L's care plan was reviewed during the final visit to give her the opportunity to ascertain her achievements and progress with the very collaborative approach. She was very satisfied and thanked the Recovery Nurse for helping her to find a coping strategy of reading love stories to improve her mood, rather than the need for medication.

**PATIENT 21 (completed all the sessions and the final assessment with the researcher)**

Sessions 1 and 2: Mrs H described the recovery goals of gaining confidence in order to prevent her daughter from worrying about her welfare. She requested the Recovery Nurse to join her in the communal lounge of the sheltered accommodation where she was intending to move soon. She had never been there without being accompanied by her

daughter or other family member and was worried that people would stare at her or not even talk to her. Mrs H was sitting alone in the communal lounge in the corner and another lady was also sitting alone in the other corner. The Recovery Nurse helped to introduce them and filled the silences with common interests such as family. They built up a rapport, while the Recovery Nurse made them a cup of tea and left them interacting in the safety of their warden controlled communal lounge.

Session 3: There was a remarkable change in her presentation. She had established a very good relationship with the other lady and had received an invitation to go to bingo in the communal lounge. She was slightly ambivalent initially about going to the event, but felt reassured by accepting the fact that lots of other people there would have a difficulty to prevent them from living independently like her. She began relating to the people around and realized that they too liked to be sociable and enjoyed being in the company of other people in the lounge. She decided to go to bingo and enjoy any next coming social event.

Sessions 4 and 5: The sessions were great source of satisfaction for the recovery nurse, as she witnessed Mrs. H fully engaged in her new social activities. She was pleased to notice her growing confidence and self reliance.

Session 6: Mrs H was again engaged in social activities and her daughter was pleased to inform RN about her mother's overall wellbeing. She was described as being better in her mood, satisfied with her move and her appetite was regaining. She was keen to restart sitting around a table to eat her meals rather than picking as she goes along. RN arranged for a table and chairs to be bought through a home support grant to encourage this positive behaviour.

**PATIENT 22 (completed all the sessions and the final assessment with the researcher)**

Session 1: Mr C was finding it difficult to come to terms with his diagnosis of dementia and gradual deterioration of his mobility. He felt a severe blow to his self esteem and confidence, when his license was revoked by the Driver and Vehicle Licensing Authority. He reacted by becoming irritable and annoyed with his wife over trivial matters and felt frustrated with himself subsequently. He was not amenable to suggestions by the Recovery Nurse of using taxi vouchers or other means of public transport. She left the information in case he changed his mind, to enable him to use these alternatives in the future.

Session 2: Mr C said that he was struggling financially and this was having an impact on his overall wellbeing. The Recovery Nurse referred for an attendance allowance and assisted completing the form with supporting evidence to enable him to be more independent and financially secure. She was also working on improving his coping strategies and providing the relevant information about the support groups for the couple to access locally.

Sessions 3 and 4: Mr and Mrs C reported feeling socially isolated since he had stopped driving. The Recovery Nurse worked on improving his insight in addition to looking at practical support available. She involved Age Concern and arranged for the couple to attend the groups. This arrangement suited them better, as it enabled them to use transport and to socialise together. They preferred and liked being together but needed a change of scenery and atmosphere. He was also seen by an occupational therapist for a functional assessment and input to enable to remain independent for as long as possible. He was accepting of this support and embraced it.

Session 5: The Recovery Nurse accompanied him to an outpatient appointment as his fifth visit in order to address his emerging symptoms of aggression. This was having an impact on his relationship with his wife and preventing him attending social groups at Age Concern which both of them enjoyed going together.

Session 6: Mr C was gradually becoming insightful about the impact of his diagnosis of Alzheimer's disease and keen to obtain information about the future, and support available. He also wished to be independent for as long as possible. He was reassured and provided supportive psychotherapy. He realized that he was not alone, he would be monitored in memory clinic and signposted and supported throughout his journey.

**PATIENT 23 (completed all the sessions and the final assessment with the researcher)**

Sessions 1 and 2: Mr D's recovery goals were to improve his self confidence and be able to cope with any changes in his physical health. He mentioned that he was managing well with his current social situation despite impairment in his memory. He had been able to visit his wife in the hospital daily for eight days by bus and care for himself independently. He was pleased and reassured by being able to carry out his responsibilities. He expressed that he did get frustrated when he could not find his keys or wallet as it slowed him down. The Recovery Nurse agreed to a plan to reduce this stress by being more imaginative and creative and looking into available options. She was surprised to see an improvement by Mr D when provided with the two sets of whistle key fobs, with one being attached to keys and other one on his wallet. He only had to whistle when he couldn't find

his wallet or keys and this helped to maintain his independence, speed up his day and reduce his frustration.

Session 3: Mr D had a hospital admission over Christmas and felt that he had lost muscle tone in his legs. We discussed the need for a home support grant to buy a mini exercise bike to build up muscle tone to increase his mobility.

Session 4: Mr D was tired during the visit and said he was going to have a rest. The Recovery Nurse used this time to complete a carer's assessment and discussed his needs and progress with wife after obtaining his consent.

Session 5: Mrs D felt more alert since having his pacemaker fitted and wished to have a review of his memory. He was anxious about gradual ongoing deterioration of his memory and improvement in his Mini Mental State Examination score did not satisfy him. He was functioning relatively well.

Session 6: Mr D was worried as he was unable to change his hospital appointment from 8:30 am. He would have to catch the 6:30 am bus and be up at 5:30 am. The Recovery Nurse reassured him that she could transport him on this occasion and arrange for taxi vouchers for future appointments. He was grateful and thankful for all the support and information he and his wife received during the recovery project. He felt equipped to deal with future situations and reassured by the support available.

**Patient 24** was lost to follow up by sudden leave of one recovery nurse and her work does not appear to have been carried out subsequently by another recovery nurse.

### **3.3 Treatment as usual group**

The experience of the subjects in the treatment as usual group was captured at the end of the study and generated some common themes including “helpful in passing the information”, helped to set up the calendar and right card for payment”, People were professional, listening and nice to have a chat with”, “felt supported and was useful to know that they can get in touch, if things change. There were some negative experiences as described by the carers that there were no prebooked appointments, they perceived the questionnaire of the study as unnecessary and disappointed that there was no such thing like psychotherapy and antidementia medication provided to their relatives. Some of the patients felt that they were mainly advised to do things and were not pleased with that approach and unfortunately one person got agitated in the presence of the worker and was not keen to continue with the visits. This process demonstrates how the recovery model may differ from the current practice of problem orientated approach involved in dementia care. The relationship between clinicians and patients in recovery model is a partnership rather than expert to patient one. This means patients play a more active role in the recovery process and family and other supporters are regarded as partners in the process.

### **3.4 Summary of the results**

34 patients completed the study randomly allocated 17 each to the recovery focus and control groups respectively. The range of cognitive impairment was from mild to moderate and the most frequent diagnoses were mild cognitive disorder and Alzheimer's dementia which were evenly distributed between the two groups.

There was a significant difference between the groups in terms of greater improvement in wellbeing as rated by the WHO – 5 Wellbeing Index in the recovery focus group compared to the control group. The secondary outcome measures in the areas of cognition, quality of life and caregiver burden showed no differences between the groups.

Case histories of the recovery focus group however, identified the main areas of improvement were improved mood, increased social interaction, reduction in carer strain and / or burden and improved self-worth and / or confidence, but there was no quantitative data to substantiate these findings.



