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**UNIVERSITY OF SOUTHAMPTON**

**FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES**

**School of Health Sciences**

**Activity engagement with people with dementia at home:  
family carers' perspectives**

by

**Pat Yin Fan Chung**

Thesis for the degree of Doctor of Philosophy

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ABSTRACT

FACULTY OF MEDICINE, HEALTH & LIFE SCIENCE  
SCHOOL OF HEALTH SCIENCES

Doctor of Philosophy

ACTIVITY ENGAGEMENT WITH PEOPLE WITH DEMENTIA AT HOME:  
FAMILY CARERS' PERSPECTIVES

by Pat Yin Fan Chung

Government policies currently emphasise the need to support those with dementia at home, and family carers are increasingly advised to engage their relative in daily activities. Knowledge about family carers' involvement in the activity needs of individuals living with dementia is fragmented. This study explored carers' decision making related to their engagement with their relative in everyday activities at home.

Following research governance and ethical approval, 30 in-depth interviews (initial and follow-up) were carried out with 15 resident-carers who were recruited via local community mental health teams. Then five focus groups were conducted through carer support groups. The majority of carers were spouses, three were daughters and one a female friend. Both the interviews and focus groups explored the experiences of involving relatives in daily activities and highlighted the carers' strategies, feelings and reflections. Themes were identified which formed a temporal model consisting of five activity patterns. These were the *usual*, *recognisable*, *illogical*, *irresponsible* and *dispossessed* patterns. The model illustrated the complexity and long-term nature of family carers' activity-related decisions. Over the passage of time carers attempted to recapture the past self of their relative through engaging them in beneficial activity. The findings provided deeper insight in the understanding of the processes by which carers negotiated strategies; and how such processes challenged the carers' own sense of self.

The model offers a new approach for occupational therapists and other healthcare professionals to guide home-based activity programmes in which carer's perspectives are taken into account. Practitioners could gain a more complete understanding of the caregiving situation, so that they can, more effectively, support the family member and hence the person with dementia more effectively. Further research will focus on developing a toolkit to enable practitioners to recognise the complexities, uncertainties and conflicting values which confront carers in their decision-making and so enhance partnership working.

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## DECLARATION OF AUTHORSHIP

I, .....**Pat Yin Fan CHUNG** ....., [please print name]

declare that the thesis entitled [enter title]

**Activity engagement with people with dementia at home: family carers’  
perspectives**.....

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
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- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
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- none of this work has been published before submission, **or** [delete as appropriate] parts of this work have been published as: [please list references]

**Signed:** .....

**Date:**.....

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## List of abbreviations

AD	Alzheimer's disease
ADL	Activity of Daily Living
AMED	Allied and Complementary Medicine database
AMPS	Assessment of motor and process skills
ASSIA	Applied Social Science Index of Abstracts
B	Biography
BPSD	Behavioural and Psychological Symptoms of Dementia
CAQDAS	Computer-Assisted Qualitative Data Analysis Software
CID-10	World Health Organisation International Classification of Disease (Tenth edition)
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CMHTOP	Community Mental Health Teams for Older People
COT	College of Occupational Therapists
CSIP	Care Services Improvement Partnership
D	Dementia
DARE	Database of Abstracts of Reviews of Effectiveness
DCM	Dementia Care Mapping
DH	Department of Health
DLB	Dementia with Lewy Bodies
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)
ENOTHE	European Network of Occupational Therapy in Higher Education
FTD	Fronto-temporal dementia
H	Health
IADL	Instrumental activity of daily living skills
IDDD	The interview of deterioration in daily activities in dementia
MCI	Mild Cognitive Impairment
MEDLINE	Medical database
MMSE	Mini Mental State Examination
MSP	Malignant social psychology
NI	Neurological
NHS	National Health Services
NICE	National Institute for Health and Clinical Excellence
NICE-SCIE	Guideline in dementia care
NSFOP	National Service Framework for Older People
NUD·IST /N6	Non-numerical Unstructured Data Indexing Searching and Theorizing
ONS	Office of National Statistics
OT	Occupational Therapy/Occupational Therapist
OTDBASE	A database of OT journal literature
OPMHN	People with Mental Health Need Services
P	Personality
PDD	Parkinson's disease dementia
R & D Group	Research and Development Group
RCT	Randomised controlled trial
SCIE	Social Care Institute for Excellence's
SCQ	The sense of competence questionnaire
SP	Social-psychological
WHO	World Health Organisation

UK  
VaD

United Kingdom  
Vascular Dementia

## **Chapter 1    Introduction**

### **1.1      Background**

In this thesis the researcher explored carers' experiences of engaging a relative with dementia in daily activities at home. By using a grounded theory approach, data were collected through interviews (phase one) and focus groups (phase two). Analysis unravelled the complex nature of the carers' perception of the activity engagement of their relatives; and this led to the development of a model of activity engagement.

My research interest is rooted in my professional background as an occupational therapist. I am inspired by the value of using meaningful activity or occupation as a catalyst to enable clients to fulfil their potential despite their disabilities, as Hasselkus (2002) states:

*'Occupation is a strong enabler for knowing one's self. To know one's self is to know one's being. One way that I know my self is through occupation and one way that my self expresses itself in the world is through occupation. Occupation helps me answer questions such as what am I meant to do? Who am I meant to be?' (p.17)*

Individuals with dementia, like all of us, have a need for meaningful activity in their daily life. They often require support to fulfil such needs as dementia progresses. Having been a community therapist for several years, I became increasingly aware of how the socio-cultural context can promote or reduce the opportunities for those with dementia. I have worked with many family members caring for their relatives at home, playing a key role in promoting the well-being of those with dementia. Nevertheless, I felt that carers often did not receive the level of support which they required.

### **1.2      Structure of the thesis**

The rationale for my research is provided in Chapters two and three. The literature review, detailed in chapter two, examines the meaning of dementia from two dominant approaches, the medical model and Kitwood's theory of dementia (1990). A need to address the socio-cultural context and interdependent nature of people with dementia and their family carers in research and practice is raised. Also, the lack of clarity about the position of carers in care provision is emphasised.

Chapter three provides a rationale for my research from the perspective of the importance of activity. This chapter examines how occupational therapists use meaningful activity as a tool to engage individuals in a therapeutic process. The review of both caregiving in dementia care and occupational therapy literature highlights significant gaps in the understanding of the potential benefits of activity in a home setting; and of carers' perspective of engaging their relatives in activities.

Chapter four sets out the research methodology and discusses the reasons why grounded theory has been chosen as the overarching framework for the present research.

Chapter five details the rationale for using in-depth interviews in the phase one study. The specific techniques and procedures of the method are explained.

Chapter six details the first analysis and the use of a series of conceptual frameworks, explaining how they facilitated the process of systematic analysis which led to the development of an emerging model of activity engagement.

Chapter seven discusses the rationale for using focus groups in phase two of the study. The specific techniques and procedures of the method are explained.

Chapter eight gives a brief introduction of the characteristics of the five focus groups and discusses how participants recognised themselves in the model of activity engagement. The model and related concepts are discussed in detail.

Chapter nine discusses three key aspects, central to this thesis, that are based on the two result chapters (six and eight). They are as follows:

- How, despite their relative's significant loss of cognitive and functional ability, family carers continue to recognise their relative's agency and their need for engagement in meaningful activities, and to continually set goals and find strategies to facilitate the person with dementia meeting these goals;
- How, in order to do this, carers had to continually negotiate boundaries with their relative;
- The model of activity engagement which will be described, in more detail, in terms of its component parts, the relationship of these components to each other, how they



change as the phases change and how the patterns merge into on another.

Finally, Chapter ten discusses the key issues which have been highlighted in the present research. These comprise:

- Examination of the link between the findings and Kitwood's work on person-centred care and an evaluation of the findings to the relevance of his concepts of well-being, agency, psychosocial needs, positive person work, retained abilities and the enriched environment.
- Evaluation of the implications for current policy; in particular: the National Dementia Strategy and the Carer's Strategy.
- Discussion of justifications for the language adopted for the Model of Activity Engagement.
- Outlines of five key messages each for family carers of people with dementia, those with dementia, Health Care Practitioners and the Alzheimer Society's public awareness campaign.
- An assessment of the quality of the present research and the findings. The policy implications, potential for future research, strength of the study and limitations of the findings will also be discussed.

### 1.3 Search strategy for the literature review sections

The search strategies for chapters two and three are presented here. Searches were undertaken with the sources as outlined in the following table:

Chapter titles	Chapter two		Chapter three
	Dementia	Caregiving in dementia care	Activity engagement and occupational therapy
Key words	<p>The search strategy used a combination of key words. These included; for example:</p> <ul style="list-style-type: none"> <li>-dementia,</li> <li>-Alzheimer's disease,</li> <li>-Vascular Dementia,</li> <li>-Lewy Bodies,</li> <li>-mild cognitive impairment,</li> <li>-treatment,</li> <li>-intervention</li> </ul>	<p>The search strategy used a combination of key words. These included; for example:</p> <ul style="list-style-type: none"> <li>-carers,</li> <li>-caregiver,</li> <li>-caregiving,</li> <li>-family,</li> <li>-co-resident carers,</li> <li>-informal carers,</li> <li>-caring,</li> <li>-carers' burden,</li> <li>-carers' stress/strain,</li> <li>-support,</li> <li>-support groups,</li> <li>-coping strategies,</li> <li>-carers intervention,</li> <li>-respite,</li> <li>-self-management,</li> <li>-home care,</li> <li>-enablement,</li> <li>-carers' perspectives,</li> <li>-carers viewpoints</li> </ul>	<p>The search strategy used a combination of key words. These included; for example</p> <ul style="list-style-type: none"> <li>-activity,</li> <li>-therapy,</li> <li>-engagement,</li> <li>-occupational therapy,</li> <li>-therapeutic activity,</li> <li>-purposeful activity,</li> <li>-rehabilitation,</li> <li>-home-based/ community-based programme,</li> <li>-Activities of daily living,</li> <li>-OT intervention,</li> <li>-randomized controlled trials,</li> <li>-aging, ageing</li> <li>-dementia,</li> <li>-Alzheimer's disease,</li> <li>-carer's training,</li> <li>-skills training,</li> <li>-groups activities,</li> <li>-adaptation,</li> <li>-environmental,</li> <li>-strategies,</li> <li>-mental health,</li> <li>-dementia,</li> <li>-OT research</li> </ul>
	<p>A number of techniques was used to help refine searching. Some examples are outlined below:</p> <ul style="list-style-type: none"> <li>- * was used to truncate terms; e.g. Therap* could access citations containing both 'therapy' and 'therapist';</li> <li>- " " were used to make a number of words into a phrase rather than separate terms (e.g. "occupational therap" or "music therap");</li> <li>- + was used to indicate that a word must be present in all hits (e.g. + carers + support). such as: 'carers and dementia', 'home-based activity', 'therapeutic activity', 'occupational therapy', 'dementia and activity', 'carers and activity'.</li> <li>- I also use free text to map subject headings via Google search.</li> </ul>		

	<p>During the search, I also used the Boolean operators to help me refine the search. This meant that I retrieved relevant articles by using the key combining terms (AND, NOT, OR) to either. This in turn enabled me to either focus the search or set limits on the search (Taylor 2007, Fink 2005).</p> <p>Also, the index terms were exploded so that the more specific forms of the term e.g. subtype of dementia would be included in the search.</p>		
<i>Computerized databases</i>	<p>These included:</p> <ul style="list-style-type: none"> <li>-MEDLINE (Medical database);</li> <li>-EMBASE (biomedical, and pharmacological subjects),</li> <li>-PubMed (MEDLINE on the Web),</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-CINAHL(Cumulative Index of Nursing and Allied Health Literature),</li> <li>-AMED (Allied and Complementary Medicine database),</li> <li>-ASSIA( Applied Social Science Index of Abstracts),</li> <li>-PsycINFO, Sociological abstracts</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-AMED,</li> <li>-OT databases e.g. OTDBASE(a database of OT journal literature),</li> <li>-PsychLit</li> <li>-PubMed</li> <li>-CINAHL,</li> <li>-ASSIA, MEDLINE</li> </ul>
<i>Years searched</i>	<p>1995 to 2009 because this can be more recent literature in the development of diagnosis, assessment and intervention for dementia</p>	<p>1985 to 2009 because I wanted to go back later for key papers relating to the use of carers support and interventions</p>	<p>1985 to 2009 because I wanted to go back later for key papers relating to the use of therapeutic activities</p>
<i>Searching websites.</i>	<p>These included :</p> <ul style="list-style-type: none"> <li>-Alzheimer's Society,</li> <li>-Medical Research Council.</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-Department of Health,</li> <li>-Office of National Statistics</li> <li>-NICE (National Institute of Clinical Excellence),</li> <li>Alzheimer's Society.</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-OT seeker</li> </ul>
<i>Specialist evidence-based databases</i>	<p>These included:</p> <ul style="list-style-type: none"> <li>-Department of Health (publications library),</li> <li>-Alzheimer's Society,</li> <li>-Age Concern</li> <li>-Help the Aged</li> <li>-NHS R &amp; D Health -</li> <li>-Technology Assessment Programme,</li> <li>-Medical Research Council</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-Cochrane Library</li> <li>Best Evidence</li> <li>-DARE (Database of Abstracts of Reviews of Effectiveness)</li> <li>-Evidence-based Medicine/Mental health/nursing</li> </ul>	<p>These included:</p> <ul style="list-style-type: none"> <li>-College of Occupational Therapists</li> </ul>
<i>Search engines and sites</i>	<a href="http://www.google.co.uk">www.google.co.uk</a>		<a href="http://www.otcats.com">www.otcats.com</a> <a href="http://www.otevidence.info">www.otevidence.info</a>
<i>Hand searches were made of key journals and references were followed up</i>			

## **Chapter 2    Dementia and caregiving -An Overview**

In this chapter I will discuss the meaning of dementia and its impact on informal carers. The experiences of carers and the UK policy in caregiving will also be highlighted. Also, a need to address the socio-cultural context and interdependent nature of the people with dementia and their family carers in research and practice will be raised.

### **2.1      The prevalence of dementia**

In the UK, around five per cent of people over 65 years, and 20 per cent of those over 80 years are believed to have dementia (Department of Health/DH 2001a). Dementia can also occur before the age of 65 years. Around 15,000 people suffer from early-onset dementia; whilst approximately 700,000 people suffer from late-onset dementia (DH 2009).

The prevalence and incidence rate of dementia rises rapidly with age, especially for those over 60 years and can rise to as much as 25 per cent in people aged 90 or over (McCullagh et al 2001; DH 2001a; Burns et al 2002). With people living longer, there are a greater number of people living with dementia (Goldsmith 1996; WHO 1998). For example, there are estimated to be 940,000 people with dementia by 2021, rising to 1.7 million by 2051 (Alzheimer's Society 2007).

Dementia is presented as an escalating social and public health problem (Schneider et al 1993; Marshall and Hutchinson 2001; DH 2005b). Neil Hunt, the Chief Executive of the Alzheimer's Society, states, 'number [s] will rise to one million by 2025. This has the potential to overwhelm the health and social care services which are already ill equipped to respond to the challenge of dementia' (Alzheimer's Society 2007, pi). A recent report points out that in England the estimated economic cost of late-onset dementia is around £14 billion a year, with an average cost of £25,000 for each service user per year (House of Commons 2008). More recently, it has been suggested that dementia costs the UK economy about £17 billion per year (DH 2009).

### **2.2      What is dementia?**

The term *dementia* is used to describe a set of signs and symptoms including problems with memory, confusion, difficulties with reasoning and communication (National

Institute for Clinical Excellence/NICE 2007). The following definition has been widely adopted:

*'Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions... Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation...Dementia produces a definite decline in intellectual functioning, and usually also some interference with personal activities of daily living, such as washing, dressing, eating, personal hygiene, excretory and toilet activities.'* (Burns et al 2002, p.3)

Dementia is not to be expected as an inevitable part of normal ageing (Stokes and Holden 1990; DH 2009). It can be caused by many conditions. On average, people may live for between seven and twelve years following diagnosis (DH 2008a). The most common causes and characteristics of dementia will be briefly outlined below.

### **2.2.1     *Alzheimer's disease***

Alzheimer's disease (AD) is the most common cause of dementia, accounting for about 50 to 60 per cent of all cases of dementia (DH 2001a; Taylor 2005; Burns and O'Brien 2006). It is characterised by the build up of amyloid plaques and neurofibrillary tangles in the brain, leading to the death of brain cells (McCullagh et al 2001; Swanson and Carnahan 2007). The onset of memory loss is slow and insidious (Swanson and Carnahan 2007). It is a progressive condition, the life expectancy is thought to be appropriately six to eight years from the time of diagnosis to death (Burns and O'Brien 2006). AD is thought to be more common in older people and in women (Mathers and Leonard 2003; Brown and HILLAM 2004; Alzheimer's society 2007). Of all cases of AD, about 5 per cent of them are under 70 years of age, 30 per cent between 70 and 80 years; and 65 per cent are over 80 years (Brown and Hillam 2004).

### **2.2.2     *Vascular Dementia and mixed dementia (Alzheimer's disease and Vascular dementia)***

Vascular Dementia (VaD) and mixed dementia (VaD and AD) dementia, together account for 27 per cent of all cases (Alzheimer's Society 2007). VaD can result from a variety of cerebrovascular problems including strokes and hypertension, which disrupt blood circulation in the brain (Swanson and Carnahan 2007). In turn, this leads to significant accumulated damage to the brain function (NICE 2007). VaD is often characterized by abrupt onset with successive stepwise deteriorations in cognitive

function (Alzheimer's Society 2009; NICE 2007). Its symptoms may include 'stroke-like symptoms', acute confusion and communication problems (Alzheimer's Society 2007); as well as difficulty in attention and executive function (Swanson and Carnahan 2007; NICE 2007). These conditions are more common in men than in women (Mathers and Leonard 2003). In recent years, it has been found that it is common for people develop both AD and VaD simultaneously, especially in those over 80 years of age (Alzheimer's Society 2007). The prognosis of VaD is similar to that of AD, with an average of seven years of life expectancy after diagnosis (Brown and Hiram 2004).

Apart from AD and VaD, there are three other common causes which account for about 8 per cent of all cases of dementia (NICE 2007). These causes include dementia with Lewy Bodies, Parkinson's disease dementia and fronto-temporal dementia. Details will be discussed below.

### ***2.2.3 Dementia with Lewy Bodies***

Dementia with Lewy Bodies (DLB) is caused by spherical-shape protein deposits developing inside cells in the brain. These deposits interrupt the brain's normal functioning, leading to problems with difficulty in memory, concentration and language skills (Aarsland et al 2004; Alzheimer society 2007). Movement disorder, visual hallucination and delusions are common in the people with DLB (Aarsland et al 2004). Moreover, parkinsonism is common (NICE 2007).

### ***2.2.4 Parkinson's disease dementia***

Parkinson's disease dementia (PDD) develops in between 30-70 per cent of people with Parkinson's disease, depending on duration and age (NICE 2007). Parkinson's disease affects approximately one per cent of people by the age of 70 years, with motor symptoms such as tremor, bradykinesia and rigidity. Most people with Parkinson's disease show minor cognitive abnormalities on formal memory test. Some of them later develop a dementia. A diagnosis of PDD could be made if people have motor features of Parkinson's disease for over a year before developing cognitive problems (Brown and Hiram 2004). The symptoms of PDD may overlap with that of DLB. Nevertheless, in PDD, parkinsonism is more severe than in DLB. Moreover, the executive dysfunction and frequency of psychiatric features in PDD are not as severe as with DLB (Aarsland et al 2004; NICE 2007).

### **2.2.5 *Fronto-temporal dementia***

Fronto-temporal dementia (FTD) affects the frontal and anterior temporal lobes of the brain. Personality, mood and behaviour are initially more affected than memory (Kaye 1998; Swanson and Carnahan 2007). This disorder used to be known as Pick's disease and is thought to affect individuals in earlier adulthood rather than in later life. The onset after 65 years of age is uncommon (Swanson and Carnahan 2007). FTD is thought to account for a high proportion of early onset dementia in younger men (NICE 2007). Communication difficulty is common in people with FTD. Progression of symptoms and functional loss can be rapid and occur in two years following the onset (Swanson and Carnahan 2007).

A review of dementia literature revealed that there have been attempts to understand the nature of dementia from different perspectives (see further details in 2.4). Two key approaches have influenced clinical practice and the direction of research in dementia care in many ways; these are the biomedical approach and the person-centred approach put forward by Kitwood (1990, 1993). I will discuss how these two approaches enhance the understanding of dementia in detail below.

## **2.3 The biomedical model**

It is widely accepted that our understanding of the nature of dementia has been predominantly influenced by the biomedical perspective (e.g. Kitwood 1990, 1995; Downs 1997; Stokes 2000; Nolan et al 2002b; Gillard et al 2005; Baldwin and Capstick 2007).

This perspective views dementia as a disease which is caused by neuro-physiological factors. The resulting problems (e.g. cognitive and behavioural) of people with dementia are therefore judged by the level of impairment resulting from disease of the brain and progressive neuro-pathological changes.

Based on the medical model, dementia is considered as a neuro-psychiatric disorder which requires medical intervention for its symptoms and signs in terms of cognitive, behavioural and psychotic problems (see section 2.2). It has been suggested that this model positions the person as a patient who does not have control over the disease (Downs et al 2006b). Moreover, within this model, carers are also viewed as patients

who suffer psychological and physical problems as a consequences of their caring role, There is a concern that the impact of a psychiatric label (i.e. dementia) on both the persons and their carers could be as disabling as the condition itself (Downs et al 2006b).

### ***2.3.1 The biomedical model and diagnosis***

The key for current management in dementia care is thought to be based on accuracy in detecting and diagnosing the pathology (Kaye 1998; Alzheimer's Society 2007). A typical diagnostic process aims to rule out as many potential medical conditions as possible (Swanson and Carnahan 2007). Methods include history taking, physical examination and laboratory testing. As a result, a clinical decision is made in terms of a subtype of dementia, as outlined earlier. However, a definite diagnosis can be made only after post-mortem (Burns et al 2002; Sanderson et al 2002; Taylor 2005; Swanson and Carnahan 2007).

The overall purpose of the diagnostic procedure is to determine if any treatable conditions might contribute to the different aspects of impairment in terms of cognitive and neurological functioning (Burns et al 2002; Burns and O'Brien 2006; DH 2001a; Alzheimer's Society 2007). Such conditions include for example: toxic disorders (e.g. alcohol related dementia), vascular factors (stroke, hypertension, diabetes mellitus); as well as metabolic and endocrine abnormalities (e.g. vitamin B12 and thyroid hormone deficiencies) (Harris 2002, Burns et al 2002; Swanson and Carnahan 2007).

In reality, differentiating diagnosis has been challenging; for example, on post-mortem examination, some people who had been diagnosed with a particular subtype of dementia were found to have a mixture of pathological characteristics of AD, DLB and VaD in their brain (NICE 2007). Also, on post mortem, some people who appeared to be cognitively intact, showed the histopathology of Alzheimer's disease in their brains (Snowdon 1997). In some cases of people with the disease, the cognitive impairment might not be noticeable before death due to various protective factors (e.g. lack of brain infarcts and other neuropathologic diseases) (Snowdon 1997). Hence, it is still unclear how the interplay of various risks factors lead to the onset of specific types of dementia. Such factors include age, genetic background, medical history and lifestyle (Alzheimer's Society 2007).



### *2.3.1.1 Early recognition of dementia*

Despite the challenge for ensuring an accurate diagnosis of dementia, the importance of early recognition of dementia and the implication for early intervention has been highlighted in dementia care literature and government policies (for example, Stokes and Holden 1990; McCullagh et al 2001; DH 2001a, 2009; NICE 2007; Swanson and Carnahan 2007).

In recent years, a term ‘mild cognitive impairment’ (MCI) has been used to describe a new syndrome. Individuals with MCI present with the early neuropathology of a dementia, particularly AD. However, the presenting symptoms do not meet the clinical criteria for a formal diagnosis (Burns and O’Brien 2006). MCI is characterised by cognitive decline which does not significantly interfere with the person’s overall functioning (Swanson and Carnahan 2007). Healthcare practitioners are advised to refer people who show signs of MCI for further assessment in order to facilitate an early identification of dementia and potential treatment (NICE 2007). Also, it is thought that early intervention may prevent further cognitive decline and dementia, as discussed earlier.

### *2.3.2 The biomedical model and treatment intervention*

Pharmacological treatment is available to address symptoms such as cognitive impairment. For example, drugs are used to increase the availability of acetylcholine, a neurotransmitter for memory and learning (Swanson and Carnahan 2007). Such treatment, however, cannot repair the damage which has already occurred in the brain tissue (Taylor 2005; Alzheimer’s Society 2007). Although some evidence has suggested that anti-dementia drugs (e.g. Aricept, Reminyl and Exelon) delay cognitive decline (Burns and O’Brien 2006), the scale of the benefit has not been considered as strong enough to secure the NHS funding for continuing the prescriptions of these drugs to people with dementia at all stages (NICE 2007). NICE (2007) has decided to restrict prescription to those whose dementia is of moderate severity (with Mini Mental State Examination score of between 10 and 20 points). Such a decision is controversial and still subject to on-going debate (Burns and O’Brien 2006; Perrin et al 2008).

Anti-psychotic drug treatment is also available for the treatment of non-cognitive symptoms of dementia including wandering, depression, aggression and hallucination,

commonly referred to as behavioural and psychological symptoms of dementia or BPSD (Burns and O'Brien 2006; Swanson and Carnahan 2007; Alzheimer's society 2007). It has been suggested that such pharmacological treatments have not always been effective; in some case, individuals suffer from the side-effects of the treatment such as over-sedation and falls (Swanson and Carnahan 2007). Therefore, it is considered that anti-psychotic drugs should be avoided when managing many types of BPSD (Burns and O'Brien 2006).

In short, despite the availability of symptomatic treatment, most subtypes of dementia are considered progressive in nature and cannot be cured by medication (Gubrium 1987; Wattis and Curran 2001; Burns et al 2002; Brown and Hiram 2004; Alzheimer's Society 2007). The symptomatic control of dementia continues to remain elusive from a biomedical point of view. There is a clear need to explore the value of non-drug therapy resulting from a lack of effective pharmacological treatment. Also, the NICE decisions mentioned above highlight that clinical decision-making around treatment intervention is often subject to wider social influences such as government policy and cost-related evaluation.

### ***2.3.3 The impact of the biomedical model of dementia***

There have been positive influences of the biomedical approach on the development of services for people with dementia and their families. For example, advances in the neurobiological understanding of dementia in past decades have helped to differentiate some of the sub-types of dementia. This has facilitated the development of various intervention strategies used in specific kinds of dementia (Miesen and Jones 1997; Stokes 2000; Swanson and Carnahan 2007). Such strategies include providing: a) treatment to slow down the progression of vascular dementia through managing the underlying cardiovascular risk factors, e.g. smoking, hypertension and arterial disease (Swanson and Carnahan 2007; NICE 2007; Alzheimer's society 2007); and b) a framework for development of transmitter replacement therapies and drugs that prevent amyloid formation in the brain (Cummings et al 1998; NICE 2007). It appears that this approach raises the hope for some people with dementia and their carers.

To date, the medical model continues to dominate our understanding of the nature of dementia and its care management (Harding and Palfrey 1997; Downs 1997; Stokes

2000; Nolan et al 2002b; Hellstrom et al 2005; Downs et al 2006b). This approach is accepted in the wider community, evidenced in currently published dementia literature (e.g. NICE-SCIE guideline on supporting people with dementia and their carers in health and social care, Dementia UK report, Living Well with Dementia: National Dementia Strategy). Consequently, the health services have been organised with the medical professionals at the centre, leading to critical clinical decisions. In reality, obtaining a diagnosis is the gateway to access specialist statutory services (Vernooij-Dassen et al 2005, Alzheimer's society 2007). It is not surprising that the public tends to have an image of the medical staff as the key profession in dementia care.

## **2.4 The development of alternative models for the understanding of dementia**

The dominant biomedical perspective has attracted a lot of criticism from the non-medical professions since the 1990's. Individuals and societies have adopted several perspectives as alternative models for the understanding of dementia. For example, Gilliard et al (2005) have advocated adopting the social model of disability in dementia care as it has the potential to focus care on the strengths and abilities of individuals rather than losses. They contended that a social model of disability may help those who are non-disabled or non-demented to understand the way in which they may discriminate against people with dementia. This in turn enables them to understand their responsibility for supporting the others with disability. However, they acknowledged that one limitation of this model is the fact that it focuses on physical disability and has not yet fully incorporated the understanding of the relationship between cognitive impairment and disability. Downs et al (2006b) have described four main explanatory models which have been used to understand the nature of dementia; and hence implications for therapeutic interventions. In the first model, dementia is considered as a neuro-psychiatric condition where symptoms and signs are required to be managed as discussed earlier (see section 2.3). Secondly, dementia has been considered as normal ageing where impaired mental functioning is seen as an inevitable result of ageing. Hence, there is no justification for the society to provide specialist health and social service resources in addition to those already available for older people. This view had been the dominant view in western cultures until the 1970s and still exists in certain cultures. Thirdly, dementia has been considered as a spiritual experience where dementia may be considered 'the result of forces of good, or more commonly, of evil' (p. 238). This explanatory model attributes changes in an older person's behaviour and

functioning to spiritual forces. Thus, strategies such as prayer, reading the Bible, and folk healing are used as interventions. This explanatory model is adopted by some people in non-western and minority ethnic communities within the western countries. Last but not least, dementia is considered as a dialectic process as proposed by the late Tom Kitwood. This model considers the experience of living with dementia as a dialectical interplay between neurological impairment, psychosocial factors and the social environment. It has been suggested that these models are rarely adopted in a pure form. Instead, they are used as part of an eclectic approach to explain the nature of dementia (Downs et al 2006b).

In this section, I will focus mainly on Kitwood's model of dementia because one of his major influences was the fact that he brought 'the person with dementia onto the centre stage in dementia care' (Woods 1999, p35). Moreover, Kitwood's concept of personhood in dementia has marked one of the most significant advances in the understanding of the nature of dementia over the past decades (Woods 2001). Also, his model is relevant to my research for two reasons: firstly, i) his approach advocates a shift from the traditional medical approach to an alternative culture in dementia care which supports the use of activity engagement offered as an intervention; ii) the approach highlights the need to understand the subjective experience of carers if the personhood of people with dementia is to be enhanced and maintained. I will discuss Kitwood's theory of dementia in more detail below.

#### ***2.4.1 Kitwood's theory of dementia***

In the UK, Kitwood and his colleagues in the Bradford Dementia Group have argued that a medical approach takes too narrow a view in explaining the relationship between the brain and the progression of dementia, and fails to take into consideration the social and psychological aspects of the understanding of dementia. For example, Kitwood (1997b) pointed out that the clinical scheme which defines the degree of dementia in terms of clinical stages, namely mild, moderate and severe, can be misleading as it only focuses on how simple neurological components impact on an individual's ability, but neglects the psychology and the uniqueness of the person. Similarly, as Bell and McGregor (1995) also emphasized, the stage theory of dementia fails to take account of the feelings, emotions and environment of the person. Thus, the biomedical model has been criticised for being too reductionist in its biological determinism and so fails to

explain several other factors about dementia (Kitwood and Bredin 1992; Kitwood 1998; Stokes 2000; Adams and Gardiner 2005).

Kitwood (1993) suggested that the process of dementia (D) was associated with not only neurological (NI) but also social-psychological (SP), personality (P), biography (B) and health (H) factors. Dementia therefore could be explained by an equation as  $D=P+B+H+NI+SP$ . These five factors interplay with one another and subsequently shape the unique experience of an individual with dementia (Kitwood 1993). Hence, the experience of dementia can be adversely affected at a neurological level by a deprived social environment, or enhanced by a supportive one. Also, it is recognised that the meaning of behaviours, and/or actions of an individual with dementia can be fully understood only within the context of his or her life history (Kitwood and Bredin 1992; Kitwood 1993). Thus, factors such as biography, life history and social factors are seen as influences in the manifestation of dementia. The dialectic model positions the person with dementia at the centre of those influencing factors and views such an individual as an active agent in his/her life (Downs et al 2006b).

Hence, Kitwood (1990, 1993) offered a theory of dementia to explain how the subjective experiences of an individual influence the process of dementia. Such an alternative understanding of dementia has important implications for the development of non-pharmacological intervention for people with dementia and their carers.

#### ***2.4.2 Personhood of people with dementia***

For Kitwood (1993), the concept of personhood of the person with dementia is the key to gaining a better understanding of the experience of the individual. Personhood has been defined as: ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood 1997a, p.8). This definition implied that the ability of the person with dementia to present the self is not reliant on his or her cognition (Kitwood and Bredin 1992; Kitwood 1998). It is the moral duty of those around this individual to support his or her personhood (Downs et al 2006b). Such definition of personhood recognises the interdependence and relationship of human being (Woods 1999). Hence, the maintenance and enhancement of personhood is closely associated with the way in which other people (e.g. carers) relate to those with dementia.

Central to the concept of personhood is the recognition that an individual with dementia has a self and has a range of psychosocial needs like all of us (Kitwood 1995). For Kitwood and Bredin (1992), the most disabling effects of dementia are the threats to one's sense of self and one's personhood. The concept of having a self in the person with dementia has also been discussed by other researchers. Sabat and Harre (1992) highlighted that they had developed a similar viewpoint to Kitwood.

Sabat (2001), exploring the selfhood of people with Alzheimer's disease (AD), concluded that certain aspects of the self persist despite cognitive impairment. Such aspects include the 'personal identity' (p.276), the 'mental and physical attributes' in the past and present (p.290). However, one aspect of the self, that is, the 'socially presented selves, or personae' (p.294) becomes vulnerable. This is because this aspect of the self is concerned with one's social identity, which is often reliant upon the cooperation of others. For Sabat, the vulnerability of this social self was as a result of being ignored by others when there was a need for assistance (Sabat 2001, 2008).

Both Sabat (2001, 2006) and Kitwood (1993, 1998) pointed out how the interpersonal relationship between people with dementia and the others (e.g. carers) can both positively and negatively impact on the quality of care. This means that, if the support for the people with dementia is not provided adequately by those who care for them, the identity and self-esteem of such people can be adversely affected.

Kitwood's view of dementia was one of a disability as he stated that 'dementing illness should be seen, primarily, as a form of disability. How a person is affected depends crucially on 'the quality of care' (Kitwood 1995, p.8). When the quality of care is poor, it is often associated with malignant social psychology (MSP). Aspects of malignancy may include: being disempowered, intimidated or being treated like a child (Kitwood 1990). The assumption which underpins this concept is that when a person has been subjected to malignant social psychology for an extended duration, his/her self-esteem is damaged. Using this approach, a problem of the person with dementia (e.g. apathy) is not considered to be inevitable in the process of dementia; rather, one that can be manifested and made worse by external factors (Kitwood and Bredin 1992; Sabat 1994; Balwin and Capstick 2007). This highlights the need to understand the social context of people with dementia.

### 2.4.3 *Personhood of the carer*

In Kitwood's view, the subjective experience of people with dementia was often influenced by other people's attitude and care practice, in particular paid carers in institutional settings (Kitwood and Bredin 1992; Kitwood 1993; Perrin 1996). The successful implementation of his alternative model therefore depended on carers' commitment, in particular institutional staff, to change their attitude and practice culture (Kitwood 1998). By highlighting the effect of malignant social psychology, Kitwood hoped to raise staff's awareness of their attitudes and actions (Kitwood 1990; 1997b; Kitwood and Bredin 1992); which would lead to them providing care in a person-centred manner (Baldwin and Capstick 2007). Nevertheless, such an approach could only be effectively delivered when the carers' own personhood is maintained; as Kitwood stated, 'the care of the whole person, moreover, requires carers to be a whole person too, cured of their mania for control' (Kitwood 1995, p.9). According to Kitwood, carers' attitudes are often influenced by the high level of psychological and physical stresses resulting from their work environment. He felt that staff should be encouraged to accept their own feelings and vulnerabilities; and be given an opportunity to express concern and foster their commitment. He stated,

*'if I know my feeling self when I am caring for another; if I know my vulnerabilities, I can lovingly take care of these, and draw on my self-knowledge as a basis for empathy'. (Kitwood 1995, p.10)*

Such self-awareness would enable carers to avoid being burnt-out (Kitwood 1995; Kitwood and Bredin 1992). This in turn would facilitate them to maintain their own personhood, and hence that of the cared-for people.

Kitwood's work highlighted the need to understand the subjective experience of carers and facilitate them to develop their skills and knowledge in dementia care. His work on the personhood of carers focused predominantly on direct care staff within institutional settings. There is limited discussion about other categories of carers such as family carers, and health and social workers within the care system (e.g. Kitwood 1995). However, Kitwood has raised an important issue regarding the need to consider the intricate relationship between the personhood of people with dementia and that of their carers.

Kitwood's work has been influential in advocating the need to understand the personhood of individuals with dementia, and to provide support for care staff in terms of training. In the 1990's there was a paradigm shift in dementia care (Woods 1995; Adams 1996; Stokes 2000). This shift was to move care practice away from regarding people with dementia as incapable, towards what Kitwood called a 'new culture of dementia care' (Kitwood and Benson 1995). Such vision continues to influence the current development of government policy in dementia care as evidenced in the NICE-SIEC guideline, emphasising that people with dementia need to be treated as individuals with a 'unique identity and biography' (NICE 2007, p.71). Overall, Kitwood's work on promoting a change in the culture of care highlights the importance of understanding not only the subjective experience of a person with dementia, but also in that of their carers if the personhood of those with dementia is to be maintained.

#### ***2.4.4 Criticisms of the Kitwood's model of dementia***

Despite the fact that the theoretical underpinning of Kitwood's alternative dementia model has a consensus as good practice, the model has not yet been widely adopted by all those who work in the field (Keady 1996; Stokes 2000). There is a concern that the influence of Kitwood's theory is limited mainly to those working within dementia care practice and his work has not been significantly acknowledged by researchers in the wider field, for example, those who research into the aetiologies and potential cure for dementia (Baldwin and Capstick 2007). Some shortcomings in Kitwood's work will be discussed below.

##### ***2.4.4.1 Lack of empirical evidence***

Kitwood's model of dementia has been criticised for its lack of empirical evidence (Adam 1996; Adams and Bartlett 2003). For example, Adam (1996) commented that Kitwood's work on dementia care mapping (DCM) was not supported by rigorous research methods and empirical evidence. The DCM is an observational method which requires trained mappers to observe people with dementia and record the main activity in which the person has been engaged; and to make a subjective rating of the person's well-being and incidents when a carer shows one of a number of 'personal detractions' where the person with dementia is considered to be devalued (NICE 2007). The purpose of such process is to gain a detailed record of the interactions with people with dementia in a particular care setting (Baldwin and Capstick 2007). Adam (1996) questioned the



validity of such an observational technique and doubted whether it was possible to infer the level of personhood from behavioural cues.

Baldwin and Capstick (2007) agreed with some of Adam's viewpoints, especially regarding the fact that Kitwood did not always discuss the methodology of the development of his theory in an explicit manner. However, they argued that the reasons for lacking empirical evidence to substantiate some of Kitwood's work could be explained by the time and environment in which he worked. In the late 80s and early 90s, Kitwood was at the beginning of developing an emerging theory of alternative model of dementia. It was difficult for him to find relevant evidence to support his claims. Baldwin and Capstick (2007) provided evidence by citing a number of Kitwood's articles which were substantiated by empirical studies (e.g. in Kitwood's critique of the medical model). It would appear that Kitwood was aware of the shortcoming of his work and made explicit such empirical challenges in his published work (e.g. Kitwood 1990, 1997a; Kitwood and Bredin 1992).

#### *2.4.4.2 Insufficiently addressing the wider social context*

Kitwood's model has been criticised for insufficiently addressing the wider social context in dementia care. Nolan et al (2002b) acknowledged that personhood has been an important concept which, for over a decade, underpinned theoretical research into practice and understanding of dementia care. However, they argued that this focus has led to insufficient acknowledgment of other aspects of dementia care, including, for example, the views of the multiple actors involved in the delivery of health and social care. Adams and Gardiner (2005) also agreed that the theory fails to address issues concerning wider social phenomena in dementia care. For instance, the concept of malignant social psychology (MSP) of people with dementia primarily considers subjective experience within a person's own environment. It does not acknowledge the impact of wider social factors such as gender, citizenship and marginalisation upon people's experience of dementia (Adams and Bartlett 2003).

On the other hand, Baldwin and Capstick (2007) argued that Kitwood did have a strong view on the impact of organisational and interpersonal culture on institutional dementia care practice. He, however, had not explicitly articulated, in his early publications, how the different factors within such culture interplayed, and influenced all those actors

working in dementia care. In 1997, Kitwood started to pay more attention to organisational frameworks. It was suggested that had Kitwood not passed away a year later, he might have developed such areas in his work (Baldwin and Capstick 2007).

#### *2.4.4.3 Inconsistency in the use of language*

It has been suggested that Kitwood used different styles of writing in order to make his ideas accessible and acceptable to variety of audiences. Hence, the use of words in Kitwood's publications is not always consistent. This introduces ambiguity and becomes a source of confusion for those who want to understand fully and to evaluate the validity of his work (Adams 1996, Adams and Gardiner 2005; Baldwin and Capstick 2007). For example, Kitwood often used the terms, caregivers, carers, direct care staff, the care worker, formal and family caregivers rather loosely in his publications (Kitwood 1995, 1997a). In his discussion about issues concerning carers, he sometimes uses the term 'carers' as 'direct care staff' (Kitwood 1995); but as both 'formal' and 'family caregivers' in other times (Kitwood 1997a). This inevitably leads to the difficulty in understanding the complex relationships not only between formal and informal carers; but also between people with dementia and their family carers. My research aimed to explore further how these factors impact on family carers' experience in terms of their interaction with the person they looked after.

#### *2.4.5 The impact of Kitwood's model of dementia*

Kitwood's model has promoted the understanding of how various bio-psychosocial factors impact on the severity of disability experienced by people with dementia. Kitwood's work facilitated the development of a more person-centred approach to improve the well-being of people with dementia and their family carers. As Nolan et al (2002b) pointed out, person-centred care has advanced debate in the dementia field, and promoted the development of new approaches to both the cared-for and the carer. It can be argued that, over the past decades, it has also been successful in promoting the value of the life experience of people with dementia. Moreover, it is evident that the concepts of the personhood and person-centeredness of people with dementia continue to influence research and practice in dementia care, as well as the development of current government policy (e.g. National Services Framework for Older People, DH 2001a).