## **4. Discussion**

### **4.1 Study Findings**

This study involved the application of recovery model principles to people with memory problems to see if they could be successfully applied to in this group and compared what difference they made in terms of outcome care compared to current clinical practices amongst outpatients' clinic attendees. It was a randomised control study in which recovery orientated diagnostic and post-diagnostic interventions were compared with treatment as usual amongst patients attending outpatients' clinics for persons with memory problems. Going by the literature review carried out at the time, it would appear that this is the first randomised controlled study of recovery orientated post diagnostic interventions of persons with dementia. The 34 patients who completed the study were equally distributed between the recovery focused care and control groups respectively with diagnoses ranging from mild cognitive disorder to dementia of mild and moderate severity. Interventions were generated by the research clinicians based on scores of various domains of Mini Wellness State Examination . This tool had been developed from the World Health Organisation Well-being Index in which the research team engaged with clinicians of various disciplines involved in the mental health care of older people to help develop a relevant tool to assess health and wellbeing in older people with memory difficulties. The research clinician who carried out the assessments using the Mini Wellness State Examination identified the needs of individual patients and generated interventions which were offered to the patients randomly allocated to the Recovery Focused Care Group. Those patients in the control group were offered treatment as usual which included monthly consultations with a member of staff discussion about their problems and care, but not offered the interventions generated by Mini-Wellness State

Examination. Patients in both groups had outcome measures completed at the onset and the end of the study. These outcome measures rated patients' cognition, depressive symptoms and quality of life as well as carer burden. The study findings revealed a greater improvement in wellbeing in the intervention group compared to the control. However in other areas such as cognition, quality of life of patients and carer burden there were no differences.

Patients interviews, carried out in the Recovery Focused Care group, suggested, a variety of specific areas of improvement such as mood, social interaction, self-esteem, confidence and carer strain / burden. The improvement seen in these areas and in the wellbeing of patients in the Recovery Focused Group could be explained by patients taking on greater responsibility in contributing to their desired goals as part of the recovery process alongside the close therapeutic relationship with the recovery nurse. However, no such benefits were elicited in the control group, as clinicians in the control group were specifically instructed to not mention the wellbeing in their monthly session with the patients. It was evident during the regular supervision meetings of the research team that the Recovery nurse had developed a very good therapeutic relationship with the patients and their carers and perhaps she was more in tune to elicit and note the above improvements over a period of time, as compared to the treatment as usual group key worker. The impact of this relationship difference on the actual results was not considered, measured or examined during the initial assessment and at the completion of the study by the researcher. Implications for clinical practice from this study suggest that application of the recovery model principles with a good therapeutic relationship with health care professionals and caregivers is likely to benefit both patients and family care-givers.

The convenience sampling was used to achieve the required number by choosing the patients referred by their GP for memory assessment to the community mental health team of elderly people. This might not be a representative of all the dementia patients in the community and might have influenced the overall results, as people who seek to see their GP and the specialist for mild memory problems are well motivated to look into the support networks, explore the drug and other available treatments and wish to plan for the future.

In a comprehensive literature review, no published randomized control study of recovery-orientated intervention in dementia was identified to be able to make any direct comparison with our study. The literature review was mainly focussing on theoretical concepts of the recovery, its applicability to old age psychiatry and clarifying the similarities and distinctions with Person Centered Care.

There were only two randomised controlled studies directly addressing the psychosocial needs of people with early dementia — one for diagnosis (Wolfs et al .2008) and the other for post-diagnostic psychotherapy (Burns et al, 2005). Burns et al,(2005) carried out a randomised controlled trial to assess whether a brief (six sessions) psychodynamic interpersonal psychotherapy could help people with Alzheimer's disease (AD) in terms of cognitive function, activities of daily living, global measure of change, and carers stress and coping. No improvement was found in the majority of the outcome measures. The principal aim of the psychotherapy was the identification of interpersonal conflicts or difficulties, which were causing or helping to maintain emotional distress. Although the authors argued that the reasons why their intervention did not work were the limited number of therapy sessions and non-involvement of carers, we believe that the selection of the therapeutic technique used in the study were probably inappropriate. It is often

debated whether psychological treatments for older people should be provided in geriatric old age mental health services or in separate psychological treatment services for adults of all ages.

Wolfs et al (2008) evaluated the clinical effects of an integrated multidisciplinary diagnostic facility for psychogeriatric patients suspected of having dementia (complex psychogeriatric problems) by randomly allocating patients to the intervention or to treatment as usual. There was an improvement in health-related quality of life at 6 months in the intervention group, whereas that of the control group had decreased. They argued that as work with older people requires additional skills such as cognitive assessment, an understanding of physical illness and an availability to liaise with hospitals and care homes, it makes sense that the development and evaluation of treatments continue to take place within the context of integrated old age psychiatry services.

Neither of the two studies described above used the integrated approach combining pre-diagnostic, diagnostic and post-diagnostic work.

The Croydon Service had both diagnostic and therapeutic elements (Banerjee et al.2007). The service evaluation consisted of data of baseline interviews and 6-month follow-up with a cohort of 290 consecutive referrals, showing significantly increased quality of life and marginal improvement in depression. Although rating instruments used in the study were different, these findings are consistent with our study, in which, similar improvement was observed. The diagnosis of dementia was made and the management plan formulated by the multidisciplinary team as a whole. The Croydon team had set six goals against which success could be judged. Those goals were: a low refusal rate from those referred (<10%), low rate of inappropriate referrals (<20%), appropriate number of referrals from minority ethnic groups, to engage with at least 60% of referrals with mild or minimally

impaired or subjective impairment only, to engage with at least 10% of cases of young-onset dementia, and to increase the number of new cases seen per year by 50%. There was no specific goal set for 'living well with dementia'. Few participants experienced the process of memory assessment as patient centred. They perceived assessment processes lengthy and drawn out leading to uncertainty. The tests and assessments were described by some participants as anxiety provoking and environment as alarming or potentially stigmatizing. Information provision and communication were variable and practitioners were not always thought to help people to make sense of their experiences. In terms of content of care, all those diagnosed as having dementia were assessed for formal programmes of individual and group psychological support and offered if appropriate. The paper neither describes any specific psychosocial intervention nor provides details of the 'team training' believed to be 'paramount'. There is no mention of 'wellnesses in the study. The model was designed to be 'easily transferable to and replicable in other area', but so far no such evidence has emerged. The only conclusion to be drawn from the study is that a highly motivated, adequately trained, and suitably staffed specialist old age psychiatry team can provide a dementia service capable of offering early diagnosis, drug treatment for people with Alzheimer's disease, and some kind of psychological support. In our view, these services are already being provided in most parts of the country. What is missing is a lack of diagnostic protocol for dementia, training in breaking the diagnosis, pre and post-diagnostic counselling and individualised psychological therapy over a sufficient period of time.

The National Dementia Strategy has ironically shifted the attention of the local commissioners from investing in the existing specialist community old age psychiatry teams to the mass production of poorly qualified 'dementia support workers'. Unless and until these dementia workers are trained and supervised by their local specialist teams, the

goal of 'living well with dementia' may remain unachievable. Given the opportunity and necessary support, community old age psychiatry teams are capable of providing both longer term recovery type work and acute home treatment in the community (Boskovic & Jha, 2009).

More recent and some older publications in dementia care refer to interventions focussing on mainly patients, while others focus both patients and carers and some exclusively on carers. The design, findings and stages of the illness are not similar to draw meaningful comparison with our study. Nevertheless, some of the interventions used are useful to discuss here to expand and explore means of improving the well being and quality of life for people with memory problems. A systematic review of effectiveness, training content and didactic methods in different care setting showed that communication skills training in dementia care significantly improves the quality of life of people with dementia and increases positive interactions in various care settings (Eggenberger, Heimerl & Bennett 2013). Communication skills training had significant impact on professional and family caregivers' communication skills, competencies, and knowledge. This study focused on one specific task and patients appeared as passive recipients of the care. In this study it would appear communications skill training proved more beneficial for the people in the later part of the illness and in different care settings.

## 4.2 Person centred care and Recovery approaches in dementia

Findings of the present study support the social construction theory, which postulates that if the attention is focused on the remaining healthy Self, composed of mental and physical attributes and related beliefs, it is possible for the afflicted person to construct worthy Self and social personae in which he or she can take pride and enjoy a measure of satisfaction (Sabat., 2002). Whilst, we agree with some of Sabat's criticism of therapeutic nihilism of what he termed as the technical or standard paradigm, our recovery narratives demonstrate that we have moved beyond the etiological debate about dementia. We have verified some of the ways of improving individual well being without being entangled in the inconsistencies and ambiguity of the theoretical concepts. It would be naive to suggest that social factors do not affect the course of the illness and, throughout the research attempts were made to mitigate the negative social impacts of the illness. We endeavoured to shift away from pessimistic and stigmatising view of dementia and aimed to instil hope and optimism. The participants of our research were well informed and were accepting of their probable diagnosis , but were empowered to identify the ways of living well despite the progressive nature of their illness. This might appear in contrast to some of the views expressed by Mental Health Recovery Practitioners that acceptance of the medical diagnosis is irrelevant, harmful or hindrance to the recovery (Stastny & Lehmann 2007). Our stance resonates with Tom Kitwood's claim that it is possible for a person with dementia to remain in a relatively high state of wellbeing provided their psychological needs are met, despite the indicators of the wellbeing being diverse. Person Centred Care lays a huge emphasis on the behaviour of the staff to promote personhood, while personal resourcefulness is considered pivotal for recovery. Recovery approach challenges the

social effects of excess medicalisation inherent in psychiatric practices, but clearly recognizes the role of biomedical contribution to dementia.

This study supports the need to address the dichotomy of the existing services, where people of working age with mental health problems receive treatment based on achievement and maintenance of optimal wellbeing and recovery compared to the widespread reluctance to apply similar in older people's services. Finally, findings of this study endorse the position statement by consultant psychiatrists that recovery ideas should provide the basis for the future direction of psychiatric practice and be applied across the major sub-specialties of psychiatry (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010).



## 5. Limitations

The study had a relatively small sample size and a number of drop-outs over the 6-month study period. Perhaps more participants should have been recruited to keep the required sample size adequate at the endpoint, although this was only designed as a feasibility study.

Another possible confounding factor was the potential for interaction between the recovery nurse therapist who worked with the research team and other members of the community mental health team who managed the treatment as usual group (control group) during the study period. This may have led to discussions about effective recovery methods being passed on to patients in the control group inadvertently.

As the study was not a double blind trial, participants in the recovery group knew from the outset that they were receiving a new psychosocial intervention and therefore may have been more receptive and positive.

We did not compare the effect of medication, like cognitive enhancer drugs, on the outcome measures due to very small numbers of the patients receiving these drugs in both the groups and appears to be advisable to do so in the future studies.

The cost effectiveness of the project was not established to ascertain the feasibility of the possible roll out to other memory services.

## **6 Suggestions for further research**

As this study was carried out for a period of six months with a relative small sample size, there is a need for a larger study over a longer period to see if our findings can be replicated. To prevent cross fertilisation of ideas between intervention and control groups, the use of multicentre sites may prevent such issues

A randomised double blind study will remove the possibility that patients being aware of their group right from the outset and may affect the outcome difference between treatment and the control group.

The main emphasis of the study was on the impact of recovery focus care on patients. Further studies may want to look more closely at the impact of well-being and recovery focussed interventions on the carers.

The use of telephone to deliver some of the recovery interventions can be explored in the future research.

## **7. Conclusions**

Recovery and wellbeing approach offers a different perspective to the treatment and management of people with memory problems and challenges the traditionally held views that the idea of recovery is associated with cure and the absence of disease. Any measure, with or without drug treatment, that supports people with dementia live happily in their own homes as long as possible is invaluable. The findings of this preliminary study support the value of integrating pre-diagnostic counselling, recovery orientated diagnostic consultation and post-diagnostic support to people with MCI and early dementia. This study has the benefits of both RCT and more empirical approach, using simple single-case designs, with the person as their own control. Above all, it provides a framework of early diagnosis and quality intervention addressing both the clinical and personal recovery needs of the individual.

A recovery approach may be particularly welcome for those with MCI diagnosis who may otherwise be left with a diagnosis of uncertainty and no input other than a recommendation for periodic reassessment for signs of dementia. People with dementia are usually not prepared for the diagnostic consultation, not always given their diagnosis and are not offered adequate post-diagnostic support. This study describes the efficacy of a new recovery-orientated dementia care package on the wellbeing of people with early dementia. The recovery-orientated package of dementia care includes pre-diagnostic counselling and wellbeing assessment, collaborative diagnostic consultation and an extended post-diagnostic support addressing their personal needs, difficulties and

expectations. This innovative recovery care package enhances the wellbeing and quality of life of people with mild cognitive impairment and early dementia.

The concept of recovery is new to dementia care and therefore needs further empirical development and evaluation. The staff training and attitudes require a shift from traditional symptom management to a progressive practice based on recovery and wellbeing. The increased adoption of the recovery approach would help create new and innovative strategies and interventions that are likely to promote well-being and maintain people with dementia in community settings.

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## Appendix 1

## Mini Wellness State Examination for older people

### TO BE COMPLETED BY CLIENTS

Client:	Age:	Date of Birth:
Interviewer/care coordinator:	Date of Interview:	
Team:	Carer:	Relationship:

We would like to know about the current state of your well-being. Please indicate for each of the following *ten* statements which is closest to how you have been feeling over the last *few weeks*. Notice that higher numbers mean better well-being.

	<i>Domains</i>		<i>All of the time</i>	<i>Often</i>	<i>Some of the time</i>	<i>Rarely</i>	<i>At no time</i>	SCORE
<b>MENTAL WELLBEING</b>								
1	<i>Life satisfaction</i>	<b>Altogether, I feel satisfied with my life</b>	4	3	2	1	0	
2	<i>Optimism</i>	<b>I feel positive and hopeful about my future</b>	4	3	2	1	0	
3	<i>Self-esteem</i>	<b>I've been feeling good about myself</b>	4	3	2	1	0	
4	<i>Mastery &amp; Feeling in control</i>	<b>I've been dealing with problems well</b>	4	3	2	1	0	
5	<i>Having a purpose in life</i>	<b>My daily life has been filled with things that interest me</b>	4	3	2	1	0	
6	<i>Sense of belonging and support</i>	<b>I've felt loved and close to other people</b>	4	3	2	1	0	
<b>EMOTIONAL WELLBEING</b>								
7	<i>Emotional state</i>	<b>I have felt cheerful and in good spirits</b>	4	3	2	1	0	
<b>PHYSICAL WELLBEING</b>								

8	<i>Physical condition</i>	<b>Health wise, I feel quite fit and able to do things myself</b>	4	3	2	1	0	
<b>FINANCIAL WELLBEING</b>								
9	<i>Financial situation</i>	<b>I've had no worries about money or finance</b>	4	3	2	1	0	
<b>SPIRITUAL WELLBEING</b>								
10	<i>Spirituality</i>	<b>I have come to understand the meaning of life</b>	4	3	2	1	0	
<b>TOTAL SCORE</b>								

**Scoring:** The raw score is calculated by totalling all *ten* answers. The raw score ranges from 0 to 40, **0** representing worst and **40** the best possible state of well-being.

---

\*Adapted from WHO well-being Index and NICE (Public health guidance 16) Mental Well-being Guidelines for older people

## **Appendix 2: Wellness Recovery Questionnaire for Older People**

(Logandene Recovery Project November 2008)

The National Institute for Health and Clinical Excellence (NICE) has defined 'mental well-being' as a state of mental health characterised by life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, and a sense of belonging and support. The Logandene 'Wellness Recovery Project' has used this definition along with *physical and spiritual wellbeing* as recovery goals for older people presenting with mental health problems. The WRQ is an 8-item scale to rate the current level of mental, physical and spiritual wellbeing of older people with mental health problems. The 8 items are rated on a 5-point scale, with 0 being 'don't know', 1 being poor and 4 being excellent, with a total score of between 0 and 32. The '0' score for 'don't know' is only scored if the client is unable to score after repeated explanations.