At present, the understanding of the term ‘dementia’ is still evolving. There has been an increasing awareness of the need to place the study of dementia care within a socio-cultural context (Wattis and Curran 2001; Innes 2001; Downs 2000; Milne and Wilkinson 2002). Given that care practice in dementia care is increasingly community-based, there is a need to develop further our understanding of the social psychological experience of family carers and how such experiences impact on their support for the cared-for people.

The next section will discuss issues relating to informal carers and why they play an important role in the delivery of home-based activity programmes for people with dementia.

## **2.5 Caregiving in Dementia**

Informal care has long been recognized as the mainstay of dementia (Evandrou et al 1986; Melzer et al 2002; Hirst 2002). The ‘Dementia UK’ report estimates that family carers save the public purse over £6 billion a year (Alzheimer’s Society 2007). In this section, I will discuss i) the nature of informal caring; ii) the policy in caregiving; iii) the experiences of carers of somebody with dementia and their caring role. The term ‘carer(s)’ will be used interchangeably with the term ‘informal carer(s)’ and ‘family carer(s)’.

### ***2.5.1 The nature of informal caregiving***

The 2001 census showed that there are about 6 million informal carers of people with many different conditions in the UK (Office of National Statistics/ONS 2006). One in six people are carers and the likelihood of women becoming carers is higher than that of men (ONS 2002). About a third of carers are caring for someone in the same household. However, nearly three-quarters of these carers do not receive regular support services (ONS 2002). It is recognized that the needs of carers have not been met by service providers in a consistent manner (Department of Health 1999a, Audit Commission 2004b). It is possible that, in reality, many carers develop their own strategies to live alongside their relatives who are affected by different levels of disabilities, including dementia of all stages.

Informal carers are not a homogeneous group (Arber and Ginn 1990; and Twigg et al 1990). The term ‘informal carers’ could be understood variously in terms of the characteristics of these carers (e.g. age, gender, employment status and where they reside), the characteristics of their dependents (e.g. age, gender and disability) and their relationships to the cared-for people (Twigg et al 1990). Caregiving activities and the role as a carer emerge from prior relationships such as husband and wife, child and parents, neighbour, siblings or partners (Pearlin et al 1990; Montgomery and Kosloski 2000).

The majority of people with dementia are cared for by a family member, usually by spouses and sometimes by children (Tobin 1995; Hirst 2002; Banerjee et al 2003; NICE 2007). It is recognised that the bulk of informal caring work, in terms of total time spent, is often provided by co-resident carers, mainly a spouse (Arber and Ginn 1990; Schneider et al 2002; NICE 2007); and sometimes by a son or daughter. Co-resident care for parents is mostly provided by a single or divorced child (Hirst 2002). Those carers who live in a household with the cared-for tend to spend more of their time looking after those individuals (DH 1999a) and offer higher levels of care (Hirst 2002). Studies have showed that over half of people with moderate to severe dementia live with co-resident carers (Schneider et al 1993, 2002). Thus, co-resident caring plays a vital role in delaying transition into residential care (Banerjee et al 2003); and therefore, has financial implications for health and social services (Schneider et al 1999, 2003).

Informal carers play an important role within the home setting. Yet services provider and professionals often lack a clear rationale for work with families (Twigg and Atkins 2002; Gillies 2000). The nature of carers’ involvement in specific activities and their relationship with others within the context of care provision is poorly understood (Clarke 1999; Nolan and Keady 2001; Nolan et al 2002b). The lack of clarity about the position of informal carers in the provision of care clouds the understanding of their role in care provision in the community, and adversely impacts on the development of effective strategies to support carers. There is a need to gain a better understanding of the concept of informal caring with a view to integrating carers fully in the changing health and social care system. My research focused on exploring the role of carers in the home setting and aimed to add to the knowledge in this area.

### ***2.5.2 Policy in caregiving***

Over the past two decades, a major theme in government long-term care policy has been to shift the balance of care towards community care from institutional care. The current UK government policy is to encourage practitioners, policy makers and service providers to work in partnership with informal carers in the delivery of treatment interventions (DH 1997, 1999b, 2003, 2005b; Audit Commission 2000; NICE 2007).

The involvement of carers in the development and implementation of intervention has long been recognised. For instance, the need to involve carers in community care policy had been reflected in the 1989 White Paper 'Caring for People' (DH 1989). The Griffiths Report has highlighted the fact that community care could not be fully implemented without the acknowledgment and support of carers (Griffiths 1988). Since then, a considerable amount of legislation and government guidance documents have been published, with a view to supporting the needs of carers.

In an attempt to acknowledge the significant role of informal carers in care provision in the community care practice, the term 'carer' was officially defined in the Carers (Recognition and Services) Act 1995. Under the terms of the Act, carers were defined as those people who provide or have an intention to provide a 'substantial amount of care' or care on a 'regular' basis (DH 1995). The passing of the Carers Act 1995 not only offered an official definition of the term 'informal carer', but also marked the turning point in carers' legal rights. Carers were encouraged to exercise their legal rights to be involved in an assessment of their own needs if they wish (Audit Commission 2000; DH 2000b). However, the Act fails to provide clarity in term of the official meaning of the terms 'substantial' and 'regular'. In reality, many practitioners did not conduct carers' assessments as they were unsure what they could offer to carers (Fruin 1998).

In 2005, a combined policy guidance entitled the Carers Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004, was published. The government promised to offer carers a wider range of choice and opportunities to 'lead a more fulfilling life' (DH 2005a, p.7). This Act required local authorities to inform carers about their rights under the Act 2000, and expected them to offer carers an assessment of their own needs, taking into consideration how the caring role impacted on their leisure, education, training and work activities (DH 2005a). This highlighted the need to understand the

relationship between carers' engagement in their own activities and their involvement in that of their relatives. This is particularly important in dementia care as it helps to gain an insight into the specific needs of this sub-group of carers.

It can be seen that central government has attempted to lay a duty on local authorities to offer carers an assessment of their needs. The scope of provisions for carers has been increased. However, the interplay between support and its impact on carers' decision-making is ambiguous. It can be argued that the full implementation of the Acts will inevitably take some time. Nevertheless, it highlights the need to listen to the carers themselves.

### ***2.5.3 Policy initiatives:***

There are a number of policy initiatives which have been set up to support carers and improve carers' services. The UK government published its strategy to support carers for the first time in the National Strategy for Carers (DH 1999a). This document highlighted the objective that all organisations involved in caring must take into consideration the viewpoint of carers. The government promised to support carers in three areas: that is, information; support in the caring responsibility; and care for their own personal needs. For example: respite care was regarded as a key intervention for carers to offer a temporary relief from caring, so that it could prolong the time for people with dementia to be cared for in the community (Lee and Cameron 2004; Arksey et al 2004).

In 2001, the National Service Framework for Older People (NSFOP) set out eight new national standards as part of the modernised NHS and Social Services (DH 2001a). Standard Seven reinforced the important role of carers of people with dementia. Also the document highlighted the role of multidisciplinary community mental health teams in supporting carers who care for such individuals in their own home.

In 2005, a guidance document, entitled 'Everybody's Business' reinforced the idea that the services for older people with mental health needs can only be considered truly person-centred if they incorporate both the views of the service users and their carers (DH 2005b). The content of this service development guide has been endorsed by the White Paper in community services, 'Our Health, Our Care, Our Say' (DH 2006a).

Moreover, a NICE-SIEC guideline reiterates the need to support people with dementia and their carers in health and social care; in particular, the right of carers to receive a separate assessment of their needs should be upheld (NICE 2007).

Despite the amount of legislation, evidence has suggested that the introduction of new legislation and policies might not have benefited those carers who are in need. *Forget Me Not* (Audit Commission 2000) and *Forget Me Not 2002* (Audit commission 2002) identified multiple areas for service improvement. Also, it has frequently been reported that the needs of carers of people with dementia are not met by service providers in a consistent manner (DH 1999a, 2005b; Pickard 2004; Alzheimer's Society 2007). For example, formal services are often provided at the discretion of professionals and service providers following a request, either by people with dementia or their carers. Services tend to be provided only if professionals think that the resources are available (Schneider et al 2002).

More recently, studies, which have examined the effectiveness of respite services and support interventions on carers, showed limited evidence in terms of their benefits to carers. For example, respite care (e.g. day care, in-home respite, host-family respite, institutional/overnight respite) had been considered as a key intervention to reduce the stress of caring (Arksey et al, 2004; Lee and Cameron 2004). However, Arksey et al (2004) found that services did not always reduce the emotional and physical stress of carers. These findings were consistent with a systematic review on respite care for people with dementia and their carers by Lee and Cameron (2004).

Likewise, a range of service interventions, which aimed at supporting and providing information to these carers, had also been thought to be beneficial as stated in the National Carers Strategy (DH 1999a). Information and support interventions for carers of people with dementia are being delivered through a variety of formats (e.g. technology, group and individualised support). Nevertheless, a systematic review by Thompson et al (2007), found that there was limited evidence to show that any types of intervention aimed at providing information to and supporting carers of people with dementia are effective, with the exception of group interventions underpinned by a psycho-educational theoretical framework. The findings of the review suggested that, even though group-based supportive interventions appeared to show some positive

effect on carers' psychological health, the extent to which the clinical benefits of group-based supportive interventions on burden or depression of carers was uncertain.

This lack of clear evidence has resulted from some methodological factors, for example: the fact that objectives for respite care were poorly defined; outcome measures for carers support services were not always shared by clinicians, researchers and carers; and the research design failed to capture carers' changing responses to interventions at different points of the caregiving journey (Arksey et al 2004; Thompson et al 2007). This raises a question as to what extent carers of people with dementia feel that they have been supported in their caring role and highlights a gap in the understanding of carers' needs for support. The next section will discuss the impact of caring on family carers and their need for skill training.

#### ***2.5.4 The experience of family carers***

##### ***2.5.4.1 Impact of caring***

Family caregiving is 'potentially a fertile ground for persistent stress' (Pearlin et al 1990, p.583) when people try to help and assist their relatives or friends with activities which they are unable to perform by themselves. Caring for family members with dementia often radically changes the lives of the carers (Teri et al 1988; Pearlin et al 1990; Robinson and Steel 1995). Over the past two decades, researchers have investigated how families coped with caring situations (e.g. Chenoweth 1986; Eagles et al 1987; Jones and Peters 1992; Duijnste 1994; Coleman et al 1994; Buck et al 1997), and this research has gone some way to understanding carers' stress. In a conceptual model proposed by Pearlin et al (1990), stress was considered as the consequence of a process which consisted of a number of interrelated components including socio-economic factors; characteristics and resources of carers; as well as primary (e.g. specific problems related to dementia) and secondary stressors (strains in carers' roles and their own activities; and diminishing self-concepts). How each of these constructs entered into and shaped the directions of carers' lives remains to be explored.

It is now widely recognised that some common factors which pose enormous strains on carers are practical, behavioural, interpersonal and social factors (Gilhooly 1984; Gilleard 1989; Levin et al 1989; Almberg et al 1997a; Brodaty et al 1997; Clarke 1999; Schneider et al 1999). Many carers often find it difficult to provide practical assistance



with aspects of daily living tasks for those with dementia (Orona 1990; Lee and Cameron 2004); and to take responsibility for the safety of the cared-for and cope with the resulting intense pressure (Mace and Rabins 1988; Almberg et al 1997a; Vikstrom et al 2008). Many carers have frequently reported having the feeling of entrapment and loss (Tebb and Jivanjee 2000; Aneshensel et al 1995; Bertrand et al 2006). They are at high risk of mental health problems and psychological distress (Donaldson et al 1998; Schneider et al 1999). Behavioural problems of the cared-for people can precipitate their admission into institutional care (Smallegan 1985; Knapman et al 1988; Perrin 1996; Stokes 2000; Banerjee et al 2003).

A growing literature on family carers' coping strategies has increased current understanding of how carers manage their caring situations. For example, an interview study by Almberg et al (1997b) which investigated the major strain and coping strategies of forty-six family carers of aged, demented relatives revealed some useful findings. They suggested that coping strategies were multi-dimensional. Those carers of people with dementia who reported more burden and burn-out tended to use emotion-focused strategies such as worrying, grieving and self-accusation; whilst those who reported less burn-out and burden were more likely to use problem-solving strategies, such as seeking support and confronting negative experiences. There was a link between carers seeking social support and not experiencing burnout. The study concluded that the effective coping strategy to address major stress and strain in caregiving was to adopt a combination of these strategies. However, the researchers acknowledged that the generalisation of the findings was limited due to the small sample and it was only part of a longitudinal project. It is still unclear how various components of coping strategies interact with the carers' experience of stress at various stages of dementia. Caregiving is a dynamic process which involves enormous variations in terms of carers' experiences and there has been a call for future research to identify features of the caregiving process that characterise particular stages of the caregiving process (Montgomery and Kosloski 2000).

Earlier research in dementia care had been criticised for over-emphasising a sense of burden and the negative aspects of the caring experience (Martin-Cook et al 2000; Downs 2000; Nolan et al 2003). In recent years, many researchers have argued that research and practice underpinned by this kind of approach could potentially create

barriers within the partnership working among the cared-for, the carers and the service providers. Nolan et al (2002b), in a review of caregiving research over the past 20 years, emphasised that the use of the stress-coping model had created studies which were inevitably too narrowly focused and thus unable to address caring circumstances adequately. For example, although previous research had pointed to the need for respite care, the uptake of such services was slow. They, therefore, concluded that the slow uptake by carers of respite care could have been due to the failure of previous research to consider the huge diversity of carers and the circumstances of their relatives.

The lack of effective intervention strategies in dementia care also brings into question the adequacy of the philosophical underpinning of person-centred care approach in practice. Such an approach leads to a focus on mainly the needs of people with dementia, and does not adequately reflect the interactions among these individuals, their carers, the others who are involved in the delivery of health and social care. This ultimately impacts on the quality of care provided. In recent years, researchers have advocated new models of care which include partnership working and an understanding of the relationships among people with dementia, their informal carers, as well as health and social care professionals. Such approaches include a relationship-centred care approach which considers that the views of all the actors involved in rehabilitation are equally significant (Nolan 2002; Keady and Nolan 2003; Adams and Gardiner 2005).

This points to a need, as a first step, to understand the carers' perspectives on which how they supported their relative's day-to-day activities. It is widely recognised that informal carers are unlikely to utilise services unless they perceive them filling a need that they have already identified for themselves in their caregiving role (Braithwaite 2000; Zarit and Leitsch 2001).

#### *2.5.4.2 Carers' need for skills training*

Many people prefer to care for their relatives at home but family care for people with dementia poses unique problems for carers (Tobin 1995). It challenges family carers to develop a range of skills (practical, psychological and educational) that have been traditionally considered as clinical and used by professionals, such as nurses and occupational therapists (Bond et al 1992). With the trend towards community care informal carers are now carrying out the same activity in their home environment.

Studies have highlighted the need to develop and enhance carers' ability to cope with the caring tasks as one of the most beneficial approaches of all interventions (Nolan and Keady 2001; Dooley and Hinojosa 2004).

The need to engage people with dementia in activities at home often presents carers with a challenge. This is particularly the case when those cared-for become apathetic and are not engaging in activity (Sainty 1995; Keady 1996; Jansson et al 2001); and when carers do not feel that they have the necessary skills to engage the cared-for in activity at home as dementia progresses (Sainty 1995; Mittelman et al 1996; Vass et al 2003). Jansson et al (2001) explored the pattern of elderly spousal caregiving in dementia in eight families and highlighted four general areas in which carers experienced difficulties. These were the activities of daily living, communication, supervision and activity stimulation. They concluded that family carers need support to engage their relative in everyday activities.

In summary, our understanding of support for carers remains patchy. Little is known about how informal carers should be supported when they engage people with dementia at home. For example, what kinds of resources and knowledge do carers need in order to engage the cared-for in activities? what might be the barriers for carers to obtain an appropriate level of support? The present study asked family carers how they viewed the activity needs of the family members and what their concerns were about engaging their family members in beneficial activities. Occupational therapists have often been seen as providers of activity programmes. The next chapter will focus on the nature of activity, health and activity engagement in dementia care from an occupational therapy perspective.

## **Chapter 3 Activity engagement and dementia**

Alongside the development of a new culture in dementia care, there is an increasing awareness of how psychological and social factors may affect the quality of life of people with dementia. Health and social care practitioners including occupational therapists are more aware of their role in supporting those with dementia. This chapter will discuss the potential benefit of activity for people with dementia and implications for those who deliver an activity programme. Moreover, the role of occupational therapy in activity engagement and its relationship to health will be highlighted.

### **3.1 Activity needs of people with dementia**

There is a need for a focus on activity because the ability of those with dementia to engage in activity reduces over time (Coppola 1998; Andersen et al 2004; Perneczky et al 2006). Engaging people with dementia to do something which is meaningful promotes individuals' interest, self-esteem and stimulates choice, social interaction, communication and relationships (e.g. Hasselkus 1992; Miller and Morris 1993; Nolan et al 1995a; Perrin 1997; Zanetti et al 1997; Archibald 1999; Godel 2000; Brown et al 2001; Pool 2001; Spector et al 2003). Also, it prevents individuals from being inactive (Pulsford 1997; Kitwood 1998). It is generally believed that engagement in activity is essential for health and psychological well-being (Woods 1995; Perrin 1996); and is considered as a fundamental human right for a human being (Mozley 2001; Perrin et al 2008).

#### ***3.1.1 Consequences of a lack of activity***

Lack of appropriate support could lead to adverse consequences. Challenging behaviour (e.g. agitation) could be considered to be the consequence of failing to communicate with, and meet the range of needs of a person with dementia (Kitwood 1995; Kolanowski 1999; Stokes 2000; Parker 2003); whilst mood change (e.g. anxiety and depression), disruptive (e.g. wandering) and dependent behaviours (e.g. following carers) could be understood as a result of failing to address the emotional, social and environmental needs of the person (Marshall 1990; Kitwood 1995; Stokes 2000). Thus, it could be suggested that if those individuals with dementia are deprived of purposeful activity, they are being subjected to the 'malignant social psychology' described by Kitwood (1995) (see section 2.4.2). This in turn will result in the development of excess

disability, a term coined by Brody et al (1971), indicating that the person's level of functioning is less than one would expect on the basis of the actual level of brain disease.

### ***3.1.2 The importance of activity engagement***

Over the last two decades, research studies have investigated the benefits of a number of therapeutic activities used in an institutional context. These include music therapy (Kneafsey 1997; Brown et al 2001; Clair 2002; Sixsmith and Gibson 2007); multi-sensory stimulation (Hope 1997); reality orientation (Holden and Woods 1982; Spector et al 1999a, Spector et al 2000); art therapy (Waller 1999); validation therapy (Bleathman and Morton 1992; Neal and Briggs 2003); reminiscence therapy (Thorgrimsen et al 2002) and basic and instrumental activities of daily living training (Backman 1996; Zanetti et al 1997).

These studies have shown some potential value; for example: in meeting psychosocial and behavioural needs (Pulsford 1997; Spector et al 1999b; Kipling and Bailey 1999; Scott and Clare 2003; Spector et al 2003; Neal and Briggs 2003); improving the quality of life for people with dementia, such as increased social contact and decreased depressive symptoms (Zanetti et al 1997; Spender and Joyce 2000; Scott and Clare 2003); facilitating relaxation; stimulating the senses and communication (Hope 1997; Kneafsey 1997; Neal and Briggs 2003); stimulating memory and conversation (Thorgrimsen et al 2002); and enhancing the emotional bonding experience and mutual engagement in both people with dementia and their carers (Clair 2002; Sixsmith and Gibson 2007). Also, some evidence has suggested that, provided that those with dementia had relatively well-preserved functions, they would benefit from participating in activities of daily living training with environmental adaptation (Backman 1996). Thus, the use of activity-based intervention has been shown to provide beneficial psychosocial and cognitive outcomes for the well-being of those with dementia.

The findings from these studies showed that the potential value of activity-based intervention depended on two key factors. The first factor was a well planned and organised activity with a clear goal linked to the individual needs of those with dementia (Pulsford 1997; Hope 1997; Spector et al 1999b; Kipling and Bailey 1999; Spector et al 2003; Neal and Briggs 2003; Harmer and Orrell 2008). The second factor

related to staff-related issues including morale, attitudes, level of manpower and skills, as well as the culture within the organisation (Perrin 1997; Pulsford 1997; Wattis and Curran 2001; Sixsmith and Gibson 2007). For example, when engaging a person with dementia in a sing-along activity, a member of staff needed to pay attention to how he/she facilitated interaction with the person to the optimum level by sitting together and singing with the person, as well as by bringing in his/her skills and qualities to the activity engagement.

It is worth noting that the focus of many of the previous studies had been largely on therapeutic activities being carried out in institutional settings such as day care, residential homes and hospitals (Marshall and Hutchinson 2001). Little research has been carried out into the potential benefits of activities being carried out in a home setting. Thorgrimsen et al (2002), carried out a pilot study of an eighteen week reminiscence intervention study. The intervention programme aimed to train carers to use the techniques with their relatives at home. There were seven couples in the experimental group and four couples in the control group. The findings of the study concluded that, people with dementia in the experimental group showed some improvements in communication and behaviour; whereas cognition and quality of life remained the same. However, there was no significant statistical difference between the two groups at follow-up due to the small sample involved in the study.

Also, Sixsmith and Gibson (2007), who aimed to explore the meaning and importance of music in everyday life, interviewed twenty-six people with dementia and their carers (sixteen in own homes, ten residential homes) and found that people's ability to appreciate and engage with music could remain relatively intact even though their verbal communication and cognitive functioning were severely impaired. This has implications for exploring new directions for therapeutic interventions for those with severe dementia at home.

### ***3.1.3 Effectiveness of activity-based therapy***

Although many small studies have been carried out with interesting findings, over the past decade the findings from several systematic reviews have highlighted a lack of concrete evidence about the effectiveness of a range of commonly used therapeutic activities. For example, Marshall and Hutchinson (2001) examined the use of activities

with people with Alzheimer's disease in a total of thirty-three studies between the period of 1991 and 2001. They concluded that these studies were generally unsatisfactory, and did not establish the effectiveness of such therapeutic intervention, owing to various methodological shortcomings. These included a lack of theoretical frameworks to guide the research studies, use of a convenience sample without systematic diagnosis, lack of clarity in defining the nature of therapies and use of a small sample size (Marshall and Hutchinson 2001). Hence, the researchers concluded that current knowledge of therapeutic activities with people with dementia is fragmented. These findings were consistent with a similar review by Melzer et al (2002).

More recently, the findings from three Cochrane Reviews suggested that the efficacy of three commonly used therapeutic activities for dementia was unclear. These were music (Vink et al 2008), validation (Neal and Briggs 2003) and reminiscence therapy (Woods et al 2008). Overall, the reviewers pointed to the shortcomings of previous studies on these therapeutic interventions, for example, poor quality of randomised controlled trials design and small sample size (Vink et al 2008, Neal and Briggs 2003 and Woods et al 2008).

Nevertheless, the reviewers concluded that although there was a lack of substantial evidence to support the efficacy of the three activities; there was equally insufficient evidence to discourage practitioners from use of these activities in dementia care. This is especially so when some significant results were found, for example, improved cognitive functioning and mood following reminiscence therapy sessions (Woods et al 2008).

Perhaps, however, some caution is necessary when establishing evidence of the effectiveness of therapeutic activities based on the Cochrane Review, as such reviews draw only on research studies from both randomised controlled (RCT) trials and controlled clinical trials (Taylor 2007). The problem with this is that, currently, there are only a few good quality RCTs available for evaluation of their relative benefits. The current evidence-based effectiveness of a range of activity-based therapy relies mainly on descriptive and observational studies rather than RCTs. Hence, it is too early to draw a firm conclusion base on the available evidence (Woods et al 2008). It has been

suggested that there is a need to consider using evidence from a variety of types and sources to influence practice and not be driven only by results from RCTs (Woods 2003).

The findings from the systematic reviews on the use of various therapeutic activities have highlighted two issues concerning the direction for future research in this area. Firstly, there is a clear need for continuing with further development and evaluation of therapeutic activities, especially when some of these activities (e.g. reminiscence) were very popular with staff, people with dementia and their family carers. Secondly, the outcome measures for activity-based therapy should consider its impact not only on those with dementia, but also on the carers (Woods et al 2008).

The lack of current evidence to support activity-based therapy should not be seen as indicating a lack of effectiveness. It is crucial to further develop our understanding of the benefits of using activity with people with dementia in diverse circumstances (Woods et al 2008). The focus of many of the previous studies had been largely on therapeutic activities being carried out in institutional settings. Little research has focused on the potential benefits of activities being carried out in a home setting and how informal carers support the activity needs of people with dementia at home.

Although current research shows that the effectiveness of various activity-based interventions is inconclusive; the use of activity-based therapy as non-pharmacological interventions for people with dementia has been recommended as good practice by the National Institute for Health and Clinical Excellence (2007). The NICE-SCIE guideline considers three key areas: a) daily living (ADL) skill training which 'can promote independence in personal care tasks (for example, dressing, feeding and washing) and maximise the use of skills and participation in their own care'(p.165-166); b) the management of challenging behaviours, because some of the positive findings, which, were drawn from a series of single case studies, could provide insights into how a range of these behaviours could be addressed; and c) therapeutic activities which could be used as psychosocial intervention for the management of coexisting emotional disorders, for example, depression, anxiety and agitation (NICE 2007).



Given that it is recognised that the effectiveness of such activities greatly depends on the characteristics and the involvement of those who deliver the activities (NICE 2008a), there is an urgent need to gain insights into how the activity needs of these individuals are being met by family carers in a home setting.

Occupational therapists have often been seen as providers of activity programmes (College of Occupational Therapists 2007a). The next section will discuss how occupational therapists can contribute to the support for the activity need of people with dementia and their carers.

### **3.2. Occupational Therapists and their role in activity engagement**

As mentioned previously, I am an occupational therapist. I have many years experience of working with people with dementia in the community. Before I started my research, I was aware that occupational therapists were increasingly expected to focus on specific activity programmes which need to be carried out by family members. As a clinician, I felt that a key part of the process was missing, that is, the need to understand the carers' perspectives of the activity need of people with dementia at home. In this section, I will discuss the following areas : i) occupational therapy in health and social context; ii) the fundamental link between occupational therapy and the two concepts of occupation and activity and the reason for using the term 'activity engagement' in this research; iii) the occupational therapy views on the relationship between health and occupation and its limitation; iv) core skills for promoting activity engagement; v) carers support from occupational therapy research and its limitations.

#### ***3.2.1 Occupational Therapy in the health and social context***

Occupational therapists work within both National Health and Social Services. They 'work with people of all ages, helping them to carry out the activities that they need or want to do in order to achieve health and satisfaction in their daily lives' (College of Occupational Therapists 2008, p.1). Their role in supporting individuals with dementia and their carers in the community has been recognised in government policies and NICE guidelines (e.g. DH 2001a; NICE 2007). More recently, the importance of occupational therapy intervention to promote the mental wellbeing of older people in primary care has also been highlighted (NICE 2008a).

The scope of occupational therapy practice is reflected in a general statement published by the College of Occupational Therapists. It states,

*‘Occupational therapists work with people who have physical, mental and/or social problems..... Their aim is to enable people to achieve as much as they can for themselves, so they get the most out of life. When people cannot do things which are important to them - such as getting dressed, having a shower, going to work, socialising or undertaking a favourite hobby - an occupational therapist can help them in many ways, based on each individual person's needs and lifestyle’ (College of Occupational Therapists 2008, p.1).*

At the heart of an occupation therapy intervention is the fact that ‘occupational therapy enables people to achieve health, well-being and life satisfaction through participation in occupation’ (College of Occupational Therapists 2004b, p.1).

### ***3.2.2 The fundamental link between occupational therapy and the two concepts of occupation and activity***

A review of the occupational therapy literature reveals that the term ‘activity’ has been used as a synonym for ‘occupation’ and ‘task’ over the past few decades. There has been increasing concern about a lack of clarity about the term ‘activity’ used by occupational therapists in a variety of specialised fields. Despite the fact that the use of activity has long been recognised as a medium of treatment intervention used by occupational therapists since its inception, there is a lack of consensus concerning the meaning of the term ‘activity’ itself. In recent years, many occupational therapy scholars advocated that these terms should not be used interchangeably by occupational therapists. They maintain that each of these terms has its own meaning and should be used appropriately according to each meaning (Finlay 1997; Wilcock 1998a; Reed and Sanderson 1999; Hersch et al 2005).

Over the past two decades, many occupational therapy scholars have attempted to define the meanings of such terms as ‘activity’ and ‘occupation’ (Wilcock 1998a; Hagedorn 2001; Christiansen 2004; Creek 2003). In response to a need to promote a consensus of the meaning of terms commonly used in the profession, the College of Occupational Therapists in the UK redefined both the terms *occupation* and *activity* following the publication of a research report entitled ‘*Occupational therapy defined as a complex intervention*’ by Jennifer Creek (2003). The purpose of the research was to provide a detailed description of current occupational therapy practice in terms of its scope and key features. The revised definitions of the two key terms are outlined below.

### 3.2.2.1 *The term occupation is defined as:*

*‘An activity or a group of activities that engages a person in everyday life, has personal meaning and provides structure to time. Occupations are seen by the individual as part of her or his identity and may be categorised as self care, productivity and /or leisure’ (College of Occupational Therapists 2004a, p.2).*

This works on the premise that the benefits of engagement in meaningful activities are based on several assumptions. For example, individuals set meaningful goals for their activities; have the capability to understand fully the nature of the chosen activities; are capable to reflect on their own experience; as well as make necessary changes if they wish to do so (Yerxa 1993; Wilcock 1993, 2001; Csikszentmihalyi 1997; Christiansen 2004). Hence, the concept of occupation reflects the subjective temporal and socio-cultural experiences of an individual.

### 3.2.2.2 *The term activity is defined as:*

*‘A task or sequence of tasks, performed by an individual or a group, that may contribute to an occupation or occupations’ (College of Occupational Therapists 2004a, p.2).*

This definition assumes that an activity is an idea which is held in people’s mind and in their shared language within their cultural context (Pierce 2003). For example, the activity of card game may be seen as a leisure pursuit. The commonsense meanings of activities enable people to communicate about generalised categories of occupational experiences in a broad sense (Pierce 2001, 2003). They are often the result of the culture in which people live (Hasselkus 2002). Hence, in occupational therapy practice, the term ‘activity’ is not considered to take account of the fact that individuals encounter different experiences in an activity and create personal meaning from it, for example, the card game may be considered by an individual as a gambling activity rather than an leisure activity. Hence, the term ‘activity’ is considered to insufficiently embrace the subjective experiences of an individual in engagement in an activity.

Within the occupational therapy profession, there is an increasing trend to use the term ‘occupation’. The shift towards an orientation for subjective occupational experience has been influenced by factors such the increased knowledge of qualitative research methods (Yerxa et al 1990). Nevertheless, many occupational therapists continue to use

the terms ‘occupation’, ‘activity’ ‘meaningful activity’ and ‘purposeful activity’ interchangeably.

### ***3.2.3 The reason for using the term ‘activity engagement’ in this research***

A full consensus on the definitions of the two terms (occupation and activity) has not yet been reached within the profession, and there is an on-going debate within the profession worldwide. The use of the word ‘activity’ in this thesis implies that I do not know if the carers’ action influences participation in ‘activities’ or ‘occupations’ for the persons with dementia (as I have not asked them); whereas the use of the term ‘activity engagement’ signifies a sense of active involvement in the chosen activity which is perceived as meaningful to those involved in it, as perceived by the carers.

## **3.3 The Occupational Therapy perspective of the relationship between health and occupation**

In occupational therapy practice, it is believed that there is a direct relationship between positive health and participation in occupations (Coppola 1998; Hagedorn 2001; Christiansen and Baum 1997; Wilcock 2001; Creek 2003; Molineux 2004).

Occupational therapy views health as ‘a dynamic functional state which enables the individual to perform his/her daily occupations to a satisfying and effective level and to respond positively to change by adapting activities to meet changing needs’ (Creek 2003, p.54). This belief is rooted in an assumption that humans are occupational beings who have ‘an innate needs to engage in occupation’ (Wilcock 2001, p.5). Hence, occupation is an integral part of being human. Through engaging in occupation, individuals learn to adjust the balanced use of capacities and how to interact with the physical and socio-cultural environment. When capacities are over-used or under-used, individuals feel stress, fatigue, isolation or boredom. This leads to increased susceptibility to ill-health and dysfunction. Circumstances which threaten individuals’ capacities to remain healthy include illness, stressful life events and environmental changes. Hence, engagement in occupation is intrinsically linked with not only everyday survival needs but also maintenance of health within one’s socio-cultural context (Wilcock 1995, 1998b, 2001). It is believed that a meaningful life depends on an individual’s ability to find occupations which are sufficiently challenging within the scope of one’s capabilities (Csikszentmihalyi 1988, 1993).

It is believed that engagement in occupations influences the identity of clients through their choice of occupation. This in turn allows them to derive a sense of uniqueness and meaningfulness through the process of doing and being (Wilcock 1998c). Each chosen goal of occupational engagement shapes further the identity of clients. Such identity forms part of their life story which is connected with past and present occupations (Christiansen 2004). In short, many occupational therapists argue that the complexity of their task lies in understanding the unique way in which every individual performs an occupation within their own socio-cultural context (Creek 2003, Duncan 2006).

### ***3.3.1 Limitations of the occupational therapy perspective on health***

It has been acknowledged that occupational therapy is considered to be a young profession (Pierce 2003). It is only in the last decade that the relationship between occupation and health has been researched with significant rigour (Molineux 2004). Despite that, a consensus about the relationship between health and occupation is emerging nationally and internationally within the profession (Hagedorn 2001; Wilcock 2001; Creek 2008; Molineux 2004).

Many occupational therapists point out that if the complexity of occupational therapy intervention is to be fully understood (Hagedorn 2001; Wilcock 2001; Molineux 2004, Creek 2008), it is crucial that there is further research into the understanding of the nature of occupation, as well as the value of the core skills and principles used in occupational therapy practice. It is hoped that the findings of this study will contribute to the development of knowledge within the profession. The next section will discuss how occupational therapists can contribute to the promotion of the use of meaningful activity with people with dementia by utilizing core skills.

## **3.4 Core skills for promoting activity engagement**

Occupational therapists use occupation as intervention in daily practice. Central to the success of such intervention is the expertise of an occupational therapist to understand the complexity of the concept of occupation, and to identify an occupation which can motivate and engage the client in working towards treatment goals (Pierce 2003). The process of engagement in occupation is facilitated by occupational therapists, using their professional principles and related skills (Creek 2003; College of Occupational Therapists 2004b). This section will discuss the principles and related core skills for

promoting occupation; and highlight how such skills can be considered by others (professionals and family carers) to enhance the effectiveness of engaging people with dementia in meaningful activities.

#### **3.4.1 Collaboration**

Occupational therapists collaborate with clients in a therapeutic process to facilitate a sense of control in the client (Creek 2003). Therapeutic partnerships with clients are based on principles such as respect for the client's autonomy, being non-directive and non-judgemental. The client is viewed as an equal partner in identifying goals and the direction of a therapy process. The therapists use empathy and listening skills to gain an understanding of the occupational needs of the client; they then guide clients to help them select a range of everyday activities which are compatible with the identified goal and abilities. People with dementia would require different degrees of assistance and support from the carers, in order to maintain and develop their capability to function, depending on their individual circumstances.

Therapists need to work in partnership with family carers in order to facilitate clients' access to a range of support and resources. For example, when a client experiences occasional forgetfulness, but still wants to cook a daily meal, the therapist may negotiate with a paid or informal carer to support the individual to do the task rather than suggesting it is too dangerous. The therapist needs to ensure there is shared understanding of the client's needs and how he or she should be supported in a consistent manner by all parties involved. Moreover, it is crucial for therapists to review their clients' needs regularly, and to work on collaborating with not only the individuals with dementia; but also their family carers at various levels; namely, identifying a range of meaningful activities, implementing an activity programme and monitoring progress.

#### **3.4.2 Assessment**

Therapists conduct assessments of clients' needs (Creek 2003), for example, using narrative interviews to identify an individual's potential abilities, strengths and limitations. The assessment also takes account of the effect of the client's physical and psychosocial environments; as well as the past history of this individual. Through this process, the therapist seeks to understand the client's perspective.

Working with individuals with dementia presents a challenge for therapists, particularly with those who, due to deteriorating memory, have difficulty in giving a personal account of their past and present experiences. Effort has to be made to find ways in which therapists can get, from their carers, a closer account and a better understanding of clients' experiences; especially from those carers who live with the person concerned. This is because such carers have a good knowledge of the person with whom they have been living for years, prior to the onset of dementia. This information can then be used for comparison with the data from the therapists' assessment, forming the basis for the development of intervention plan. The ethical aspects of using proxy information to obtain a view of people with dementia have been discussed in literature (e.g. Clarke 1999; Vass et al 2003). For example, one of the key issues that has been raised is whether the views of the individuals are ignored when developing outcome measures for intervention, as there is a concern that they are judged as lacking in competency to offer an accurate report on their current situation (Cotrell and Schulz 1993, Cantley and Smith 2007). This leads to the use of their carers as a proxy for gaining the viewpoints of individuals with dementia. There are arguments which support the belief that people with dementia are able to provide accurate and valid reports of their experience of service provision. Nevertheless, these studies have mainly included people at a less severe stage of dementia (Bamford and Bruce 2000). On the other hand, studies found that spousal carers' estimates of the level of functioning of people with dementia in certain daily living tasks were accurate (e.g. Gitlin et al 2001) and were not influenced significantly by the psychosocial (e.g. sense of self-efficacy, carers' sense of resentment) and functional factors (e.g. the severity of patients' cognitive impairment) (Davis et al 2006). Hence, research on the accuracy of using carers as proxy is inconclusive.

### **3.4.3 Enablement**

Therapists support clients to explore and maintain balance in their everyday activities (Creek 2003) so that they achieve a sense of being relaxed, and productive. This may mean that the therapist assists the client to structure daily routines so that goals become achievable. Central to the concept of enabling is ensuring that the client participates actively in the intervention (Duncan 2006). It is important for therapists to work on creating a supportive and adaptive environment for participation in meaningful activities. Carers play an important role in promoting such an environment.

Enabling a relative with dementia in everyday activities is likely to affect carers' own occupational needs. The needs of both the individuals with dementia and their carers are intricately linked. Also, the interests of the clients and their family carers can conflict, and the therapists are challenged to use their core skills and principles to the full. It is crucial that therapists appreciate carers' skills and competence in their caring role. They must balance the tensions between the need to promote the independence of people with dementia against the need to enhance the autonomy of carers' decision-making. Also, they must understand what carers expect of them in working with their relative and with the carers themselves.

#### **3.4.4 Engagement**

Therapists help clients identify and solve problems in engaging in day-to-day activities (Creek 2003). Processes can be associated with developing a skill, solving a problem, gaining insight into their own situation and building confidence. Engagement in the selected activity facilitates a client's ability to develop insight into his/her own strengths and seek to identify continuous actions to achieve self-directed goals. The chosen activity needs to be related to the client's experience, motivation and capabilities. Factors which can enhance the process of activity engagement include focusing on strengths and abilities rather than deficits; working at the client's own pace in a respectful and collaborative manner; and creating a supportive atmosphere (Creek 2008).

The extent to which occupational therapists can support their clients depends on various factors within the clients' environment; for example, the degree to which dementia affects the client, and the level of available support (social, cognitive and built-environmental). Inevitably, therapists need to negotiate with carers and ask them to take responsibility for monitoring their relative's participation in activities; and to resolve problems with their relatives as they occur. In some circumstances, this may mean that the therapists recommend that carers receive practical training; this in turn would enable carers to learn the skills needed to enable their relatives in activity engagement.

#### **3.4.5 Environmental adaptation:**

Therapists can offer advice on adapting the environment (Creek 2003). Environmental adaptation can involve physical, technological, cultural and social aspects. For example,



the therapist may advise their clients with unsteady gait to perform an activity in a sitting position and to organise the necessary tools within easy reach. Occupational therapists are also involved in the provision of assistive technology to support people with dementia and their carers (College of Occupational Therapists 2007b; Beech and Roberts 2008). Assistive technology ranges from simple devices (e.g. bathing aids, automatic calendars) to sophisticated products (e.g. Telecare systems to monitor people through sensors installed in their home). In order to ensure the efficacy of the intervention, the therapists need to enable the clients to select and use an appropriate device to support the performance of the chosen activities. Also, they need to work with both the clients and their carers to regularly evaluate the usefulness of the device. This in turn minimises MSP in the environment.

#### **3.4.6        *Therapeutic use of activity***

Therapists conduct an analysis of an activity prior to making decisions about its appropriateness for the client. The rationale for an activity analysis approach is to identify a meaningful activity and use it as a therapeutic tool to fulfil clients' goals (College of Occupational Therapy 2004b; Hersch et al 2005; Creek 2008). For example, cooking a meal could be used to develop a skill, or creating an end product, or promote a relationship. The goal-setting has to be directed by the clients. Therapists use their knowledge about the inherent characteristics of cooking; for example, the skills required for its performance (e.g. motor-sensory, psycho-social, and cognitive), the task sequences and the interpersonal demands. During the activity engagement process, the therapists grade and adjust the level of skills demanded of their clients. This is to enable the clients to achieve measurable success which will motivate them further.

In summary, occupational therapists deploy a range of core skills and principles to underpin their practice. These skills enable them to develop an in-depth knowledge of their clients and how they interact with the environment. This in turn helps them bring meaningful activities into the lives of people with dementia and their carers. As can be seen above, the principles and beliefs of occupational therapy, in dementia care, are consistent with the concept of person-centeredness in dementia care (Kitwood 1997a). This concept focuses on the person as a whole, drawing on his or her strengths and taking into account declining abilities. The principles of occupational therapists, which emphasise interdisciplinary and multidisciplinary working, are in keeping with the

concept of a relationship-centred care approach (Keady and Nolan 2003; Adams and Gardiner 2005). With the increasing emphasis on community care, the home is increasingly becoming the location where occupational therapists and other healthcare professionals implement an activity programme for people with dementia. It can be suggested that these principles and skills could be learnt by others (professionals and family carers) who are expected to enhance the level of activity engagement with those with dementia. The following section will examine the available evidence for occupational therapy research in supporting carers to engage their relatives who are living with dementia in activity.