### **Instruction for Interviewers**

The Wellness Recovery Questionnaire is administered in interview format to older people with dementia and other mental health problems following the instruction below:

*Give the following instructions:*

**"I want to ask you some questions about your wellbeing and how you rate different aspects of your life using one of four words; poor, fair, good, or excellent. We want to find out how you feel about your current situation in different areas of your life such as mental wellbeing, physical health and spiritual satisfaction. If you are not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.**

Try to get answers for ALL questions and **circle** her/his. If the client says that some days are better than others, ask him or her to rate how he/she has been feeling *most of the time lately*. Please score '0' *only* when the client fails to rate despite repeated explanations and attempts (usually in cases of dementia). If the client is unable to choose a response to a particular item or items, its reasons should be noted in the comments. Following each question, explore how the client, carer and the care coordinator help achieve that particular wellness recovery goal.

**Client's name:**

**Carer's name and relationship:**

---

### **1. Life Satisfaction Score:**

#### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the **client** may like to undertake to enhance their life satisfaction
  - a.
  - b.
  - c.
- Activities that their **carer** may like to undertake to enhance client's life satisfaction
  - a.
  - b.



- c..
- Needs identified by the care coordinator to help the client achieve maximum life satisfaction:
  - a.
  - b.
  - c.

## 2. **Optimism Score:**

### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the *client* may like to undertake to enhance their *optimism*
  - a.
  - b.
  - c.
- Activities that their *carer* may like to undertake to enhance client's *optimism*
  - a.
  - b.
  - c..
- Needs identified by the care coordinator to help the client *feel optimistic* again
  - a.
  - b.
  - c.

## 3. **Self-esteem Score:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the *client* may like to undertake to enhance their *self-esteem*
  - a.
  - b.
  - c.
- Activities that their *carer* may like to undertake to enhance client's life satisfaction
  - a.
  - b.
  - c..

- Needs identified by the care coordinator to help the client achieve maximum *self-esteem*
  - a.
  - b.
  - c.

#### **4. *Mastery and feeling in control:***

##### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the client may like to undertake to enhance their sense of mastery and feeling in control
  - a.
  - b.
  - c.
- Activities that their carer may like to undertake to enhance client's mastery and feeling in control
  - a.
  - b.
  - c..
- Actions that the care coordinator might take to help the client regain sense of mastery and feeling in control:
  - a.
  - b.
  - c.

#### **5. *Having a purpose in life Score:***

##### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the *client* may like to undertake to enhance their *purpose in life*
  - a.
  - b.
  - c.
- Activities that their *carer* may like to undertake to enhance client's life satisfaction
  - a.
  - b.

- c..
- Needs identified by the care coordinator to help the client achieve maximum feeling of *purpose in life*
- a.
- b.
- c.

## 6. ***Sense of belonging and support Score:***

### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the client may like to undertake to enhance their sense of belonging and support
  - a.
  - b.
  - c.
- Activities that their carer may like to undertake to enhance client's life satisfaction
  - a.
  - b.
  - c..
- Needs identified by the care coordinator to help the client achieve maximum *sense of belonging and support*.
  - a.
  - b.
  - c.

## 7. ***Physical Wellbeing Score:***

### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the *client* may like to undertake to enhance their *physical wellbeing*
  - a.
  - b.
  - c.

- Activities that their *carer* may like to undertake to enhance client's life satisfaction
  - a.
  - b.
  - c..
- Needs identified by the care coordinator to help the client achieve maximum *physical wellbeing*:
  - a.
  - b.
  - c.

## 8. **Spiritual wellbeing Score:**

### **Comments:**

For the chosen answer, the care coordinator should discuss with client and carers the following points?

- Activities that the *client* may like to undertake to enhance their *spiritual wellbeing*
  - a.
  - b.
  - c.
- Activities that their *carer* may like to undertake to enhance client's life satisfaction
  - a.
  - b.
  - c..
- Needs identified by the care coordinator to help the client achieve maximum *Spiritual wellbeing*:
  - a.
  - b.
  - c.

### **Summary and Comments:**

### **Action Plan for each item** (to be transferred to client's care plan):

- 1
- 2
- 3

4  
5  
6  
7  
8

**Care coordinator:**

**Signature:**

**Date of Interview:**

## Appendix 3



**Psychiatric Research Unit**  
WHO Collaborating Centre in Mental Health

### WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	<i>Over the last two weeks</i>	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<b>1</b>	<b>I have felt cheerful and in good spirits</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>2</b>	<b>I have felt calm and relaxed</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>3</b>	<b>I have felt active and vigorous</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>4</b>	<b>I woke up feeling fresh and rested</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<b>5</b>	<b>My daily life has been filled with things that interest me</b>	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

#### Scoring:

The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

## Appendix 4: The Mini Mental State Examination

The Mini Mental State Examination (MMSE) is a widely used method for assessing cognitive functions. As a clinical instrument, the MMSE has been used to detect impairment, follow the course of an illness, and monitor response to treatment. The MMSE has also been used as a research tool to screen for cognitive disorders in epidemiological studies and follow cognitive changes in clinical trials.

The Mini Mental State Examination (MMSE) is a tool that can be used to systematically and thoroughly assess mental status. It is an 11-question measure that tests five areas of cognitive function: orientation, registration, attention and calculation, recall, and language. The maximum score is 30. A score of 23 or lower is indicative of cognitive impairment. The MMSE takes only 5-10 minutes to administer and is therefore practical to use repeatedly and routinely.

MMSE has a test/re-test reliability of 0.89 and inter-rater reliability of 0.83.

### Orientation

What is the (year) (season) (date) (day) (month)? 5

Where are we: (country) (city) (part of city) (number of flat/house) (name of street)? 5

### Registration

Name three objects: one second to say each.

Then ask the patient to name all three after you have said them.

Give one point for each correct answer. 3

Then repeat them until he learns all three.

Count trials and record.

### TRIALS

#### Attention and calculation

Serial 7s: one point for each correct.

Stop after five answers. 5

Alternatively spell 'world' backwards.

#### Recall

Ask for the three objects repeated above.

3 □

Give one point for each correct.

### **Language**

Name a pencil and watch (two points).

Repeat the following: 'No ifs, ands or buts' (one point).

Follow a three-stage command: 'Take a paper in your right hand,  
fold it in half and put it on the floor' (three points).

9 □

Read and obey the following: Close your eyes (one point).

Write a sentence (one point).

Copy a design (one point).