### **3.5 Occupational therapy research to support carers to enhance the activity engagement in people with dementia**

A review of literature has revealed that research into occupational therapy in dementia care is limited. Nevertheless, there are a small number of papers which have demonstrated some positive outcomes of occupational therapy for both the activity engagement of people with dementia and the individualised skill training for carers. In this section, these papers will be discussed in more depth.

#### ***3.5.1 Skill training to accommodate the executive skill and memory deficits of people with dementia***

Family carers may benefit from skill training to support their relatives with difficulty in their executive functions (e.g. planning and sequencing a task) which were affected by dementia. Although not an intervention study, by examining data from seventy-two people living with early Alzheimer's disease and their spouses who took part in longitudinal studies conducted by the Washington University Alzheimer's Disease Research Centre, Baum (1995) explored how occupation could be used to minimize both the disturbing behaviours of those with dementia and the stress experienced by the carers. Data were drawn from functional tests for those with dementia and interviews with their carers. These included: i) Zarit Burden Interview, Memory and Behaviour Checklist and Activity Card Sort; and ii) Short Portable Mental Status Questionnaire and Kitchen Task Assessment. The analysis was based on a structural equation method. The researcher argued that such method allowed the hypothesised model to be formulated as a system of equations which enabled relationships of variables to be tested. Procedures were developed to examine the relationships between the causal

relationships of all variables in a hypothesized model which was concerned with the link between the relationships between carer's stress (both demand and emotion-focused); and the deficits of those with dementia (i.e. memory deficits, executive functions, disturbing behaviour, basic self-care ability, and level of occupational engagement). The researcher concluded that there was a need to train carers to make allowance for the executive skill and memory deficits of their relatives with dementia. The study was underpinned by a person-environment framework in which carers were seen as part of the context, including cognitive, physical and social aspects, which supported their relatives. The researcher highlighted the need to enable carers to provide an enriched environment for supporting their relatives to engage in meaningful activities. Nevertheless, she acknowledged that the findings of the study were inconclusive, future studies will need to further explore the relationships between continued occupation engagement and the underlying deficits of memory, planning and organisation; and how such relationships impact on carers' level of stress. The findings highlighted the need for on-going research in occupational therapy so that the potential benefit of occupational engagement on people with dementia and their carers can be better understood.

### ***3.5.2 Training in environmental strategies***

Gitlin et al (2001) aimed to evaluate how training in environmental strategies enabled family carers to support the everyday activities of individuals with mild to moderate dementia in a randomised controlled trial study. The intervention involved five ninety minutes home visits by occupational therapists who offered education, physical and social environmental modification to both their clients and carers. Two hundred and two family carers were enrolled, but thirty-one participants (from both the experimental groups and the control group) dropped out of the study due to illnesses and extended vacation. The programme focused on promoting the environmental problem-solving skills of the carers, so ultimately supporting those with dementia to improve their activity of daily living (ADL); and the instrumental activity of daily living skills (IADL) as evidenced by significant differences in the score on the modified Functional Independence Measure (i.e. carers in the experimental group reported less decline in IADL dependence in the people with dementia). Moreover, the intervention resulted in an increase in the reported self-efficacy of their carers. Limitations of the study were that the study relied on carers' rating of the level of ADL and IADL dependence of the

people with dementia. Also, the researchers commented that the time frame for the programme could have been longer with a higher level of support for carers. They noted that some carers were highly selective in their acceptance of environmental strategies. In some cases, carers required a longer period of time to decide whether to try out some of the recommended practical strategies. The researchers recommended that there was a need for occupational therapists to gain further understanding of the complex reality of the carers' experience.

It would appear that, when offering support to those with dementia, the person-environment framework is a useful guide for occupational therapists in assessing the competence level of carers' environmental problem-solving skills. However, such framework offers limited scope for the understanding of the experience of family carers in various situations over time. This has implication for understanding how carers make subtle decisions about whether they would accept or turn down a recommended intervention programme for those with dementia and themselves.

### **3.5.3      *Encouraging carers to achieve a mental break with restorative effect***

In a phenomenological interview study, Watts and Teitelman (2005) explored how fifteen family carers of individuals with Alzheimer's disease managed to take a restorative mental break, enabling them to cope with the demands of their caring role. The results showed that carers need to be introduced to occupations which enable them to achieve a mental break. Such occupations included engagement in absorbing, pleasurable and productive activities. Therapists helped carers to do this by two methods: firstly, by identifying strategies to safely engage their relative in everyday activities; secondly, by creating opportunity for the carer's own engagement in activities of interest to them. The researchers recommended that future research needs to understand the ethics of caregiving if occupational therapists are to facilitate collaborative working with carers. Otherwise, therapists run a risk recommending intervention that may be ignored by carers as inappropriate. These findings are in keeping with a previous study which stressed a need to develop a better understanding of the 'invisible work of caregiving' (Hasselkus 1988, p.690).

#### ***3.5.4 Using national occupational therapy guidelines for individualised home-based intervention***

In a randomised controlled trial study by Graff et al (2006), the researchers used a system-based intervention protocol which was developed from an occupational therapy guideline for practice in a particular health region in the Netherlands to ensure standardised practice. The aim of this study was to determine the effectiveness of community-based occupational therapy on both the daily functioning of people with dementia and the sense of competence of their carers. The protocol (with detailed procedures for assessments, goal setting and treatment) was developed through a pilot study and built on the basis of consensus among a national panel of qualified occupational therapists.

In this study, one hundred and thirty-five people with mild and moderate dementia were recruited from a memory clinic and the day clinic of a geriatrics department. People with severe behavioural or psychological symptoms, severe illnesses and clinical depression were excluded. Treatment intervention consisted of ten one-hour sessions held over five weeks and focused on both the cared-for and their carers. The first four sessions were used to facilitate both the clients and their carers to choose meaningful activities and prioritise them. The remaining six sessions aimed at providing interventions for both their clients (e.g. focusing on the performance of daily activities with the support of compensatory and environment strategies); and the carers (e.g. providing training to use supervision, problem-solving and coping strategies to maintain their relatives' and their own autonomy and social participation). Both the clients and carers were assessed at baseline (before the intervention), six weeks, and then twelve weeks (follow-up measurement). Following the intervention, the need for assistance in performing daily activities was reduced in the people with dementia as evidenced by the improved scores for their daily functioning, based on the assessment of motor and process skills (AMPS) and the performance scale of the interview of deterioration in daily activities in dementia (IDDD). In addition, the scores for carers were improved on the sense of competence questionnaire (SCQ). Also, at one week after completion of the occupational therapy programme, the carers felt more competent in their ability to provide supervision to sustain the daily performance of these individuals. This effect remained seven weeks after completion of the programme. Hence, the occupational therapy home-based therapy programme improved the daily functioning of those with

dementia and reduced the level of care from their main carers. The findings were consistent with their previous studies (Graff et al 2003, 2006), highlighting that individualised support for carers led to positive outcomes in home-based intervention.

Nevertheless, the researchers acknowledged that there were limitations in the findings since they could not carry out a double blind study because both the clients and their carers knew which therapy they received. Also the researchers commented that it was not possible to blind the occupational therapist to treatment.

Despite some shortcomings in research, it is encouraging to see randomised controlled studies being carried out in the field of occupational therapy in dementia care; especially when carers' needs, in terms of their sense of competences and quality of life, were being addressed in a structured approach. Nevertheless, the home-based programme lasted for only five weeks. It is unclear how the interventions would address the on-going changes experienced by carers, in terms of their sense of competence, as their relatives' everyday performances decline over a longer time.

### ***3.5.5 Limitations of the occupational therapy research studies in dementia care and gaps in knowledge***

Research into the effectiveness of occupational therapy in supporting family carers in their activity engagement during the journey of caregiving is limited. Generalisation of the findings of these studies is limited by weak methodological designs, convenience sample and small sizes. The studies focused mainly on the activity needs of people with mild and moderate dementia, and their carers. Hence, knowledge about the continuing activity needs of people with all stages of dementia and the impact on their carers is fragmented. Also, the published studies were conducted outside the UK and it may not be appropriate to generalise from these findings for the UK due to different health and social care systems. There is an urgent need for research into the understanding of carers' experience of engaging their relatives in everyday activities; and how they develop their coping strategies to continue engaging their relatives in occupation pursuits at home during their caregiving journey.

The previous studies indicate the central position of carers in supporting occupational therapists to implement activity programmes in a community setting; for occupational therapists cannot fulfil their role without the support of family carers.

### **3.6 Conclusion**

To conclude, a review of occupational therapy literature reveals that little is known about how carers manage to engage those with dementia in activity at home. If an home-based activity programme is to be based on the best evidence, it is imperative that occupational therapists gain an insight into : i) the extent to which informal carers could encourage the cared-for to engage in beneficial activities; and ii) the strategies they could employ in different situations during the caregiving journey.

Although the initial impetus for the current research has been from an occupational therapy perspective it is felt that the findings will be useful for other health care professionals. The present study aimed to explore, from the carers' viewpoint, issues concerning the engagement of a person with dementia in his or her own home, by listening to the carers themselves. This will ultimately facilitate the development of a practice framework which can be used to guide practice in dementia care. The aim of the first phase of the present research was to explore co-resident carers' understanding and perception of the need for beneficial activity for people with dementia living at home. The specific objectives of the current study are stated in chapter 5 (see 5.2.3). The next chapter will discuss the methodology used for the present study.

## **Chapter 4     Qualitative Research Methodology**

### **4.1     Rationale**

Qualitative research methodology was considered the most appropriate framework for this study. The reasons for choosing this kind of methodology will be briefly discussed.

#### ***4.1.1   Ontological position:***

The ontological consideration of research is concerned with what we believe about the form and nature of reality (Denzin et al 2005; Patton 2002). It is possible to consider whether there is one reality which forms a singular ‘truth’; or if there are multiple realities which form only part of the truth, or many different ‘truths’. The nature of ‘truth’ is one of the constructed realities in a specific circumstance. This idea is the basis of postmodernism, which over the past few decades has had an impact on the understanding of how knowledge is developed. The concept of postmodernism challenges the ideas which human beings used to take for granted in the nineteenth and first half of the twentieth century, such as universal truth and the objectivity of rational science (Jones and Jones 1998).

The ontological position I take is one of the relativist and constructivist social world. Such a view on the social world assumes that there are multiple constructed realities (Denzin et al 2005). The way in which people interpret their lived experience reflects their construction of reality (Denzin and Lincoln 1998a). ‘Constructions are not more or less “true”, in any absolute sense, but simply more or less informed and/or sophisticated’ (Denzin et al 1994, p.110-111). For example, the social reality, which I investigated, was the social reality of carers of people with dementia who were involved with the cared-for in everyday activities in a home setting. Thus, the carers’ lived experiences and their understanding of the reality of the subject matter, which hold true for the carers, were considered part of the social reality.

#### ***4.1.2   Epistemological position:***

The epistemological perspective is concerned with the understanding of how knowledge is constructed (Silverman 2006); and the relationship between the inquirer and the known (Denzin and Lincoln 2002). The epistemological position I took was a subjectivist and interactional stance. This perspective assumes ‘the inquirer and the



object of investigation are assumed to be interactively linked so that the “findings” are literally created as the investigation proceeds’ (Denzin et al 1994, p.111). Hence, the ‘knower and respondent cocreate understandings’ (Denzin and Lincoln 2008, p.32); and they interact and shape one another’s knowledge (Denzin et al 2005).

I took the stance that the analytical process had taken account of my own interpretation of my understanding of the data. As Strauss (1987) stated, ‘theory ought to be developed in intimate relationship with data, with researchers fully aware of themselves as instruments for developing that general theory’ (p.6). For example, using qualitative methodology, the present project generated specific knowledge about the carers’ social reality by studying carers of people with dementia in their domestic settings. The analysis ultimately provided an alternative understanding of the engagement of people with dementia in activities at home from carers’ perspectives.

#### ***4.1.3 Methodological consideration:***

Methodological consideration is concerned with the general approach used to study research topics (Patton 2002; Denzin et al 2005, Denzin and Lincoln 2008). This includes, for example, the choice they make about the research topic, methods of data gathering and the analysis adopted (Silverman 2006). In a broad sense, the methodological approach I used was qualitative research as the overall aim of the present study was to explore carers’ understanding and perception of the activity engagement of people with dementia with whom they lived.

Qualitative methodology offered a form of social inquiry which allowed me to explore ways in which participants interpreted and made sense of their lived experience. This is relevant to the present study as there is a widespread belief that the experience and knowledge of carers of people with dementia need to be understood (Perrin and May 2000, Charlesworth 2001), especially when they are considered to be ‘experts’ within the context of care for the individuals whom they support (Nolan et al 1995b; Nolan et al 2002a).

A grounded theory approach was considered the most useful methodology for the present research. The reasons for adopting this approach will be briefly discussed in the next section.

## **4.2 Reasons for using grounded theory for the present study**

According to Mason (1996), the decision to adopt a specific strategy for individual study should be based on the nature of the questions which are being asked; and the researcher's circumstances. For the purpose of the present study, alternative approaches were considered. These included phenomenological, ethnographical and a grounded theory approach. Following a process of weighing up the advantages and disadvantages of different approaches, a grounded theory approach was considered to be appropriate to the research question being asked. The decisions for choosing the framework of the grounded theory approach for the present study are discussed below.

### ***4.2.1 The decision to use the grounded theory approach as opposed to a phenomenological study***

Phenomenological study focuses on exploring the lived experience of individuals under study. Researchers seek to understand the way in which a phenomenon is experienced (Creswell 2003; Finlay 2006). This contributes to a deep understanding of lived experiences by exposing taken for granted assumptions (Starks 2007). Analysis involves the use of thick description and close analysis of lived experience to understand how meaning is created. The main aim of the researcher is to provide rich textured description of the lived experience (Finlay and Ballinger 2006). If the purpose of my research was to capture the lived experience of carers in their caring role, a phenomenological approach could have been a useful strategy to enable me to obtain a deep description of what it would be like for carers of people with dementia in such a role. As I was interested in exploring a particular aspect of carers' lived experience in caring (that is, activity engagement with someone they looked after), rather than all aspects of carers' experience in their role, a phenomenological approach did not seem to be appropriate for the current study. Also, as I aimed at developing a substantive theory in the area under study, it appeared that this approach could not offer a strategy which addressed sufficiently the aims and objectives of the present study.

### ***4.2.2 The decision to use the grounded theory approach as opposed to ethnographical study***

Ethnographical study aims to offer a description and interpretation of the culture and social structure of a particular social group of interest or concern (e.g. organisation,

community). Researchers conduct fieldwork that requires them to engage in participant observation through a prolonged immersion in the context under study (Finlay 2006). Hence, participant observation is very closely associated with ethnographic study. The goal of the researchers is to produce thick description and promote an understanding of the particular culture from inside perspective which is not imposed by external ideas. This approach is useful when little is known about a particular culture, or where there have been misleading assumptions or prejudices about the culture of a group (Robson 2002). The focus of my research was to explore specific processes (i.e. engagement in activity) between a person with dementia and a carer rather than the culture within a home environment. Hence, an ethnographic approach did not seem to be appropriate for my research.

Grounded theory methods provided strategies to gather rich data throughout the research process by enabling me to study social processes. According to Strauss and Corbin (1998), the term 'process' is concerned with how people interact and how this interaction changes over time. For example, the process which I explored was the processes by which carers of people with dementia engaged the cared-for in everyday routine activities. This involved carers' narratives of their actions, thoughts and feelings during the process of engaging their relatives in activities. Studying these processes, helped me gain an understanding of what was happening, for instance, how carers interacted with their relatives during the interactions, how such interactions changed over the period of carers' caregiving, and what were the meanings of the actions. A grounded theory approach also enabled me to identify the factors which led to a certain process of interaction occurring in a specific situation. Strauss and Corbin (1998) referred to such factors, which influenced the process of the interaction, as the structural conditions. Grounded theory method enables researchers to study both the structural conditions and the process of a phenomenon through the use of a provisional framework at different stages of the enquiry (example of frameworks will be discussed in the Chapter 5). This in turn enabled me to capture the changes of interaction over time.

Also, a grounded theory approach is considered a useful approach when little is known about the area under investigation (Holloway 1997; Robson 2002). Given that little is known about issues concerning the topic under study, for example, i) how informal carers perceive the use of everyday activities to maintain the well-being of people with

dementia and themselves; and ii) how informal carers use the knowledge to involve individuals with dementia in beneficial activities, it is therefore appropriate to use grounded theory for the present study.

I also adopted the grounded theory method as it provided me with a set of principles to collect and analyse data in order to construct a theory which was grounded in the data (Charmaz 2004, 2006). This method offered me an analytical tool to interact with the data through constant comparison and theoretical sampling. In turn, it enabled me to develop an explanatory theory of the basic social process of carers' perceptions of the activity needs of people with dementia at home (as opposed to institutional settings). Detail about the grounded theory methods will be discussed in chapter 5).

### **4.3 Grounded Theory**

#### ***4.3.1 Historical background of grounded theory - a brief overview***

The grounded theory approach, which was adopted in the present study, was initially developed by Glaser and Strauss in the 1960's. Glaser was educated at Columbia University where his thinking about research was influenced by Columbia University's positivist tradition. He focused on the logic and systematic aspects of grounded theory approach and advocated that it was crucial to ensure that the strategies for conducting qualitative research were explicitly specified in a systematic manner (Charmaz 2004, 2006).

Strauss was educated at the University of Chicago where his approach to research was influenced by the Chicago school of pragmatism and field research tradition (Strauss and Corbin 1998). Pragmatism assumes that human beings are active and creative. 'In pragmatist philosophy, meanings emerge through practical actions to solve problems, and through actions people come to know the world' (Charmaz 2006, p.188). Hence, Strauss stressed the importance of studying process, action and meaning and the Chicago tradition of ethnographic research (Charmaz 2004). His version of grounded theory also reflected his adoption of symbolic interactionism which assumes that people think about their actions rather than just respond to stimuli in a mechanical manner. For him, subjective and social meanings were shaped by how people use their language and often emerged through action. Most importantly, the construction of action was the key concern which needed to be addressed (Charmaz 2006).

Hence, the philosophical underpinning of Strauss's version of grounded theory was particularly relevant to my research. In my research, I aimed to listen to carers' narratives about their interpretation of how they were involved in the everyday activities of their cared-for relatives with dementia over time; and how they reacted to the changes and developed subsequent strategies as the dementia of their relatives progressed.

Despite a contrasting philosophical background between Glaser and Strauss's philosophical perspectives, they both shared an interest in studying fundamental social or social psychological processes within a social setting. In 1967, they published their pioneering book entitled *Discovery of Grounded Theory*, which provided a rationale for the development of this approach at a time when qualitative research was not seen as having any scientific merit. They contended that the grounded theory approach was based on the systematic generation of theory from data through an empirical research process; and discussed how a range of methods could be utilised to ensure the development of theory in a systematic and rigorous manner.

Glaser and Strauss (1967) maintained that researchers should not begin a grounded theory study with any preconceived ideas in mind, but only an area of study; and then allow evolving theories to emerge from the data. For them, the process of data collection, analysis, and the development of theory were interrelated. They argued that grounded theories were highly applicable to the study of daily realities of a substantive area because they were derived from the data of the study. Hence, these kinds of theories have a potential to promote an insight into issues concerning the substantive area. Furthermore, Glaser and Strauss stated that the concept of validation was implicit in the grounded theory approach, which meant that the validity could be ensured if researchers followed a specific set of recommended criteria (Strauss and Glaser 1967; Glaser, 1978; Strauss 1987). This was because they had to defend qualitative research at a critical time in social science history when it was assumed that qualitative research only produced descriptive case studies rather than developed theories; and it was 'impressionistic and unsystematic' (Charmaz 2004, p.498).

Hence, Glaser and Strauss, for the first time in the 1960s, discussed the possibility of using specific methods and strategies to demonstrate the rigour and validity of

developing theory using qualitative analysis in a way which was systematic and transparent.

However, they have since been criticised for being vague. This subsequently invited a number of criticisms from other researchers in the following decades (e.g. Charmaz 1994b; Denzin and Lincoln 1998b). These criticisms included issues in relation to the fact that definitions for many of the terminologies and techniques had not been clarified. These included for example, the major procedures for constant comparison and theoretical sampling; the concepts of analytical tools and coding to conduct analysis; the notion of process and structure; as well as clear criteria to judge the credibility of the research. Moreover, their critics commented that both the founders adopted a positivist and objectivist method to qualitative research (e.g. Guba and Lincoln 1994; Lincoln and Guba 2000; Charmaz 2000). This meant that they assumed that there was an external reality that researchers could discover and record as an unbiased observer (Charmaz 2001, 2004).

Since the publication of the *Discovery Book*, Strauss and Glaser have published other books separately to fill in major gaps noted to the original book, and to update the development of grounded theory methodology (Glaser 1978; Strauss 1987; Glaser 1992). Nevertheless, they appeared to find resonance in their approaches to grounded theory and were reinforcing one another's ideas for the following few decades. For example, Glaser (1978) acknowledged that, although some of the terminologies and specific recommended procedures used in his and Strauss' grounded theory books were not identical, he maintained that all of those terms expressed an identical stance toward qualitative analysis.

Many years later, in 1998, the second edition of the *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* was published by the then late Strauss and the co-author Corbin, in which the authors clarified many of the issues of the first edition, which had been refuted by Glaser in 1992. In this book, Strauss also acknowledged some differences between his and Glaser's version of grounded theory (Strauss and Corbin 1998). Despite this, the book was seen as a significant step towards the development of rigour in the grounded research method (Patton 2002).

Over the past few decades, alongside the divergence in the opinions of the original authors about what grounded theory is, others have written about grounded theory (for example, Swanson 1986; Charmaz 1994a; Dey 1999; Clarke and Friese 2007; Bryant and Charmaz 2007); as well as the original authors (Glaser 1978; Strauss 1987; Glaser 1992) to further explicate the procedures and techniques of grounded theory through their experiences in using them. Some of these procedures and principles were useful for my research, for example: firstly, there was recognition that the development of more explicit procedure guidelines for qualitative analysis was necessary, especially when postgraduate education and research had been expanding (Dey 2007). Secondly, computer software was considered as a useful means to support the management of the massive amount of data and as an audit trail of data collection and analysis (Stern 2007; Dey 2007). Thirdly, the use of diagrams could be used to organise ideas and concepts (Lempert 2007; Clarke and Friese 2007).

Strauss and Corbin (1998) acknowledged that a number of guidelines and procedures had been developed through the research experience of using grounded theory, which further enhanced the effectiveness of this methodology and promoted the creativity of researchers. However, they emphasised that researchers who use their version of the grounded theory methodology needed to consider the conceptions of grounded theory from not only the original *Discovery* book, but also the later more pragmatic and balanced alternations/amendments of that book (Strauss and Corbin 1997, 1998). Hence, it was important that I took a pragmatic approach when adopting the guidelines of grounded theory methods for my research.

#### **4.3.2 *Constructivist grounded theory***

I also broadly subscribed to the constructivist grounded theory version (Charmaz 2001, 2006) because this perspective takes current qualitative methodological developments into account; for example, taking a reflective stance about how knowledge is constructed through interaction between the researchers and the participants.

Charmaz (2000, 2005) contended that the constructivist grounded theory method moved the post positivism approach to a revised form of interpretative inquiry which emphasised its emergent and constructivist element by using flexible and heuristic

strategies (as opposed to prescriptive guidelines). I took a constructivist approach which can be interpreted in terms of there being a material reality but that any social reality (i.e. the meaning of the world) is constructed. I aimed to learn how the participants ‘construct their experience through their actions, intentions, beliefs and feelings’ (Charmaz 2000, p. 499). Also, the analyses focused on understanding the lived experiences from the people concerned. Hence, I attempted to clarify: a) what participants defined as their own view about reality; and b) meanings from not only the participants, but also those of my own as a researcher. Moreover, in my research, I tried to make explicit my own position (e.g. values, perspectives and situations); and how I shaped and analysed the data through interaction with my research participants.

Despite the fact that the methods and procedures being used by many grounded theorists have been modified; the major features of grounded theory, namely, constant comparison, theoretical sampling and the analytical tools have been retained (Strauss and Corbin 1998; Charmaz 2007). These will be discussed in the following section.

### ***4.3.3 The major characteristics of grounded theory***

The major characteristics of this kind of research method include:

#### ***4.3.3.1 Theory development***

A grounded theory approach advocates the discovery of theory or the extension of existing theory by using theoretical sampling for data collection, and the constant comparative method for the qualitative analysis of the data (Glaser and Strauss 1967). There are mainly two basic types of theory building, substantive and formal. Substantive theories are often derived from studying a specific area (Strauss and Corbin 1998). A substantive theory offers a theoretical explanation of ‘a delimited problem in a particular area, such as family relationship, or formal organisation’ (Charmaz 2006, p.189); whereas formal theories arise from studying phenomena under a variety of conditions. Formal theory presents a ‘generic issue or process that cuts across several substantive areas of study’ (Charmaz 2006, p.187). Charmaz (2006) has suggested that a theory which is concerned with the formation of identity is a formal theory because it contributes to the understanding of behaviour in diverse areas such as juvenile gangs and the socialisation of professionals. Both the substantive and formal theories, however, can be considered as middle-range theories because ‘they fall between the



minor working hypotheses of everyday life and the all-inclusive grand theories,’ (Strauss and Corbin 1998, p.32). They signify a set of well-developed categories that are related to each other logically and theoretically through statements of relationship within a theoretical framework. Strauss and Corbin (1998) maintained that since these statements are ‘constructed out of data by the researchers’ (Strauss and Corbin 1998, p.145), such statements should have an ability to explain, predict events and guide action of its users. Hence, the theory should apply to many different circumstances of a given phenomenon under study. The purpose of the present study was to develop a theory at the substantive level.

#### *4.3.3.2 Theoretical sampling*

This refers to recruiting samples according to the emerging concepts with a view to further developing the properties (i.e. *characteristics*) and dimensional range (i.e. *the range of qualities within which properties of a category vary*) of the concepts (Strauss 1987; Strauss and Corbin 1998). When conducting theoretical sampling, the researcher seeks people and events to ‘illuminate the boundaries and relevance of the categories’ (Charmaz 2006, p.189). Throughout the research process, the selection criterion for sampling is based on its theoretical relevance to the development of an emerging theory. The characteristics of each concept are then related to each other for their similarities and differences, as well as relationships to one another (Glaser and Strauss 1967; Glaser 1978; Strauss 1987; Strauss and Corbin 1998). This necessitates researchers to use constant comparative methods (Charmaz 2000).

In general, theoretical sampling is interrelated with the data gathering process and analysis throughout the research process. I took measures to adhere to the principles of this kind of sampling method; and provided strategies to select samples at different stages of analysis, depending on its relevancy to the developing theory. This issue will be discussed further in the next chapter (see 5.4.7).

#### *4.3.3.3 Constant comparison*

This refers to the constant comparison of existing data to incoming data, data to concepts, and the initial concepts to emerging concepts with a view to exploring, to the fullest extent, variations in patterns in the data, until no more new concepts emerge (Strauss and Corbin 1998). Details will be discussed further in the next chapter.

#### *4.3.3.4 Other features*

These include strategies in terms of the use of a coding system, and questions (i.e. asking who? when? where? what consequences? how frequently? and why? during the analysis). The use of questions aims at enhancing researchers' understanding of the theoretical issues, and opening up the data, and thinking of potential categories including their properties and dimensions (Glaser and Strauss 1967). Detail of specific techniques and coding system I used for the present study will be discussed in chapter 5 (see 5.6.2.1).

To summarise, these major features of grounded theory are considered essential analytical procedures (Strauss and Corbin 1990, 1998); enabling researchers to achieve the following goals: i) sensitivity towards theoretical issues; ii) awareness of unrecognised bias; and iii) ability to overcome some analytic blockages or barriers.

#### **4.4 The position of the researcher**

Given that my professional background is an occupational therapy lecturer who has a principal interest in the relationships of activity, well-being of people with dementia and their carers, I often ask questions about how people manage activities, as well as the impact of various activities on the individual's health and well-being. In addition, having worked with people with dementia and their carers in the community for many years within the health and social care structure, my philosophical stance is inevitably shaped by the experience and interactions I have had with this particular client group and their carers. Hence, my perspective, values and experiences have influenced the way in which I carried out the research process.

Denzin (2001) pointed out that qualitative researcher is often involved in the social world in which a substantive area is being studied. When evaluating the rigour and credibility of the present study, I was guided by a range of principles for demonstrating rigour and quality in qualitative research throughout the research process. For example, I adopted the constant comparative method of a grounded theory approach, taking the findings back to the participants for their comments on the findings and checking if they recognised themselves in them. I also used reflexivity throughout the research process (please see 5.7.4 for detail). Issues concerning the criterion for evaluation of the study will be discussed further in chapter five (see 5.7).

#### **4.5 Reasons for data collection methods used**

While using a grounded theory approach, data were collected through interviews (phase one) and focus groups (phase two). The reasons for using in-depth interviews for data collection rather than alternative methods in phase one will be discussed in chapter 5 (see 5.1.2); whereas the reasons for using focus group will be discussed in chapter 7 (see 7.3.1).

During the process of inquiry, in-depth interviews (phase one) and focus groups (phase two) were used to elicit the value-laden aspect of the social reality of the informal carers in relation to how they managed to engage people with dementia in activities at home. Data were generated through several sources. For example, firstly, a dialectical interchange between the participants and myself, which also included issues I raised with the participants in the interviews and focus groups. The fully transcribed transcripts formed a major source of the data for analysis; secondly, my field notes and memos which recorded my observations and preliminary analysis; thirdly, relevant literature I used to alert me if the research topic addressed a gap in knowledge within caregiving in dementia care. Through synthesising and interpreting these data, I explored co-residents carers' perspectives of how the activity engagement of the cared-for persons changed over time, and how carers reacted to the changes in terms of the development of strategies.

In the beginning of my research, I had considered the use of participant observation. A major advantage of this method is that it allows researchers to gather information by actively participating in the everyday life of the participants to 'carefully observe their joys and sufferings as a way of obtaining material for social scientific study' (Tedlock 2008, p.151). Nevertheless, the use of participant observation might not be appropriate for my research for three reasons. One, given that co-resident carers in the present study often took on a round-the-clock caring responsibility, and in potentially unstable daily circumstances, the presence of a researcher who observed them for a long period of time in their home setting might add further strain on carers in a possibly already tense environment. Secondly, carers might behave differently with the presence of a researcher and therefore it was doubtful if an insider's perspective could be elicited by using such approach. Thirdly, the presence of the researcher in the home setting might

confuse the person with dementia who had a varying degree of cognitive impairment. This would have a knock on effect on the actions and behaviour of the carers. Hence, I felt that participant observation may have been intrusive to both the carers and the people they cared for although it could potentially provide a rich source of data for the present study. Furthermore, a practical problem with observation is the large time commitment if an immersion in the culture of the research setting is to be achieved (Robson 2002). Given that carers often spent years caring for their relatives, using the participant observation method would mean that I would have needed to spend a great deal of time observing participants' actions at different points during the course of their caregiving; whereas in-depth interviews allowed me to collect data through listening to participants' account of their experiences in a relatively shorter time frame in phase one.

#### **4.6 Conclusion**

To summarise, grounded theory offered a useful approach for the present study. As a result, the findings of the present study not only contributed to a deeper understanding of the process in which the activity needs of people with dementia were being met by their carers at home; but also facilitated the process of developing ideas from the data, and generated a substantive theory from such data. This was an essential first step to identifying and developing a more realistic intervention strategy to meet the needs of both people with dementia and their carers in their homes. This will ultimately enable occupational therapists and other service providers to deliver evidence-based services which comply with national requirements, and are consistent with the professional consensus on good practice.

## **Chapter 5     Method - Phase One Study**

### **5.1     Overall Design**

#### ***5.1.1    Grounded theory approach***

Grounded theory methods provided useful research strategies for studying carers' perceptions of the activity needs of people with dementia at home. In phase one, data were collected via in-depth interviews. Through the process of data analysis, I aimed to generate ideas and concepts which facilitated the development of theory, inductively and deductively, using the constant comparative method. As Strauss (1987, p.14) stated, 'many people mistakenly refer to grounded theory as "inductive theory"...But as we - Strauss and Glaser - have indicated, all three aspects of inquiry (induction, deduction, and verification) are absolutely essential'. For example, my previous clinical experience within community mental health teams and knowledge led me to develop an initial idea about an area of study. I then raised the initial question of how carers involved people with dementia in activities. Hence, the initial idea for the research study and concepts for investigation were derived both from literature and my previous experience. In this sense, it could be said that deductions were made from literature in the form of hypotheses that led to my initial decision for sampling (see section 5.3.2 for detail). However, I was conscious that the initial general research area and related concepts were provisional ideas at this stage. I needed to keep an open mind about these initial concepts and avoid any taken-for-granted assumptions. Once the data collection from the first few interviews began, I looked for evidence to support or reject the initial ideas by comparing them with the incoming concepts in the data. Thus, I developed my understanding of an emerging research model based on issues raised by the participants, rather than on any preconceived ideas about the research area under study.

#### ***5.1.2    The reasons for using interviews for data collection***

For the purpose of the phase one study, alternative methods of data gathering techniques were initially considered. These included: i) postal questionnaires; ii) participant observation; and iii) focus groups. The major advantages of a face-to-face in-depth interview over the other methods are summarised as follows:

#### *5.1.2.1 Interview versus postal questionnaire*

Questionnaires are usually less expensive to administer. They have the potential to cover a wider area and gather data from a great number of people (Bourque and Fielder 1995; Robson 2002). However, I wanted to obtain in-depth and detailed responses from participants, and to elicit information that was both complex and emotional (Chenitz and Swanson 1986; Gillham 2005).

An interview enabled the participants to respond more fully and allowed me a greater flexibility in interacting with the participants (Gillham 2005; Denzin 2001). In addition, interviewing allowed me to co-create an agenda with participants within an interview; whereas in using a questionnaire, I would have set the agenda for the process of inquiry without the participants. As Denzin (2001) pointed out, the use of interviews underlies the assumption that ‘meanings, understandings, and interpretations cannot be standardized; they cannot be obtained through the use of a formal, fixed-choice questionnaire...[an interview] should be give-and-take between two persons’ (p. 66). Hence, a questionnaire would have limited my opportunity to interact with the participants and ask them to clarify issues during the process of data collection.

#### *5.1.2.2 Interview versus participant observation*

Participant observation allows researcher to gather information from the ‘observed talk and action of participants’ in the real setting (Huberman and Miles, 2002, p.106). This would cover actual behaviour, not just perceptions of events, giving much more information about what actually happens. Despite this key advantage, participant observation was not appropriate for the phase one study of my research for various reasons as discussed in earlier in section 4.2.2.

#### *5.1.2.3 Interview versus focus group*

Although using a group interview offers a potentially inexpensive method, which generates cumulative and rich data by talking to several people at the same time (Fontana and Frey 1998, 2008), nevertheless, ‘the emerging group culture may interfere with individual expression’ when investigating topics of a sensitive nature in a group format (Fontana and Frey 1998, p.55). The initial aim of the phase one study was to explore carers’ perspectives in their engagement with their relatives’ everyday routine activities; individual interviews allowed greater flexibility in communication and in

eliciting information from participants. The co-resident carers were encouraged to confront and discuss their own difficulties and successes. They needed to be able to discuss these issues without having any sense of guilt or devolution of duty imposed upon them by others. The face-to-face interview which lasted between one and two hours helped me develop rapport with the participants which, in turn, possibly facilitated responses to sensitive questions which were potentially embarrassing or threatening in nature.

Also, I interviewed participants in their own home which offered me the opportunity to observe participants' home environment where they organized daily activities for their relative. This provided a rich context for data being collected through the research process (Fontana and Frey 1998). For example, during interviews, participants often showed me the layout of the home settings such as the kitchen, living rooms and garden which facilitated my understanding of how carers organised everyday activities for their relative within the home environment and the meanings attached to such activities.

## **5.2 Aim**

### **5.2.1 Initial aim**

The initial aim was to explore co-resident carers' understanding and perception of the need for beneficial activity for people with dementia living at home.

### **5.2.2 Definitions**

For the purpose of the study, concepts such as co-resident carers, beneficial activity, people with dementia and home are defined below:

- a) Co-resident carers refer to people living with an individual with dementia in the same household for at least two years. They considered themselves as carers, and had been offering some level of caring responsibilities to a person with dementia.
- b) Beneficial activity refers to any daily living activities that had positive meaning for people with dementia who engaged in them, as perceived by the co-resident carers.
- c) People with dementia refer to people who had been formally given a diagnosis of dementia including senile dementia of the Alzheimer's type, vascular dementia or dementia with Lewy's bodies.
- d) Home refers to where both the carers and the people with dementia resided.

### **5.2.3 Objectives**

In order to achieve the aim, the following objectives were to be addressed.

To explore co-resident carers' perceptions of:

- a) What the characteristics of beneficial activity were for people with dementia.
- b) How beneficial activity affected the lives of the cared-for.
- c) How beneficial activity affected their own lives.
- d) How they managed to make judgments about the level of functioning of the cared-for, in order to engage them in activities which were considered to be beneficial.
- e) The factors which created barriers that prevented the people with dementia engaging in such activities.
- f) The factors which affected the degree to which co-resident carers felt they could influence how the people with dementia engaged in beneficial activities.

### **5.2.4 The final aim of the research**

As the study progressed, owing to its exploratory nature the aim of the study changed. This section outlines how the final aim and research question of the study developed from the original aim of the study.

One aspect which I found difficult was that, as an occupational therapist, I felt that I knew what I meant by beneficial activity, that is, engagement that signifies a sense of active involvement in the chosen activities which are perceived as meaningful to those involved in it. Nevertheless, when talking with people in general, this technical, professional term did not always make sense to them but they were happy to talk about everyday activities in general. This opened up the field for discussion and the aims of the study broadened into everyday activities in general.

Through using a series of frameworks, I explored the social processes by which family carers engaged their relative in everyday routine activities at home. This involved listening to carers' accounts of their thoughts, actions and feelings when they engaged their relative in everyday occupations. Studying these processes of engagement, helped me to gain an understanding of what was happening - for instance, how carers perceived the difficulties they encountered, how these changed over time; and how they developed



subsequent strategies to meet their relative's continuing activity needs. I began to realise that the processes by which family carers engaged their relative in the everyday routine activities were very complex and long-term.

A recurrent theme which emerged as important to carers themselves was their activity-related decision-making. Carers frequently talked about having to take over the responsibility of making constant and complex decisions for their relative, and the complexity of the processes involved. Due to the enormous amount of data that I could have gathered I decided to focus on this aspect - furthering understanding of carers' activity-related decision-making processes.

Therefore the final aim of the research was: *to explore co-resident carers' decision-making processes related to their engagement in the everyday routine activities of their relative.*

### **5.3. Participants**

#### **5.3.1 Inclusion and exclusion criteria**

The inclusion criteria incorporated those people who:

a) had been living in the same household with a cared-for person who had been given a confirmed diagnosis of dementia.

b) had been offering some level of caring responsibility to the cared-for with dementia for at least two years prior to an initial interview. These carers:

- would probably have an awareness of the extent to which the person with dementia had changed his/her long-term habits, routines and ways of performing daily activity as a result of the illness;
  - would probably have experience in involving the individual with dementia in some kinds of activities when carrying out their caring responsibilities; and
  - would probably have had experience of being confronted with difficult circumstances when attempting to engage the person with dementia in activities which they considered beneficial to this individual. These carers were, therefore, in a better position to offer insights into issues being raised by the research questions.
- If there was more than one carer who looked after an individual with dementia in the same household, they would also be invited to take part in the study.

- c) had been living in a household supported by a Community Mental Health Team for Older People in East Kent.
- d) the consultant psychiatrists of the community teams could confirm whether they were looking after someone with a confirmed diagnosis.
- e) were willing to be interviewed and talk for between one and two hours on audiotape.

The exclusion criteria excluded those who were unable to:

- a) take part in an audio-taped interview due to difficulties in communicating freely as a result of any medical conditions which affect their speech. These people included for example, those suffering from stroke and learning disabilities.
- b) communicate in English because financial resources were not available to pay for an interpretation service.

### **5.3.2 *Initial sampling issues***

At the beginning of the present study, there were many sampling issues that I had to think through.

Co-resident carers were a significant group, so this was the one I chose for the phase one study. I used purposive sampling methods for the selection of participants (Morgan and Scannell 1998). I concentrated on gaining as many differing perspectives in order to gather a wide range of relevant data (Strauss and Corbin 1998). The participants varied in gender, age, marital relationships and the duration of caring responsibility, all of which I felt may affect their perceptions.

I initially estimated that between 25 and 30 participants would be included in the sampling procedure, although the final numbers would be guided by the emerging theory. As Chenitz and Swanson (1986, p.70) pointed out, ‘only 20-50 interviews are necessary to elicit major repetitive themes of the topic under study’; whilst Stern (2007) suggested that she usually required 20 - 30 interviews to reach saturation of the categories.

### **5.3.3 *Ongoing sampling issues***

Nevertheless, once the research process started, and the analysis of the data progressed, I tried to adhere to the principle of theoretical sampling (see 4.3.3.2) as far as I possibly could during the research process. This meant that the selection criteria for sampling were based on its theoretical relevance to the development of an emerging theory (Glaser and Strauss 1967; Strauss and Corbin 1990, 1998). For example, following the preliminary analysis, I developed concepts such as being a carer, sharing and understanding (see 6.1.2 for details). The data for the analysis came from a female spouse, a male spouse and a female daughter. I therefore decided to interview a carer who had a different relationship to the cared-for (i.e. a female friend who was not a spouse) so that I could explore the emerging concepts in more depth. Through selection of samples, guided by analysis, I was able to not only generate the diversity of relevant data, but also further the development of the properties of the categories. Theoretical sampling became increasingly focused when the main categories (such as illogical and dispossessed activity patterns) emerged (see detail in section 6.2). At this point, theoretical sampling was achieved by choosing participants who were most likely to provide me with incidents and events which would allow me to further refine and develop those emergent categories for theory development. For example, I made an effort to recruit people who were caring for a relative with much longer duration, or who were not spousal carers.

I realised that it was impossible to achieve theoretical sampling in a true sense. This was perhaps due to the fact that it was difficult to both access a sufficient number of participants and maintain a pool of potential participants for the theoretical sampling at all times in the busy community clinical settings.

## **5.4 Procedure prior to data collection**

### **5.4.1 *Use of literature***

The use of literature prior to data collection in grounded theory is a controversial topic. Glaser and Strauss (1967) maintained that researchers do not need to review all of the literature prior to a study because they should not begin any studies with preconceived assumptions. However, Strauss and Corbin (1990, 1998) acknowledged that researchers need to use literature to prepare an appropriate research question for the purpose of ethical approval for research projects.

I adopted a pragmatic approach to the use of literature, firstly, because I had to prepare a protocol for ethics approval. By conducting a literature review around the subject under investigation, I was able to develop a general area for the research topic to indicate a substantive area of a study; and to highlight gaps in knowledge prior to the study. This also allowed me to justify the rationale for the study to other people involved in the research process (for example, management team, consultants and frontline workers in the recruitment teams).

Secondly it assisted me with the initial sampling decisions as highlighted in section 5.3.2

Thirdly, later during data collection I compared emerging concepts to those already highlighted in the literature; this helped to alert me to concepts which were significant to the development of an emerging theory in a substantive area and develop theoretical sensitivity (Bartlett and Payne 1997). I kept an open mind to new data from fieldwork, and to replace and refine earlier concepts by using strategies such as constant comparison method. This was to help me avoid preconception of learnt concepts during the process of data analysis (Strauss and Corbin 1998; Charmaz 2006; Dey 2007).

#### ***5.4.2 Trust approval***

The research was conducted within areas covered by two Community Mental Health Teams for Older People (CMHTOP) within an Older People with Mental Health Need Services (OPMHN) in East Kent. These two teams covered two geographical areas where I had previous experience of working.

Prior to the implementation of the study, issues concerning ethics, research governance, informed consent and confidentiality were considered. During the process of planning for the research protocol and gaining access to the potential participants, I took measures to ensure that the guidelines of the clinical governance framework for health and social care were adhered to.

This study began before the national research governance guidelines were in place. Prior to submission of the protocol to the Local Ethics Committee covering the geographical areas of the data collection in East Kent, I submitted a copy of the research

protocol to the Research and Development Group for the Mental Health Directorate of the East Kent NHS Partnership Trust (R& D Group) for scientific review and management approval.

#### ***5.4.3 Ethical approval***

Once the letter of approval was obtained from the chairperson of the R & D Group (Appendix 1), I submitted an application to the East Kent Local Research Ethics Committee, including a copy of the scientific referees report from the R & D Group for ethical approval. Ethical approval was granted in October 2003 (Appendix 2). There were several ethical issues raised with this research including safeguarding confidentiality: a) of the personal records: keeping them with the researcher at all times when not in locked cabinet; b) of data: coding the audio-tapes with numbers and keeping them securely in locked filing cabinets, transcripts were only reviewed by me and my supervisors during the period of study; c) within reports: by using pseudonyms; and d) within conference presentations.

Moreover, during the interviews, I took care to ensure that the interviews would not unduly distress the participants. If the participants became upset in the interview as they talked about the experience of caring for individuals with dementia, I switched off the tape recorder at once and offered them reassurance. I then asked if they would like to continue with the interview. If the participant preferred to end the interview, this would take place. If the participant wanted to arrange to be interviewed on another day, their wishes were respected. Having worked as a community occupational therapist with clients with mental health problems and their carers for many years in my previous job, I was able to utilize my clinical and counselling skills to deal with any difficult circumstances when they arose. Also, I advised participants to discuss issues further with their GP or other relevant professionals as required. In addition, prior to the research study, I had sought the support of the Head of the Psychology Department of the NHS Trust where phase one of the study was conducted; I could refer the participants to the psychology services for further support if required. Consent would be obtained from the participants prior to making the referral.

#### **5.4.4 Research governance**

It was important to ensure that data were stored in a manner that satisfied the Data Protection Act 1998. Hence, I took measures to ensure that the Data Protection Principles were adhered to at all times and that all reasonable efforts were made to secure the participants' consent to subsequent use of data.

Following ethical approval, I approached the Head of the Occupational Therapy Department to assist with setting up an honorary contract with the East Kent NHS Partnership Trust prior to conducting the research within the Trust. This contract allowed me access to information of a confidential nature. During the course of this contract, the Head Occupational Therapist acted as a line manager for me within the Trust.

Also, I contacted the insurance administrator of the University of Southampton to obtain insurance cover for the approved research project. I subsequently received a statement of professional indemnity (Appendix 3).

#### **5.4.5 Risk assessment**

I followed the Health and Safety policy of the University of Southampton and any special regulations within the Trust when carrying out research activities. For example, I adopted the research fieldwork risk assessment guidelines as set out in the School Lone Policy prior to making arrangements to meet the participants. I took particular care of issues regarding the potential hazards to the researcher as a lone worker. I identified the potential hazards which might occur whilst getting to and from locations. Procedures were subsequently developed to minimize the potential risks, including areas en-route to the location, at the location, and crossed after visits (details of risk assessment can be seen in Appendix 4).

#### **5.4.6 Gaining access to the setting**

Prior to gaining ethical approval, I spoke with the consultants of the Community Mental Health Teams and the occupational therapy manager, and they had all agreed to support my research study once I obtained the ethical approval and research governance.

Following the ethical approval, I ensured that all relevant staff of the clinical teams and all relevant managers of the Older People with Mental Health Needs were informed of my research project, and offered support to the implementation of the study. The following steps were taken:

- a) I sent a letter (Appendix 5) together with an abbreviated protocol to each consultant with a view to explaining the nature of the research and gaining their permission to access potential participants.
- b) I then conducted a series of meetings with the consultant psychiatrists and the clinicians to explain the procedure of selecting potential participants.
- c) I also informed all relevant managers of the Older People with Mental Health Needs about the nature of the research project. These managers included the Medical Director, the Director of Health and Social Care, the Heads of the Community Psychiatric Nurses Services, the Psychology Services and the Occupational Therapy Services. A meeting was offered for them to ask questions.

#### ***5.4.7 Creation of a participant pool***

In an attempt to follow the principle of theoretical sampling procedure throughout the study, I asked the consultants to help me develop a pool of potential participants and to provide me with some demographic data by completing a record sheet for each carer they contacted on my behalf.

I provided the consultants with an information pack with a supplementary note (see Appendix 6) which explained the procedures for selecting potential participants and using the register. The benefits of using a register of a pool of potential participants and the record sheet were to ensure that I would have:

- i) sufficient samples for the analysis at different stages of data collection and analysis;
- ii) greater flexibility in selecting samples by adopting the principle of theoretical sampling throughout the process of data gathering;
- iii) an opportunity to provide a practice guide for the consultants to follow the process of selecting potential participants for the study;
- iv) a chance to streamline the administrative procedure for the consultants; and
- v) the autonomy to double check if the participants fulfilled the criteria prior to an invitation letter being sent out. For example, on one occasion, I was able to identify a

participant who was suspected to be suffering from memory loss at the time. I therefore requested the consultants to withdraw the potential participant from the register following a discussion with the psychiatrist involved in the recruitment procedure.

Thus, the record sheet in the information pack provided me not only with an understanding of the initial profile of the potential participants, but also useful information from which I selected targeted participants as the research progressed.

#### **5.4.8 Recruitment of participants**

Following the consultants' approval, they identified potential participants from their caseloads. The potential participants were invited to take part in two interviews via invitation letters with a reply slip sent via the consultants (see Appendix 7). Once I received the reply slips from the participants, indicating they were happy to be contacted, I then contacted them by telephone initially to:

- a) explain the nature of the research and inform them that I would send them a pack with a detailed information sheet and an information leaflet for sharing with the people they cared for (see Appendix 8 a & b), encouraging them to explain the nature of the project to the people they cared for (where appropriate), so that these individuals were aware of what was going on;
- b) ask them to sign the consent forms (see Appendix 9) and to return them using enclosed self-addressed envelopes if they agreed to the interviews taking place;
- c) reassure them that confidentiality would be maintained at all times.

### **5.5 Data collection - conducting interviews**

#### **5.5.1 The development of an interview guide**

I developed an initial interview guide. The questions were broadly divided into two sections covering factual and open ended questions (see Appendix 10). The order of the questions was arranged according to the degrees of complexity, going from the general to the specific. Questions asked in the early part were considered to be non-threatening and easy for the participants to answer. More complex questions or questions relating to potentially embarrassing subjects were asked towards the end of the session when rapport had been developed to its highest level, and individual participants had built up trust with me.



The overall aim of the guide was to act as a guideline for the interview. The phrasing and the sequence of the questions were adjusted depending on both the response of an individual participant and the aims of the specific data collection process.

### **5.5.2 *Piloting***

Prior to the study, I conducted a pilot study with two participants who had been chosen by the same criteria as those in the research (Hollway 1997; Gillham 2005). They agreed to take part in a tape-recorded interview in their own home. They were recruited through my previous work connection. The overall aims of the pilot were to:

- test my practical skills in using the equipment (audio-cassette recorder) so that I could avoid or minimize mishaps;
- practice the interview guide so that I could make changes in question wording and identify prompts as required;
- practice my interviewing technique in order to promote my confidence in conducting a research project (Hollway 1997; Gillham 2005).

Following the pilot study, I shared sections of the tape-recorded interviews with my supervisors in order to obtain their feedback and comments on my interviewing skills. This enabled me to gain insight into the strength and weakness of my interviewing technique.

The pilot study went well and gave me confidence in the use of the equipment and the interview guide. It appeared that the interview guide which offered a broad, open-ended set of questions was an appropriate tool for the phase one study. It enabled me to explore carers' perceptions of their involvement in the activity engagement of their relatives. The prompts were useful when I needed to follow up the interviewee's responses. As a result, I felt that there was no need to reduce the number of topics or questions under each topic heading. No major amendments were needed for the interview guide.

On reflection, I realised that there was a real difference between conducting interviews for clinical work and research purposes. One key message I learnt from this experience was that, having been a practitioner in dementia care for many years and having conducted numerous interviews with the carers of people with dementia, I could

potentially fall into the trap of putting professional interest before the interest of the carers of people with dementia. For example, I had a tendency to offer prompts to questions too soon rather than allow participants enough time to give me accounts of their experiences in their own time. This was because I entered my research study with preconceived assumptions about the circumstances of the participants resulting from my professional background as a therapist.

The insight I gained from the pilot study was that I had become aware of the need to take measures to keep an open-mind about the data and to avoid potential biases when conducting the research project. One of the strategies I have since adopted was to regularly reflect on the experience after an interview. It was crucial for me to raise the awareness of my own thoughts and preconceived ideas I had before an interview so that I could work on strategies to minimize its influence. Moreover, I had also become aware that I needed to remind myself frequently to sit back and listen to interviewees, as well as make efforts to reassure them so that they felt free to express their views.

### **5.5.3 Initial interviews**

Participants were invited to take part in two in-depth audio-taped interviews. The duration of the interviews ranged from 90 to 120 minutes. On arrival, I went over the information sheets for participants again if necessary and checked that written consent was given. Once the person was settled we moved onto the interview itself. Areas covered by the interview were:

- how participants involved the cared-for-person in activities which were considered beneficial to the person;
- concerns they had;
- whether they felt that they could influence how the cared-for person engaged in activities;
- how they would like to be supported during the process of involving individuals with dementia in activities at home;
- what kinds of help or assistance they would like to receive in order to enable them to involve the cared-for activities; and
- what kinds of issues they would like professionals to know about in respect of activity engagement for people with dementia.

Following each visit, I kept a record of the following information including: code number of each interview, data of the interviews, age, gender, other information pertinent to the research question, the span of time allocation for data gathering, and the arrangement for follow-up visit. This information sheet was then attached to the top of each interview after it was transcribed to help retrieve demographic data and specific interview content.

#### ***5.5.4 Follow-up interviews/member checking***

Each participant was informed that I would conduct a follow-up interview within two months of the initial interview. The aim of this interview was to invite the participant to clarify meanings within their interviews as part of the process of analysis. As Swanson (1986, p.69) stated, it might be necessary for the researchers to see participants over time in order to ‘account for phases in a process or to check their perceptions of phenomena which arise later in the study’.

During the follow-up interviews, I took issues which had been identified from the analysis of around two to three interviews back to each participant for their comments. This meant that I conducted member-checking with the participants by taking emerging concepts back to them for their confirmation (Holloway and Wheeler 2002; Charmaz 2006). Each participant was told that those were issues raised by carers involved in the project so far and that I introduced each issue by saying, ‘...is this something that is an issue for you? (or not), in what way is it /or isn't it etc’, and used the key point as a starting point for a general discussion around the area. Through this process, I was able to check if and to what extent the emerging concepts/categories fitted with each participant’s experiences. This then enabled me to refine and develop the properties of these categories, as well as to generate new categories.

### **5.6 Analysis**

#### ***5.6.1 Transcription and storage***

All interviews were transcribed verbatim, coded line-by-line and then analysed using open coding and axial coding at the initial stage of data analysis (see details in 5.6.2.1). I familiarized myself with interview data by listening to each recorded interview and reading through each transcript at least three or four times. This offered me not only an overall feel for the content of each of the transcripts but also an opportunity to interact

deeply with the data. As Strauss (1987) highlighted, listening and transcription are essential processes of data analysis. Through the process of listening and reading, I took the following measures to prepare the transcripts for further analysis as outline below:

- a) Checking through the transcripts against the audio-tape and identifying any areas of the tape interviews that had recorded badly and were difficult to hear.
- b) Ensuring that all transcripts were set out in a consistent format for analysis (Gillham 2005). For example, I used capital letters for main questions, and italics for supplementary questions, prompts and probes. I labelled each transcript with a letter and number, as well as stating whether it was from a follow-up interview. This was to ensure that the source of a particular statement could be referenced: for example, C1 would mean the first interviewee; C1f meant follow up interview. Each participant had a code number and pseudonym. Quotations in text were identified by code and line numbers (e.g. C1f : 20-23). Material that was not transcribed because inaudible was marked by squared brackets [...]; whilst information about the expressions of mood, emotion and tone were inserted in closed brackets using italics, e.g. (*raised tone, looking very angry*). Appropriate punctuation was used for speech. An ellipsis (three or more dots) was used to show how speech patterns are represented. Hyphen ( - ) was used to indicate pauses. Speech hesitations such as umm, err were transcribed to illustrate the ways which different participants conveyed their messages across. An example of how the transcripts were set out and how transcription notations were used can be seen in a typical page of transcription in Appendix 11.
- c) Once the transcripts were prepared, I entered them into a Computer-Assisted Qualitative Data Analysis Software (CAQDAS) programme, that is, NUD·IST 6 (Non-numerical Unstructured Data Indexing Searching and Theorizing), commonly known as N6. The N6 programme provided me with some facilities which enhanced the process of data management and analysis. For example, I used the document system to store, sort, search and pull out parts of documents within the document system. Once I imported the documents (i.e. data) onto the system, I was able to browse and code text on screen. Hence, some advantages of this program were its ability to help me see the immediate effects of my actions, such as coding and

recoding (Gahan and Hannibal 1999), and potentially save time for some administrative work (Seale 2000). I found that I had no longer to manually cut and paste sections of documents for analysis as I did for a previous postgraduate research project (MSc).

I used the document system in N6 mainly as ways to manage the data of my research project electronically. The key tasks are outlined below:

- store transcripts so that the data could be retrieved electronically,
- organize all transcripts for the coding process on screen,
- explore data on screen using line-by line coding,
- use the index system (free nodes and tree nodes) to assist with, naming/renaming and coding. That meant that I could organise the codes at descriptive and more abstract levels and move them around electronically as they were refined and developed,
- write notes on memos to assist with reflexivity and audit trail,
- produce print-out when I needed to work with a hard copy of a document or sections of a document outside the computer.

In short, I used the document system in N6 to manage the data of my research project electronically. This in turn facilitated the process of linking data and developing concepts through coding to some degree. Gahan and Hannibal (1999) pointed out that researchers can maximize the use of the N6 by not only importing transcripts into the software, but also making notes about substantive statements and their related codes, so that they can present data in a tree diagram or matrix form. I limited the use of N6 mainly for data management as I did not want to be restricted to the possible N6 structures provided. As Gillham (2005, p.147) stated that ‘computers are the most versatile machines ever produced but they are still machines: they can only be used intelligently by the human mind’.

### **5.6.2 Overall analysis**

During the research process, I used the constant comparison method to compare data throughout the study. This meant that the characteristics of each concept were compared to the incoming data for their similarities and differences, as well as relationships to one another. This procedure maximized opportunities to generate variations among

concepts, as well as to check and refine categories. The relationships between patterns were then identified and analyzed. As the research study continued to progress further, the sampling for later interviews became more focused with a view to collecting specific data to further develop the properties of emerging categories by using the theoretical sampling method and constant comparisons. This process was ongoing until the point of saturation was reached. Saturation implies that same concepts and ideas came up frequently but there was no more new data emerged for further analysis (Glaser and Strauss 1967; Holloway 1997; Strauss and Corbin 1998). It seemed that this was reached for several categories towards the later part of the first phase of this study. Such categories included recognisable pattern and illogical activity patterns (details can be seen section 6.2). I will now describe the data analysis strategies in more detail.

#### *5.6.2.1 Coding system*

Strauss and Corbin (1990, 1998) have suggested that there are three major types of coding, namely, open, axial, and selective coding. This will be discussed below:

##### *a) The use of open coding*

The main purposes of open coding were to : i) open up data, that was generating concepts and developing categories from the data to the fullest extent; and ii) determine the characteristics of the concepts and categories for further analysis.

I used the open coding method to conduct the initial analysis, as it helped to promote the generation of concepts and developed the characteristics of these concepts from the data. An example of how coding was carried can be found in Appendix 12. During this process, I examined each line of data, studying actions and events within. Hence, line-by-line coding provided a basis for constant comparison and development of concepts from data. As Charmaz (2005) suggested, this kind of coding enables the researcher to make ‘a close study of the data and lays the foundation for synthesizing it’ (p.517).

##### *b) The use of axial coding*

In later interviews, I also used axial coding to explore variations in patterns in the data (Strauss and Corbin 1998; Strauss 1994). The purposes of using axial coding for the present study were to facilitate the process of: i) relating categories with a view to further developing their characteristics in terms of properties and dimensions; ii) linking

a category to its subcategories through statements to indicate how they were related to each other; and iii) identifying circumstances associated with a phenomenon under study by using a coding framework. Examples of the identified concepts could be seen in the poster presentation (Appendix 13).

The actual process of axial coding was complex. When I used axial coding, I also conducted the analysis by adopting the principles of a coding paradigm. The coding paradigm is an organisation scheme or framework which helps to denote condition, context, action/ interactional strategies and consequences (Strauss and Corbin 1990, 1998). An illustration of how I explored these components of a specific phenomenon can be seen in a memo in Appendix 15. Strauss and Corbin maintained that researchers could use axial coding together with the coding framework as a strategy to help them think theoretically and comparatively about data in a systematic way during analysis. This enabled me to capture the dynamic flow of the events and the complex nature of relationships among the concepts and categories. Charmaz (2000) agreed that these procedures could be helpful to novice researchers, especially if they wanted to develop a theory which is more complex and denser. Nevertheless, I was aware that I needed to keep an open mind about the emerging data and avoid being imposed upon by using a framework in a rigid manner.

#### *c) The use of selective coding*

Strauss and Corbin (1998, p.160) highlighted, ‘selective coding is the process of integrating and refining the theory’, and should not be initiated until major categories are finally developed in order to minimize the risk of premature development of theory (Strauss and Corbin 1990, 1998). Thus, I used selective coding at later stages of the analysis when core categories were being identified. This coding was more conceptual and focused than line-by-line coding.

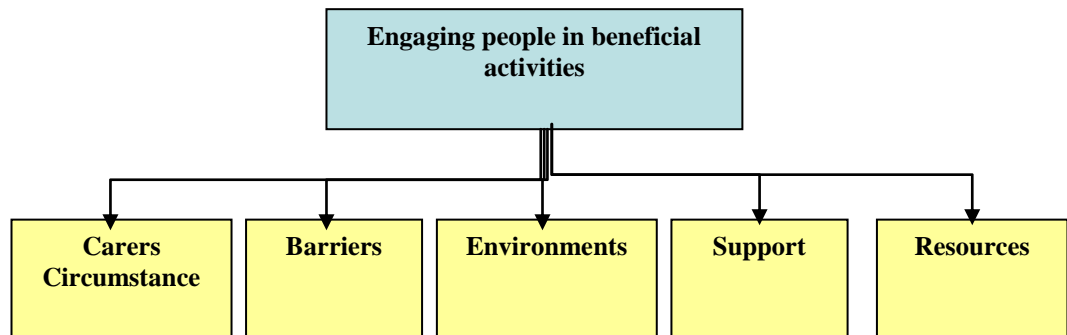
#### *5.6.2.2 Use of conceptual frameworks*

As discussed in section 4.2.2, Strauss and Corbin (1998) have suggested that the process and structure of a phenomenon are inextricably linked, so I used a series of frameworks as organisational schemes to denote the relationships between some features of the structural conditions and the process of the phenomenon under study (details of how

they were used can be seen in Chapter 6). In this section, I will discuss how Framework One was used to assist with the sampling decision prior to fieldwork.

- Framework One - prior to fieldwork

**Figure 5.1 : Framework One**  
(before data collection)



In my study, I started with a provisional research question about how carers engaged their relative with dementia in beneficial activities. Prior to fieldwork, Framework One was developed to provide a strategy to guide the initial data collection and analysis once the fieldwork commenced. Data were based on literature and my previous clinical experience as a community occupational therapist in the mental health field. For example, reflecting on the literature, I found that there were no studies that directly related to the question: what are the carers' views of involving people with dementia in beneficial activities at home? Nevertheless, the general literature of caring for people with dementia indicated several factors which might influence the process of engaging people with dementia in activity at home. These were:

- carers' circumstances (e.g. gender, relationships, age, motivation for caring and lifestyles, knowledge of dementia and social network);
- barriers (e.g. lacking of availability of outside help at the appropriate time, ineffective coping strategies and inflexible services);
- environments (e.g. transport, accessibility, type of dwelling, cultural context, legislation and policy);
- support (e.g. family, professional and societal support); and
- resources (i.e. caring related information, equipment related to activity, time availability and finances).

With this in mind, 'Framework One' was developed to:

- outline the general area of study;



- (ii) highlight the general features of the structural conditions which might influence the process of engagement; and
- (iii) link the hypothetical relationships between the general research area and those identified concepts.

The five concepts above provided a useful beginning point for me to study the process of how carers engaged people with dementia at home and to explore further factors which impacted on the process of engagement.

This framework was first used as starting point for: i) making decision for initial sampling as discussed in the sampling section; and ii) making comparisons of data once the data collection commenced. I used Framework One not only to ensure the grounding of the concepts in data, but also to facilitate the pursuit of the lines of enquiry through the process of verification, deduction and induction. Once the research progressed, I moved on to refine some concepts and develop the theoretical explanation of the emerging categories. As a result, a series of conceptual frameworks unfolded as new lines of enquiry emerged (see further details of Framework Two, Three and Four in chapter six).

#### *5.6.2.3 Constant comparison*

I have constantly compared the existing data to incoming data, and the initial concepts to emerging concepts. For example, i) different participants were compared including their views, actions, situations and experiences; ii) data from the same participants were compared with themselves at different points in time; and iii) incidents were compared with incidents (Charmaz 2000).

#### *5.6.2.4 Negative case analysis*

Throughout the research process, I regularly sought out ‘negative instances or contradictory cases’ in relation to the development of analytic ideas (Mason 1996, p.94). This meant that I looked for cases (e.g. individuals, situation, or themes) which did not easily fit into the developing analysis but might provide alternative explanations to the hypothesis or developing theory (Robson 2002; Holloway and Wheeler 2002, Charmaz 2006). This led to the revision and refinement of the working hypothesis, and ultimately strengthened the explanations and enhanced the validity of the research (Mason 1996; Strauss and Corbin 1998; Holloway and Wheeler 2002). For example, in

the earlier stage of my analysis, when I attempted to theorize the concept of *sharing*, I hypothesised that carers were not able to share their everyday experiences and emotions with their relatives as dementia progressed. This was also associated with an assumption that when carers began to see their relative as a child, they found it increasingly difficult to share their feelings with them.

This hypothesis was rejected when I put forward this statement to a female spousal carer for her comments. She disagreed and stated that ‘this is not my case’. She explained that as her husband became more dependent on her for almost all aspects of everyday routine activities, she became more motherly. She felt strongly that even though he was childlike, he was considerate of her emotional needs and showed affection to her from time to time. She felt that there was an equal share between them in terms of emotions.

This negative case alerted me that the concept of *sharing* had different meanings to different carers at different time. There were different aspects of sharing in terms of everyday physical tasks, everyday communications, feelings and emotional support. This led me to refine my working hypothesis to the following statement. That is, carers have increasing difficulty in sharing their everyday experiences and emotions as the dementia of their relative progressed; and that their relatives have increasing difficulty in showing an appreciation of carers’ effort during the process of caregiving. As time goes on, carers also realise that their feelings and relationships to their relative change. Towards the middle and later stage, many carers often described their relative as a child. This symbolized role reversal and changes in relationship. Many carers felt that they were no longer getting any meaningful responses from their relative, hence there was no sharing. On the other hand, some carers still felt that they continued to share the feelings and emotions with their relative in terms of affection and companionship, even though their relative became increasingly dependent on them physically.

Hence, this case analysis enabled me to compare the similarities and differences between existing data and contradictory data, to check the extent to which it contradicted my working analysis; and to develop further the variations of the concept. This also raised my awareness about the need to explore further issues such as i) the temporal factors of a process; ii) the meanings of the concept to the carers and its

relationship to passage with time; and iii) how this issue of sharing influenced carers' involvement in their relative's everyday routine activities .

Negative case analyses helped me develop the confidence that 'the explanations or interpretations derived from the data are the most valid and plausible and can account for the alternative cases' (Holloway and Wheeler 2002, p.259).

#### *5.6.2.5 Use of field diary and memos*

I kept a field diary to: i) record notes from observations during and after interviews to capture the behaviour and mood of the participants (Holloway and Wheeler 2002); and ii) facilitate continuous reflections during the process of data collection and analysis. Chenitz (1986, p.76) stated that, in grounded theory, field notes could be used to 'trigger the researcher's memory when typing full notes from the site' (see Appendix 14 re observation from field notes).

I also used memos to keep a record of the analysis, identification of the characteristics of concepts and categories, questions raised during the process of analysis, development of concepts and categories, and directions for further data collection in this grounded theory study. The use of memos enabled me to organise retrievable data for sorting, and cross-referencing which is a feature of grounded theory (Strauss and Corbin 1990, 1998; Charmaz 2000). An illustration of how memos were used for analyses can be found in Appendix 15.

In short, both the field diary and memos were essential tools to be used in conducting the phase one study. They provided an audit trail for the development of a theory in a systematic manner.

#### *5.6.2.6 Theoretical sensitivity*

Theoretical sensitivity enables researchers to overcome analytic blockages or barriers and be sensitive towards theoretical issues. This ability might be developed through professional and personal experience (Glaser and Strauss 1967; Strauss 1987; Holloway 1997; Strauss and Corbin 1998).

My theoretical sensitivity came mainly from my professional background as an occupational therapist, my previous experience as a community practitioner in mental health teams, as well as being a lecturer in occupational therapy. This experience has enabled me to develop an ability to be sensitive to issues, raised by participants, which would be important to them. However, my previous knowledge could be seen as a source of bias when conducting a grounded theory study (Strauss and Glaser 1967). In order to minimize potential bias during data collection and analysis, I adopted various procedures to enable me to keep an open mind about new concepts. For example, I used the line-by-line coding to conduct the analysis, for it helped me interact with the data (Charmaz 2005). I also developed my theoretical sensitivity through a range of research training activities such as: regular supervision meetings with my PhD supervisors, conference presentations (Appendix 16), seminars and workshops relating to research methods, as well as the use of relevant literature. Moreover, my theoretical sensitivity was also enhanced by other activities such as being reflexive (see detail in 5.5.2) and regularly reflecting on the criteria I used when designing and conducting the present research study. Issues regarding reflexivity will also be highlighted in 5.7.4.

## **5.7 Criteria for evaluation of qualitative research and rigor in grounded theory**

As mentioned in chapter 4, in this study I adopted a constructivist approach. Conducting research from this position, I aimed to explore the social realities of co-resident carers of people with dementia in their activity engagement with their relative. I needed to make transparent the ways in which I made decisions for accessing information about the phenomena and the extent to which I contributed to the viewpoints of the participants involved. I also needed to make explicit my own aim and objectives of my research, my decision-making process for the study and how my professional perspectives might influence my research.

In grounded theory, the analysis is considered both a science and an art. It is a science because it maintains a certain degree of rigour, and that the analysis is grounded in data. It is an art because its 'creativity manifests itself in the ability of researchers to aptly name categories, ask stimulating questions, and make comparisons, and extract an innovative, integrated, realistic scheme from masses of unorganised raw data' (Strauss and Corbin 1998, p. 434). Grounded theory methods provided me with a set of procedures not only to ensure a balance between science and creativity during the

process of analysis; but also to address issues concerning the evaluations of the quality and rigor of a qualitative study.

### **5.7.1 Credibility**

Credibility can be concerned with the participants in a study recognising themselves in the data. One method I used to verify the findings was through member checking (Charmaz 2006), that is, taking ideas back to research participants to see if they could identify with the issues (as described in section 5.5.4). Another commonly used method is triangulation which aims to overcome the potential biases based on a single perspective (Holloway 1997). I did not use this method in phase one. Nevertheless, I regularly discussed the data and my analysis with my supervisors and checked if they would agree with my interpretations. Their regular feedback often facilitated my thinking of other possibilities for the explanation of the findings and emerging concepts.

Strauss and Corbin (1990, 1998) suggested that when evaluating the credibility of work using grounded theory, it is crucial to consider the components of the research process through which the emerging theory is developed; for example, sampling, development of categories, negative cases analysis and if there is a strong link between the data and analysis.

Hence, I made explicit how the research process was carried out in a systematic and rigorous manner, for example, i) justifying my decisions for sampling, ii) when developing concepts, making explicit the structural conditions that were pertaining to certain phenomena, the range of strategies to handle these problems, and what consequences had occurred because of those actions (see appendix 15 for an illustration); and iii) adopting the principle of theoretical sampling as far as I possibly could as discussed earlier. This was because the more systematic and widespread the theoretical sampling was, the more structural conditions and variations could be discovered in the data and built into the theory. Ultimately, it facilitated the development of a theory which had an explanatory power. The difficulty in conducting the theoretical sampling had also been highlighted. In the next chapter, I will discuss issues such as how the concepts were systematically generated from data; and how I developed conceptual frameworks to guide the data collection and analyses at different

stages of this project, as well as how concepts had emerged under a series of different conditions.

In addition, during the research process, I regularly sought out not only instances or cases which confirmed my working analysis, but also negative cases (e.g. themes, concepts) which appeared to challenge the explanation of emerging concepts (Mason 1996; Holloway and Wheeler 2002). When a negative instance occurred, I tried to trace the conditions or contexts which led to the events and phenomenon. This in turn enabled me to examine whether the negative case indicated a variation which would need to be followed by pursuing a new line of inquiry; or whether it indicated a mistake in my initial thinking which needed to be rectified (Strauss and Corbin 1990). See an example in analysis section (5.6.2.4.)

### ***5.7.2 Ensuring grounding of a study***

When developing the theoretical categories of my study, I largely adopted Strauss and Corbin's (1990, 1998) guidelines as a means to enable the empirical grounding of my research. Strauss and Corbin's (1998) and Corbin and Strauss's (2008) criteria for judging the quality and rigor of research using grounded theory methods include fit, applicability, concept generation, contextualization of concepts, logic, depth, variation, creativity, sensitivity and use of memos. I will discuss how I addressed these aspects in the following:

- Fit refers to whether findings resonate with the experience of the participants involved. In order to ensure the findings made sense to the participants, I conducted member checking, that is, follow-up interview, in phase one study.
- Applicability refers to the usefulness of the findings and whether they offer new explanations or insights. The findings suggested that new insight concerning carers' perspective of their engagement in the everyday activity with their relative was emerging from the first phase of the present study.
- Concept generation is concerned with whether the concepts were systematically related and developed in terms of their properties and dimensions. In the result chapter for the phase one study (chapters 6), I aimed to systematically present the concepts around emerging themes. I also attempted to demonstrate how the concepts were generated through the use of coding and how they were related and developed through a series of coding frameworks.

- Contextualization of concepts is concerned with whether sufficient contexts have been covered. In both chapters 2 and 3, I attempted to cover a range of contextual factors which led to carers' experiences in perception of the activity patterns of their relative with dementia during the course of caregiving.
- Logic refers to whether the methodological decisions were made explicit, and if the methods of data collection and analysis were appropriate. The methodological decision was discussed in both chapter 4 and this chapter, highlighting the appropriate reasons for using grounded theory as an overarching methodology and in-depth interview for data gathering and analysis.
- Depth and variation are concerned with whether there was sufficient depth covered in the analysis and if there were variations built into the findings. In the result chapter, I tried to demonstrate the depth of the analysis in phase one, and how the five key themes were developed. Variations were built in through the sampling procedures in phase one study. The structural conditions under which variations developed were also explained.
- Creativity is concerned with whether the findings were presented in a creative and innovative manner and said something new. The five preliminary findings which emerged from the phase one study suggested that some new ideas regarding to carers' experiences were emerging.
- Sensitivity refers to researcher's ability to demonstrate sensitivity to the participants and to the data. As discussed earlier, throughout the phase one study, I have drawn on my own analytic ability, theoretical sensitivity and research skills to convey the findings. I also tried to make them transparent in the method chapter.
- Use of memos is another criterion for judging the grounding of the research. As discussed earlier in 5.6.2.5, I explained how I used memos during the process of analysis, development of concepts and categories in this grounded theory study (Strauss and Corbin 1998; Corbin and Strauss 2008).

In short, the process of ensuring the grounding of the development of categories, it enhanced the rigor of my research study.

### **5.7.3 *Transferability***

The term of transferability is similar to the terms used in quantitative research for external validity and generalisability (Holloway 1997). This means that the findings of a

study in one context can be transferred to similar circumstances or participants. Strategies which qualitative researchers use to enhance the transferability of research include thick description and accurate details of the research process. Such strategies aim to enable peers and the readers to have a clear picture of the research process (Holloway 1997). Throughout the present study, I adopted these principles to guide the process of sampling, data collection and analysis in order to enhance the transferability of my research. For example, I detailed the process of decision-making for sampling.

#### **5.7.4 Reflexivity**

Reflexivity involves ‘critical self-reflection, focusing on the ways a researcher’s social background, assumptions, positioning and behaviour affect the research process’ (Finlay 2006, p 21). Throughout the research process, I adopted a reflexive approach. I reflected critically on myself as a tool in the research process, taking into consideration of my own background. This included my own theoretical perspectives, my justification for the selection of research topic and methods used, my way of interacting with the participants and my reactions to participants’ accounts.

Reinharz (1997) suggested that researchers have three types of selves, namely, research based selves, brought selves (the selves that ‘historically, socially, and personally create our standpoint’, p.5) and situational created selves. Each of these selves has an influence on the research process including the way the data was collected and analysed. Hence, I made an attempt to ‘interrogate each of ourselves regarding the ways in which research efforts are shaped’ (Lincoln and Guba 2000, p.183). For example, how my brought self (as an occupational therapist, and lecturer) might have an impact on the way which participants reacted to me during interviews. It could be that some participants considered me to be an expert in the subject, and as such, offered me answers which they thought what I wanted to hear rather than telling me their opinions about the subject.

In the early stage of the research process, I did consider introducing myself only as a novice researcher, rather than my professional status. Nevertheless, shortly after the research process began, I realised that my past experience (as a community mental health occupational therapist in dementia care) gave me the advantage in accessing the gatekeepers about my research and to convince them of the relevance of my research to



future practice in the dementia care field. Hence, I decided that it was important for me to position myself as not only a researcher, but also as an occupational therapist who was interested in the research topic. I also felt that the in-depth and the follow-up interviews, which lasted for over an hour, offered an opportunity to enable participants to appreciate that I was genuinely interested in understanding their perspective.

During the data collection process, I was surprised that many participants thanked me for being interested in listening to their stories, and trying to understand their viewpoints. Some participants even said to me that I was the first person to whom they could tell their stories and ‘open their heart’ to me. This suggested that participants felt comfortable talking with me. They perceived me as someone who was familiar with the research topic. This enhanced the credibility of the present research; Charmaz (2005, p.528) pointed out that researchers need to ‘achieve intimate familiarity’ with the research setting and the study topic when considering the credibility of a qualitative research.

To conclude, throughout the research process, I employed reflexivity to make explicit how my own background and position might impact on the processes, data collection and analysis. I attempted to adopt a set of strategies to ensure rigour, credibility and transferability of the phase one study by using a set of guidelines for evaluating qualitative research. The next chapter will discuss how the grounded theory approach has enabled the development of conceptual frameworks to facilitate the pursuit of the lines of enquiry during the research process. This process was on-going throughout the study. Four conceptual frameworks had emerged over time. The analysis led to a development of a model of activity engagement.

## Chapter 6 Results of the Phase One Study

This chapter discusses two aspects: i) how the conceptual frameworks emerged at the end of each stage of the analysis and how they facilitated systematic analysis through processes including induction, deduction, and verification; and ii) the detailed description of the key themes which were identified, refined and developed through an ongoing process of alternating data collection and analysis.

In phase one of the study, four conceptual frameworks were developed over time. They enabled me to look for supporting and non-supporting data when developing analytic categories with respect to the understanding of the carers' perspectives of engaging people with dementia in activities.

In this section, the terms *carers or participants* will refer to co-resident-carers of people with dementia, whilst the term *relative* will refer to the people with dementia who live with, and are cared for by their carers at home. The term *relative* is used as it indicated that all participants who took part in the study were spouses, children or partners. Extracts from transcripts will be identified by a code, for example, *C1*. Within the text, pseudonyms will be used to maintain participants' anonymity. The letter *f* will follow the codes when the extracts were from follow-up interviews, for example, *C1f*.

### 6.1 The Development of the Conceptual Frameworks

#### 6.1.1 Framework One – prior to fieldwork

The purpose of using the framework one to provide a strategy to guide the initial sampling and analysis has been discussed in section 5.6.2.1.

#### 6.1.2 Framework Two

A second framework was developed following six interviews (three initial and three follow-up interviews) with two spousal carers, that is, a husband aged 76 years, and a wife (2<sup>nd</sup> marriage) aged over 65 years; and 1 daughter (female, widow; aged 59 years). The characteristics of participants are outlined in the Table 6.1 below.

**Table 6.1: Characteristics of participants (three initial participants)**

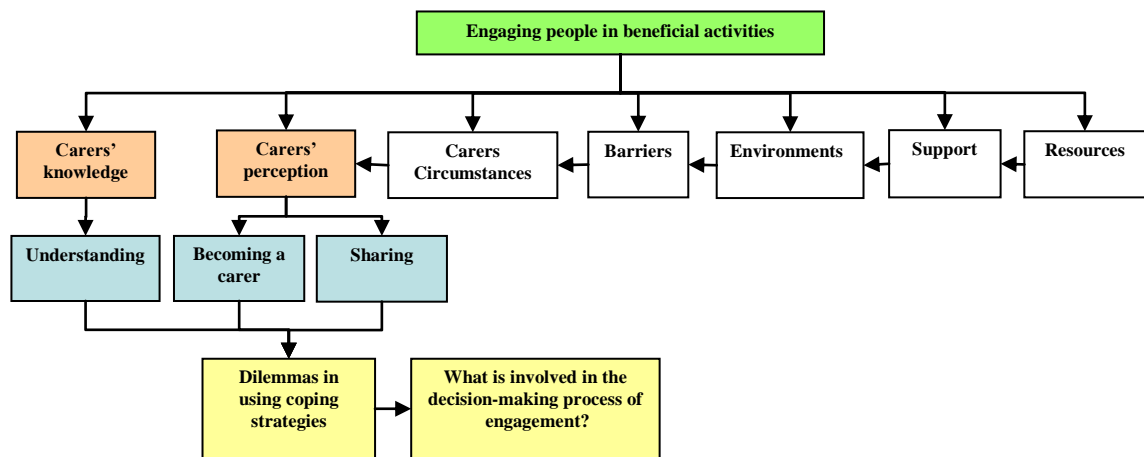
Interviews	<i>C1</i> *Sheila	<i>C2</i> *Jim	<i>C3</i> *Carole
<b>Gender and relationship of carers</b>	Female/Wife	Male/Husband	Female/Daughter
<b>Age range (carers/cared-for ) in years</b>	Over 65(77)	76(76)	59(89)
<b>Length of time for caring (in years)</b>	5	3½	2
<b>Length of time living together (in years)</b>	20	47	2

\*pseudonyms are used throughout

As stated above, the length of time participants had been spent looking after their relative ranged between 2 and 5 years, whilst the length of time carers had been living with their relative ranged between 2 years and 47 years. The age of the relatives ranged between 77 and 89 years.

Certain central concerns were frequently raised by participants and could be defined by the concepts '*carers' knowledge*' and '*carers' perceptions*'. This generated several other concepts which were associated with the roles of carers. These included '*becoming a carer*', '*understanding*', '*sharing*' and '*dilemmas in using coping strategies*'. Another key issue which concerned carers was the difficulty in making decisions about the involvement of their relative in everyday activities. As a result, it became necessary to shift the focus of the investigation from the general themes (e.g. carers' knowledge and perceptions) to a more specific one (decision-making processes). The diagram below illustrates how the new research focus emerged following the initial stage of the analysis (see figure 6.1). The emerging concept '*becoming a carer*' will be discussed below as it sets a good basis for this thesis. This will be followed by the emerging concepts '*dilemmas in using coping strategies*' and decision-making processes as these became central concepts in this thesis. For details of the other concepts (i.e. '*understanding*' and '*sharing*', please refer to Appendix 17).