Total score



## Appendix 5: Cornell Scale for Depression in Dementia

Cornell Scale for Depression in Dementia					
Name	Age	Sex	Date		
<input type="checkbox"/> Inpatient <input type="checkbox"/> Aged care home resident <input type="checkbox"/> Outpatient					
<b>SCORING SYSTEM</b>					
A = unable to evaluate    0 = absent    1 = mild or intermittent    2 = severe					
Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.					
<b>A. Mood related signs</b>					
1. Anxiety: anxious expression, ruminations, worrying		A	0	1	2
2. Sadness: sad expression, sad voice, tearfulness		A	0	1	2
3. Lack of reactivity to pleasant events		A	0	1	2
4. Irritability: easily annoyed, short tempered		A	0	1	2
<b>B. Behavioural disturbance</b>					
5. Agitation: restlessness, hand wringing, hair pulling		A	0	1	2
6. Retardation: slow movement, slow speech, slow reactions		A	0	1	2
7. Multiple physical complaints (score 0 if GI symptoms only)		A	0	1	2
8. Loss of interest: less involved in usual activities (Score only if change acutely, ie. in less than 1 month)		A	0	1	2
<b>C. Physical signs</b>					
9. Appetite loss: eating less than usual		A	0	1	2
10. Weight loss (score 2 if greater than 5 lb in 1 month)		A	0	1	2
11. Lack of energy: fatigues easily, unable to sustain activities (Score only if occurred acutely, ie. in less than 1 month)		A	0	1	2
<b>D. Cyclic functions</b>					
12. Diurnal variation of mood: symptoms worse in the morning		A	0	1	2
13. Difficulty falling asleep: later than usual for this individual		A	0	1	2
14. Multiple awakenings during sleep		A	0	1	2
15. Early morning awakening: earlier than usual for this individual		A	0	1	2
<b>E. Ideational disturbance</b>					
16. Suicide: feels life is not worth living, has suicidal wishes or makes suicide attempt		A	0	1	2
17. Poor self esteem: self blame, self depreciation, feelings of failure		A	0	1	2
18. Pessimism: anticipation of the worst		A	0	1	2
19. Mood congruent delusions: delusions of poverty, illness or loss		A	0	1	2

## Appendix 6: The Euro-QoL 5D



**Health Questionnaire**

***English version for the UK***

***(validated for Ireland)***

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**

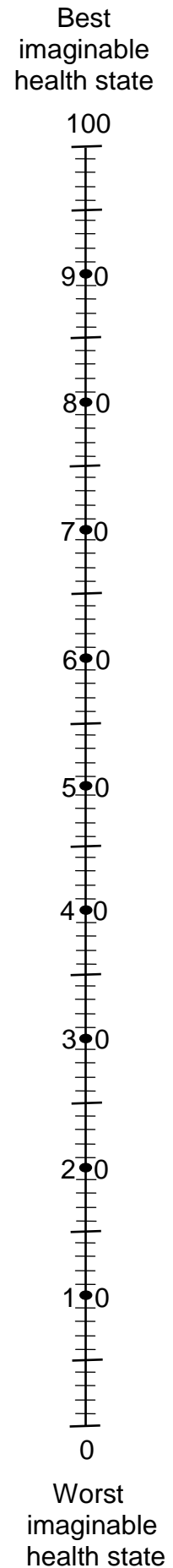
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**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.



# Appendix 7 - The Zarit Burden Interview

## The Zarit Burden Interview

Circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4

18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way.

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.

## **Appendix 8: INFORMATION SHEET**

**Title of Project: Effectiveness of recovery-focused mental health care of older people with dementia –a randomised controlled trial**

**Name of Researchers: Dr. Farida Jan & Dr. Arun Jha**

We would like to ask you to take part in a research study. This information sheet will tell you about the study so please read it carefully. Take as much time as you need to decide whether or not you wish to take part. Please feel free to ask questions and to take this information away and discuss it with other people (your family for example). If you have any further questions after our meeting, please feel free to contact us on the numbers provided at the bottom of this sheet.

### **WHAT IS THE PURPOSE OF THE STUDY?**

As people grow older they sometimes become forgetful. These memory problems may affect their life in different ways. For instance, they may feel frustrated because of their inability to perform as well as before. They may worry about their future as well. These problems can affect their wellbeing. We believe that older people with memory problems can be helped using specific psychological techniques to boost their wellbeing and quality of life. We have developed a recovery-focused instrument called Mini Wellness State Examination (MWeSE) to help people recover their wellbeing. We are interested in finding out whether MWeSE is better than traditional methods of caring.

### **WHY HAVE I BEEN CHOSEN?**

We are asking you take part in our study because you have been referred to our Specialist Mental Health Team for older people at Logandene for the assessment of your memory problems.

## **DO I HAVE TO TAKE PART?**

You do not have to take part in this study. If you would prefer not to take part, you do not have to give a reason. If you do not take part, your care will not be affected in any way. If you would like to take part, we will ask you to read and keep this information sheet. You will also be asked to read and sign a consent form to show that you understand what is involved in this study. If you do decide to take part, and later change your mind, please tell us. You are free to stop taking part whenever you like and you do not have to give a reason.

## **Who is taking part in the study?**

This research involves group of people who have been diagnosed with early and moderate degrees of Dementia, . This study aims to recruit around fifty people in total.

## **WHAT WILL HAPPEN IF I TAKE PART?**

If you decide to take part, one of our team members, will ask you to do some short tasks. These could be done here at the outpatient clinic or, if you would prefer, we could visit you at your home. The main purpose of the study is to help you recover your wellbeing by using a specially designed instrument called Mini Wellness State Examination (MWeSE) questionnaire. The MWeSE comprises of 10 different questions related to life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, sense of belonging and support, emotional state, physical condition, financial situation, and spirituality. At the initial interview, the clinician would rate you on each of these domains and explore ways and means to improve the score. For example, if the score on the domain of 'self esteem' is 2, the clinician would discuss with you and your family the following points: Activities that you may like to undertake to enhance your self-esteem and activities that your family may like to undertake to enhance your life satisfaction. The clinician would then identify the needs to help you achieve your maximum self-esteem. A similar exercise would be repeated for each of the domains which require improvement. Finally, after discussing with you, all those action plans would be summarised and incorporated in your care plan. You would be encouraged and assisted to work according to the care plan during subsequent visits, at least once a month or more frequently depending on your needs for next six months. There are no other tasks apart from these.

You will be free to take a break whenever you like. Please tell us if you would like a rest, even if you are in the middle of doing one of the tasks



.If you do choose to take part in this research study, we will ask you to complete one more questionnaires related to your quality of life before and six months into the study. We may approach you to complete some of these questionnaires on third occasion 12 months after the completion of the study. You do not have to do this additional task but it will provide us with some very useful information if you can. Even if you choose to do the task only twice, we will still be very grateful for your participation.

### **What if I have questions or concerns?**

If you have any further questions about the research, please feel free to contact the researchers via email, telephone or post, details of which are mentioned towards the end of this information sheet. In the unlikely event that you feel unhappy about the way you have been treated, please contact the Trust's Patient Advice Liaison service (PALS) on ..... or you can contact the Independent Complaints Advisory Service on.....if you are not still satisfied.

### **What are the benefits of taking part?**

It is hoped that this research will assist in finding out whether a different type of care would be more beneficial in understanding the difficulties of people with memory problems and deliver a level of care which we think is better than the standard care being delivered so far. This would open new avenues to further explore and better understand this issue and an opportunity to put systems in place to improve the confidence of this group of patients in the system and to improve the services.

### **What do I have to do?**

If after reading this information sheet you would like to take part in the research, you will be given it to keep and will be asked to sign two consent forms. You will keep one copy of the signed consent form and the researchers will keep another copy. You will then be asked to meet with the researcher for up to an hour monthly for six months

### **Your GP will be informed**

If you decide to take part in the study, GP will be informed about your participation.

### **Advice about dealing any possible emotional distress**

If you experience any emotional distress as a direct result of taking part in this research, please visit your General Practitioner (GP), psychiatrist or care co-ordinator for advice and give this sheet to him/her so that he/she has some information on the study.

### **WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

The results of this study will be completely anonymous and your answers will be seen by the research team only.

### **Who has reviewed this study?**

This study was reviewed by Hertfordshire partnership research and development Ethics Committee and given a sound ethical opinion for conduct in the NHS. We would like to thank you for reading this information sheet. If you would like more information on the study or would like to discuss anything in more detail please contact me on

#### **Dr. Farida Jan**

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## Appendix 9

# CONSENT FORM

***Title of Project:* Effectiveness of recovery-focused mental health care of older people with dementia –a randomised controlled trial**

**Name of Researchers: Dr. Farida Jan & Dr. Arun Jha**

**Please initial box**

1. I confirm that I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from Hertfordshire Partnership NHS Trust and The University of Hertfordshire, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4 I agree to take part in the above study.