**Figure 6.1: Framework Two**  
**(Developed after the first 3 initial and 3 follow-up interviews)**



#### 6.1.2.1 The concept of 'becoming a carer'

The quote below from Sheila (pseudonym) highlighted key aspects described by the majority of the participants.

*'I think you just have to realise that you are a carer, you're not a wife any more, you're not a companion any more, you're just the person that runs the nursing home for this particular person (laughs), and that's it, really...carers come with a role, yes, because unless you have a role I don't think you can do it... But we're not trained to do that job are we. You have to learn by experience.'* [C1]

Participants recognised gradually over a period of time that they had to adopt a new role. They made constant adjustments and developed strategies for managing the relationship with and activity and wellbeing of their relative. In doing so, they experienced a loss of their pre-existing roles (e.g. wife) and found themselves having to take up unexpected new duties without much choice. These issues were recurrent themes in the data from all three participants.

All participants talked about the experiences of taking on a new job as carer without proper training. They used their previous parenting skills (and one person utilised her teaching skills) to manage what was considered childlike behaviour. I was interested to note that the male carer seemed to have greater difficulty in appreciating the reason why the 'child' he was caring for was not as receptive to his approach as a normal child would be. He often described the experiences of involving his relative as a battle 'everything is such a battle'; whilst the two female carers tended to described their experiences of involving their relative as 'just like being a mother'. There might be

differences in the ways which male and female carers involved their relatives in activities.

As I carried out the analysis throughout this stage, I continued to find out whether these emerging concepts came up in further interviews and data analysis or not.

#### 6.1.2.2 *The concept of 'dilemmas in using coping strategies'*

All participants were faced with some dilemmas in choosing appropriate strategies to engage their relative in everyday routine activities. This was reflected from the quote by Jim below:

*'She [wife] just strokes them (the cats) you know, she won't feed them. I mean she could feed them quite easily, I mean it isn't an earth shattering task to put a bit of food in that basin but by the time... if I were to suggest that she feeds them I would have to tell her where the food is, then I would have to tell her where the scissors are so that she could open the packet, then I would have to remind her where the bowl is and like so many other jobs in the house it's far quicker to do them myself...' [C2]*

Jim acknowledged that it was much easier for him to do a task by himself when he expected that his wife would rely heavily on his step-by-step instruction. All participants talked about how time-consuming it could be when they attempted to involve their relative in everyday activities. Strategies they used included breaking a familiar activity into smaller manageable sub-tasks, encouraging their relative to take part in each sub-task, monitoring the performance and offering assistance to their relative as they went along. Despite their efforts all three participants talked about having lost their patience with their relative at some point during the process of engagement.

Carers had difficulty in identifying meaningful goals for their relatives. Their relatives did not appear to appreciate the time and effort made. Their roles were multi-tasked in nature, for example, taking responsibilities for everyday caring tasks, household chores and financial management. The nature of their roles and responsibilities became more complex as the dementia of their relative progressed. It was not surprising that all carers expressed concern about the difficulty in making decisions about ways in which they engaged their relative in everyday routine activities as time went on during the course of caregiving.

The following section will further discuss why two key aspects emerged as a new line of enquiry for the next stage of analysis.

#### *6.1.2.3 Why was it important to look at 'decision-making' and how it changed over time?*

A few recurrent themes (for example, becoming a carer and understanding) continued to emerge as important to participants themselves. Towards the end of this stage of analysis, it became clear that a primary concern for participants was associated with the process of their decision-making in engagement. For example, all participants frequently talked about having to take over the responsibility of making constant and complex decisions for their relative in respect to the engagement in activities, and how such an experience had increased tensions and conflicts in their relationships. In the absence of a clear meaning of the term '*dementia*' and a clear picture of its implications all participants found it increasingly hard to make decisions for their relative. They based engagement mainly on their previous knowledge of what their relative used to enjoy doing. Participants who had been caring for their relative for several years often talked about how their perceptions of the activity needs of their relative changed over time as the functioning of the relative gradually deteriorated. It seemed that issues concerning decision-making of engagement involved a gradual process in which constant adjustments were expected. Hence, it was important to investigate at the next stage of analysis : i) issues concerning carers' decision-making in respect of the engagement of their relative in activity; and ii) how these issues related to each other within the context of decision-making.

#### **6.1.3 Framework Three**

Data in this phase of analysis were collected from eight interviews (that is, another four participants). Two spousal carers: 2 female aged 67 years and 65 years; one partner: female friend (widow) aged 76 years; and one daughter aged 50 years. The characteristics of these additional participants are outlined in Table 6.2 below.

**Table 6.2: Characteristics of four additional participants**

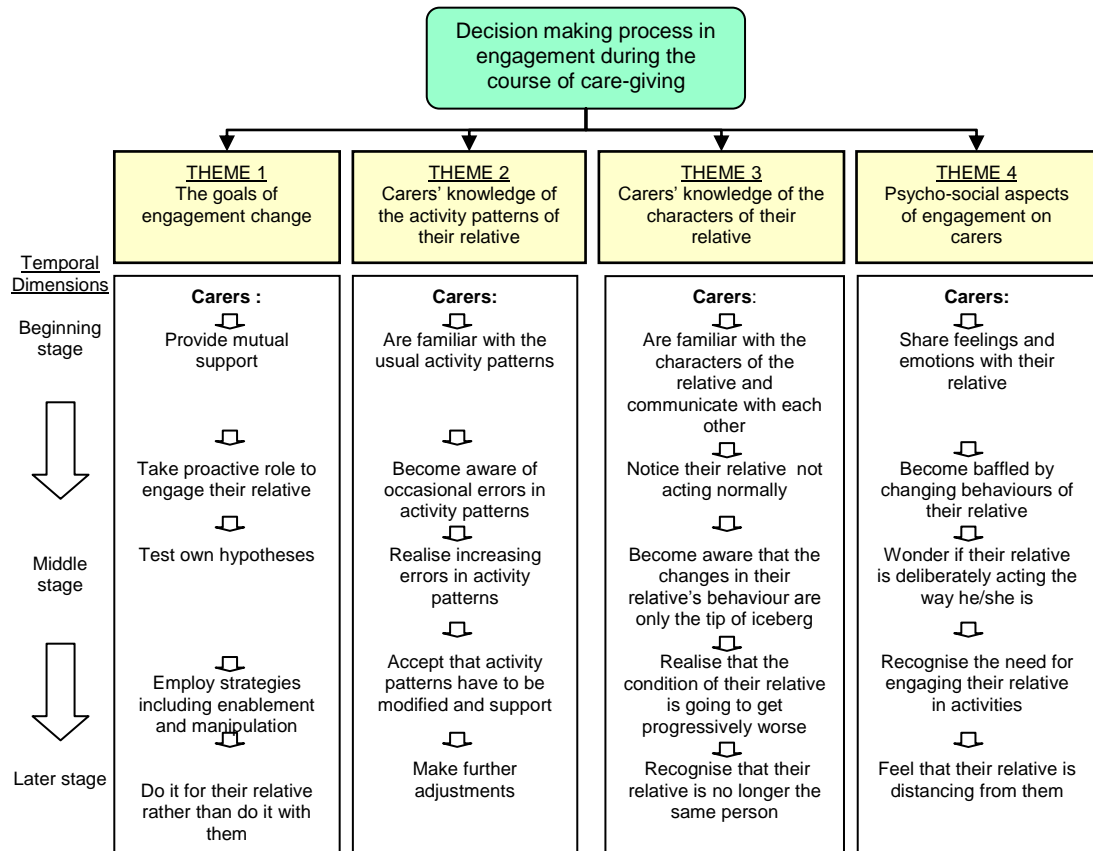
<b>Interviews</b>	<b><i>C4</i> *Susan</b>	<b><i>C5</i> *Jean</b>	<b><i>C6</i> *Julie</b>	<b><i>C7</i> *Helen</b>
<b>Gender/ relationship of carers</b>	Female/Wife	Female/Partner	Female/Daughter	Female/Wife
<b>Age range (carers/cared-for) in years</b>	76(77)	67(74)	Over 50(85)	Over 65(74)
<b>Length of time for caring (in years)</b>	3	4	5	2
<b>Length of time living together (in years)</b>	13	50	5	35

\*pseudonyms are used throughout

The length of time participants had been looking after their relative ranged between 2 and 5 years, whilst the length of time carers had been living with their relative ranged between 5 years and 50 years. The age of cared-for people ranged between 74 and 85 years.

During these interviews, all participants raised issues with respect to the decision-making process of the engagement of their relative in activities. These issues included the goals of engagement, the psychosocial impact of engagement, as well as their knowledge of the activity patterns and characters of their relative. It was interesting to note that carers often talked about how aspects of these factors changed over time during the course of caregiving. From this, four conceptual themes emerged and formed Framework Three (see figure 6.2). The diagram outlined the four themes (i.e. properties of decision-making); the range of variability of each theme (i.e. dimensions); as well as the relationships among all concepts.

**Figure 6.2: Framework Three**  
(developed after 4 additional initial and follow-up interviews)



In general, this framework provided me with a strategy to: i) look for how categories related to their sub-categories and to further develop categories in terms of their properties and dimensions using axial coding, as outlined in the chapter 5; ii) sample incidents and events which enabled me to identify significant variations within each of the dimensional range of each of the properties; and iii) compare the existing concepts with the new data from later interviews for similarities and differences in order to refine the four themes.

Following the preliminary analysis at this stage, the findings continued to bring new insight into the understanding of how carers engaged individuals with dementia in activities. Based on key issues highlighted in Figure 6.2, I will briefly discuss how the participants spoke of factors which influenced their decisions about the engagement of people with dementia in activities over time.



#### 6.1.3.1 Theme One: The goal and nature of the engagement over time

A central issue, which was discussed by all participants, was concerned with the changing orientation of the nature or the goals of engagement over time. This could be illustrated in the quote from Helen:

*'He has got a nice car. He used to want to go [to car shows], for a start, to show off the car. He loves it when people want to see in the bonnet. I can't see what is magic about what's underneath the bonnet of a car but ok. A lot of men do enjoy these things.... we used to go to the Jaguar events and really enjoy that and go somewhere with the car- and with other couples...Now is the time of year-I have booked him for the shows that we normally go to every year. I'd cleaned the car. Whether we will go or not I don't know. I think I might even go on my own. Oh, I don't know whether I will. I don't suppose I will, but you know...it is an effort because he never remembers we have got a show on and ....then he would say, " why didn't I know about this, I don't want to go, you go on your own", it does spoil it.'* [C7f]

Carers often experienced high level of stress when they had to set goals for engagement for their relative. This was partly because, prior to the course of caregiving, carers and their relatives often worked on the basis of some kind of mutual agreement with respect to responsibilities for the normal running of the household tasks. The boundaries of involvement in activities tended to be negotiable and non-interfering. Each party had an understanding of each other's roles and responsibilities once the agreements were established. When carers started noticing that a relative experienced difficulty with something they were formerly engaged in, they often took on a proactive role to encourage their relative.

Some carers were often unaware of the causes of the problems which were experienced by their relative at the early stage of caregiving. It appeared that at the beginning of the caring relationship, carers usually aimed to enable their relative to carry on with their everyday routine. Carers tended to emphasise the use of familiar activities because these kinds of activities enabled their relative and themselves to maintain their normal routine. As time went on, when carers realised that their relative had become increasingly dependent on their support, they faced a dilemma between maintaining the focus of enablement and coercing their relative to take part in activities which were perceived to be important by the carers themselves. This could be illustrated by a quote from Sheila:

*'I have to put my foot down about things which are important to me ... but things that I think are necessary, and are necessary for his well-being'. [C1]*

Carers often adjusted the goals of activities for their relative when they perceived that the ability of their relative continued to deteriorate, in particular when the dementia reached later stages. For carers, making constant decisions on adjusting the goal of engagement for their relative was often complex as they had to strike a balance between being meaningful to their relative and being practical for themselves. This could be illustrated by the extract from Jim's quote:

*'It (going out) does me some good. It may be selfish on my part, but if I am here she (wife) is sitting in the armchair cuddling a cat and saying can I help you, are you alright, and that's all. There's no input whatsoever from her side, but if I've got her outside I can at least have a bit of a conversation.'* [C2]

However, towards the later stage of the course of caregiving, carers' decisions on the goals of the engagement often focused on doing it for, rather than doing it with their relative, as seen in the quote from Carole:

*'You're looking after somebody, you don't want them to go out like - for instance, I mean my father would get dressed but he could be wearing a very strange combination of garments, have three vests on the top, or have his pyjama top underneath his clothes - so it's obvious, you have to do certain things for them.'* [C3]

In short, all participants talked about how the nature of engaging their relative in activities changed over time. It seemed that the goals of the engagement changed as these carers became increasingly aware of a change in their relative's behavior and functioning. As the course of caregiving went on, the goals of engagement tended to work on the principles of providing, at times, comfort and compensations for deficits. This made it increasingly difficult for them to maintain a balance between a wish to enable their relative to be involved in activities with their assistance, and a wish to protect them from encountering a failure.

The next section will discuss how carers' knowledge of activity patterns of their relative appeared to impact on the decision-making of the carers.

#### *6.1.3.2 Theme Two: Carers' knowledge of activity patterns*

Another factor, which was discussed by all participants, was concerned with carers' knowledge of the changing activity patterns of their relative. This can be reflected on the following quote by Jean:

*'Last time he was writing a cheque and I would check it to see if it was right, now I write the cheque and say, "is that what you want to do", he knows where the bank is because it has always been his bank, and hand the cheque over and come back with the money. but as far as sort of paying a bill or anything is concerned, I will write the cheque out and get him to sign it'. [C5]*

Carers had knowledge of the usual patterns of everyday routine activities which their relative used to engage in as well as how and when those activities would have been pursued. Those pre-existing activity patterns were often considered not only meaningful but also valuable to the roles, responsibilities and lifestyles of their relative. The above mentioned quote by Jean highlighted how carers were able to pick up errors and events of changes in the activity patterns of their relative. Carers therefore managed to judge the extent to which their relative was still capable of achieving the normal standard of performance over time. Hence, they were in the best position to support their relative to continue carrying out their everyday activities which were meaningful to the roles and responsibilities of their relative. During the process of engagement, carers used strategies such as encouraging, reminding, coercing, nagging, and manipulating.

All participants spoke of how the activity patterns of their relative gradually changed to the extent that such patterns were no longer, as the dementia progressed, able to sustain the pre-existing life roles, responsibilities and lifestyles of their relative. Then, carers often found themselves increasingly feeling responsible for modifying the activity patterns of their relative. There was a sense of motivation, determination and commitment to the caring roles.

#### *6.1.3.3 Theme Three: Carers' knowledge of the character of their relative*

This section explored an aspect of decision-making, which was talked about by all participants, that is, carers' knowledge of the character of their relative, and how it changed over time. This could be seen illustrated in the following quote by Sheila:

*'I used to take him [husband] to a big, big garden [name of the place] it has connections with a racing driver who died in a crash and I took him there because of the racing car connections...and I thought the tie up would be a nice thing for him, and it was for a little while but it's gone now. If I take him over there, he doesn't want to walk round the gardens. No point, he's not in the least bit interested in it as a place, it doesn't have any meaning'. [C1]*

This spousal carer attempted to engage her husband in an activity which he used to be proud of and once associated strongly with the car racing community, as her husband

used to take part in many major car racing events and published numerous books in relation to those events prior to the onset of dementia. Carers often had the knowledge of the personal characteristics of their relative and recognised changes of their relative through their awareness of changes in personality traits. All participants talked about the extent to which the usual behaviour and mode of communication of their relative gradually altered from the usual personality traits of their relative to some strange behaviour. These changes could be noted by how these individuals communicated their wishes, wants and preferences to their carers as the dementia progressed. All participants talked about how they were baffled by the changes in their relative's character.

At the early stage of the caregiving process, carers often developed their own hypotheses about the causes of the changes. For example, some carers felt that the changes might have resulted from changing relationships between themselves and their relative, or the effects of aging or retirement. As time went on, carers slowly recognised that the change in character was only the tip of the iceberg. In other words, it was not just a change in personality, but an ability to reason and perform normal everyday responsibilities and life roles in the relationship. For some carers, such recognition could take a long time.

As the dementia of their relative got worse, these carers often commented that the relative was no longer the same person they once knew. This inevitably had an impact on the psychosocial well-being of the carers. The next section explores how the psychosocial impact of engaging their relative in activities at home might have affected the decision-making of carers.

#### *6.1.3.4 Theme Four: Psychosocial impact of engagement.*

Last but not least, another recurrent theme, which was discussed by all participants, was concerned with the personal and psychosocial impact of engagement on the carers themselves, and how it changed over time.

Many carers were distressed when they perceived that their relative began to lose their abilities to share their daily experiences, emotions and feelings with the carers who

lived with and cared for them, this could be quite a devastating experience as illustrated by a quote from Sheila:

*‘Well, the only way, the only way you can work it is by realising that trying to share something with him, you know, you try and share three things one day, and that’s not too bad, and the next day you can only share two things, and the next day you only share one thing, and the next day you don’t share anything at all. Over a period of time, what kind of thing would you be sharing’. [C1]*

Carers often experienced a sense of tension, conflict, anger, betrayal and helplessness, as well as losing control of the situation when trying to engage their relative in activities. These issues recurred in data from all the interviews. During the course of caregiving, carers often struggled with taking over the control of the caring situation. All participants talked about being reluctant to intrude on the privacy of their relative. Many carers were often in a dilemma over whether they should have made a decision for their relative or facilitated their relative to make decisions for themselves as the reasoning ability of the relative got worse. All participants talked about how they were overwhelmed by the responsibilities which imposed on their everyday life. This often resulted in carers feeling frustrated about taking on the caring roles. This could be reflected in the following quote from Susan:

*‘...you take on a new responsibility... it’s not a job for which you have any training and it’s not a job that you want to be doing a lot of the time and I can tell you there’s a lot of resentment in me and a lot of anger and a lot of pain all muddled up and sometimes there’s a lot of dislike’. [C4]*

All participants spoke of feeling obliged to take responsibility for looking after their relative and becoming aware of a need to engage their relative in activities. This was particularly the case when carers had been caring for those individuals who reached the middle stage of dementia and beyond.

It seemed that during the process of caregiving, there were incidents which intensified feelings. For example, some carers found themselves increasingly shocked by the increasing frequency of evidence of changes in the activity patterns and character of their relative. For some carers, this led to a process of feeling further separated from their relative, in particular at an emotional level. In general, it often took quite a long time for carers to appreciate what had been going on with their relative. Some participants spoke of the difficulty for them to commit themselves within an indefinite timeframe. This could be seen in the following quote by a daughter, Carole:

*'I think the most difficult thing is I'm not working. Because I love my work and also I can't go out when I just feel like it, you know, I've had to miss lots of occasions, the people I used to work with were my social life as well, and we had lots of reunions and parties and I haven't been able to go'. [C3]*

Demands to take up the responsibility to engage their relative in everyday activities/matters had an impact on carers. This could pose a challenge to the carers, in particular when they perceived that the changing activity patterns and the character of their relatives were no longer consistent with what they used to be familiar with. Carers often developed their own principles for engagement. This included, for example, trying not to get emotional about the caring situations in order to cope with their responsibilities and to take control of their own life. This could have a negative impact on carers' sense of own ability, for they became increasingly aware of their own limitations in their role as carers. It was not surprising that carers often complained of feeling exhausted and separated from their former normal self, as they perceived the functioning of their relative to be deteriorating over time.

#### **6.1.4 Framework Four - the main framework**

The fourth framework was developed following another sixteen interviews (that is, another eight participants) which were used to form the main framework for the thesis. There were 8 spousal carers (5 female). The characteristics of the additional participants will be outlined in Table 6.3 below.

**Table 6.3: Characteristics of eight additional participants**

Interviews	<i>C8</i> *Margaret	<i>C9</i> *Ron	<i>C10</i> *Steve	<i>C11</i> *Jill	<i>C12</i> *Lillian	<i>C13</i> *Ann	<i>C14</i> *Linda	<i>C15</i> *Jack
<b>Gender/ relationship of carers</b>	Female/ Wife	Male/ Husband	Male/ Husband	Female/ Wife	Female/ Wife	Female/ Wife	Female/ Wife	Male/ Husband
<b>Age range (carers /cared-for) years</b>	77 (78)	50's (53)	73 (74)	75 (78)	85 (85)	84 (94)	Over 65 (77)	85 (85)
<b>Length of time for caring (in years)</b>	4	2	4	3½	6	4	2	4
<b>Length of time living together (in years)</b>	40	23	46	56	21	26	Over 20	64

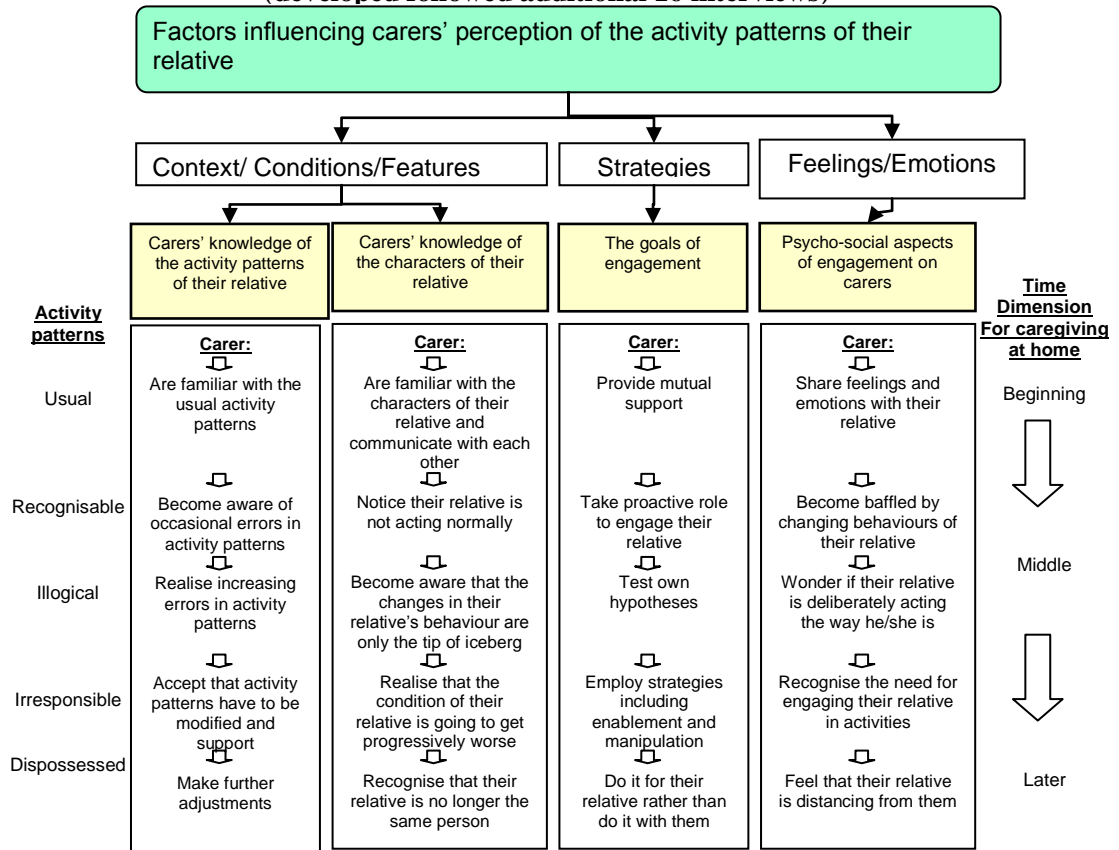
\*pseudonyms are used throughout

The length of time participants had been looking after their relative ranged between 2 and 6 years, whilst the length of time carers had been living with their relative ranged between 20 years and 64 years. The age of cared-for people ranged between 50's and 94 years.

During the later interviews in phase one, I continued to : i) look for incidents and events that maximized the dimensional range or variations of each of the four themes as shown in figure 6.2; ii) explore the relationships among the four themes and their sub-themes; and iii) develop further and integrate the themes for theory development. During this stage of the analysis, I frequently asked questions such as: What were the variations in carers' knowledge of their relatives' activity patterns? What were the variations in carers' strategies/actions? What were the relationships among the four themes? What were the context/conditions which led to the actions? What were the consequences of the actions? Who were involved over time? and When and why did events happen?

Through asking questions of the data set, five concepts (i.e. *usual, recognisable, illogical, irresponsible and dispossessed patterns*) emerged and formed Framework Four, as shown in figure 6.3 below. These five concepts emerged along the dimensional range which cut across all of the earlier four themes. The emerging concepts reflected how the carers' perception of their relative's activity patterns changed with the passage of time, during the course of caregiving at home. The diagram also highlighted that the two factors (i.e. carers' knowledge of activity patterns and character of their relative) created the main context out of which the different strategies/the goals of engagement emerged within different activity patterns. The consequences of the actions had an impact on carers' feelings and emotions. Thus, the five patterns represented five temporal phases in the activity engagement continuum of people with dementia at home. Each pattern incorporated specific circumstances/context which impacted on carers' actions, emotions and feelings. This in turn triggered a different set of actions and consequences for participants and their relatives in the next stages of activity engagement. The following figure (6.3) outlined key categories and how various aspects of each emerging categories changed over time during the course of caregiving.

**Figure 6.3: Framework Four**  
(developed followed additional 16 interviews)

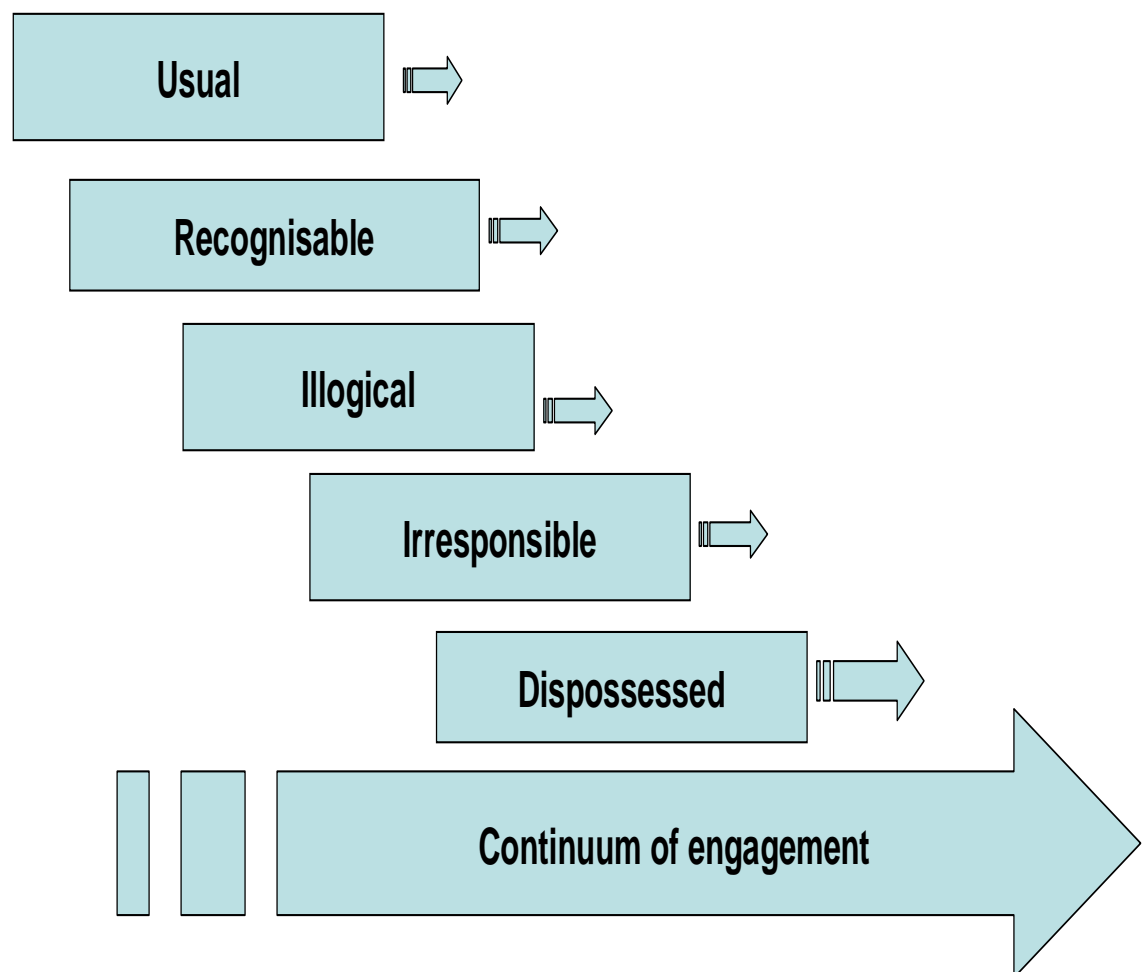


Framework Four provided a strategy to facilitate the understanding of the process of engagement in activity from carers' perspectives over time. The findings suggested that carers' perceptions of their involvement with people with dementia moved along a continuum of engagement through five activity patterns, that is, from the *usual pattern* through a *recognisable*, then *illogical*, then *irresponsible* through to a *dispossessed* pattern (as shown in Figure 6.4 below). Sometimes patterns overlapped and could occur at the same time. Each pattern in the continuum was reflected in carers' strategies relating to activity engagement with their relative, and their associated feelings at different times during the course of caregiving.



**Figure 6.4:** Activity patterns as perceived by carers of relative with dementia

# Activity patterns



I will outline the five activity patterns and sub-themes below:

## 6.2 Development of the model of activity engagement

Each of the five patterns will be discussed below in more detail. In each pattern, key points of each pattern will be outlined in a Table respectively, prior to the descriptions of the findings. In each Table, I outline the key points under three separate columns, i.e. features (specific circumstances and contextual factors for the development of strategies); strategies for activity engagement; and feelings and emotions. This is because I wanted to highlight the fact that each pattern incorporated a specific context which influenced carers' decision-making on strategies, and their emotions/feelings. Although I list 'feelings and emotions' separately in the Tables, I will not discuss them separately within the text, except when relevant to 'features' and 'strategies'. This is because the aim of the present study was to explore carers' perception of how they engaged their relative in activities. Hence, below I present only the details of features and strategies of each pattern.

### 6.2.1 The concept of usual activity pattern

**Table 6.4 The usual activity pattern**

Features	Strategies	Feelings and emotions
<p>1) <i>an awareness of the activity patterns of one another</i></p> <ul style="list-style-type: none"> <li>• <i>self reliant</i></li> <li>• <i>mutual understanding</i></li> <li>• <i>boundary of involvement</i></li> </ul> <p>2) <i>familiarity with the usual behavioural and communication modes</i></p>	<p>1) <i>negotiating boundaries of involvement</i></p> <p>2) <i>compromising</i></p>	<ul style="list-style-type: none"> <li>• <i>respect for autonomy</i></li> </ul>

#### 6.2.1.1 Key features

The concept of *usual activity pattern* reflected the 'normal' involvement of each individual in the partnership. Participants were aware of normal activity patterns of their relative. Within the household, both the carers and their relative had specific roles (e.g. husband, wife, daughter and partner). The majority of the participants considered their relative as self reliant in their everyday activities. They shared various everyday activities together whilst maintaining independence in certain aspects of everyday activities, as highlighted in the quote below by Linda:

*'We were never a couple that lived in each others pockets anyhow, we always had quite individual interests, but we went out together'. [C14]*

Carers and their relative often had established boundaries in terms of their involvement in everyday household routines such as handling their finance, gardening and the everyday manual maintenance work in the house; for example, Ann said:

*'He'd got his financial affairs and I'd got mine, and so we always kept separate our own financial affairs, but had joint accounts in the middle to which we both contributed to pay, you know, the general upkeep of everything... , twenty-six years we've been married, and until just recently I hadn't any idea of all his bits and pieces of where he'd got money in shares of whatever, it never concerned me, I wasn't bothered, I wasn't interested in it at all'. [C13f]*

Another key feature of the usual activity pattern was associated with the fact that participants were familiar with the usual behavioural and communication modes as reflected in the following quote by Margaret:

*'Well, my husband played for their bowls club. But he didn't like competitions, he wanted to play for pleasure; because the competitions they'd got, you must win, you must win, and he didn't like that. He wanted to play and enjoy the game, so he didn't play in competitions very much'. [C8f]*

Implicit in this quote was that carers often had an insight into the feelings and emotions associated with the activities which their relative enjoyed doing. Carers might pursue very different activities to their relative in respect of their everyday routine activities (e.g. domestic household tasks and leisure pursuits), but they had an awareness of the activity patterns of their relative. Interdependency in the relationship was apparent.

#### 6.2.1.2 The strategy/goal of engagement

Many participants would try to support one another's needs and wishes. They tried not to cross the boundaries unless they came to a mutual understanding, as Lillian said:

*'My husband used to keep the books. In the beginning when he started making mistakes, you know he put a bill in twice as having been paid, and put it in again, and of course when we got the bank statement, I checked the bank statement with him: we'd call the items over. And of course it didn't balance. And I found he'd made these mistakes...we came to a mutual understanding that I help out, so we did it together'. [C12]*

By negotiating with her husband, Lillian avoided misunderstandings with her husband and maintained a harmonious relationship.

Prior to the onset of dementia, carers and their relative often had established processes which enabled normal negotiation in the partnership and shared activities, motivating each other and supporting each other in their activities. This is reflected in the following quote by Margaret:

*'In the church, the ladies have a Ladies' meeting, and my husband used to sometimes go down and meet them for that. It was his idea that we should have a tea-party in our garden, and they loved it. ... But of course you have to have transport for that sort of thing, he and some others used to provide transport and as the ladies got older and people moved away, we were lost for cars. And he couldn't do eighteen ladies, you know..., So we stopped it ... it gave him an incentive to get our garden extra special attention... And he stopped doing the garden after that...I had to pay someone to do it'. [C8f]*

In short, on looking back, participants talked about how they felt their own lives and activities were changed because the *usual activity pattern* had been affected.

### 6.2.2 The concept of recognisable activity pattern

**Table 6.5 The recognisable activity pattern**

Features	Strategies	Feelings and emotions
<b>1)aware of occasional changes</b> <ul style="list-style-type: none"> <li>retrospective recognition</li> </ul> <b>2)difficult to pinpoint</b> <ul style="list-style-type: none"> <li>separate activities</li> <li>just being forgetful</li> <li>insidious</li> </ul> <b>3)concern for changes in characters</b> <ul style="list-style-type: none"> <li>being self-centred</li> <li>being manipulative</li> </ul>	<b>1)logical reason</b> <ul style="list-style-type: none"> <li>expected aged-related change, chronic illness, retirement and life style change in later life</li> </ul> <b>2)reality checking</b> <b>3)boundaries renegotiation</b> <b>4)seeking for GP's advice</b> <ul style="list-style-type: none"> <li>positive experiences</li> <li>negative experiences</li> </ul>	<ul style="list-style-type: none"> <li>annoyance</li> <li>tensions and conflicts</li> <li>suspicious</li> <li>worry</li> <li>sense of hope</li> </ul>

#### 6.2.2.1 Key features

The *recognisable activity pattern* represented the time when carers became aware of occasional changes in the activity patterns of their relative who did not always achieve their normal standard of performance in various areas of everyday activities. This pattern was often identified retrospectively as at the time they did not recognise that it was the start of a more dramatic change.

Almost all participants became aware of occasional changes in the activity patterns of their relative (e.g. being forgetful, making mistakes on an everyday task) but were not unduly concerned at the time as illustrated in a quote by a partner, Susan:

*'And you know few years back, he [my partner] had great friends there [name of the next county]. One was in hospital and he was going up and down twice a week making no trouble of it... But, um, on one occasion, we went together, we were six hours getting there! We got lost ...And of course I didn't realise that this [dementia] was coming on'. [C4f]*

Often it was difficult to pinpoint exactly what was going wrong with their relative because carers and their relative spent a lot of the time in separate activities. This was specially the case when they both were involved in separate everyday routines. An example of these was when both or one of the carers and their relative were working prior to the onset of dementia; for example Ron said:

*'The first thing that happened was that my wife was asked to stop work because of the condition [not coping with her job due to stress], and I didn't really understand it, but in the home situation where there is, you know, more familiarity and so on, I hadn't noticed it initially... Erm, she had never been a totally organised or logical person, but there again, I mean, she got more degrees than me, erm, and she's an [title of healthcare professional] ...she left work, erm, I sort of didn't know there was a work problem until then'. [C9f]*

Often changes were put down to the insidious nature of ageing and general ignorance of what dementia was which contributed to the difficulty in appreciating an underlying problem.

At this point, although many participants noticed some changes in their relative's everyday routine activity resulting from forgetfulness, they expressed more concern about the change in their relative's character and how it affected their relationship, for example Susan said:

*'When I was in the first year before we [self and partner] went to see a psychiatrist..., you know it was such a change in character that I wondered if he [partner] was putting it on, you see, because he used to be so helpful and now he doesn't lift a finger of any sort and I was angry at the beginning because I accused him of being lazy'. [C4]*

It appeared that their relative becoming disinterested, more self-centred and less involved in the shared responsibility of the partnership increasingly annoyed some carers. Tensions and conflicts often arose in the relationship, particularly when carers had some doubt as to whether their relative was becoming manipulative.

#### 6.2.2.2 Strategies

As can be seen from Table 6.5 there were four key strategies which will be discussed below:

Many participants tried to find logical reasons to help them explain the perceived changes in their relative's character and behaviour. Often they attributed the causes to age-related decline, history of illnesses, work-related stress, retirement and its negative consequences on lifestyle. For example Jean said:

*'I thought it was a combination of the fact that my husband had had an operation for cancer, which was cured; I thought it was a combination of the fact that he was retired, and that he hadn't got any real hobbies, erm, I thought all those added to it, and I just thought basically he had sort of just given up on life, or given up being interested in anything, ... he was just prepared to just sit on the settee and watch the television'. [C5f]*

Some carers wondered if it was an extension of an existing personality trait, for example, Jean's husband had never been an active partner, involved in daily routines at home, before his retirement.

Participants often used activity engagement as a reality check to find out if their relative was still able to contribute to some everyday household management tasks for which they were responsible. This can be seen in the quote below by Lillian:

*'In the beginning he [husband] contributed; he did the dusting. I mean, like most men, he wouldn't do it off his own bat, but if you said "Will you Hoover the carpets?" He'd Hoover the carpets. Well now, he wouldn't know really how to work the Hoover, and I wouldn't trust him with it because he'd probably say I have done it'. [C12]*

This carer was using hoovering to assess her husband's performance and then confirmed her suspicions that her husband's poor performance was not just due to his attitude towards the task but also his loss of ability in using the Hoover.

Initially, the majority of the carers considered the issues as private ones and tried to work together with their relatives in order to renegotiate their boundaries of involvement in respect to the everyday domestic routines.

Nevertheless, when carers' suspicions were raised by the changing activity patterns and the personality of their relative, many turned to their GP for advice and assistance. The

process of investigation, however, could be lengthy (for example, over two years). The problem with this lengthy investigation was that, by the time a diagnosis of dementia was made, the level of functioning and memory of the individuals with dementia had often deteriorated further. Nevertheless, a confirmed diagnosis was seen as positive by several people, for example Ann said:

*'When I was actually told that he had Alzheimer's. I almost felt better, because up to then I thought well, am I just being impatient, you know, intolerant. I mean, I knew he was pretty vague, but is he as bad as I think he is, so in a way therefore, it was quite a relief when he was diagnosed as having Alzheimer's and being sort of, well, moderately bad. You know - so then I thought well, at least it's not me. And so now, I've sort of got to get on with it as best I can'. [C13]*

On the other hand, many participants felt angry that the medical professions sometimes failed to give a clear-cut diagnosis about the problem of their relative, as illustrated by Linda who was a retired nurse and cared for her husband who was a GP:

*'First they [the doctors in a hospital] said it was Alzheimer's, then they said it was Parkinson's, then I think it is settled that he's had a mild stroke of the right hemisphere of the brain so that there's something in there that is really responsible for all the, erm, symptoms and signs that he has shown... And they did say poignantly that 'You know, your husband has Alzheimer's, your husband has this and that.... So what caused the stroke? Was it on the way to Alzheimer's or Parkinson's, you know... that is a bit, erm, of a hit and miss affair'. [C14f]*

Many participants felt undermined by the medical professionals because they often failed to address the social, emotional and psychological impacts of the diagnosis on the persons and the carers as highlighted by Julie:

*'You know, they had the tests and these questions..., so there was that and then there was the brain scan and these were the results, but this, not the day to day if you say, like the living ...I mean they won't have had any detail like you have heard this afternoon [in the interview] of how we live and how mum functions. That wasn't part of it and yet for me that is the most important thing because it really doesn't matter what the brain scan shows, it really doesn't matter whether she[my mother] gets 25 out of 30 or 30 out of 30, what really matters is her quality of life... And as a knock on, my quality of life because I mean now it isn't just her quality of life it is mine as well and the implications are my partner and the whole, so, and of course that hasn't been addressed at all in any way'. [C6]*

Often this kind of practice and attitude continued with other healthcare workers and formal services (e.g. social services and health services).

Many participants also expressed their frustration that they were seen as invisible by formal services as illustrated by a quote below from Helen:

*'I find the whole thing perfectly stupid in that the consultant's letter comes addressed to my husband, with a suggestion that - 'It might be a good idea if you brought somebody with you'. (Laughs) This is perfectly stupid. If I didn't open the letter, we'd never get there'. [C7f]*

In this phase, carers' activity involvement with their relative was usually based on an understanding of the usual boundaries of involvement but needing to make some adjustments within the relationship and family to manage the situation.

### 6.2.3 The concept of illogical activity pattern

**Table 6.6 The illogical activity pattern**

Features	Strategies	Feelings and emotions
<b>1) significant changes, e.g. personal care, routine household tasks, life-long pastimes</b> <ul style="list-style-type: none"> <li>doing it wrong</li> <li>lacking motivation</li> </ul>	<b>1) a sense of identity</b> <ul style="list-style-type: none"> <li>challenging carer's sense of self</li> <li>time to switch off</li> </ul>	<ul style="list-style-type: none"> <li>dilemma, confusion.</li> <li>impatient, helpless</li> <li>shock</li> <li>sense of self being challenged</li> <li>resentful, hurt, guilty</li> </ul>
<b>2) the tip of an iceberg</b> <ul style="list-style-type: none"> <li>increasing confusion, poor reasoning ability</li> <li>less able to engage in meaningful conversation</li> <li>active mind at night</li> <li>struggling with everyday management</li> </ul>	<b>2) calculated risk vs. renegotiation to relinquish</b> <ul style="list-style-type: none"> <li>balancing the risky activity and disengagement</li> </ul>	

#### 6.2.3.1 Key features

The *illogical activity pattern* represented the time when carers perceived the activity patterns of their relative as being impossible to understand. For example, some participants noticed significant changes in the way in which their relative managed their own personal care tasks as illustrated in the following quote by Lillian:

*'My husband... And he'll put his pyjamas on, but over – he takes his trousers off – but he'll put his pyjamas on over everything else. And then, if you say to him "Why have you got your pyjamas over everything else?" I'll say "Most people don't do that", he'll take his pyjamas off and go to bed in his shirt and underpants (laughs)... And it's every night – it's not just once, You just give up in the end'. [C12]*

Many participants also noticed that their relative failed to achieve their own usual standard of performance in respect of the everyday domestic household chores, as shown in the following quote by Ron:



*'She's [my wife] not doing as much as she used to. She does a bit of gardening, but doesn't necessarily... tidy up after herself. And the same round the house: that can take almost longer than doing it yourself – well, slight exaggeration, I think, but err... there has been considerable deterioration: you know, ironing: again, she finds she gets things inside-out urm and things like that so on'. [C9]*

On the other hand, some participants found that their relative became less willing to engage in many routine activities in general. They attributed such a change in their relative to poor motivation or 'being lazy'. As time went on, they gradually became concerned that the perceived problem of their relative was just the tip of an iceberg.

Many carers realised that their relative experienced not only forgetfulness, but also increasing confusion and poor reasoning ability, as Ron also said:

*'Logic doesn't work because they don't follow the logic and as I am actually [a person] who is supposedly totally logical and so on, I find that very frustrating. You know, you can't explain things so that they can accept it... So yes, you don't use logic you just try other things, like other suggestions or counter suggestions'. [C9f]*

It came as a shock to carers when they noticed that their relative had difficulty in engaging in a meaningful conversation with them. Jean, in the quote below, was surprised to discover that her husband's response to her questions was like a 'reflex action':

*'He [my husband] still has – he had a very good sense of humour, and he was very fond of puns, and silly little ... jokes, and he'll still come out with them, but they all be the ones he used years ago, ... I always feel it's almost like a reflex action: as if it never reached his brain... without, almost, being aware of what he's saying'. [C5f]*

As this phenomenon happened more frequently, many participants gradually came to terms with the fact that they would have difficulty in relying on their relative's account to describe their experiences, or share their emotions, thoughts and feelings with them in a consistent and meaningful way. This could have an adverse impact on the relationship between carers and their relatives. This problem could be aggregated when carers' sleeping patterns were disturbed by the unusual behaviours of their relative during the night times. As Margaret said:

*'He [my husband] used to be a sidesman at the church (after retirement). Well, - he would disturb me at night, because he had to be up at seven to go to the eight o'clock service, so half the night he'd be up saying, "Is it time to get up yet?" ...*

*“Do I go now?” – “No, you don’t”. Like a child waiting to go to a party, really. He thinks, that’s my thing, you know, so I’ve got to get ready for it’. [C8]*

Many carers experienced difficulty in handling situations during the night. The problem could be exacerbated when their relative became disorientated and became aggressive to them during the encounters. The following quote also illustrated how such a problem could also lead to increasing conflicts and tensions between the carers and their relative, as Carole said:

*‘It was not just the fact that he’d [father] get up and get dressed in the middle of the night, that was one of the worst points, that’s when he could be quite aggressive and rude. I really hated it, because you could wake up at three in the morning and realised that all the lights were on, was downstairs, got his coat on trying to get out of the front door. And I used to loath him then. So I said, “you’d get back to bed and you go through the door”, as I push him through the door, he tries to hit me... that depressing isn’t it? or even worse... I don’t think he knew who I was’. [C3]*

This challenged her sense of self and identity, as Carole was wondering who she was to the aggressive man during the confrontation with her father. Many carers described feeling helplessness, isolation, and anger.

In this pattern, those participants who cared for a relative without a confirmed diagnosis of dementia would usually make contact with their GPs for further investigation. As in the previous pattern, many participants acknowledged that they found themselves struggling with the everyday management of the everyday caring even though their relative had received a diagnosis. This is reflected in the quote by Julie below:

*‘At first when he [consultant psychiatrist] said, you know, about the dementia..., I thought ‘Ah! I’ve got a label... Now I can understand why she [my mother] is behaving like this ... But then it was like, that didn’t help me at all, because it didn’t explain, really. No, no. And it wasn’t like, you know, she’s got this physical thing, and means that this is how she will behave, and how she will progress, and this is what we can do, you know, this is what we can do to help...and I’m trying to manage it, and as time’s going by, I’m doing it less and less well’. [C6f]*

Many participants, like Julie, often commented that they did not receive sufficient support and advice for their role as a carer.

In this pattern, many participants were being confronted with a range of issues; for example, What was the speed of deterioration of their relative? How would medication

make a difference to their relative's memory problem? What was their new role/responsibility in supporting their relative? Should they interfere in the personal affairs of their relative? How long would the whole process take? What should they do next? The questions were often left to be answered by the carers themselves.

#### 6.2.3.2 Strategies

As can be seen in Table 6.6, there are two categories. I am going to discuss them in detail below.

Many participants helped their relative maintain a sense of identity for as long as possible, through participation in their pre-existing interests and roles. For example, Jean said,

*'I've had to sort out what he [my husband] does with the cricket club, and I mean, he was actually president of the cricket club, well I know the president is an honorary position ...but we've now worked some sort of system down there where he remains as president...they're putting a new one in, more or less, so that he remains as president and someone else does all the speeches, the social work, and all that sort of thing. And in that way he is still involved... I don't know if it does him any good or not, but you feel it might. And I think it would be cruel to write him off as not being interested at all, because you don't know how interested they are, how interested somebody is'. [C5f]*

Jean worked hard, as many of the carers did, to enable her husband to continue his involvement in a life-long interest and role despite the fact that she was uncertain if he would ultimately benefit from her input. Implicit in the quote was that she had to tell her husband's friends about her husband's diagnosis in order to get them on board to support her goal in terms of engaging her husband's role in the club. By doing so, she also set up a supportive environment for her husband to continue engaging in his role as a president of the club.

Hence, carers' decision-making was a complex process, involving knowledge of the meaning of a particular activity to their relative, the possible impact of cessation of such an activity on the well-being of these individuals and their ability to mobilise the resources. It required their commitment and perseverance. Their patience was constantly being taxed by having to keep up with the process.

The caregiving situations often challenged carers' ability to renegotiate their boundary of involvement in the partnership. Some carers felt defeated and lost their sense of self when their relative appeared to make unilateral decisions to withdraw from activities which they both shared in the past, as Helen said:

*'He [husband] can't be bothered with anything..., because I enjoy life, at least I always did. I don't enjoy looking after him, I have to say. But it's just my lot; so to speak ... Going on holiday is out of the question. He doesn't want to go out. I bully him to go out, and sometimes I think I will just go on my own because it is so difficult to get him off the chair. It is a huge change...it's really a dreadful thing, ...I mean, I thought cancer and things were bad, I haven't had it: stroke seems to be one of the worst things you could have medically, but this[dementia] – because it takes so many lives. It has taken my own life, really, but I won't let it..., I get very down sometimes and I think 'I'm not going to let it get me down', but inevitably I have forgotten what normal is'. [C7]*

This carer felt upset and angry that her husband rejected all her attempts to re-engage him in activities which they both enjoyed in the past. Resulting from repeated failure of her efforts, she reappraised the meaning of her own life.

When their relative became less involved in their everyday routines in the partnership, some carers felt that their dream for the future was threatened. This forced them to reconsider their identity and the meaning of an emerging new role, i.e. being a carer. This is especially the case for those carers who had been looking forward to an active lifestyle after retirement and in later life.

Carers often expressed a need for having time out to switch off from their daily caring routines. It was interesting to note that those carers who were still working found that an opportunity away from home enabled them to relieve their frustration and maintain part of their identity as a worker, as Ron said:

*'I think erm the fact that I have a job to think about as well helps, so that I can take out my frustration on whatever. Erm, but yes, the thought of being a sole carer full-time erm is pretty worrying'. [C9f]*

Some carers were still able to pursue a job as long as they felt that their relative was still capable of pursuing their own activities to some degree without supervision from the carers.

The majority of the participants talked about having to ascertain the level of risk for certain everyday activities in which their relative was involved; and occasionally to take calculated risks when engaging their relative in activities.

The dilemma, which carers often faced, was reflected in the quote by Susan below:

*'Although I have to let him [my partner] go ahead with that [driving] by himself, but we only go local because I drive him to all other places, it's safer, ... Err, I'm conscious of the fact that he's got a lethal weapon under him, the car, but as I said to [name of the consultant], I will stop immediately if I think he is driving dangerously...so if I said to him, "now [name of partner], you've got to stop driving" he would just say, "well I'm not going to", you see'. [C4]*

Many participants found it difficult to influence their relative's decision-making. Despite the best intention of carers, attempts to renegotiate the boundary of activity engagement with their relative often gave rise to increasing tensions and conflicts between the carers and their relative.

To sum up, the frequent occurrences of illogical behaviour began to disturb carers' previous understanding of their relative's character, established over their years together. It challenged carers to maintain their relative's identity and their own. As time went on, it came as a shock to the carers when they realised that the activity patterns of their relative would not be able to return to 'normal'. The majority of the participants found themselves developing strategies based on their own assumptions rather than professional advice. As Julie said:

*'Erm, I think just by –, you know, like you and I – you know, professional listening to the things, you know, what happened. If I'd had someone here and say, 'This has happened, that happened, this is how I feel, you know, this is what has gone on' – just that - if I had a professional to talk to I think some of these issues perhaps would have been made clearer, you know, I would have been able to understand what was going on perhaps more, rather than having all these conflicting messages you know, and from friends, my partner, and how I felt'. [C6f]*

Hence, many participants resented that they rarely received appropriate support from the professionals at the right time.

#### 6.2.4 The concept of irresponsible activity pattern

**Table 6.7 The irresponsible activity pattern**

Features	Strategies	Emotions and feelings
<b>1) incapable of taking responsibilities for everyday activities</b> <ul style="list-style-type: none"> <li>inability to appreciate the long-standing interests</li> </ul>	<b>1) encourage 'being active'</b> <ul style="list-style-type: none"> <li>going out</li> <li>an irreversible cost</li> </ul>	<ul style="list-style-type: none"> <li>strain and frustration</li> <li>physical and emotional consequence</li> <li>exhaustion</li> <li>mixed feeling of sadness, loss, resentment and helplessness.</li> </ul>
<b>2) vulnerability and unsafe</b>	<b>2) gaining a sense of control of the routine of caring activities</b> <ul style="list-style-type: none"> <li>finding own meaning to care for the person</li> </ul>	
<b>3) role reversal</b> <ul style="list-style-type: none"> <li>no give and take relationship</li> <li>Resentment and feelings of helplessness</li> </ul>	<b>3) utilising external resources</b> <ul style="list-style-type: none"> <li>day care</li> <li>personal care</li> </ul>	
<b>4) societal expectations</b>		
<b>5) interference vs. non-interference</b>		

##### 6.2.4.1 Key features

As can be seen in Table 6.7, five sub-categories emerged in the *irresponsible activity pattern*. The detail of these categories will be discussed in further details below.

This pattern represented a time when participants perceived that their relative was incapable of taking responsibility for their everyday activities. The majority of the carers became increasingly fearful for the safety of their relative and therefore lost confidence in their relative's ability to manage their own self-care activities and most of the household management tasks. As Ann said,

*'I didn't want him[my husband] to go in the kitchen, because of you know filling the kettle and then remembering how to press it on, or how to turn it off, even, you see, that err, I wouldn't like to trust him with that... Then with the telephone, he didn't know what to do, he'd erm, it always stood there, and he would answer it and then put it down, and if he answered it before I could get to it, I would say, "Well, who was that?" "Oh, I don't know". And I'd say, "Was it a man or a woman?" "Oh, I don't know", do you know what I mean'. [C13f]*

Many participants came to the realisation that their relative became increasingly vulnerable and gradually lost the ability to appreciate not only the details involved in their past interests, but also the meaning of these activities to themselves and their carers.

Despite the difficulties many carers continued to involve their relative in some aspects of their previous duties until they discovered a major hurdle along the process of engagement. As Susan said;

*'I said [to my partner], "There's my British Telecom bill there. Would you post it for me?" - because just outside the flats there's a post box. "Yes". So he was gone an hour and a half, and then he came back and I said "Did you post my letter?" He said "Yes".... So, the following day when I got in the car, his car, there was my British Telecom bill on the seat'. [C4f]*

Many carers often experienced role reversal when they increasingly took over the duties and responsibilities of their relative. Many carers acknowledged that it was no longer 'give and take' in the relationships as highlighted in the quote below by Lillian:

*'It is as if you are the only one who is having any input into the situation. It's like things being sucked out of you, towards them, because you are putting it all in and – it's not their fault – but they are taking all the time. No longer is it give and take: in a marriage situation, one is giving, one is taking'. [C12f]*

There was a sense of loss and resentment even though the majority of the carers realised that their relative had dementia. Many carers often found it difficult to cope with the emotional consequence of having to come to terms with taking over the responsibility for looking after their relative.

Risk was still a big issue for many of the carers. They felt that there was societal pressure on them to protect their relative from being hurt as shown in a quote below by Linda:

*'They [staff in the day centre] said you must fetch him [my husband]: [I thought] if he is sensible enough to walk home, let him! To me, I believe in rehabilitation... he gets into a habit where he's got used to doing what he used to do [walk home from a day centre by himself], and then suddenly he isn't doing it, it's like... they[staff] are worried thinking why can't she [me] come and pick him [my husband] up, you know'. [C14]*

This carer explained that she used to worry a lot when her husband first insisted on walking back home from the day centre on his own. The journey took about forty-five minutes, from an isolated country house through a country lane with busy traffic to the city centre. Some sections of this lane had no pavement for pedestrians. On numerous occasions, this carer had tried to persuade her husband not to go out on his own without success. As a result, she had to give in to her husband's argument and supported him to carry on walking to the property on foot. Hence, this carer tried to comfort herself that

by supporting her husband to do what he wanted to do, she helped him get some physical exercise and therapy at the very least.

Many carers resented the judgment of them by professionals concerning issues such as the perceptions of risk-taking with their relative's daily routines. This presented carers with a challenge to cope with in their roles because they worried that they could be blamed for the perceived negative consequences of their decision-making. Moreover, many were frustrated as they felt that their capability as carers was being undermined by the authority figures.

Many participants talked about the dilemma they frequently faced when attempting to intervene in the process of activity engagement. For example, they had the prospect of having to deal with verbal and sometimes physically aggressive behaviour from their relative when they attempted to assist them with their everyday activities, as Jill said

*'I don't want to upset him[my husband] because he gets really cross and he shouts a lot and everything, so I just go along, you know..., so I am learning all the time. Because I used to argue with him a lot in the beginning and I didn't really know his mood swings and I didn't know what was happening to him and then we had arguments and then he grabs hold of my hands and go "arrrrrrr", and shouts at me and everything, "oh gosh", you know. See now I don't argue, I don't shout'. [C11]*

Many carers learnt from their own experiences how to avoid confrontation with their relative when engaging them in everyday activities. The need to develop different ways of communication with their relative further increased the strain on their relationship. Generally speaking, judging by the changing activity patterns of their relative, many carers convinced themselves that their relative failed to both take responsibility for their own actions, and relate to others in an appropriate manner.

#### 6.2.4.2 Strategies

Most of the carers spoke of how they encouraged their relative to stay 'active' or 'being involved' in some kind of activities such as domestic chores. By keeping their relative active either in the body or mind, they wished to prevent their relatives from sitting idle, as Lillian said:

*'Well, I, erm: when I say "Will you Hoover through for me?" or "Do this and that" – you see, I try to keep him[my husband] active so that he won't get in that chair and go off to sleep. Mind you, I have to come in to see, because the middle*



*bit gets done and the outside doesn't exist, sort of thing... But if you want to work on somebody and get a good result you've got to keep on in there, haven't you'? [C12]*

It was interesting to note that this participant had severe arthritis and cardiac problem. She felt that she had no choice but had to keep her husband in a productive role so that he could contribute to the household tasks with her supervision. By doing so, she also convinced herself that the speed of her husband's deterioration with his dementia was slower than that expected by the professionals.

Another commonly used activity which carers used to keep them active was to make them get out of the house. Many participants continued to take their relative out on a ride or shopping as a way of keeping their relative active, as Jim said

*'It's been like that for a long time, she [my wife] just sits. If she doesn't sit she will be lying and sleeping...I mean she has no real conversation apart from asking me 20 or 30 times a day whether I'm alright... It may be selfish on my part, but if I am here, she is sitting in the armchair... There's no input whatsoever from her side, but if I've got her outside, I can at least have a bit of a conversation about [name of a local city] and what's going on and the shops'. [C2]*

By taking his wife on a ride in a car on a familiar route, this carer attempted to stimulate a more meaningful response from his wife during their encounters. He also enjoyed reminiscing about the good time he had with his wife in the past.

As the dementia progressed, many carers found getting their relative out of the house and being active became increasingly difficult. This was specially the case when their relative had increasing problems associated with dementia, such as deteriorated mobility, incontinence, as well as increased disorientation and confusion. Nevertheless, several carers took their relative on holiday as part of their well-established lifestyle, despite difficulties. Many carers managed to continue their regular outings for quite a while until they realised their relative did not seem to gain much benefit from the trips and it was no longer worth the hassle to organise the outings.

Despite the fact that many carers made efforts to engage their relative in activities with a view to finding meaningful ways to interact with their relative, they acknowledged

that activity engagement did incur an irreversible cost to them as illustrated the quote below by Jim:

*'How far you can involve them is variable. If they don't want to do it, you coerce to do it, or you just have to bully them into doing it. I realise what I have to do now, for example, she[my wife] can't even walk up to the car without me keep telling her, this way, that way, she's like a child. They depend on you, I realise that. But that as it goes on, it involves an irreversible cost on our own expenses'. [C2f]*

Carers wanted to take responsibility for the care of their relative. Nevertheless, many felt resentful that their life became increasingly restrictive as their relative's behaviour became more childlike.

Many participants spoke of how they felt overwhelmed by their role as a carer and the need to become increasingly able to multi-task. Many felt that they needed to develop a sense of control in their own everyday caring routines and set a priority for certain activities as necessary and important to their relative. The following quote from Carole highlights this point when looking after her father:

*'If you're in charge of this person... because you have to do certain things. You want them to be clean, and like my father to be picked up by the van [to attend a day centre]. They're first, and then you have done all those. If you haven't washed your hair for a week, go and wash your hair. Erm, and then you have the time, to do the things that you think he might enjoy, go down to [the name of seafront] and buy an ice cream.....You're looking after them; you don't want them to go out with food all over their clothes. The way they might if they were left to themselves'. [C3f]*

Some carers felt that such a direct approach to involvement was being manipulative on their part. This was especially the case when the carers had been the less dominant one in the partnership. Carers were often uncertain if their relative would appreciate their efforts in helping them with specific tasks.

Being in control also meant that they had to control the caring routine by accepting help from others even if their relative was reluctant to accept external services, as Sheila said:

*'I had to take control of the situation with the help from other people [accepting external services] and they said "you must do it for yourself, otherwise you will start to really, really dislike the person you're having to look after" because it's very demanding and you have to give up whatever interests you have to looking after that person and it's extremely frustrating'. [C1]*

Thus the feeling of being in control could be enhanced by the acceptance of external services. As time went on, many carers realised that they needed to utilise resources beyond their own practical and emotional resources. Some carers regarded day care, home care and sitting service as means to share their role as the main provider for everyday caring activities including personal activities, entertainment and socialisation. They also viewed those service as alternatives to offer them a break from caring and to ensure that their relative was not left alone without continuous supervision for their safety. This often meant that carers frequently decided to balance their own activity need against that of the activity need of their relative.

The majority of the participants talked about using day care as a way for their relative to receive both supervision for a few hours and some kind of low-key social contact and stimulation. It was interesting to note that many participants stated that they would only use day care as a last resort when they felt that their relative required continuous supervision which they were no longer able to provide (e.g. resulting from own health problem, work commitment); and/ or when they felt that they ran out of their own resources (e.g. ideas, physical and mental strength) to entertain their relative at home, especially in the beginning of this phase.

The majority of the participants had a negative image about day centres, as reflected in the following quote by Carole:

*'Somebody said, "The trouble with day care centres is they're full of old people", and that was an old person who said that and I know exactly what they mean. I can see them from the bus that picks up my father that they're professional old, their clothes are different, they dress like old ladies and old men with strange hats, so they are what I call the professional old and they go along and act like old people. Well my father wasn't like that... I used to see the Age Concern bus, and I'm sorry but they all look like very old people, just sitting there... And like why why, are you all like this? As if, you have given up. You don't have to be like this, you don't have to give up. I mean [name of the day centre] is wonderful, they give them a meal and they have quizzes and things, but hey, I mean, come on a bit more than this'. [C3]*

This carer's father was in his early 90's. However, she did not see him as one of those old people who was contented to just sit and do nothing. Implicit in the quote was that she felt that her father's self image and identity were submerged in a category of 'old people' with very little individuality. Many carers could not see the real meaning of the day care services for their relative, as Steve said:

*'I mean I obviously don't know what they do with her [wife] at the centre ...But I think they get people throwing a ball, sitting round in a circle. That's all about it really.... it is just a cop out for me, it just gives me some time, like having some time away, and I am paying somebody else to look after her, give her some food or drinks... Other than that, when she comes out of the centre, it is the end of conversation. I mean she won't tell me who the other people are'. [C10]*

This left many carers feeling guilty when using day care services, especially when they had to 'drag' their relatives to the door when the taxi-drivers from the centres picked their relative up from home.

Many carers were disappointed that day care services often put people into general categories such as 'dementia' and 'old people' without addressing their individual needs and preferences, in respect to activity engagement. They felt that there was a lack of specialist day care services, especially for people with younger-onset dementia.

Generally speaking, many participants whose relative attended day care were left puzzling what kinds of stimulations or activities their relative received as they could never get a sensible reply from their relative when they returned home. It was interesting to note that participants who provided their own transport for their relative seemed to be better informed about activities their relative engaged in during the day. This was probably because they were more likely to be regularly in contact with the staff. Nevertheless, that also meant that they had less free time for themselves. This implied that there were very few reaching out services for carers to help them realise the real meaning, for themselves and their relative, of using day care.

Another everyday activity with which carers often required assistance was in personal care tasks. Many carers felt that they had to relinquish caring responsibilities to service provisions resulting from the changing atmosphere in the home as Margaret said:

*'From the point of view of personal hygiene, I had to have social services bath him every day, and then of course they would go and he[my husband] would need changing and he didn't like it. He would – I have had cancer and this arm I wear a sleeve to keep the swelling down, and if he was going to hit me he always hit me in the arm. ..., he was just so frustrated he would throw out and it was always that way and it always – I don't know whether he was awkward or deliberately doing it or what but it was always on that arm, but he never ever lifted a finger to anybody else'. [C8]*

Some female spousal carers commented that their relative who was resistive to their assistance with personal care did not always show resistance to assistance offered by paid carers. Many carers felt resentful that their relative seemed to present themselves in a much better way to strangers when they came to their home. Some carers regarded this as a failure in their role and began to lose the confidence in their ability to provide care for their relative, as Jill said:

*'I couldn't get over the fact that a lady [health care assistant] walks in, and she says, 'Good morning. I'm (whatever the name is) and I've come to bath you' – and he [husband] would go like a lamb and be bathed....and yet he would not let me bath him and undress him,... was his wife and, you know, he didn't want me to interfere with that side'. [C11]*

Implicit in that was that service providers for personal care activities might need to be more sensitive to carers' feeling when introducing a paid carer to assist their relative with intimate personal care activities.

In this pattern, often carers had exhausted a great deal of their personal resources and felt that they had to accept outside help. Carers' engagement in their relative's everyday needs appeared to be largely driven by carers' needs. Some felt increasingly resentful and guilty for having to intrude increasingly on the privacy of their relative and to take over their decision-making, sometimes without their knowledge.

### 6.2.5 The concept of dispossessed activity pattern

**Table 6.8 The dispossessed activity pattern**

Features	Strategies	Feelings and emotions
<b>1) dependent on carers for almost all aspects of everyday activities</b>  <b>2) changing atmosphere at home</b> <ul style="list-style-type: none"> <li>being a prisoner</li> <li>unable to recognise own home</li> <li>leaving home during night time</li> </ul> <b>3) distancing from their relative</b> <ul style="list-style-type: none"> <li>not the same person</li> <li>meaning of significant events changed dramatically</li> <li>confused by lucid moment</li> </ul>	<b>1) passive activity for mental stimulation</b> <ul style="list-style-type: none"> <li>time to pursue own interest</li> </ul> <b>2) security and comfort</b>  <b>3) emotionally detached</b> <ul style="list-style-type: none"> <li>hiding own emotion</li> </ul>	<ul style="list-style-type: none"> <li>obliged to take responsibility</li> <li>frightened to leave their relative unsupervised</li> <li>profound feelings of loss and sadness</li> <li>distanced emotionally and psychologically</li> <li>resentful</li> <li>Sense of self being challenged</li> <li>uncertainty</li> </ul>

#### 6.2.5.1 Key features

As can be seen in Table 6.8, there are three main categories of features. I am going to discuss them in detail below.

In this pattern, participants perceived that their relative had become dependent on them for almost all aspects of everyday activities including personal hygiene, dietary and medical needs. At this point, the majority of the participants noticed that their relative was increasingly unaware of the severity of their own problems and its impact on their own and their carers' lives. The activity patterns of their relative were no longer able to sustain their roles and responsibilities as illustrated in the following quote by Margaret:

*'This Sunday morning, he [my husband] had been wandering about in his pyjamas, but he'd got his shoes on instead of his slippers. And I looked down, and he passed a motion all the way through down through his pyjamas, into his shoes. And I said "What on earth has happened?" "Not me", he said, "Nothing to do with me"... he didn't know what was happening... he was in such a mess, I ran the bath and I said come on you have to get in the bath. And he wouldn't get in. He stood there'. [C8]*

This carer was shocked by the fact that her husband was so confused that he was not able to make sense of the incontinence problem. The problem of frequent double incontinence had been raised by some participants as an indicator for consideration for nursing care admission.

Many participants witnessed that their relative's basic life skills were disappearing and being replaced with increasing infantile and offensive behaviours. As Jill said:

*'He [my husband] gets, just like a child. Sometimes he is worse than like a child. And if he gets really ratty sometimes, when I keep on. I say you haven't had a shave, come on clean your cheek. You see all hygienic things he doesn't want to know anymore and I have to. I mean if he goes to the toilet he can't wipe his bum properly so I say let me know if you have a poo, but he won't. But sometimes I know. I say don't pull your trousers I will go and wipe your bum... Because he stains all his underpants so when I can catch him I can clean it up straight away, you know'. [C11]*

Many carers experienced profound feelings of loss, sadness and resentment. They spoke of how they lost their previous identity in the partnership over time as their relative was not involved in the partnership any more, as can be seen in the quote below by Shelia:

*'Of course...I mean, As I say, you're no longer a wife, you're not sharing companionship... so you have to realise well that's gone. That's just not there any more'. [C1]*

Many participants also found it difficult to see their relative as the person they once knew. The following quote showed how a spousal carer perceived human quality of her husband being taken away by dementia. As Jean said:

*'I don't actually think they are themselves at all. Superficially they look the same. They sound the same. They even make the same remarks: but the intellect is not involved. I don't think they are, they're not the same person at all..., what you've got. I think maybe you get left with probably the worst characteristics. Apparently, when we grow up we all learn to cover up our worst characteristics, in a way, and now suddenly they sort of reappear...I think you end up with possibly the person's underlying faults, without the things that they have learnt to put on top to make them nice'. [C5f]*

Carers were being faced with the reality that their relative had been deskilled and disengaged from many meaningful activities which they once valued.

Many participants also spoke of how their relative gradually became unaware of any significant events in the family as Margaret said:

*'He [my husband] forgot birthdays, wedding anniversaries, and one day about three years ago, I said to him "You forgot our wedding anniversary". "I'm so sorry," he said, "We'll go out for a meal tomorrow". And I said "All right". But when tomorrow came we didn't go for a meal: he just forgot... the final thing that did it, was the funeral of his mother. Because he'd got the black tie and white shirt, suit on, everything. But he didn't know'. [C8]*

Many carers often talked about how confused and upset they became when dealing with episodes of lucid moments of their relative. As Ann said:

*'I think the most difficult time is when they are lucid and you think this is alright and then in two minutes it's all gone, and in that lucid time you are relating to them as you would have done before, but then suddenly it changes so fast and you are completely taken aback and you feel quite hurt'. [C13]*

They found it difficult to deal with the realities in which their relative was being the person they shared their past with for a short while, and being a stranger to their relative for most of the time. They had to constantly adjust their coping strategies and related to their relative accordingly.

As time went on, many participants also felt that their lifestyle became even more restrictive as illustrated by Susan:

*'I cannot go out anywhere except to ... I mean, I can't have the dream. That's my biggest headache. I feel being in a prison'. [C4]*

Some carers were also upset by the fact that their relative frequently failed to recognise their own home as shown in the following quote by Steve:

*'Well, I try to convince her [wife] ...she is at home, I see familiar things in the room: I say "Well, you know where we are, don't you?" And I point out things- I say "That's your bed there", and so on. You see, she often thinks there's somebody in the bed, erm, there's somebody in there...' [C10]*

The impact of confusional states on carers was exacerbated when it happened frequently during the night time.

Most importantly, the meaning of and the atmosphere in the home changed as the balance of activity engagement between carers and their relative was tipped.

#### 6.2.5.2 Strategies

As can be seen in Table 6.8, there were three main categories of strategies. I am going to discuss them in detail below.

A key strategy which carers used was to provide their relative with passive activity for mental stimulation, as Ann said:

*'Sitting there that's all yes, so I have to think of things to amuse him [husband], you know, like as I say if I read bits out of the paper or put the music on or whatever...he smiles or he laughs or, you know, makes a comment, that's all we can do really... otherwise we'd both sit there in silence wouldn't we, not very cheerful'. [C13]*

Some carers often tried to engage their relative in some sort of everyday conversation in order to keep their relative stimulated.

In this phase, many carers found stimulating their relative much harder than ever before, but also realised that the home atmosphere was no longer stimulating enough for both their relative and themselves. The majority of the carers would have had some kinds of services as a mean to offer stimulation to their relative. Despite that many participants still found themselves having to think of some activity to stimulate their relative when they were at home alone with them.



Another strategy often raised by participants was the need to provide their relative with security and comfort as a priority of their caring responsibilities, as Jean said:

*'I think security is probably his [husband] most important thing: security, comfort and food. Which is like, when your intellect has gone, isn't it? It is, sort of, the animal things that are left, really, or the child things. I mean, I won't say that is all of him, but those are the things that worry him, if something goes wrong in any of those departments'. [C5f]*

Many carers spoke of how their relatives were gradually becoming distant from them emotionally and psychologically. Despite that, they tried to continue engaging their relative in daily routines by hiding their emotion while they tried to get on with other perceived responsibilities. This can be as shown in the following quote by Sheila:

*'Once you get to the point where you think I'm in charge and you think if I wasn't here he wouldn't feed himself, A, he [husband] can't drive, B, he can't get anywhere because he can't walk, he can't feed himself, he can't keep himself clean, he couldn't keep his clothes clean, he wouldn't live. He couldn't make food, he just would not exist, and then you realise that yes, you are in charge'. [C1f]*

By hiding her emotion, this carer was able to develop her confidence in making continued readjustments with the tasks for her husband in respect of management of the self and household tasks.

In this pattern, the goals of activity engagement focused on *doing for* their relative rather than *doing with* them. Many carers began to realise that they had to take overall control of the caring circumstance.

In summary, Framework Four provided a strategy to facilitate the understanding of the process of engagement in activity from carers' perspectives over time. I used the Framework Four to guide data analysis in the second phase of the present study. This in turn facilitated further development and saturation of core categories (that is, the usual, recognisable, illogical, irresponsible and dispossessed patterns) as the study progressed. The preliminary findings of the engagement of activity model have been published in a peer reviewed journal (Appendix 18). The next chapter will discuss the method of data collection and analysis for phase two study.

## **Chapter 7     Method - Phase Two study**

### **7.1     Aim**

The ongoing aim was to explore co-resident carers' perceptions and understanding of their own patterns of engagement in activity with people with dementia at home.

### **7.2     Objectives**

In order to achieve this aim, the following objectives were addressed:

*To explore co-resident carers' perceptions of:*

- a) The characteristics of different perceived patterns of engagement in activity (identified in the first phase of the study) with people with dementia from informal carers' perspective;
- b) How different perceived activity patterns impacted on their decision-making about the kinds of activities people with dementia might require;
- c) The barriers that prevented them from engaging people with dementia in activity
- d) How engagement in activity with people with dementia impacted on carers' own lives.

### **7.3     Overall design**

In phase two, I wanted to explore the co-resident carers' understanding and perception of the activity engagement of people with dementia further. Hence, qualitative research and using grounded theory as my methodology was still felt to be appropriate. The reasons for adopting a grounded theory approach have been discussed in Chapter 4. In this phase focus groups were used as the data collection tool. The aims of this focus group study were threefold:

- i) to allow feedback from participants about the findings from phase one study; and conduct member-checking by the members of the focus groups in order to see whether they could recognise themselves in the model developed so far, and to see if it made sense to them;
- ii) to serve as a source of follow-up data to further develop, and refine the emerging concepts and categories from phase one of the study;
- iii) to facilitate the process of saturation of core categories for theory development.

### ***7.3.1 The rationale for using focus groups***

I decided to use focus groups because

- a) I wanted to get opinions on the model created so far, and felt that this would be easier and create more open discussion if a group could discuss what worked and what didn't work, as an individual may feel that they had to agree with me in an individual interview.
- b) The focus groups would allow me to collect and generate rich data (Fontana and Frey 1998, 2008; Stewart et al 2007) from a number of people in a cost effective way.
- c) The use of focus groups also allowed the participants more time to reflect and to recall experiences; as well as to stimulate opinion in one another (Lofland and Lofland 1995; Barbour 2007; Fontana and Frey 2008); allowing 'observations for how and why individuals accept, or reject others' ideas' (Stewart et al 2007, p. 9).

Also it was felt that, unlike phase one which was purely exploratory, a key aim of this phase was to seek participants' views about the emerging findings from phase one and to refine the model. Although the topics discussed may still have been sensitive (which usually would preclude a focus group) (Fontana and Frey 1998), it was felt that people would nevertheless be able to discuss issues within a group environment (and this was found to be the case).

## **7.4 Participants**

### ***7.4.1 Inclusion criteria***

People who:

- a) had been living/lived in the same household with the person who had been given a diagnosis of having a dementia;
- b) felt that they were still providing/ had provided some levels of caring; responsibilities for the person with dementia in the same household for at least two years. This meant that I included people who had actually stopped their direct caring role (to be discussed further below). Data from these participants helped to integrate and refine concepts/categories of the model of activity engagement which had emerged from the first phase of the present study, as they could reflect on all activity patterns within the model.

- c) attended carers' support groups for carers of people with dementia which were organised by voluntary organisations within the areas covered by Kent Social Services Council.
- d) were willing to take part in group interviews which were expected to last about an hour and which were audiotaped.

#### **7.4.2 *Exclusion criteria***

People who were unable to:

- take part in audio taped focus group interviews due to the difficulties in communicating freely as a result of any medical conditions, which affected their speech. These people might include, for example, those experiencing stroke, Parkinson's disease, and learning disabilities.
- communicate in English; this was because of the nature of the research study, it was critical for each participant to feel free to take part in a group discussion. Financial resources were not available to pay for an interpretation service.

#### **7.4.3 *Sampling issues***

At the beginning of the phase two study, the following sampling issues were considered:

##### **7.4.3.1 *Sampling method:***

To a degree, I used purposive sampling to select the participants for the groups. I wanted people who had specific experience of caregiving, for at least two years, so that they were most likely to generate the most productive data from focus group discussions (Morgan and Scannell 1998; Macnaghten and Myers 2004). It was expected that the participants would come from a diverse background in terms of their relationships to people with dementia, the characteristics of the person they cared for, the duration of caring responsibility, employment status, gender, age and marital relationships. This would allow the generation of the diversity of relevant data and facilitate constant comparisons of existing and incoming concepts and categories.

I also adhered to the principle of theoretical sampling as far as I possibly could.

Towards the end of the phase one analysis, it became clear that in order to discover more variations in the categories in terms of their properties and dimensions, it would be necessary to have more participants who had already experienced all of the 'activity

patterns' on the continuum. Hence, I decided to recruit samples from not only the co-resident carers who were still caring for their relative, but also those co-resident carers who had actually stopped their direct caring role as their relative might have died or entered a nursing home. This was because the latter group was in a better position to offer insights into issues concerning the activity patterns of their relative, in particular in the 'dispossessed pattern' on the activity engagement continuum.

#### *7.4.3.2 Decision about the number of groups and group size*

It was expected that five focus groups would be conducted, although the final numbers were guided by the emerging theory. Recommendations on typical group size per session vary a great deal; for example; from five to twelve (Carey 1994), four to eight (Holloway and Wheeler 2002); six to ten (Morgan 1998) to as many as from eight to twelve (Stewart et al 2007). It was decided that the optimal size of each group would be between four and six participants. This was partly because I learned from participants' comments in phase one that many felt frustrated that they were not given sufficient time to address issues in-depth when attending carer support meetings; and partly because from my previous experience as a community occupational therapist, I was aware that a smaller group would allow me to have time to create an environment in which participants would feel safe and exchange their opinions more freely, especially when the discussions could potentially bring up emotionally charged subjects. Also, with a small group of six or fewer, each carer had more time to tell his or her personal story and expressed opinion (Morgan and Scannell 1998). Ultimately, this allowed me to learn about participants' relatively detailed account of their experiences or thoughts.

#### *7.4.3.3 Decision about the composition and compatibility of the group participants*

Of the five groups I initially decided that four groups would be composed of participants who were still caring for and living with their relative with dementia at home, and one group would consist of participants who no longer lived with their relative. It was hoped that this strategy would help to bring compatible participants to each individual group, and in turn promote group cohesiveness and dynamics (Morgan 1998; Morgan and Scannell 1998; and Stewart et al 2007). Nevertheless, this plan had to be modified at the time of recruitment. This will be discussed in section 7.7.1.

#### *7.4.3.4 Accessing participants*

The participants were recruited from naturally occurring groups, that is, the carers' support groups for carers of people with dementia within the districts where carers resided. The potential disadvantages of recruiting group members who might have already known one another will be discussed in section 7.7.1. These were organized by three charities linked with carers, old age and dementia who received some financial support from Social Services. Some groups were jointly managed by two organizations.

I restricted the sample criteria to only those participants who had registered with these chosen organizations for support. The significance of this decision was fourfold:

- i) co-resident carers of people with dementia were often tied up with their busy commitment as discussed in Chapter 5. Hence one way to reach such individuals was to go to places where they were likely to gather for shared interest as a carer;
- ii) these organisations were the main providers of support groups for carers of people with dementia;
- iii) the co-coordinators/managers of these organisations were likely to be in a position to offer a venue;
- iv) the co-coordinators/managers of these organisations were in a better position to do screening for participants who were caring or had cared for their relative at home with a confirmed diagnosis of dementia. This was to minimize one of the methodological shortcomings which had been addressed in previous carers' research, that is, recruiting carers of people with unconfirmed diagnosis through carers' groups.

### **7.5 Procedure prior to data collection**

Prior to the implementation of the study, issues concerning ethics, research governance, informed consent and confidentiality were considered. During the process of planning, I took measures to ensure that the guidelines of the research governance framework for health and social care were adhered to. A brief discussion of each steps of implementation can be found below.

#### ***7.5.1 Initial contact with service providers***

I met with the gatekeepers (e.g. the coordinators and managers of carers support groups) to obtain informal agreement of support for the implementation of my research once

ethical approval had been granted. I was not required to get letters of agreement from the collaborators at the time when I carried out this research.

#### ***7.5.2 Peer review by two internal reviewers, Southampton University***

I submitted a protocol to the School of Health Professions and Rehabilitation Sciences for internal peer review in June 2006. A project evaluation form/peer review report (PeerRev II) was issued in August 2006, confirming that I could proceed with the application for external ethical approval and research governance (Appendix 19). Following the completion of the review, I also obtained the clearance from the Criminal Record Bureau.

#### ***7.5.3 Social Services Research and Ethics approval***

Once the final peer review report was obtained from the Director of Research, University of Southampton, I submitted an application form to the Kent County Social Services Research Governance and Ethics Committee, together with all supporting documents, including a copy of the referees report. Ethical issues were addressed as stated previously in section 5.4.3. In addition, I highlighted several issues concerning the confidentiality of running focus groups. These included safeguarding confidentiality of participants in each group. For example, at the beginning of each focus group, participants were advised that anonymity of all participants would be maintained by: a) both the researcher and the observer; and b) the group members themselves through respecting the privacy of individual participants through not disclosing information raised by an individual elsewhere without their permission.

#### ***7.5.4 Research Governance***

Issues concerning research governance for social care (e.g. Data Protection Act, Health and Safety Act, professional indemnity, Risk assessment) were considered. Prior to submitting the application form for research and ethical approval, I approached the research manager of the Kent Social Services Research Governance and Ethics Committee for her advice. I was informed that the Committee undertook both the governance and ethics procedures. Also, it was confirmed that I would not require an honorary contract for the implementation of this project. This was because the participants of this project were carers who attended carers' support groups organised by voluntary organizations rather than statutory services.