5 I give permission for the GP to be informed

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Name of Patient

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Date

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Signature

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Name of Person taking consent  
(if different from researcher)

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Date

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Signature

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Researcher

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Signature

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Date

## APPENDIX 10: Publication



### **Effectiveness of a recovery-orientated psychiatric intervention package on the wellbeing of people with early dementia: a preliminary randomised controlled trial**

Arun Jha; Farida Jan; Tim Gale; Charmaine Newman

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#### **Keywords:**

- mild cognitive impairment (MCI);
- early dementia;
- recovery approach;
- wellbeing;
- psychiatric assessment;
- disclosing diagnosis;
- RCT

# Abstract

## Objective

To investigate whether recovery-orientated psychiatric assessment and therapeutic intervention enhances the wellbeing of people with dementia and their family carers.

## Methods

In a preliminary randomised controlled trial, 48 people with early dementia were recruited. Of 34 who completed the trial, 17 were in the recovery and 17 in the treatment as usual group. Recovery participants received a recovery-focused pre-diagnostic wellbeing assessment and counselling, diagnostic consultation with written feedback and post-diagnostic support over a period of 6 months using the WHO Wellbeing Index as the primary measure, and Mini Mental State Examination, Cornell Scale for Depression in Dementia, EUROQOL and Zarit Burden Interview as secondary outcome measures.

## Results

People in the recovery group showed a significant improvement in the WHO Wellbeing Index (18.3 for recovery vs 9.46 for treatment as usual;  $t=-2.28$ ,  $p=0.03$ ), with trends of improvement in other outcome measures.

## Conclusions

This trial shows that a recovery-focused diagnostic consultation and post-diagnostic support enhance the wellbeing of people with mild cognitive impairment and early dementia.

# Introduction

Early diagnosis and quality treatment are the key components of the National Dementia Strategy in the UK (Department of Health,). Having a diagnosis of mild cognitive impairment (MCI) or dementia is only the start of the process, and people are often left with a diagnosis but little support during the early stages of their illness. This requires responding to the need of the person for information about their condition and their role in its management. This is similar to the new discipline of the 'recovery-orientated psychiatric practice' (Sainsbury Centre for Mental Health,) in general adult psychiatry where recovery has traditionally been regarded as predominantly about symptom alleviation, but recent research supports a holistic perspective that incorporates personal factors as well as symptoms (Hill *et al.*;; Jha *et al*). Old age psychiatric services have been built on a foundation of person-centred care (PCC) in the early 1990s (Kitwood,), adopted by the National Service Framework for older people in 2001 (Department of Health, [2001](#)) and re-emphasised by the NICE dementia guidance in 2006 (National Collaborating Centre for Mental Health, [2006](#)). However, PCC lacks clarity regarding the nature of the term and evidence base (James, [2007](#)). Professionals have difficulty choosing from the overlapping concepts and measures of quality of life, wellbeing, recovery and PCC. Slade ([2010](#)), drawing evidence from positive psychology, puts 'wellbeing' at the heart of 'recovery' of the person.

We have developed a wellbeing-based recovery-orientated assessment and intervention, and the main aim of this feasibility study is to investigate whether this recovery approach enhances the wellbeing of people with early dementia and their family. The trial registration number is REC reference: 09/H0311/73. We have also followed the CONSORT standard statement guidelines and flow diagram in this paper (Schulz *et al.* [2010](#)).

# Methods

## Sample

We used a single-blind randomised controlled study design. The sample was determined using a power calculation based on the mean expected change between control and study groups. We assumed a pooled standard deviation of 3 points, on the basis of the estimates of score dispersion in patients referred to the local specialist mental health team (SMHT) for older people (i.e. range 8–16 points). A minimum sample size per group of 25 was required, assuming alpha and beta levels of 5% and 10%, respectively.

## Study participants

All consecutive referrals to the SMHT with memory problems or suspected dementia were eligible for the study. The team has a catchment area of about 14 000 older people (aged 65 years and above) in Hemel Hempstead and surrounding villages in Hertfordshire, UK. Patients and carers were given written information about the study to consider for 24 h before being asked to sign the consent form. Their GPs were also informed of the proposed study.

## Initial psychiatric assessment

On referral, every patient was allocated to a SMHT member for initial psychiatric assessment. The routine cognitive tests included the Mini Mental State Examination (MMSE), clock drawing test on a pre-drawn circle and verbal fluency test. Patients' GPs were requested to arrange necessary blood tests and an ECG. A CT head scan was organised for borderline and atypical cases.

## Randomisation

Following the initial assessment, every eligible patient was subjected to a randomisation procedure. The project statistician (TG) had prepared a computer-generated randomisation list to allocate participants to the intervention group (recovery) or control



group (treatment as usual, TAU). Using the randomisation list, the team secretary allocated cases in the intervention group to a research nurse (CN) and control group cases to other nurses of the team (Figure 1). The clinical team members were blind to this procedure, and the random allocation sequence was also concealed from the rest of the study team. The research psychiatrist (FJ), who carried out the assessments at baseline and after the 6-month study period, was not involved in participants' clinical care and was blind to which group the participants belonged to. Each assessment lasted for at least an hour.

**Figure 1.** Flowchart for randomisation, assessment, follow-up and interventions (adapted from CONSORT, [www.consort-statement.org](http://www.consort-statement.org)).

## **Interventions: wellbeing-based recovery-orientated approach**

### **Measurement of holistic wellbeing**

There are many wellbeing measures, one of which, the WHO Wellbeing Index (WHO-5; Heun *et al.*), has been validated to assess and monitor wellbeing in an older population. For the definition of wellbeing, we used the NICE guidance on the mental wellbeing of older people (National Institute for Clinical Excellence,), which defines 'mental wellbeing' using six components: life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, and a sense of belonging and support.

To create a tool that would facilitate recovery action planning, based on the person's holistic wellbeing, we added physical, financial, emotional and spiritual domains to the NICE mental wellbeing framework. To assess these 10 wellbeing domains during the recovery interview, we developed a brief wellness questionnaire adapting the positively laid-out phraseology of the WHO-5. This new 10-item instrument comprises five domains — six items for mental wellbeing and one each for emotional (*I have been feeling cheerful and in good spirits*), physical (*Health wise, I feel quite fit and able to do things myself*), financial (*I've had no worries about money or finance*) and spiritual (*I have come to understand the meaning of life*) domains. We named it the Mini Wellness State Examination (MWeSE) for ease of remembering. Each item in the MWeSE is a statement, which the patient was asked to endorse using a 4-point scale (Appendix). The assessment started with an opening sentence 'we would like to know about the current state of your

wellbeing. Please indicate for each of the following 10 statements which is closest to how you have been over the last few weeks'. Response options ranged from 4 (*all the time*) to 0 (*at no time*). The total score ranges from 0 to 40, 0 representing the worst and 40 the best possible state of wellbeing for the person at a given point of time. It is worth noting that the MWeSE is a tool for identifying needs to be targeted in the intervention and not a research measure.

## **Two phases of the intervention**

The intervention was offered in two phases: clinical phase and a post-diagnostic recovery phase (Figure). The clinical phase used a tripartite model consisting of three components: (a) pre-diagnostic counselling and wellbeing assessment; (b) therapeutic diagnostic consultation; and (c) written feedback. The post-diagnostic recovery phase included monthly home visits by the recovery nurse for at least 6 months. All participants in the recovery group were aware that they were on a recovery programme, as they all had an information sheet and consented to participate.

**Figure 2.** Flow of participants through recovery intervention process.

### **Clinical phase**

#### **Pre-diagnostic counselling and wellbeing assessment**

Following the initial psychiatric assessment, the research nurse carried out a wellbeing assessment using the MWeSE, preferably in the presence of family members.

The clinician would rate the individual on each of the 10 wellbeing items and explore ways and means to improving the score. For instance, if the score on the domain of self-esteem was 2, the clinician would explore with the individual and their family potential activities or strategies that the individual may like to undertake to enhance their self-esteem. A similar exercise would be repeated for each item requiring improvement. Finally, all those action plans would be summarised and incorporated in the individual's recovery care plan to be implemented during the post-diagnostic recovery phase.

#### **Therapeutic diagnostic assessment**

Patients, along with a family member, were invited to the diagnostic clinic for an hour-long consultation. The psychiatrist carried out a brief assessment to confirm the findings of the initial assessment, avoiding a more traditional information-gathering approach to avoid limitation of interaction with the patient. The patient's concerns relating to test results, especially CT scan, were also addressed. A more collaborative approach was adopted by focusing on the patient's subjective experience and their strengths or areas of intact functioning, which families could use to facilitate optimal functioning. Given that persons experiencing cognitive change are at risk of viewing themselves negatively, attempts were made to reframe their self-concept, for instance, by explaining that changes are due to an identifiable disorder rather than personal failings or undesirable personality traits. Towards the end, patients and their family were individually invited to ask any remaining questions to which answers were given, checking for their satisfaction with the responses.

## **Diagnosis and feedback**

Patients and their family were sensitively given the diagnosis and prognosis along with a treatment plan including drugs for dementia, if eligible. They were encouraged to ask questions or clarify queries related to the diagnosis and treatment. The presence of family or friends allowed the clinician to assist with difference of opinion, respond to individual questions and facilitate the patient–family interaction.

To supplement the feedback session, the patient was sent an individualised letter outlining the outcome of the assessment, diagnosis and a collaborative treatment plan, and a summary of discussion of their key questions and queries was posted to them with a copy of the letter sent to their GP.

## **Recovery phase**

During this phase, every participant was offered post-diagnostic counselling and support at the monthly visits lasting at least an hour for 6 months. Instead of adopting any particular model, a common sense 'here and now' approach was used for counselling. The first visit was mainly to discuss any unresolved issue overlooked at the diagnostic clinic. They were assisted to alleviate anxiety regarding diagnosis and treatment plan. The visit also provided an opportunity where the nurse would enquire into any changes that had occurred since the previous assessment sessions, re-establish rapport and modify interpretations if necessary.

During subsequent visits, individuals were encouraged and assisted to work on the wellbeing-based recovery care plan. A recovery-focused approach was adopted primarily to assist the patient in feeling understood, seen and listened to by the visiting nurse, and to provide the patient with information and understanding to allow improved insight, acceptance and the ability to move forward with his or her life. Throughout the recovery phase, instead of focusing on their illness, individuals were encouraged to think in terms of their roles as a wife, mother, funny granny, caring brother or sister, and sensitive and loving person.

## Treatment as usual

Patients in this group were offered a fixed package of care on monthly visits for 6 months without previously being assessed for wellbeing or attending a dedicated diagnostic clinic. Following the initial assessment, they were offered further outpatient appointments if felt necessary by the assessing team member or requested by the patient or their family. Those requiring anti-dementia drugs and other treatments were offered services when appropriate. Each monthly hour-long contact consisted of general conversation around neutral topics or issues raised during the meeting by the individual and their family. Team members were advised to avoid initiating conversation regarding their quality of life and wellbeing unless raised by them.

## Outcome measures

The WHO-5 (Heun *et al.*) was the primary outcome measure. The range of possible scores is 0–25 (five questions on a 6-point Likert scale scored 0–5), with higher score indicating greater wellbeing. All scores were multiplied by 4 to give a percentage score, which is often recommended as the best way of monitoring change in an individual patient.

There were four secondary measure instruments including the MMSE (Folstein *et al.*), Cornell Scale for Depression in Dementia (Alexopoulos *et al.*), EUROQOL (EQ-5D; The EuroQol Group,) and Zarit (Caregiver) Burden Interview (Zarit *et al.*). The MMSE assesses the degree of cognitive impairment, and people scoring between 23 and 10 were considered having mild to moderate degree of dementia, and those scoring 24 or above had suspected dementia or a mild cognitive disorder diagnosis using ICD-10 criteria (World Health Organisation,). The Cornell Scale for Depression in Dementia is a 19-item depression scale designed to measure the severity of depression in people with dementia.

Higher score indicates more severe depression. The EQ-5D descriptive system measures health related quality of life and has been validated in a number of European countries, including the UK. The EQ-5D was scored by using five items rather than visual analogue measure. The revised 22-item Zarit Burden Interview assesses the caregiver's perceived care burden.

## **Statistical analysis**

Although this was a randomised study, the relatively small sample size meant that the groups would not necessarily be matched at baseline on the various outcome measures. These variations were accounted for in a multiple regression model. The independent variables in each model were the following: (i) treatment group (recovery vs TAU); (ii) sex (M vs F); (iii) partner (yes vs no); and (iv) baseline score on the relevant outcome measure (for example, if the regression model was looking at change in the WHO-5 score, then the initial WHO-5 score would be an independent variable in the model). The dependent variable was change in outcome measure (endpoint–baseline), and a separate regression model was used for each of the five outcome measures.

## Results

Out of 60 participants approached, only 48 were recruited to the study (Figure), of which 31 were female. Only 34 of these continued to the final assessment rating at 6 months. The reasons for dropouts in both groups were moving out of the area, becoming physically unwell and progression of dementia. Of those reaching final assessment, 17 were in the recovery group (study) and 17 were in the TAU (control) group (Figure).

The baseline characteristics of the sample are given in Table. Patients in both groups were comparable in terms of their age, gender and degree of cognitive impairment at the baseline. Age range varied from 53 to 79 years; mean age for recovery group was 78.47 ( $\pm 8$ ) years, and for TAU, it was 79 ( $\pm 7.6$ ) years.

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**Table 1. Demographic characteristics of the sample at baseline**

	<b>Recovery (study) group</b>	<b>TAU (control) group</b>
	<b>(<i>n</i>=24)</b>	<b>(<i>n</i>=24)</b>
1. MMSE, Mini Mental State Examination; TAU, treatment as usual.		
Participants		
Mean age in years ( $\pm$ SD)	78.47 ( $\pm$ 8)	79 ( $\pm$ 7.6)
Male	7	9
Married	13	13
ICD-10 diagnoses		
Mild cognitive disorder	8	11
Dementia in Alzheimer's disease	9	8
Vascular dementia	4	3
Other dementias	3	2
Degree of cognitive impairment		
Suspected dementia (MMSE >24)	11	10
Mild dementia (MMSE 20–23)	6	7
Moderate dementia (MMSE <20)	7	7

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Table also shows the number of cases with mild cognitive disorder (ICD-10 F06.7) and various types of dementia (ICD-10 diagnosis); other dementias included dementia in Parkinson's disease. Clearly, a great majority had a diagnosis of non-Alzheimer's dementia or suspected dementia and therefore did not receive cholinesterase inhibitors.

Table displays the mean ( $\pm$ SD) scores on each of the five outcome measures, at baseline and endpoint. The mean score reflects percentages.

**Table 2. Mean ( $\pm$ SD) scores on outcome measures at baseline and endpoint**

Measures	Baseline		Endpoint	
	Recovery	TAU	Recovery	TAU
1. CSDD, Cornell Scale for Depression in Dementia; EQ-5D, EUROQOL; MMSE, Mini Mental State Examination; TAU, treatment as usual; WHO-5, WHO Wellbeing Index; ZBI, Zarit Burden Interview.				
WHO-5	39 ( $\pm$ 16)	52 ( $\pm$ 13)	61 ( $\pm$ 10)	58 ( $\pm$ 13)
MMSE	21 ( $\pm$ 6)	23 ( $\pm$ 5)	21 ( $\pm$ 6)	22 ( $\pm$ 6)
CSDD	6.4 ( $\pm$ 2.6)	6.9 ( $\pm$ 3)	4 ( $\pm$ 1.7)	4.5 ( $\pm$ 1.8)
EQ-5D	60 ( $\pm$ 14)	68 ( $\pm$ 52)	64 ( $\pm$ 12)	66 ( $\pm$ 10)
ZBI	39 ( $\pm$ 18)	25 ( $\pm$ 14)	33 ( $\pm$ 15)	29 ( $\pm$ 20)

Analysis of score change across time must also take into account the variability between groups that exists at baseline. The only statistically significant difference was on the primary outcome measure (WHO-5 score), for which the recovery group showed greater improvement (Table).