When applying for research and ethical approval, I submitted the application form along with the following documents including: the proposal, report of the peer review and indemnity from the University of Southampton; risk assessment, consent form for participants, information sheet for participants and interview guide. Approval was obtained from the Committee in 2006 (Appendix 20).

#### *7.5.4.1 Submission of application to the University research governance office for indemnity cover and research sponsorship*

I liaised with the University of Southampton who acted as sponsors of the research and provided indemnity (Appendix 21). I also submitted a copy of the risk assessment to the Research Governance Administrator at the University.

#### *7.5.4.2 Adhering to the Data Protection Act*

It was important to ensure that data were stored in a manner that satisfied the Data Protection Act 1998. The measures I took were similar to those for phase one. Details can be referred to Appendix 22.

#### **7.5.5 Risk assessment**

I followed the Health and Safety policy of the University of Southampton and any special regulations within the County Social Service' research procedures when carrying out research activities. I paid particular attention to issues regarding the potential hazards to the participant, researcher and observer; and working in an unfamiliar environment. The details can be seen in Appendix 23.

#### **7.5.6 Gaining access to the participants**

Once the ethical and research governance approval and indemnity were in place, I sought permission to access the participants, and to hold a focus group within each organisation from the managers/coordinators/key contacts of the organisations involved. These coordinators had been contacted informally as highlighted earlier. At this stage, my aim was to ensure that all the gatekeepers, including the managers/coordinators/key workers of all the organisations of the carers' support groups were fully informed about the nature of the research.



In order to ensure that all staff of the organizations supported the implementation of the research project, I took the following actions:

- a) I sent a letter (Appendix 24) together with an abbreviated protocol to each coordinator/ manager with a view to restating the nature of the research and gaining their permission to access potential participants.
- b) I conducted a series of meetings with the managers and relevant members of staff to explain the procedure of selecting potential participants, including the use of inclusion and exclusion criteria. I was also available for them to ask questions via email and phone during the process of recruitment.
- c) I negotiated with the managers/coordinators to hold focus groups in the venues where participants had their regular meetings. When the locations of the carers support groups were in a public place, I had to look for a suitable venue where privacy, comfort and convenience could be ensured (an example of this is in 7.6.2).

At this point, two out of the eight possible carers support groups had temporarily been interrupted resulting from staff sickness. Also, the manager of one of the carer support groups felt that she did not want to commit herself to support to the research project due to staff shortage in her establishment.

#### ***7.5.7 Gaining access to participants***

Following the managers' approval, individual coordinators started looking through their registers in order to identify potential participants according to the selection criteria. These managers invited the potential participants to take part in a focus group discussion via invitation letters with a reply slip (see Appendix 25). Once I received the reply slips from the participants, indicating they were happy to be contacted, I then contacted them by telephone initially to:

- a) explain the nature of the research and inform them that a detailed information sheet with a reply slip (Appendix 26) would be sent to them. I also encouraged them to explain the nature of the project to the people they cared for where appropriate, so that these individuals were aware of what was happening;
- b) ask them to return the reply slip in a pre-paid envelope if they agreed to attend the focus interviews;
- c) ask them to bring the completed consent form (see Appendix 27) and registration form (see Appendix 28) with them when they attended the focus group meeting or to

return them using the enclosed self-addressed envelopes if they agreed to take part in the focus group discussion;

d) reassure them that their participation was voluntary and that confidentiality was maintained by myself at all times.

## **7.6 Data Collection – conducting focus group**

### ***7.6.1 The development of a focus group schedule***

I adopted general principles when developing the focus group topic guide. The questions were sequenced: i) from the more broadly defined topics to a more specific discussion (Krueger 1998a); and ii) by the relative's significance to the research questions (Morgan and Scannell 1998; Stewart et al 2007).

Hence, the questions I asked in the early part of the interview guide were general and non-threatening. This offered participants an opportunity to voice their views on the research topic before the transition to the more focused discussion. The more complex questions or questions relating to potentially embarrassing subjects were asked towards the second half of the session when rapport was likely to have been developed to its highest level, and participants had built up trust with other groups' members and myself as the moderator. I had to adjust the phrasing and the sequence of the questions depending on the responses of group participants. I also used probing strategies such as clarifying any inconsistency in the data as appropriate, and moving things forward (according to the focus group guide). When making decisions about how and what kinds of probes to use, I took account of the emotional needs, verbal and non-verbal responses of participants. Most importantly, the topic guide had to be used in a flexible way throughout each group interview in order to enable the participants to feel free to talk about their views.

All members of each focus group were asked to talk about their thoughts and feelings related to the following issues:

- How the activity patterns of their relative had changed since the beginning of their caring responsibilities.
- An example of when he/she tried to involve his/her relative/family member in an everyday activity but it didn't work.

- An example of when he/she has successfully involved his/her relative/family member in an everyday activity which was good for the person.
- The different activity patterns which had emerged from the first phase of the study. (i.e. recognisable, illogical, irresponsible and dispossessed)
- How they would like to be assisted and supported during the caring process.
- Any issues in relation to activity they think professionals should know about?

At the end of the focus group, I offered all participants an opportunity to ask any further questions in relation to the research study. The interview guide and the rationale for the questions can be found in Appendix 29.

### ***7.6.2 Setting up the groups: location and meeting room***

Once appropriate numbers of participants had agreed to take part in a focus group, I negotiated with individual managers to set up focus groups in the venue provided by individual organisations. As a result, the meetings for group one, three, four and five were held within the premises of the respective organizations. Nevertheless, I had to find a meeting room for group two as the usual carer support meetings were held in public places (e.g. café within a shopping mall). I explored various options such as community centres, GP surgeries, local health centre and local community hospital. Several factors had to be considered when identifying the most appropriate venue; for example, privacy and size of the room, accessibility, transport and costing. Finally, I decided to hold the second focus group in a staff training room at a local community hospital. The reason for choosing such a location was because this local community hospital was known to all participants and the head of the occupational therapy department was happy to support the implementation of any research concerning carers' needs.

The location of each of the meetings was familiar to all group members and accessible for people with disabilities.

### ***7.6.3 Maintaining contact with prospective participants***

Systemic notification procedures and personalized invitation are crucial if those participants who had been invited actually attend the group (Morgan and Scannell 1998). Hence, once I managed to confirm the time, date and venue of the each of the group interview, I informed each prospective participant by phone and then in writing.

In the letter, I also offered these individuals further information about the general topic for the interview. This was a response to requests I had from some prospective participants who asked if I could give them some examples of what kinds of questions I might ask them to talk about. By offering participants further general information, I could promote participants' interest in the study and the likelihood of participation in the focus group discussion (Stewart et al 2007).

The day before the focus group, I telephoned all prospective participants reminding them of the session and checking whether they intended to take part.

#### ***7.6.4 Preparing the observer***

All five focus groups were attended by an observer. This was so that the observer could: i) offer feedback on the way in which each group was moderated during the debriefing session, e.g. overall impression, key ideas, notable group dynamics; ii) make notes of the body language of participants e.g. sign of agreeing, frustration and concern throughout the discussion; iii) take comprehensive notes in case the tape did not work; and iv) assist with unpredictable disruptions during the discussion (Morgan and Scannell 1998).

There were three volunteers who agreed to be an observer for the focus groups. Two of them were occupational therapy lecturers; one of them was a senior nurse researcher. One of the occupational therapy lecturers was able to sit in three groups. They all had experienced of conducting groups (treatment groups, students seminars or focus groups). They were aware of the use of group dynamics and had an understanding of research processes. Hence, they did not require any training in terms of group work, e.g. how their verbal and non-verbal communication might have had an impact on the participants; as well as the need to remain objective and open-minded about the participants.

In order to ensure that all observers used a consistent approach, I adopted the following principles:

- providing transport for them to attend the session;
- having a brief session with the observer to go through the research protocol and the topic guide before the meeting;

- agreeing on some specific roles during the focus group as highlighted earlier;
- taking part in the debriefing session shortly after the focus group. I found it extremely useful to have the feedback from an observer. This in turn helped me reflect on the weakness and strength of my moderating skills.

### ***7.6.5 Conducting focus groups***

The observer and I usually arrived at the venue between half an hour to one hour before the session in order to set up the meeting room. This included setting up discussion tables which were useful for the cassette recorder, microphone and the paperwork; as well as organizing chairs around discussion tables. I noted that some facilities offered us coffee tables whilst others provided long rectangular tables. I made sure that participants and myself sat round the tables and that we all could see one another during the discussion. I also set up refreshment and registration tables in a reception area for potential participants to meet on arrival. However, this was not always possible due to the size of the room. When this happened, we had to serve refreshments on the discussion table prior to the discussion. This meant that we had to quickly tidy up the table and set up the equipment just before the focus group started. This inevitably led to some delay in starting the sessions. In such situations, I then checked with the participants if they were happy to stay behind to make up the lost time (usually around 10 to 15 minutes). This did not seem to cause participants any concern.

All participants were invited to attend about 15 to 30 minutes before the focus group itself. When they arrived, I collected: a) a copy of the signed the consent forms; and b) a completed registration form which aimed to collect background information about the participants.

In the beginning of each focus group, I reminded participants that I was there to listen to their views and thoughts on those issues, both positive and negative; and there were no right or wrong answers but different points of view. This was to encourage all participants to share their point of views even if their views differed from what others had said; and that I valued each one of their contributions to the topic of interest as a researcher and a learner (who tried to understand carers' viewpoints; rather than an expert). It was crucial to declare my position and set the tone for the discussion at this point; in particular as they were aware of my professional background.

The focus group discussion schedule was used in a flexible way throughout each group interview in order to enable the participants to feel free to talk about their views. Initially, the participants were asked to have a discussion based on their experiences of how the activity patterns had changed since they were first involved in a caring role. They also commented on the emerging themes (i.e. the five activity patterns) from stage one, and how these experiences compared with their own. I showed participants a diagram of the five patterns, together with a handout which gave a brief description of the different patterns. The diagram and handout acted as a visual prompt to enable participants to view the relationships among the five patterns on a continuum and to help prompt discussion of both consensus and controversial opinions (Appendix 30).

At the end of the discussions, I provided them with a brief summary (about five minutes), highlighting the key points of the discussion for their comments.

#### ***7.6.6 After the focus groups***

Once the group discussions had been completed, I thanked the participants and also sent them thanks in writing. Following each group discussion, I completed a fact sheet which contained information such as code number of each group interview and participant (coded), interview site (coded), date of the interviews, gender, other information pertinent to the research question, the number of participants from each site, the span of time allocation for data gathering. This information was obtained in a manner, which would facilitate constant comparison and the theoretical sampling procedures. This information sheet was attached to the top of each group discussion after it was transcribed to help retrieve demography data and specific group discussion content.

#### ***7.6.7 Being a moderator***

During the focus group, I adopted the general principles for being a moderator (Morgan and Scannell 1998). These are listed below:

- When participants asked for my opinion about issues being raised, I invited other participants' to offer their comments by saying 'what do people think?' I found this usually worked well. If individual participants required some reassurance, I offered factual information on occasion.

- I was aware of how my own characteristics might inhibit or foster openness within the group, as a moderator is not in a neutral position in terms of their personal background (Krueger 1998b). For example, I was aware that there were several factors which helped participants identify themselves with me and therefore feel relaxed, and comfortable in the focus groups. These included: firstly, participants knew that I had once worked with people with dementia and their carers in community mental health teams; secondly, participants were aware that my professional background was an occupational therapist who has an interest in activity engagement; and thirdly, I presented myself as a researcher who showed a passion to explore carers' experiences in dementia care. These factors helped participants feel comfortable and free to discuss their opinions in the focus groups. It is worth noting that many participants acknowledged openly that they wanted to support any research to do with dementia care and issues to do with support of carers. This was because the majority felt that carers' needs were marginalized. Moreover, many carers had experienced great difficulty in engaging their relative in everyday routine activities, and were eager to take up the opportunity to talk about the topic of interest. On the other hand, my personal background could have acted as an inhibitor for their participation if they believed that I was the expert and became hesitant to contribute their opinions. Hence, I needed to be sensitive to how participants reacted to my verbal and nonverbal communications during the meeting and adjusted my behaviour accordingly.
- I had to manage the group dynamics (e.g. Morgan 1997, 1998; Krueger 1998b) by controlling the timing for each questions, facilitating quiet and shy participants to elaborate their views, especially when they tended to use non-verbal gestures; ensuring dominant participants gave others opportunity to share their comments. I had to be very tactful when exercising my role as a moderator.
- I summarized the discussion and checked with the participants if my perception was accurate. When presenting the brief summaries, I also tried to observe the non-verbal signs of the participants for signs of agreement, hesitation or confusion; so that I could then invite comments and make corrections.

## **7.7 Lessons learnt from reflecting on the focus groups**

The pre-pilot study for the phase two was a small-scale trial run of the practice of equipment and interviewing/listening technique with a very small number of

participants who had been carers but not necessary met the same criteria as those in the research (Gillham 2005). It was exploratory with the overall aims to: i) discover any potential technical problem which could occur when the research started so that they could be avoided or minimized; and ii) offer an opportunity to practice my interviewing technique in order to promote my confidence in conducting focus groups. From this experience, I learnt that it was a challenging task to moderate a focus group in order to encourage free-flowing discussions among the participants. I needed to use not only good listening, but also group dynamic skills. Also, in order to obtain good quality data from the tape-recorded session, I needed to encourage participants to speak up, so that all their comments could be captured on tape. I realized that it was important to remind participants to try to talk only one at a time. In addition, I found that the topic guide provided a useful structure to help participants to focus their discussions within the timeframe. No major changes were required. Nevertheless, I became more aware of the need to use the guide in a flexible manner and provided prompts as appropriate if effective discussions were to be enhanced.

It was crucial to reflect on the experience from the first focus group onwards in order to identify what lessons could be learned from it in terms of group composition, topic guide, location and the impact of using a tape-recorder and having an observer in the group. The detail will be discussed below:

### ***7.7.1 Group composition***

I initially decided to recruit four groups which would be composed of participants who were still caring for and living with their relative with dementia at home, and one group of participants who were ex-carers. However, two months following the recruitment for the first and second groups, I received a positive reply only from two ex-carers and four carers were who were still caring for their relatives at home. By this time, several participants were anxious that they had not yet received a confirmation letter about the details of the focus group meeting. Some of them had agreed to take part in the focus group over five weeks earlier. I was concerned that they might lose their enthusiasm about their participation. Also, I was aware that some of the participants' circumstances were changing rapidly (illness of their relative). Hence, it was more appropriate to hold the focus group when they felt that they could manage to attend at the time. As a result,



I felt that I had to make a decision to mix the two types of participants in a focus group. Such decision to modify the initial plan was based on the practicality of the situation.

The other participants appeared to be interested in how the carer living separately made the decision about sending his wife into a residential care home six months previously. His narrative was particularly useful in that it offered insight into what it was like for carers prior to the end point of their actual home caregiving experience (either resulting in institutional care or death). His story triggered some participants to talk about the dilemma and guilt they were facing. This experience reassured me that it was helpful to mix participants who were no longer providing actual caring responsibility at home with those who still were. I could still compare the differences and similarities of views between two distinct participants' types by using the constant comparison method. Hence, mixed participants were recruited for each separate group.

Initially, I had recruited six participants for the focus group. One female spousal carer withdrew from the study as her husband died. On the day one carer was not able to attend because she had to provide child care for her daughter with short notice. These incidents showed that securing recruitment for focus groups was not a straight forward task as potential participants' circumstances could change rapidly during a short period of time. Thus, the exact composition of the group members could not always be predicted.

It was interesting to note that all participants but one had met one another in other events for carers before. This might have led to potential disadvantages. For example, those who have known each other might sit together and break off into private conversations during a discussion; or they might be obliged to agree with one another rather than to express own opinion (Morgan and Scannell 1998). However this was not the case, they all seemed to be quite supportive of one another during the discussion and could disagree as well as agree. It seemed that they were all happy to openly discuss their own problems and concerns. Moderation helped to promote the trust and cohesiveness among the members.

### **7.7.2 Topic guide**

It seemed that the questions were logically organised; the first three broad questions were sufficient to generate lively and prolonged discussion among the participants. I tended to take a less directive approach at this stage. On reflecting after group one, I decided I needed to tighten the timeframe in order to allow more time for the rest of the questions. Participants seemed interested in the model of the activity patterns. The visual prompts generated lively discussion.

### **7.7.3 Location**

The location of the focus groups has an impact on the group dynamics and interactions. When focus groups are being held in a familiar environment and are easily accessible by transport, they are likely to appeal to the participants (Morgan and Scannell 1998; Krueger and Casey 2000; Stewart et al 2007).

I had to be sensitive to the fact that it was a very emotional experience for participants to talk and share their caring experience with others. I noted that many participants were very passionate about their spouses' health circumstances and frequently referred to them as 'the loved one' in the discussion. For example, during the meeting, a couple of male carers showed signs of anxiety (i.e. muscle twisting, choking up) when talking about their experiences. Hence, it reinforced the idea that it was important to keep participants in the locality where they were familiar with the environment and people involved.

It was interesting to note that, on their departure, all participants thanked me for giving them an opportunity to take part in the discussion group and acknowledged that it was helpful for them to talk about their experience. A couple of them also thanked me for the way in which the group discussion was handled as talking about caring experiences was a very emotional and sensitive subject for them. Hence, it would appear that the group participants felt secure in exchanging their opinions with others in a group setting. This ultimately increased the usefulness and quality of focus group data (Stewart et al 2007).

#### ***7.7.4 Impact of having an observer in the group***

The observer always sat outside the circle (e.g. in a corner of a room where she could observe the interaction of the group members) so she did not cause any distraction to the group members. I noted that once the meeting started, the participants seemed to have forgotten the presence of the observer.

I found it very helpful to have an observer for each group before the group even started. The reasons were twofold: Firstly, I could work out a welcome strategy with her to ensure that we maintained a warm and friendly environment in a coordinated manner. For example, before the discussion began, the observer always assisted with small-talk, and organized refreshment until all participants arrived. This offered me time to sort out all the paperwork e.g. collecting the consent forms and registration forms and going through the topic guide. Secondly, I made use of the opportunity to observe how participants interacted with one another; and checked if they felt relaxed and comfortable. This enabled me to obtain an insight into participants' styles of communication, e.g. a tendency to be outspoken or a bit shy.

#### ***7.7.5 Appropriateness of using focus group in phase two***

Focus groups provided me with a useful strategy to gain insights into how data were generated through the interactions among the participants in scheduled discussions. I found it interesting to hear how participants examined and challenged one another and sometimes their own assumptions and attitudes about concepts. Data generated through this process helped to contribute to further refinement and saturation of some concepts/categories.

Nevertheless, I was aware that group discussions might cause participants to reveal information which was both complex and emotional. This was particularly the case for co-resident carers of people with dementia in the present study who took on a round-the-clock caring responsibility as highlighted in phase one study. Hence, I paid particular attention to the management of group dynamics and creating a supportive environment throughout the whole time of the meeting.

## **7.8 Overall analysis**

In phase two, grounded theory methods continued to provide rigorous procedures for conducting research because they allowed me to check, synthesize, refine, and develop theoretical ideas about the data in a systematic manner (Charmaz 2004).

I continued to use the Framework Four (figure 6.3) as a strategy to compare data from each group member within each focus group initially and then across all of the other groups. During the analysis, I looked for incidents and events that maximized the dimensional range or variations of each of the five themes as shown in the Framework. I also explored the relationships among the five themes and their sub-themes. By using the constant comparison method, I refined the themes/concepts. This in turn facilitated further development and saturation of core categories for theory development.

All focus group discussions were transcribed verbatim as in phase one. Each transcript was coded by using the coding system, especially selective coding (see 5.6.2.1). The concepts/categories were refined, developed and adapted by the constant comparison method until no new categories emerged.

Nud\*ist 6 computer software package continued to be used to assist with the management and storage of data. This in turn enhanced the qualitative data analysis.

## **7.9 Rigour in the phase two of the study**

I continued to employ reflexivity during the research process and to make explicit the ways in which I made decisions for data collection and analysis, as well as the extent to which I attributed to the viewpoints of the participants involved. Rigour continued to be maintained by employing criteria such as credibility, transferability, and attention to ensuring grounding of the research and participants' validations. Strategies included member checking, negative case analysis and use of memos as described previously (see section 5.7). Also, I continued to use Strauss and Corbin's (1990, 1998) and Corbin and Strauss' (2008) criteria for ensuring the grounding of the data. Such criteria included fit, applicability, concept generation, contextualisation of concepts, logic, depth, sensitivity, use of memos, variation as described previously (section 5.7).

- Fit : I invited participants to comment on the different activity patterns. Many commented that they could see themselves in the different patterns. Some also

reacted emotionally when they realised that the patterns appeared to capture their experiences, as shown in the next chapter. This suggested that the findings rang true with the participants for whom the research was intended.

- **Applicability** : the findings suggested that the development of the model of activity patterns offered a new insight and better understanding of carers' engagement in the everyday activities of people with dementia in a domestic setting with implications for practice that will be discussed in the final chapter.
- **Concept generation** : in the next chapter, I will present how the new concepts were generated and how categories were refined and redeveloped, taking into account the new insights emerging from the focus groups. I also attempt to demonstrate how the model of engagement was finally developed.
- **Contextualisation** : the context which provided background information for the final development of the model has been covered throughout this thesis and will be discussed further the final chapter.
- **Logic** : I am able to demonstrate the logical link between my justification of the research topic, the methodology and method used and the findings.
- **Depth of analysis** : this will be demonstrated in the following chapter.
- **Sensitivity** : I have drawn on my own analytical ability, theoretical sensitivity and research skills to convey the findings.
- **Use of memos** : I used memos as an important tool to help me organize retrievable data for sorting, and cross-referencing (Strauss and Corbin 1998; Charmaz 2000).
- **Variation** : Variations were built in through the sampling procedures in phase two study as discussed earlier in this chapter.

To summarize, I was aware that sampling of the participants, and the way in which I conducted the focus group could have a major influence on what I learnt from the members of the focus groups (Morgan and Scannell 1998). Hence, I have attempted to provide a detailed account of how the participants were systematically recruited during the research process in this chapter. Participants were recruited from a diverse background. Through the interactions among the members, they challenged and clarified each other's viewpoints. This in turn enriched my understanding of carers' perspectives on activity engagement. Also, the richness of the data was promoted by factors such as the openness the group members and their motivation to take part in this research. The next chapter will describe the result of the phase two study.

## Chapter 8 Analysis of the Phase Two Study

This chapter will present the findings of the phase two study. Firstly, I will describe the characteristics of the participants of each of the five focus groups; then briefly discuss how participants recognised themselves in the five activity patterns; and finally, I will discuss the key changes in some of the categories of the five patterns in terms of specific context/features and strategies.

### 8.1 Description of the groups

Twenty-one participants (13 female) took part in five focus groups. Participants included twenty spouses and one daughter (aged approximately between 40 and 90 years), looking after relatives (aged approximately between 50 and 80 years). Among participants, fourteen were still living with their relatives and seven of them were former resident-carers. Of the seven ex-resident carers, four carers still cared for their relatives who had been admitted into a care home; whilst the other three carers' relatives had died within the last eighteen months prior to the focus group meetings. I will now discuss the characteristics of each group. Pseudonyms will be used throughout this section.

#### 8.1.1 Group one (G1)

**Table 8.1: Characteristics of participants**

Focus group One	1 <sup>st</sup> *Nora	2 <sup>nd</sup> *Simon	3 <sup>rd</sup> *Norman	4 <sup>th</sup> *Audrey	5 <sup>th</sup> *Brian	6 <sup>th</sup>
Gender and relationship of carers	Female/ Wife	Male/ Husband	Male/ Husband	Female/ Wife	Male/ Husband	Female/ wife
Age range	70's(78)	80's (79)	91 (84)	79 (83)	80's (85)	-Unable to attend -Details unknown
Carers (cared-for)						
Length of time for caring (in years)	7	3-3½	9	2	8	
Length of time living together (in years)	45	58	65	58	60	
Stage of dementia as perceived by carers	Last stage	Middle stage	Advanced stage	Middle stage	Advanced stage	Retired
Employment status (carers)	Retired	Retired	Retired	Retired	Retired	
Caring status	At home	At home	At home	At home	At residential care	At residential care

\*pseudonyms are used throughout

From Table 8.1, it can be seen that there was a mix of gender, the participants were all over 70 years, and had lived with their relatives for a long time. The time of caring for

their relatives varied quite a lot from just over two to nine years. The majority of spouses lived at home with their partner but one person's wife lived in a residential home. One ex-carer was not able to turn up at the meeting as highlighted previously in chapter 7.

The focus group meeting was held in a quiet room at a day centre for older people. Three participants were able to attend the focus group when their relatives were attending the specialist dementia day-care in the same building; whilst one participant managed to ask his daughter to sit with his wife at home.

### 8.1.2 Group Two (G2)

**Table 8.2 : Characteristics of participants**

Focus Group Two	1 <sup>st</sup> *Mavis	2 <sup>nd</sup> *Helen	3 <sup>rd</sup> *Liz	4 <sup>th</sup> *Sandra	5 <sup>th</sup> *Dave	6 <sup>th</sup>
<b>Gender and relationship of carers</b>	Female/ Wife	Female/ Wife	Female/ Wife	Female/ Wife	Male/ Husband	Female/ Wife
<b>Age range Carers (cared-for) in years</b>	50's(59)	60's(74)	60's(68)	60's(69)	70's(76)	-Unable to attend -Details unknown
<b>Length of time living together (in years)</b>	27	42	22	40	56	
<b>Types of dementia (length of time with diagnosis in years)</b>	Early onset dementia (7)	Vascular dementia (3)	AD severe stage (4)	Lewy body AD (4)	Multi-infarct dementia (8)	
<b>Length of time for caring</b>	7	3	5	3	26	
<b>Stage of dementia as perceived by carers</b>	Moderate to severe	Mild to moderate	Advanced	Advanced	Advanced	
<b>Employment status (carers)</b>	Full-time	Part-time	Retired	Retired	Volunteer	
<b>Caring status</b>	At home	At home	At residential care	Died 18 months ago	Died about 6 months ago	Died about 1 yr ago

\*pseudonyms are used throughout

As can be seen in Table 8.2, five participants (4 female) took part in the 2<sup>nd</sup> focus group. The focus group meeting was held in a training room in a local community hospital.

As with Group One, all participants were spousal carers (aged between mid-50's and mid-70's). Despite that, majority of them were younger than those in group one. Two female spouses were still looking after their spouses (aged between late-50's and mid-70's) at home, and held a paid job; Mavis (pseudonyms are used throughout) owned her

business and Helen worked part-time as a supply teacher. Three of the carers had relatives who no longer lived with them (aged ranged from mid-50's to mid-70's). Liz visited her husband in a care home daily. Both Sandra and Dave's relatives died within the last 18 months.

Initially, six participants agreed to take part. One of them was not able to attend the meeting due to the fact that her daughter was unwell and she had to provide childcare for her daughter.

Several points which were worth noting were:

- Dave spent the longest time of caring for his wife, including fourteen years at home and twelve years in a care home until she had died six months previously. His experience highlighted that carers often carried on providing some care for their relative after they had been admitted to long-term care.
- Helen had also taken part in the phase one study. During the focus group, she seemed quiet. I felt that her behaviour might have been due to the fact that she found it easier to discuss her experience on a one-to-one situation. She might have thought that she had already spoken to me about her viewpoints on a range of issues in phase one. Nevertheless, she seemed very attentive when others spoke. She also used lots of non-verbal behaviour (e.g. nodding or facial expressions) during the discussion. I frequently invited her to join in the discussions with others group members in order to ensure that she felt free to express her viewpoints and clarify issues raised by the others. This strategy seemed to work well. At the end of the meeting, she told me that it was not as easy to talk in a group but she had found the discussions useful. It would seem that her voluntary participation in both the phase one and two studies highlighted that she was motivated to take part in my study.



### 8.1.3 Group Three (G3)

**Table 8.3 : Characteristics of participants**

Focus Group Three	1 <sup>st</sup> *Ruth	2 <sup>nd</sup> *Roger	3 <sup>rd</sup> *Raymond	4 <sup>th</sup> Unable to attend	5 <sup>th</sup> Unable to attend
<b>Gender and relationship of carers</b>	Female/ Wife	Male/ Husband	Male/ Husband	Female/ Wife	Female/ Wife
<b>Age range Carers(cared-for) in years</b>	60's(71)	60's(60)	80's(84)	Changed her mind	Details unknown
<b>Length of time living together (in years)</b>	36	41	65	- Details unknown	- Dementia Confirmed
<b>Types of dementia (length of time with diagnosis in years)</b>	AD (5)	CADASIL (10)	AD-Medium (10)	- Dementia (3 months)	few year ago in Wales, recently moved into the city to be near family
<b>Length of time for caring</b>	4	15	12	-	
<b>Stage of dementia as perceived by carers</b>	Advanced	Early to middle	Advanced		
<b>Employment status (carers)</b>	Volunteer	Part-time	Retired		
<b>Caring status</b>	At home	At home	At residential care	At home	At home

\*pseudonyms are used throughout

As can be seen in Table 8.3, the participants included one female and two male carers. They were spousal carers (aged between 60 and mid-80's). Of the three carers, two were looking after their spouses (aged early 60's and 70's) at home. They both worked part-time (one as a volunteer, the other as a gardener). One carer's wife (aged mid-80's) had been admitted to a care home about four months earlier. The length of time participants had spent on looking after their relatives ranged between 4 and 15 years, whilst the length of time carers had been living with relatives ranged between 36 years and 65 years.

Initially, five potential participants agreed to take part in the focus group interview. One carer was not able to attend the meeting due to the fact that her husband became unwell. Another potential participant changed her mind when I contacted her to confirm the details of the meeting. She told me that her husband has been given a confirmed diagnosis of early-onset dementia only about couple of months ago. Hence, she was unsure whether she could cope with talking about her experience in a group. This highlighted that the recruitment procedure enabled participants to have sufficient time to decide if they would like to take part in the study on voluntary basis without feeling pressurised.

The focus group meeting was held in the same room used for a group run at the day centre for older people. Two of the participants were able to attend the focus group while their relatives were attending daycare within the building.

Two points were worth noting in this group. Firstly, Ruth brought some paintings along to the focus group meeting. These paintings were created by her husband over many years. They illustrated the extent to which her husband had deteriorated and how she adapted the activity for him over time. By showing others her husband's work, she elicited a lot of responses and questions from the other group members.

Secondly, it was worth noting that Roger's wife has been given a diagnosis of *CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy)* over ten years ago. It is a genetic condition, a disease of young adults and presents with migraines with or without an aura, mood disturbances, focal neurologic deficits, strokes, and dementia. Roger felt that he had not been fully informed about the condition or its relationship to dementia. As a result, he has always considered his wife's problem to be a neurological condition rather than dementia, especially when he noted that his wife had episodes of mini-strokes and emboli over the previous fifteen years. It appeared that he had difficulty in accepting that his wife had dementia even though his wife had recently been referred to a dementia day centre. Despite that, Roger acknowledged that the focus group meeting had helped him not only to realise that his wife has got dementia; but also to prepare for his caring role.

#### 8.1.4 Group Four (G4)

**Table 8.4 : Characteristics of participants**

Focus Group Four	1 <sup>st</sup> *Ellen	2 <sup>nd</sup> *Keith	3 <sup>rd</sup> *Eric	4 <sup>th</sup> *Karen
Gender and relationship of carers	Female/ Wife	Male/ Husband	Male/ Husband	Female/ Daughter
Age range Carers (cared-for) in years	60's(71)	60's(62)	40's(60)	60's(86)
Length of time living together (in years)	35	38	23	2
Types of dementia (length of time with diagnosis in years)	Mild dementia /AD (1)	Dementia (4)	AD (2½)	Dementia (2 )
Length of time for caring	2	4	4	2
Stage of dementia as perceived by carers	Mild dementia 18 months ago	Middle stage	Early stage	Verging in the middle- severe dementia
Employment status (carers)	Part-time	Part-time	Full time	Retired
Caring status	At home	At home	At home	At home

As can be seen in the Table 8.4, four participants (2 female, 2 male) took part in the 4th focus group. They included three spousal carers and one daughter (aged between mid-40's and mid-60's), looking after their relatives (aged between early 60's and mid-80's, 3 female and 1 male). The length of time participants had spent on looking after their relatives ranged between 2 and 4 years.

On average, they were younger than participants in Group One and Three, but similar to that of Group Two. Moreover, all but one were still working, either full-time or part-time on flexi hours. Karen retired as a teacher and arranged for her mother to move into her house about 2 years ago when she realised that her mother was not able to manage in her own house. She had thought that she was just supporting her mother with her old age until she started living with her. Her mother had recently been admitted to the hospital for investigation following a rapid deterioration of her physical health. Karen acknowledged that she was pondering the idea of long-term care for her mother at this point.

The focus group meeting was held in a training room within the headquarters of an organisation. A point worth noting was that recruitment in this geographical area had been difficult. Following ten invitation letters which were sent to potential participants, two participants replied positively that they wanted to take part in the study within the first three weeks. There was a gap of six weeks before I received a response from the fourth potential participant. Four weeks after that I decided to arrange to set up this fourth focus group, as it was important to ensure that the potential participants would not lose their enthusiasm about their involvement in the project.

### 8.1.5 Group Five (G5)

**Table 8.5 : Characteristics of participants**

Focus Group Five	1 <sup>st</sup> *Joy	2 <sup>nd</sup> *Janet	3 <sup>rd</sup> *Joan	4 <sup>th</sup> *Lorna	5 <sup>th</sup>
Gender and relationship of carers	Female/ Wife	Female/ Wife	Female/ Wife	Female/ Wife	Male/ Son
Age range Carers (cared-for) in years	70's(80)	60's(78)	60's(70)	70's(70s)	Not able to attend - About 2 years
Length of time living together	59	41	45	46	
Types of dementia (length of time with diagnosis in years)	AD (5)	Dementia (4)	Advanced dementia (6)	AD (5)	
Length of time for caring	5	8	5	8	
Stage of dementia as perceived by carers	Middle	Middle	Advanced	Advanced	
Employment status (carers)	Retired	Retired	Retired	Volunteer	
Caring status	At home	At home	At residential care	Died 11 months ago	Move into mother's house

\*pseudonyms are used throughout

As can be seen in Table 8.5, four participants took part in the fifth focus group and were all female spousal carers (aged between late 60's and mid-70's). They had lived with their relatives for a long time ranging between 41 years and 59 years. Two of them were looking after their relatives (aged between mid-70's and early 80's, 2 male) at home. The other two were ex-carers. One of the carer's husband (aged 70) had been admitted to a care home; the other carer's husband died about 11 months earlier. The length of time participants had spent on looking after their relatives ranged between 5 and 8 years.

The focus group meeting was held in a quiet room at a day centre for older people. Initially five potential participants agreed to take part in the study. However, one of them did not turn up for the meeting. I later phoned him and found out that he had an emergency situation to deal with on that morning as his daughter had to go to the hospital relating to her pregnancy. This carer had retired and was divorced. He had moved into his mother's house to look after her about two years ago but continued to manage his own house at the same time. His involvement would have enriched the insight into child-carer's perspectives on activity engagement.

In summary, participants were recruited from diverse backgrounds. Such different backgrounds stimulated members to discuss a range of issues in respect of activity engagement of people with dementia. Through the interactions among the group,

members challenged and clarified other's viewpoints. This in turn enriched my understanding of carers' perspectives on activity engagement.

Moreover, the richness of the data was also promoted by the cohesiveness and the motivation of the participants. For example, in group two, Sandra suffered with deep vein thrombosis and pain in her legs. She was determined to attend the meeting by arranging a taxi to take her to the venue. I also learnt that Liz's car had broken down on her way to the meeting and managed to ask Mavis to bring her to the meeting. She then called the car rescue service after the meeting. In Group three, Ruth brought along some of her husband's paintings to the focus group as discussed earlier. At the end of each focus group, almost all participants stated that it was useful for them to talk together about their experiences as carers' views were not often heard by the professionals.

I noted that, in some groups, some participants met one another socially through the carers support network. This could have acted as a barrier for some participants as they might not have felt comfortable discussing certain issues in the company of familiar faces. Also the pre-existing friendships might have made them less aware of the need to make their viewpoints explicit to other group members. Nevertheless, as a moderator, I utilised a range of strategies to facilitate the group dynamic. Details about how group cohesiveness and openness in discussions were facilitated have been discussed in Chapter 7.

## **8.2 The five activity patterns and the activity continuum**

This section will discuss whether participants recognised themselves and their experiences in the model of activity engagement. Extracts from transcripts will be identified by a name following by the group number at the end of a quote, for example, *Brian: '...' G1*. Pseudonyms will be used to maintain participants' anonymity.

### ***8.2.1 Did the participants recognise themselves in the model of activity engagement?***

During each focus group session, the participants were asked to have a discussion based on their experiences of how the activity patterns had changed since they were first involved in a caring role and to comment on the model of activity engagement.

#### *8.2.1.1 The usual activity pattern*

This pattern was not the key focus of the focus group discussions. The usual activity pattern was presented to the participants as the pattern which represented whatever they themselves perceived as normal for their relative prior to the onset of dementia. All participants seemed happy with the brief explanation of the usual pattern.

Participants began the discussions with a recognisable activity pattern which was followed by the other patterns, one at a time. Data for the usual pattern were sought from the entire data set of focus groups. This was because during the discussions, participants often highlighted what the usual activity patterns were for themselves and their relatives when they talked about their experiences. When I conducted the analysis for the usual activity pattern, I looked for incidents and events which contained data concerning such as what participants and their relatives used to do, to enjoy and how to behave together. Typically, I listened to phrases such as ‘she/he used to’, ‘I/we no longer’, ‘in the past’, and incidents when participants had to take over responsibilities from their relatives.

#### *8.2.1.2 The recognisable activity pattern*

This pattern represented a retrospective recognition of the tale-tell signs of dementia in the beginning. All participants agreed that the features of this pattern on the handout reflected their earliest experience on the activity continuum. Nevertheless, some participants highlighted that it was difficult to recall the early stage of the caregiving journey in details as illustrated in the following quote by Eric:

*The trouble is, you know, four and a half years ago, four years ago is a job to remember. [G4]*

It was possible that participants forgot the successive phases of their experience. Despite that, all participants were able to contribute to the discussions in respect of the features of this pattern. No participants disagreed with the key features of this pattern on the handout.

There were two potential participants who did not take part in the study but whose experiences may enable them to share a more recent memory of this pattern. One of them had been informed that her husband had dementia two months earlier before she signed the consent form to take part in Group Three. A few days before the focus group,

she told me that she wished to withdraw her consent to participate in the study for several reasons. Firstly, she felt that she would not be able to contribute much to the discussion due to her limited experience as being a carer; secondly, she was not ready to talk about her experience in front of other people at such an early stage; thirdly, she needed more time to gain an understanding of the implications of dementia on her husband and herself following the diagnosis before she could share her experience.

The other carer who would have been able to share recent experience about this stage was a female spousal carer. This carer's husband was diagnosed for dementia six months prior to her verbal consent to take part in the focus group. However, she informed me that she wanted to withdraw her consent to take part in my study because she had just been notified that her husband had not got dementia.

These incidents highlighted that it was difficult to recruit participants who were in the beginning of this pattern. This may have been partly because carers may not have obtained a diagnosis. Even for those who had sought medical advice, they might have been too preoccupied with the uncertainty and anxiety at that point. Many carers might be wondering what was happening to their relative. It was possible that many carers would prefer to spend more time by themselves or with their relative to work out their feelings privately.

#### 8.2.1.3 *The illogical activity pattern*

All participants gave examples of how they related to the features of this pattern, as illustrated in an excerpt below:

- Keith: *Well, I probably see...I can relate to all of this [features of the illogical pattern], yes, I certainly can – I still underestimate the degree of effort that is involved in trying to, as it were, be normal – not normal, but as normal as you can be. (all nodding)*
- Karen: *Yes, and what they think is normal*
- Ellen: *And they feel embarrassed, don't they?*
- Eric: *People would come out with reasons why she (my wife) hasn't done this or why she has done this.*
- Karen: *Yes, exactly... yes... yes (raise her tone and voice).*
- Eric: *Well unless you say no you haven't done that I used to say, 'you hadn't done it,' it made it worse when I said 'you haven't done it'; ...which just used to turn into an argument, and I would say to myself, 'control it, she is not well, she is ill, don't argue with her, just agree with her'. And that is what I do now. (raise his tone and voice, looking angry, all nodding, Keith-sigh)*

Karen: *It is very hard to get into that pattern (illogical), isn't it? (looking sad)*  
Eric: *It is (still looking angry).*  
Karen: *Like with the cushions she (my mother) thought were cats and dogs and I used to say "but I don't have any cats and dogs". I used to argue with her for a while and think well no, I have got to keep – I thought it was best to – I wanted to keep her with me, the way I thought. I wanted to stop her going down that road of dementia and it was my way of protecting her and keeping her to say no, that is not them, you know.*  
Eric: *You can't do it... (raise his tone and voice)*  
Karen: *No, I can't. That was what I was like at the beginning, which was probably very cruel. (looking sad)*  
Ellen: *Yes, but you don't know any different (all nodding) [G4]*

Many carers became frustrated as they had increasing difficulty in maintaining a rational and meaningful conversation with their relative. This also implied that carers often struggled to re-orientate their relative to the reality and reason with them using usual logic.

#### 8.2.1.4 The irresponsible activity pattern

The majority of the participants acknowledged that they recognised themselves in this pattern as shown in the following quote by Janet:

*This is it. I think it (irresponsible activity pattern) is exactly where I am now on this sheet. [G5]*

Some participants also talked about how they became overwhelmed with the responsibility for looking after the everyday activity needs of their relative as reflected in the following quote by Sandra whose husband died about 12 months ago:

*'I think there comes a point with this one, irresponsible, when you are so keyed up, I think, when you are so keyed up, you are, you are just not there, you are just a machine that she wants to make sure that he doesn't fall, machine that he doesn't fall, where is he, has he done this, has he done that one...the irresponsible stage was one of the hardest and if you could get help then – he didn't want another woman there, you know, he didn't want another woman [care assistant] flopping around, he's not interested, he just wanted me, I was therefore everything else'. [G2]*

At this point, many carers came to terms with the reality that they had to accept outside help to support them with their caring role. Moreover, the majority of the participants were facing the dilemma of balancing their decisions about maintaining their relative's wishes and developing control of their caring responsibility.