**Table 3. Estimated marginal mean score change for each outcome measure**

Measure	Change in score: estimated marginal mean (accounting for baseline variation)		Significance
	Recovery	TAU	
1. CSDD, Cornell Scale for Depression in Dementia; EQ-5D, EUROQOL; MMSE, Mini Mental State Examination; TAU, treatment as usual; WHO-5, WHO Wellbeing Index; ZBI, Zarit Burden Interview.			
WHO-5	18.3	9.46	$t=-2.28, p=0.03$
MMSE	-0.06	0.7	$t=0.79, p=0.44$
CSDD	-2.56	-2.53	$t=0.88, p=0.38$
EQ-5D	3.82	-2.1	$t=0.44, p=0.66$
ZBI	3.8	-1.3	$t=-0.12, p=0.90$

Age did not correlate with change in any of the outcome measures, and there appears to be no difference between married and widowed people.

## Recovery stories

This section provides a snapshot of what participants and the recovery nurse (CN) thought of the lexicon of recovery within what is a terminal condition with a declining trajectory across a number of cognitive, behavioural and social domains.

### Participant

Mrs. A lived in a residential home and had a diagnosis of MCI. During the post-diagnostic wellbeing assessment, her following needs were identified and addressed:

- She had a fall and lost her confidence in walking. Eventually, her mobility deteriorated and required the use of a hoist, which lowered her emotional state score in the MWeSE. CN discussed with the physiotherapist, occupational therapist and GP who agreed to use Mrs. A's home support grant to purchase a mini exercise bike to build up muscle tone in her legs. The care home staff devised a care plan to use the mini bike twice a day. Mrs. A and her husband agreed to the care plan. Two months later, she was walking around with a Zimmer frame and was very thankful to the recovery project for listening to what was important to her.
- She wanted to be a 'fun Gran who makes cakes, not the boring one who sits in the corner'. As her cake-making skill was still intact, she was able to make cakes with some support and encouragement. CN enabled the family to come closer to what is normal rather than remaining trapped in the patient–carer role.
- She also felt that the carers were always in a rush and took over her personal care and did not interact with her. Her personalised care plan stated that she was able to wash her face and she liked warm rather than hot water. CN communicated to the staff to encourage what Mrs. A was able to do herself. These little changes allowed her to look forward to personal care rather than dreading it.
- She had a 12-month-old grandson who always cried when he came to visit Granny, and that cut the family visits short. CN encouraged her to go to the local Tesco to buy some toys. That kept the grandson entertained and allowed her relatives to stay longer for a more enjoyable and quality visit.

### Recovery nurse

The research nurse (CN) who conducted the intervention found the work gratifying, especially when she enabled participants to feel like 'a wife, a mum, funny, caring, sensitive, loving' rather than focusing on the illness.

## Discussion

This is the first successful preliminary randomised controlled trial (RCT) of a recovery-orientated diagnostic and post-diagnostic intervention showing significant improvement in the wellbeing of people with early dementia irrespective of their age, degree of cognitive impairment, gender and marital status.

The only limitation of the study is the relatively small sample size, which was exacerbated by dropouts during the 6-month study period. Perhaps more participants should have been recruited to keep the required sample size adequate at the endpoint, although this was only designed as a feasibility study. Another possible confounding factor may be that the recovery nurse met with the research team at weekly meetings to discuss clinical issues and difficulties during the study period. Other CMHT members were kept out from these meetings to maintain the usual package (TAU) of care routinely provided by the team. Similarly, because it was not a double blind trial, participants in the recovery group knew from the outset that they were receiving a new psychosocial intervention and therefore may have been more receptive and positive.

To date, there are only two Randomised Control Trials directly addressing the psychosocial needs of people with early dementia — one for diagnosis (Wolfs *et al.*) and the other for post-diagnostic psychotherapy (Burns *et al.*). None used the integrated approach combining pre-diagnostic, diagnostic and post-diagnostic work. There is no published trial of recovery-orientated intervention in dementia, making any direct comparison impossible.

The Croydon Service had both diagnostic and therapeutic elements. The service evaluation report (Banerjee *et al.*) presents data of baseline interviews and 6-month follow-up with a cohort of 290 consecutive referrals, showing significantly increased quality of life and marginal improvement in depression. Although rating instruments used in the study were different, these findings are consistent with the present study, which, however, also showed similar improvement in the control group.

Previous randomised clinical trials have focused on the non-pharmacological intervention with either depression (Teri *et al.*) or behavioural disturbances (Teri *et al.*) associated with dementia, and both interventions were dependent on family caregiver's involvement. An Australian cluster-randomised trial (Chenoweth *et al.*) investigated the effectiveness of

PCC and dementia care mapping on the agitated behaviour of people in nursing homes, which has little or no relevance to community-dwelling individuals.

Recovery and wellbeing approach provides a different paradigm that helps patients think and plan beyond their quality of life. Adams () reviewed the literature relating to the use of recovery approach and the people with dementia, particularly their nursing care, and found that the recovery approach shares many ideas with person-centred approaches to dementia care in relation to wellbeing, social inclusion, self-management and hope. Experiences of participants and recovery nurse in our study are in keeping with Adams's findings and represent progressive nursing practice to promote wellbeing and maintain people with dementia in community settings. Our findings also support the social construction theory that if attention is focused on remaining healthy Self 2, composed of mental and physical attributes and related beliefs, it is possible for the afflicted person to construct worthy Self 3 social personae in which he or she can take pride and enjoy a measure of satisfaction (Sabat,).

Finally, findings of this study endorse the position statement by consultant psychiatrists that recovery ideas should provide the basis for the future direction of psychiatric practice and be applied across the major sub-specialties of psychiatry (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010).

# Conclusions

Any measure, with or without drug treatment, that supports people with dementia live happily in their own homes as long as possible is invaluable. The findings of this preliminary study support the value of integrating pre-diagnostic counselling, recovery-orientated diagnostic consultation and post-diagnostic support to people with MCI and early dementia. It has the benefits of both RCT and more empirical approach, using simple single-case designs, with the person as their own control. Above all, it provides a framework of early diagnosis and quality intervention addressing both the clinical and personal recovery needs of the individual. A recovery approach may be particularly welcome for those with MCI diagnosis who may otherwise be left with a diagnosis of uncertainty and no input other than a recommendation for periodic reassessment for signs of dementia.

## Conflict of interest

None declared.

## Key points

- People with dementia are usually not prepared for the diagnostic consultation, not always given their diagnosis and are not offered adequate post-diagnostic support.
- This paper describes the efficacy of a new recovery-orientated dementia care package on the wellbeing of people with early dementia.
- The recovery-orientated package of dementia care includes pre-diagnostic counselling and wellbeing assessment, collaborative diagnostic consultation and an extended post-diagnostic support addressing their personal needs, difficulties and expectations.
- This innovative recovery care package enhances the wellbeing and quality of life of people with mild cognitive impairment and early dementia.

## Acknowledgement

We would like to thank Sigrid Chiltern, deputy manager of the Dacorum CMHT for older people, for supporting the project and allowing team members to persevere with the research despite staff shortage and mounting workload.

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