#### 8.2.1.5 *The dispossessed activity pattern*

Some participants stated that the pattern reflected their experience as the dementia of their relative progressed to an advanced stage. Many participants agreed that within this pattern, they felt that their relative had lost their previous human quality which was once familiar to the participants themselves as Ruth said:

*‘Well, I mean everything [on the handout] is true for me really because even, oh, sort of two years ago I was probably saying it was like looking after a two year old, like looking after a toddler’[G3]*

This carer acknowledged that given the caring circumstance, she has been considering the option of long-term care for her husband.

One ex-carer suggested that the dispossessed activity pattern could be seen as ‘totally irresponsible’ on their relative’s part. As Brian said:

*‘About the word dispossessed. It is being more – totally irresponsible. You have got totally irresponsible’. [G1]*

Some participants also felt that carers themselves became ‘dispossessed’ in this pattern as Sandra said:

*‘Dispossessed is exactly..., you are dispossessed. You can’t do but just keep that balance of the one thing and you have to make a decision like that when you have to come to a situation like that... what is the timetable, I mean, how long do the different patterns last ....I don’t know what to say- in my husband’s case, it had been rapid. Looking back, it has been rapid with my husband[toward to end stage] and the whole cycle has finished- you have been losing your life and when you look back, and these are the perfect patterns, some of them overlap a bit and then they continue ...it is right? But I think, there is a time when I think you have to say ...I can’t take anymore’. [G2]*

This participant felt that the ‘patterns’ were a ‘perfect’ way to describe the ‘whole cycle’ of her experience of engaging her husband in activity engagement as a carer. It appeared that she felt reassured that the patterns explained what she had gone through in her caring role. It was interesting to note that those participants who felt that they had not yet reached this pattern anticipated that they would reach this pattern in a later stage of their caring role, as illustrated in a quote by Helen:

*‘Well, I am not at dispossessed yet, I don’t have to do all those things....I am not down to here. I’m at illogical’. [G2]*

Implicit in this quote was that many participants not only recognised themselves in the patterns but also used the model to gauge where they were at on their caregiving

journey. Despite this, some participants commented that although they agreed with the general framework of the model, they would have liked to see more details of each of the patterns. They however appreciated that the model was still being developed through the research process.

In short, no participants disagreed with the general features of the model. They also agreed that several patterns overlapped and could occur at the same time. The development of their strategies was associated with their emotions and feelings at different times during the course of caregiving at home. The process of engaging their relative in everyday routines was both a physical and emotional journey for carers. The next section will discuss the details of some key findings from the groups which enabled the refinement of the key categories (five activity patterns).

### **8.3 The main changes to the characteristics of the five main activity patterns**

The five patterns represented five temporal phases in the activity engagement continuum of people with dementia at home. Each pattern incorporated specific circumstances /context which impacted on carers' actions, emotions and feelings. This in turn triggered a different set of actions and consequences for participants and their relatives in the next stages of activity engagement.

Data collection from phase two continued to bring new insights into the understanding of how carers engaged individuals with dementia in activities and facilitated the process of saturation of categories. Data promoted further understanding of the context/ factors which led to the development of strategies for activity engagement, and the consequences of such strategies in the five activity patterns. This in turn enabled me to further synthesize, refine and develop the properties of the five main categories. This section will focus on discussing the key changes in each of the categories, highlighting the turning points from one pattern to another. The main changes will be highlighted by underlining them in the table of each of the patterns and then they will be discussed in more detail.

### 8.3.1 The major changes in the usual activity pattern

**Table 8.6: The usual activity pattern**

Features/ context	Strategies	Feelings/emotions
<b>1) awareness of the activity patterns of one another</b> <ul style="list-style-type: none"> <li>• self-reliant</li> <li>• mutual understanding</li> <li>• boundary of involvement</li> </ul>	<b>1) negotiating boundaries of involvement</b>  <b>2) compromising</b>	<ul style="list-style-type: none"> <li>• mutual understanding</li> <li>• respect for autonomy and independency</li> </ul>
<b>2) familiarity with the usual behavioural and communication modes</b> <ul style="list-style-type: none"> <li>• <u>personality and temperament</u></li> </ul>		

#### 8.3.1.1 Key changes to the features

The main change was the refinement of the category *familiarity with the usual behavioural and communication modes* of the relative. This category was further developed from a general understanding of the emotional aspect of carers' involvement in their relative's activity engagement. It highlighted an understanding of how the *personality and temperament* of the person affected their engagement. For example, the following discussions illustrated how participants described the different personalities of their relatives, such as 'being a worrier' and 'being stubborn' and how such personalities influenced the presentation of their relative's dementia:

- Karen: *I think dementia is a personal thing...each person with dementia has their own individual dementia to themselves (looking puzzled and seeking for others to respond).*
- Ellen: *Yes, they still own their own personality.*
- Karen: *Yes, it comes through somehow like that, doesn't it? (looking reassured that others seem to agree)*
- Ellen: *But it is still the same. My husband is quite and – not, it is just the way he is, but dementia hasn't changed that (looking thoughtful).*
- Karen: *Mum was a worrier and the dementia brought that out ten fold.*
- Eric: *My wife is very outgoing and she still is. She still is outgoing but more so because of the dementia. It sort of –*
- Ellen: *They don't give it up.*
- Eric: *No (raise tone and voice).*
- Ellen: *Why should they, they are still that person.*
- Eric: *She [wife] is more stroppy, more arrogant and won't do this and won't do that and cooperation is out of the window sometimes.*
- Ellen: *I find that... my husband is quiet, who is quiet... there is still the stubbornness there.*
- Eric: *Yes, but your husband is not verbal is he. I mean my wife, she can give you a real ear bashing (looking frustrated, raising his tone).*
- Ellen: *I get the looks. I get the looks.*
- Karen: *The personality is strong. [G2]*

Carers' perception of changes in their relative was often influenced by how they reacted to the carers' actions during daily interaction. This in turn influenced the ways which carers negotiated with their relative in respect of the boundary of involvement in the relatives' activity engagement. Respect for relative's individuality and self-determination to hold onto their value and belief was evident.

The usual activity pattern highlighted some taken-for-granted assumptions and strategies which carers and their relative employed to negotiate changes in their everyday routine activities. The turning point from the usual to the recognisable activity patterns signified that carers became conscious of some changes in their relative's behaviour but could not pinpoint what the problem was. Such a turning point was not clear cut, especially in the beginning phase of the recognisable activity pattern. Nevertheless, the usual activity pattern served as a starting point for the model of activity engagement, revealing that carers' perception of apparent changes in their relative's activity patterns had a root in the past experience with their relative.

### 8.3.2 Recognisable activity pattern

**Table 8.7 The recognisable activity pattern**

Features	Strategies	Feelings/ emotions
<b>1) growing awareness of the occasional changes</b> <ul style="list-style-type: none"> <li>retrospective recognition</li> </ul> <b>2) having difficulty in pinpointing</b> <ul style="list-style-type: none"> <li>separate activities</li> <li><u>gloss over things</u></li> </ul> <b>3) focusing on changes in characters and relationship</b> <ul style="list-style-type: none"> <li>self-centred</li> <li><u>tactless</u></li> <li><u>deception</u></li> </ul>	<b>1) developing logical reasons</b> <ul style="list-style-type: none"> <li><u>life transition in middle age and late life</u></li> <li><u>multiple and chronic illnesses</u></li> <li><u>stress-related health problem</u></li> </ul> <b>2) checking reality by using engaging in activity as an indicator</b> <b>3) renegotiating boundaries</b> <ul style="list-style-type: none"> <li>direct approach</li> <li><u>secretly taking over</u></li> </ul> <b>4) balancing personal issue vs medical need</b> <ul style="list-style-type: none"> <li><u>occurrence of shocking events</u></li> <li>seeking advice from GP</li> </ul>	<ul style="list-style-type: none"> <li>confused</li> <li>annoyance</li> <li>suspicious</li> <li>ashamed</li> <li>sense of hope</li> </ul>

### 8.3.2.1 Key changes in the features

As seen in Table 8.7, two categories have been revised:

Firstly, the category of *difficulty in pinpointing* was refined to incorporate the concept of *gloss over*. Many participants acknowledged that they tended to gloss over things in life, as illustrated in a discussion below by two participants below:

- Joan: *My husband was a carpenter and joiner...he really cared for the tools but then he started, you know, [behaviour strangely] ... And when he actually went into the home [residential care], my son-in-law tidied out his shed, ..., there was cups that had gone missing...they were all mouldy and mildew and silly little things and you think to yourself, yes, that has been going on probably for a number of years before the diagnosis, so perhaps it was coming and you don't notice.*
- Lorna: *Or you don't want to notice I think.*
- Joan: *Or you don't know about it [dementia], don't know enough about it.*
- Lorna: *No you don't, and I think you just carry on with your life and just think oh, it is just a blip and you just don't take any notice do you.*
- Joan: *But the bad days get more frequent.*
- Lorna: *I think initially you don't really want to accept that there is a problem anyway.*
- Joan: *No.*
- Lorna: *You tend to gloss over things, don't you?[G5]*

Many participants had not wished to accept that there was a problem initially. This attitude was exacerbated by the insufficient knowledge about the warning signs of dementia.

Secondly, the category, *focusing on changes in characters and relationship*, was refined to highlight that *deception by their relative* created a barrier which did not enable them to recognise the warning sign at the time. Looking back, they realised that their relative often tried to cover up their own problem in the beginning, as illustrated in the following discussion:

- Dave: *She (my wife) was acting completely out of character at that time. She did not give any indication that there was some thing wrong with her mind...and I found...for the past five years working for the carers support and giving care in the nursing home [where his wife lived]. They, not all of them (persons with dementia), a lot of them tend to try and keep it in themselves and they will be very deceptive to their family members.*
- Mavis: *They are actually quite clever, is the right word; I think. Clever with regards to covering up.*
- Liz: *Yes, I agree [G2]*

Many carers felt hurt that their relative did not always share with them the full extent of their problem. Some carers raised an issue that such deception made it even more difficult for other family members to appreciate the extent of their relative's problems in everyday life at home, as illustrated in a discussion below:

- Lorna: *Well, my husband's youngest son - he was my second husband, his youngest son, up to six months before he died would not accept that his father had got a problem because he only ever popped in for half an hour at the most; and during that half an hour he would put on such a façade. He used to say to me I don't know what you are on about, there is nothing wrong with dad, he is fine [raised her voice].*
- Joan: *Yes, oh yes.*
- Janet: *They are not aware; my daughter said to me you are doing far too much for dad, that is all that is wrong. You are just doing far too much for him. And I thought you have no idea [looking angry].*
- Lorna: *That is right, as soon as you are out the door, they [persons with dementia] relapse back and you think oh dear, yes. [G5] [all nodding]*

Implicit in this excerpt is that the general lack of understanding of dementia hindered effective communication between carers and their relatives; as well as the main carers and other family members. This situation became intensified when the step-children became more involved in supporting the activity needs of relative as the dementia progressed.

#### 8.3.2.2 *Changes to the strategies/ goals of engagement*

As can be seen in the Table 8.7, three categories had been refined. I will discuss the key changes below:

Firstly, the concept *developing own reasoning* had been re-developed to include *life transitions in middle age and late life; multiple and chronic illnesses and stress-related health problems*.

Carers often made assumptions that changes in their relative were results of life transitions in middle age and later life including entering menopausal age and retirement. Such assumptions affected their involvement in their relative's activity engagement. For example, Dave, in his 70's, reflected on his understanding of his wife's problem about 20 years ago when she started to act out of character. He said:

*'My wife was 50 years of age. I didn't know that there was anything wrong with her for maybe 8 or 10 years. She was just doing things which were out of*

*character, ...I thought being 50 years of age – I thought perhaps there was no problems, it was her menopause that sort of thing. And this went on for say between 8 and 10 years'. [G2]*

This carer assumed that his wife's problem was an inevitable response to the aging process, and felt that nothing could have been done to address his wife's problem for several years. Implicit in the quote is that there is a negative stereotyping image of ageing.

Moreover, many participants attributed the apparent changes in their relative to their chronic health problems prior to the onset of dementia. These included both mental and physical conditions such as partially sighted, impaired hearing, posterior cortical atrophy, minor cardiac arrests, or anxiety. For example, Eric attributed the changes in his wife's ability to engage in her everyday activity (i.e. driving) to her chronic mental health problem. As he said:

*'I had a couple of phone calls from the school where my wife used to teach saying that she had been seen going round a roundabout three times and ... when she was driving. And I wouldn't say I believe – whether she had a mental breakdown through school because she used to come through the front door, and she used to get into the car shouting as she was going to school...I realise now that she didn't know what exit to take. She forgot what exit to take. ... I really believe that that (stress) contributed towards her Alzheimer's'. [G4]*

This carer dismissed the warning sign of the apparent changes in his wife's driving in favour of 'stress from work'. He, however, had since assisted his wife with her work whenever she brought it home. Moreover, some carers felt embarrassed to talk about problems related to their relative, especially when such problem was linked to mental health.

Implicit in the discussions above was that chronic and co-existing illnesses were common. This often clouded carers' understanding of what were the actual causes for the changes in their relative's functioning and behaviour. Many participants did not consider a need to seek additional advice for investigating their relative's problem, as long as their relative's activity pattern remained recognisable to them. Moreover, people with chronic health problems did not seem to be involved in any rehabilitation programmes in regard to their lifestyle changes resulting from chronic health issues.

Secondly, the category, *renegotiating boundary of involvement*, was refined to also include the concept of *secretly taking over*.

Many participants found it difficult to directly negotiate with their relative in respect to allowing them to take over some of the everyday responsibilities. Hence, they secretly took over their relative's roles and responsibilities. As Roger said:

*'When you first notice the little things ... you don't really want to sort of draw their attention to it because at the early stages you still think you know, I am clever, we will get you over this sort of thing... you don't want to bring it to their attention so that it sort of knocks their confidence or self-esteem back, ... I never did anything and then until five years ago when my wife was in hospital; but if my wife sees me doing her jobs, like the ironing, cooking...she has a terrible job to accept it...you know. It was, in fact it got that you would try and do a bit of housework whilst she was still asleep you know'. [G3]*

By not drawing his wife's attention to her difficulty in managing her role as a wife, Roger enabled her to maintain her self-esteem and confidence. Implicit in this was that everyday mundane activities gave people a role and identity in the partnership. Carers often worked hard to respect each others' role.

Nevertheless, through compensation for their relative's role with or without their knowledge, many participants began to re-establish the boundaries of involvement with them. Despite that, the majority of the participants considered their relatives to be in control of what they wanted to do. Many felt that their relative's circumstances were going to improve with the passage of time.

Thirdly, a new category, *balancing personal issue and medical need* was developed from the initial category, *seeking for GP advice* in phase one. It aimed to highlight how participants were forced to push the boundary and work on getting their relative to see their problem as a medical concern rather than continue to treat it as a private concern between themselves and their carers.

A factor which alerted carers to the need of seeking medical advice for their relative's problem was the *occurrence of shocking events*. One such shocking event was the realisation that there was a dramatic change in their relative in terms of normal take-for-granted everyday tasks as illustrated in the example below by Keith:



*‘The first time I was really concerned that something was happening... my wife used to drive very slowly at night, I mean very slowly, which was, I mean she had been at the station (railway) and it took her ages to get home and I was a bit short tempered from time to time and there was one time when she couldn’t find the station. That was a real shock – she came to meet me and she wasn’t there, and she couldn’t actually find the station’. [G4]*

Another event which had frequently highlighted by participants was the occurrence of disturbing behaviours such as aggressive behaviour and hallucinations.

As time went on, an accumulation of incidents of changes continued to raise carers’ suspicion about what was happening to their relative. Some participants contacted their GP for medical advice. Several themes associated with the effects of seeking GP advice were similar to phase one. Nevertheless, the following issues were worth noting. First of all, some non co-resident carers and bereaved carers were disappointed that the prescription of medication gave them and their relative’s false hope for a possible cure. Some carers reported that this had led to preoccupation with medical cure and loss of motivation for activity engagement. Also, many participants and their relative had to travel regularly from their home town in southeast England to London in order to obtain diagnosis from a specialist. The process of seeking diagnosis placed a high level of stress on both the carers and their relatives and incurred a cost on carers and their relative in term of financial, physical and emotional resources.

To sum up, in the recognisable activity pattern, participants considered that their relatives were able to make decisions for themselves and fulfil their usual responsibilities. At this point, the majority of the participants have not yet recognised their role as ‘carers’. However, for those carers whose had already been involved in caring for their relative in respect of other health conditions tended to see their caring role as a temporary situation. Carers’ activity involvement with their relative was largely based on mutual understanding and sharing within the relationship.

The turning point from the recognisable activity pattern to the illogical activity pattern was when carers realised that their relative started acting in an obviously illogical manner and making frequent inappropriate decisions for themselves and that the apparent changes were just the tip of the iceberg of the problem.

### 8.3.3 Illogical activity pattern

**Table 8.8: The illogical activity pattern**

Features	Strategies	Feelings and emotions
<p>1) <i>significant changes in everyday activities</i></p> <ul style="list-style-type: none"> <li>• <i>doing a half job</i></li> <li>• <i>lacking motivation</i></li> </ul> <p>2) <i>the tip of an iceberg</i></p> <ul style="list-style-type: none"> <li>• <u><i>engaging in dangerous activity</i></u></li> <li>• <u><i>making inappropriate decisions</i></u></li> <li>• <i>less able to engage in a meaningful conversation</i></li> <li>• <u><i>struggling to deal with fragmented services</i></u></li> <li>• <i>struggling with everyday management</i></li> </ul>	<p>1) <i>a sense of identity</i></p> <ul style="list-style-type: none"> <li>• <u><i>providing a routine</i></u></li> <li>• <u><i>enabling the person to feel in control</i></u></li> </ul> <p>2) <i>taking calculated risk</i></p> <ul style="list-style-type: none"> <li>• <i>balancing risky activity and disengagement</i></li> <li>• <u><i>effects of disengaging from dangerous activities</i></u></li> </ul> <p>3) <u><i>telling vs not telling others</i></u></p> <ul style="list-style-type: none"> <li>• <u><i>creating social support</i></u></li> <li>• <u><i>minimizing misunderstanding</i></u></li> <li>• <u><i>barriers to talk</i></u></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Dilemma</i></li> <li>• <i>Impatient</i></li> <li>• <i>resentful</i></li> <li>• <i>hurtful</i></li> <li>• <i>guilty</i></li> <li>• <i>sense of shock</i></li> <li>• <i>sense of self being challenged</i></li> <li>• <i>disappointment and frustrations</i></li> </ul>

#### 8.3.3.1 Main changes to the features

The category, *tip of the iceberg* was redeveloped to incorporate the concepts of *engaging in dangerous activity*, *making inappropriate decisions*, *struggling to deal with fragmented services*.

Participants frequently noticed significant events of changes which were associated with performing an activity in a less recognisable and logical manner. An issue which was raised by many carers was that their relative engaged in dangerous activities. For examples, Eric said:

*‘What happened the other day, I got home from work and believe it or not – she (my wife) had been ironing. But now she has got all the collars round the wrong way, sleeves in and out and she had a two and a half inch burn on her arm; – and I asked her how she had done it and she couldn’t remember; and I went into our living room and there is a burn, a mark, where the iron had sat on the carpet so obviously she had burnt her arm and wandered off most probably into the kitchen, to put it under water, and left the iron on the carpet’. [ G4]*

Carers were increasingly shocked by the changes in their relative’s normal standard of functioning, especially when their relative did not seem to be able to appreciate risk in their everyday life.

Many carers also became increasingly concerned that their relative made inappropriate decisions about some critical everyday routine activities. These included handling

finances, dealing with electrical appliances and keeping hospital appointments. For example, one participant discovered by accident that her husband sent off several cheques for the purchase of a dozen bottles of wine following the delivery. As these events occurred more frequently and became more unpredictable, it demanded that carers became more alert and watchful of their relative's everyday performance and behaviour. Carers realised that the problems associated with their relative's activity patterns and behaviours were just the tips of the iceberg.

Moreover, many participants were left to struggle with fragmented medical services by themselves following a diagnosis. The frustration which many participants experienced is reflected in a quote by Joan below:

*'Well, the psychiatrist (at the specialist clinic) said it was sort of quite well advanced to be diagnosed so easily and ... my husband and I didn't know what to do. I said you know, "What have we got to do now". He said "Well, you know, go and see your doctor (GP) and then the ball will start rolling". So my daughter and I made an appointment to see the doctor and we sat down in front of the doctor... he said "Well what do you expect me to do?" And I said "Well I haven't got a clue what I am supposed to do, who I am supposed to contact". So he said, "You will have to phone social services". And with that we were sort of bundled out of the door ...I mean it is hard enough getting your head around it and I mean I was only 58 when my husband was diagnosed and to sort of get your head around that when you have got plans to enjoy your retirement'. [G5]*

Many participants were expected to sort out the care arrangement for their relative and for themselves. It was not uncommon for carers to experience disappointment and frustration resulting from being caught within the fragmented health and care services. Moreover, carers often did not receive sufficient information and practical support to assist them with the everyday management of their caring role. Implicit in this quote is that provision and advice on rehabilitation or activity engagement for people with dementia was seldom addressed.

#### *8.3.3.2 Changes to strategies/ goals of engagement*

As can be seen in Table 8.8, there were key changes in three categories. Details will be discussed below:

Firstly, the category, *maintaining a sense of identity*, was developed to include the concepts *providing a routine* and *enabling the person to feel in control*.

Data revealed a further range of approaches which carers used to promote their relative's sense of identity. One such approach was to initiate a routine for their relative to perform a task. This was especially the case when their relative would have forgotten to do it if they were left on their own, as Ellen said:

*'He [my husband] does, he still does things for himself but I have to encourage him to get in the bath, so we have a sort of routine. I have my bath and then he jumps in after, because then he has got into a routine of doing it and I sort out all his clean clothes. He would probably put the same clothes on after a bath'. [G4]*

Hence, it was useful to provide a structure to guide/enable their relative to continue doing various familiar tasks. Implicit in this is that many carers saw the potential to promote the independence of their relative by offering them step-by-step guidance. However, some participants became wary that they had to be careful when implementing such strategy as their relative became resentful of their involvement if they did not manage to use appropriate kinds of guidance.

Many carers attempted to help their relative to maintain a sense of self by enabling them to feel being in control in terms of decision-making. For example, Keith said:

*'My wife really loves the garden – she is absorbed by it... What she likes doing is buying plants and I have to go along and buy all the plants but the bit that I don't like it that they lie there at the bottom of the garden; you know, she can be in the garden – doing, achieving very little; but she feels it is the thing that she always did; so I like her to be in the garden and she still feels, the way she does things, although they are different, because she still feels in control of the garden, but she clearly isn't any longer, but it is the one thing – is both her comfort and her confidence'. [G4]*

This carer maintained his wife's confidence in gardening activity by supporting her to make specific activity-related decision; and by creating an environment for her to become absorbed in such an activity. Implicit in this was that he was able to promote the continuity in his wife's personality traits through her engagement in a familiar pastime.

In short, many carers worked hard to promote a sense of identity by engaging their relative in routine everyday activities such as familiar hobbies, self-care and household tasks. Nevertheless, such an involvement often incurred a cost on carers in terms of their financial, emotional and physical input.

Secondly, the concept of *taking calculated risks* was refined to include *effects of disengaging from dangerous activities*.

Many participants faced the dilemma of making decision to disengage their relative from performing some everyday routine activities which they used to be responsible for doing or enjoy doing them, as Dave said:

*‘One time, so long ago, she was home one day but I went into the kitchen and I found that she [my wife] was washing the kitchen with kitchen roll, she also put ...all the sockets went into the water... And that is when I decided that if she went into the kitchen that I would follow her. I would do whatever had to be done in the kitchen from then on’. [G2]*

Making decisions about disengaging their relative from a range of ‘dangerous activities’ often led to long-lasting psychological impact on carers. This was reflected in a discussion below by two former carers:

- Joan: *My husband hated me because I said he was going to stop (driving)... I think what frightened me was when he went through red lights...And straight out onto the roundabout. You know (looking angry and sad).*
- Lorna: *Yes.*
- Joan: *I said look, they [professionals] have just told you, you must stop driving as from now. “Well” he said “I don’t care about what he (the doctor) said. I can drive”. Of course I had to take the car keys away and then I thought well I will keep the car and then we can go out. And he wouldn’t set foot in the car with me driving. He would go out with my daughter but not with me. (raise her voice)*
- Lorna: *My husband always said it was me that stopped him driving. I said but the doctor has told you, you mustn’t drive anymore because of the medication you are on but he always always resented that and he always used to tell people she stopped me driving you know(looking frustrated).*
- Joan: *That is what my husband always used to say.*
- Lorna: *And I was – when he was talking about it, it was always SHE stopped me driving.*
- Moderator: *How does that make you feel?*
- Lorna: *That hurts (looking upset).*
- Joan: *Yes.*
- Lorna: *Very hurtful. [G5]*

Some carers felt hurt for a long time after the decision was made. Many carers found that disengaging their relative from an activity often meant that their relative’s and their own lifestyles had to change. The impact of the cessation of an activity depended on its

level of importance and meaning to the participants and their relatives. It had practical and emotional consequences on both carers and their relatives. Despite that, carers and their relative were not given any support on how to address issues regarding making adjustment to their changing lifestyle.

Thirdly, a new category, *telling others*, was developed as a strategy to highlight that carers attempted to create a supportive environment to enable continuing participation in family and social activities. Many participants talked about facing the dilemma of whether or not to tell friends and family about their relative's diagnosis. This had an impact on how carers support their relative in social engagement either on their own or with their carers.

Initially, many participants supported their relative's decision not to disclose the diagnosis to others. This enabled carers themselves and their relatives to keep their everyday life as normal for as long as they could manage. As Keith said:

*'It is difficult to tell others what is going on in the household. We, I mean, ...it seems ages ago – because at first- didn't want people to know, obviously. She (my wife) was very accepting herself that something was wrong. That wasn't a problem, we didn't have a problem in denying that something was wrong.... she didn't want other people to know, very understandably; and that was the case for quite a while. But then she began to find that more and more difficult because of her own ability to talk to people, was perhaps getting less, but at the same time so much of, you know'. [G4]*

Often, carers and their relative managed to work together and utilise their own resources to manage their situation. As time went on, carers faced a dilemma of breaking their promise to their relative when they realised that their relative became less able to work with them to cover up their problem.

Many participants found that they had to tell others about their relative's diagnosis for various reasons. For example, they did not have reasons to cover up their relative's odd behaviour when in others' company. Moreover, some wanted to prepare their family and friends to be aware of the changes in their relative's behaviour. This implied that through telling others, carers often tried to mobilise their social network in order to provide a supportive environment for their relative's social engagement.

However, many found that once they disclosed the diagnosis of dementia, their social network and activities gradually became narrower. One major barrier for carers was that

the public did not know how to handle the subject of dementia. This can be illustrated in a discussion below:

- Ellen: *It is like we had these friends we have known for years...now, and the last time I met this person, had a chat with her in town, and actually said oh my husband has got dementia, Alzheimer's; oh well we are all forgetful. So you know, she was saying it was in my mind ... well you don't want to tell people,*
- Eric: *People don't know about it. You have got to understand -*
- Karen: *No, people have never – I have never spoken to anybody about dementia until mum got it and then I speak to other people like here. It is not something that has been talked about a lot.*
- Eric: *Nobody seems to know, to know about it, do they?*
- Karen: *No they don't, no. it (dementia) doesn't' come out like other illnesses does it.*
- Ellen: *Difficult to talk.*
- Eric: *And everybody will say, oh I am forgetful as well.*
- Karen: *Yes, exactly. [G4]*

Many participants felt that there was a stigma attached to dementia. As the dementia progressed, many felt being increasingly excluded from their social network and the wider community over time.

In some families, members stopped visiting the person with dementia once they knew about the diagnosis, as can be showed in the quote below by Joan:

*'I have had four children, two boys and two girls; and the eldest son – well, he has cut himself off from the family, he just, he doesn't want to know – as long as it is not interfering with his life'. [G5]*

This quote revealed that the main carers could not always expect support from family members for various reasons, for example, some children got upset that they might inherit Alzheimer's disease and therefore tried to distance themselves from their parent; some children had their own family and work commitments. Despite that, many carers received high level of support from their family and friends.

To sum up, in the illogical activity pattern, many carers frequently experienced sense of shock and distress by the unexpected changes in activity patterns and the characters of their relative. They were frustrated that their relative played a less productive role in the partnership and became less able to take responsibility for their daily decision-making.

The turning point from the illogical activity pattern to the irresponsible activity pattern was when carers realised that they found it increasingly difficult to negotiate with their relative on equal ground as the thinking of their relative became increasingly irrational. At this point, they started losing confidence in their relative's ability to manage major duties in the household. This posed increasing challenges to carers' own sense of self as they had to further appraise their role in the relationship.

### 8.3.4 Key changes in the irresponsible activity pattern

**Table 8.9: The irresponsible activity pattern**

Features	Strategies	Emotions/ feelings
<b>1) incapability of taking responsibilities for everyday activities</b> <ul style="list-style-type: none"> <li>inability to appreciate the long-standing activities</li> <li><u>floating pottering</u></li> <li><u>losing trust</u></li> </ul>	<b>1) being active</b> <ul style="list-style-type: none"> <li>preventing idleness</li> <li><u>adapting a familiar activity to a safe activity</u></li> <li><u>turning disruptive behaviour into a meaningful doing</u></li> <li><u>developing new way of communicating</u></li> <li><u>finding a trigger to encourage activity engagement</u> <ul style="list-style-type: none"> <li>going out and possible barriers</li> </ul> </li> <li>an irreversible cost</li> </ul>	<ul style="list-style-type: none"> <li>hurtful</li> <li>physical and emotional consequence</li> <li>exhaustion.</li> <li>mixed feeling of sadness, loss, resentment and helplessness.</li> <li>conflicts and tension</li> <li>fear</li> <li>sad-losing dignity</li> <li>resentment and feelings of helplessness</li> <li>entrapment</li> </ul>
<b>2) vulnerability and unsafe</b>	<b>2) a sense of control of the routine of caring activities-</b> <ul style="list-style-type: none"> <li>finding own meaning to care for the person</li> <li><u>evolving role</u></li> </ul>	
<b>3) role reversal</b> <ul style="list-style-type: none"> <li>no give and take relationship</li> <li><u>isolation</u></li> </ul>	<b>3) utilising external resources for activity engagement</b> <ul style="list-style-type: none"> <li>day care and barrier</li> <li>personal care and barrier</li> <li><u>being a failure</u></li> </ul>	
<b>4) societal expectations</b> <ul style="list-style-type: none"> <li><u>carers' existence being threatened</u></li> </ul>		
<b>5) intermittent explosive outbursts</b> <ul style="list-style-type: none"> <li><u>triggers for aggressive behaviours</u></li> <li><u>hallucination</u></li> </ul>		

#### 8.3.4.1 Key changes to the features

As can be seen in Table 8.9, four categories had been redeveloped:

Firstly, the category, *incapability of taking responsibilities for everyday activities*, was developed to include *floating and pottering*.



Participants raised an issue that their relative frequently appeared to be floating around or pottering around in the house acting inappropriately and aimlessly. Many participants had taken over a range of major household duties from their relative. This was especially the case when their relative's concentration and reasoning ability deteriorated further. Moreover, their relative gradually lost the ability to appreciate the meaning of those familiar activities.

At this point, many carers realised they could no longer trust their relative to be left on their own in their own house to do things on their own initiative, as Joan said:

*'I think one of the hardest things was like: if I had to go out anywhere like to a doctors appointment or anything like that I had to ask somebody to come and sit with my husband; and I found that really hard you know – because you sort of, you are treating him like a child. That is what I always felt and that hurt, to think you know, you couldn't just go out because somebody had to be there because of what he would do, or what he wouldn't do to be more truthful'. [G5]*

This quote revealed that the supervisory responsibility was imposed on them. Carers had to protect their relative from harm. Many carers felt hurt that their relative was no longer able to take part in decision-making with carers themselves.

Secondly, the category, *role reversal*, was refined to include *isolation*. Many participants felt lonely and isolated whilst overwhelmed by the demand of the caring role, as Janet said:

*'I say to myself oh I'm, I will never get – I do a lot of talking to myself – I will never get through it because there is a lot to do. There is money matters and the garden and everything else, and then he is being difficult. I tell him off but there is no response. He doesn't say oh I am sorry, I wish I could help you. In a way I keep thinking – it is an awful dream – and suddenly he will be as he used to be. I was in denial for a long time. And I talk about it quite freely but I used not to'. [G5]*

This quote implied that carers found it increasingly difficult to hold on to their previous role. Nevertheless, they lived for those moments when their relative became lucid and related to them as who they used to be. It was hard for carers to come to terms with the conflicting feelings of passion, loss, isolation and resentment. Such feelings could be exacerbated by carers' own physical health problems and other commitments.

Thirdly, the category, *societal expectation*, was refined to reveal that many participants felt that their own *existence was threatened*. Many carers raised an issue that there was

societal pressure on them to provide care for their relative. They considered that in fact society needed to take some responsibilities to support the carers who were caring for a person with dementia. This was particular the case for carers of younger-onset dementia and carers who still worked. As Ellen said:

*‘Well they [family] have got to work, they have got to earn their money, they have got mortgages; they are all working. It is so hard to involve them, this won’t work – well, I will bring it up when I meet with the care manager next time because you have got to be at the day centre’. [G4]*

This carer worked part-time and was frustrated that her husband’s care manager failed to find an appropriate specialist day centre for him whilst she was at work. For some carers, giving up their work in order to provide full time caring was unthinkable and would jeopardise their employment and livelihood. For those who did not have a paid job, they often talked about how the society expected them to be a good carer. Many spoke of the feeling of being entrapped in their caring role. Thus, the caregiving situations challenged carers’ sense of self.

Fourthly, the category of *interference vs. non-interference* was replaced by *intermittent explosive outburst*. This was to highlight how *aggressive behaviours* and *hallucination* acted as barriers for carers’ involvement in their relatives’ everyday routine activities.

An example of this can be illustrated in the following quote by Nora:

*‘Well about a year ago he started to wet the bed so we have developed from that, so I can’t get him out of bed so I bought a bed that lifts up the head and the feet but he fights me. He is beginning to grab my wrists. I wouldn’t say he is violent, so that is the stage he has got to. He doesn’t remember anything. He doesn’t really speak coherently. When he tries he – you have to be, patience is a thing I try to maintain. I don’t know if there is anything else I can do’. [G1]*

This carer worked on her own initiative and brought a piece of expensive equipment to help with her husband to get on and off a bed. However, she was frustrated by the hostile reactions of her husband when using the equipment to help him get out of bed. She felt sad that her husband did not appreciate her effort in helping him with his mobility problem. Implicit in this quote is that a piece of potentially beneficial equipment could become a trigger for aggressive behaviour in the person with dementia if the equipment was not introduced sensitively. Hence, aggression could be provoked by the lack of knowledge and skills in working with people with dementia.

Another common trigger for aggressive behaviour was the presence of hallucinations. Many participants were confronted by their relative's hallucinations. Some participants attempted to challenge their relative with their reality; other tried to understand the motive behind their relative's behaviours with a view to communicating with them in a more meaningful way. However, even with the best intention, carers sometimes felt helpless in such situations. An example of this is illustrated by Sandra below:

*'The only thing I could not control is the violence...from being lovely to being aggressive, I mean, he said, "you kidnapped me, I will take you to court, I am going to" – crazy things he said. From there, if it got to the point where he threw the table at me and everything that was on it, you know – I then used words that I have never used in my life, swearing, really swearing, you know, so just really angry. You know, he changed from really nice to really aggressive and to control the aggression, – It was all shock and horror. He was shouting at me, you know, I said, "please", you know. And then it was a cuddle and then it settled down, you know, it was a routine. It never went away, it was me and nobody else in there. You are the carer, you sit there and have a good cry'. [G2]*

This quote revealed that many carers tried to maintain intimacy with their relative by engaging their relative in their everyday routine activities. Despite that, many felt fearful and isolated when they had to deal with aggressive behaviours and hallucinations without support.

#### 8.3.4.2 *Changes to strategies/ goals of engagement*

As can be seen in Table 8.9, three categories have been revised:

Firstly the concept of *being active* was refined to include *adapting a familiar activity, turning disruptive behaviour into a meaningful doing, developing new way of communicating, and finding a trigger to encourage activity engagement*.

Many carers made an effort to use activities as a medium to keep their relative stay 'active', as Nora said:

*'I try to encourage him to dance and sing. I have a limited amount of success. He stands up and I put my arms around him, I know he is not very steady but he remembers what he has to do more or less and I do a lot of singing you know, to cheer myself up and I will say come on, you know this. I am always looking for ways to keep his mind – you know. I don't want him to slink, slump, slurp, I don't know the word – sink into a kind of chair'. [G1]*

By keeping their relative active, carers attempted to prevent them from being an object disappearing in the background. This also implied that carers tried to maintain a positive relationship with their relative.

Many carers attempted to explore various means to motivate their relative to keep their mind and body active.

Many participants spoke of a need to *adapt a familiar activity* in order to enable their relative to take part in some kinds of activities which they used to enjoy doing, for example, Ruth said:

*'My husband used to love as a hobby was fishing, so you can imagine fishing with flies and that. I used to get him out in the garden, I used to put the rods on the table or something and I would sort of help him with just, sort of put a line on and pretend to cast, and say yes, we might go fishing next week so lets just get them out and have a look at them and that sort of thing.'* [G3]

Carers adapted a familiar activity in order to match the requirements of the task to their relative's declining abilities. Moreover, this often happened in parallel with the adapting the home environment in order to make it safe for the person with dementia. Implicit in this quote is that carers had to be flexible, persistent and creative. Carers also needed to regularly monitor their relative's changing performance and to adjust the environment and the task accordingly.

Nevertheless, some participants acknowledged that they were not adventurous enough to think of how to adapt an activity for their relative to do at home. However, they were frustrated to see their relative being idle and becoming less able.

Many participants were concerned that their relative was active but in a disruptive manner. They had to turn disruptive behaviour into meaningful doing. The following example illustrated how a carer distracted her husband from engaging in disruptive activities (e.g. following her round) into a more meaningful activity (e.g. helping her out with cooking tasks). This is illustrated by Janet:

*'My husband – kind of following me around. So I have tried things like helping with the vegetables and things like that. Because he was always quite a good cook, he used to like cooking and some days he could do it and other days he couldn't... and some days it will be chopped in minute little slices, and other days it will be in big chunks, but I think well it doesn't really matter'.* [G5]

Implicit in this is that carers had to negotiate with their relative and agree a manageable goal for a task which was also meaningful to both their relative and themselves.

Moreover, carers also needed to adjust their own standard and value of the task performance; as well as to provide appropriate level of guidance and supervision to their relatives. This also meant that they considered the process of doing a task as more important than achieving a final product.

Moreover, it was crucial for carers to communicate with their relative at the right level in order to enable them to perform a task. Many participants realised that they had to develop a *new way of communication with their relatives*, as illustrated in the conversation below:

Janet: *I ...really noticed that I have to try and think of different ways of explaining something and sometimes you can say it in one way and he won't know what you are talking about.*

Lorna: *No, sometimes you will say something to him and he looks at you as though you are speaking a foreign language.*

Janet: *Yes, you turn it around and try and say it in a different way and then he will understand. And I think that is certainly, I mean I have realised that I can only tell him one thing at a time. [G5]*

This quote revealed that it was crucial for carers to find ways to enable their relative to comprehend their everyday encounters. This meant that carers became more directive in their approach.

Many participants often found it difficult to motivate their relative to engage in everyday routine activities in which they would like them to take part. Many raised an issue that it was important for carers to find *the right trigger to encourage activity engagement*. An example of this is illustrated by Sandra below:

*'I found it most difficult was motivating him [my husband]. He didn't want to get out of bed and then gradually, he was never away from home... So I have to motivate him to do something...He always loved music, but there was one – It is the Ink Spots. If I wanted him out of bed, wanted him to do anything, to go for a walk, the Ink Spots... when he heard the Ink Spots it was amazing and suddenly his face was calmer, I mean, ....something clicked and then he would get up and then I could dress him and we would have breakfast, and then he was happy. And if you had him in that mood, that happy, then you can suggest, we went for a walk - that music- it was just the motivator'. [G2]*

Implicit in this quote is that certain kinds of activity could be used as a trigger to elicit a change of mood of the person with dementia from being aggressive to being calm. This in turn enabled carers to work cooperatively with their relative in terms of taking part in a range of everyday routine activities.

It was interesting to note that many participants talked about using music as a trigger for motivating their relative to take part in other activities such as dressing, dancing. Some participants also used *going out* (e.g. a trip to the shop, a ride in a car) as a medium to stimulate their relative to engage in a more meaningful conversation or social engagement.

Secondly, the category, *sense of control of the routine of caring activities*, was refined to include *evolving role*.

Many participants realised that their role as a carer was evolving constantly. Hence, they had to accept the fact that they had to develop not only a sense of control of the routine, but also their own rules about the caring role, as shown in the following discussion:

Roger: *I don't think you could ever come up with a set of rules and say right, well, if you want to be a good carer you have got to do this, this, this and this, because every patient, for want of a better word, is so different, in temperament, in everything. To me, I find that you know, you have just got to find your own way, your own role, to do that person and it just, somehow evolves as time goes on, you know.*

Raymond: *Yes, I agree strongly with what you says about that because that is the reason why I have never joined the local branch of the Alzheimer's, I have gone to meetings where people have voiced their problems, I have felt again and again, these are all individual problems which don't relate to me and the feeling that ones own problems are so individual is the predominant one, as far as I am concerned. [G3]*

This implied that many carers appreciated support to develop their role as a carer. However, they were disappointed that services were often unable to enhance their sense of control (e.g. structure of the routines). This was partly because services were often too rigid which did not address their constantly changing needs; and partly because they tended to view carers as a homogeneous group. For example, many participants talked about a wish to have someone come into their home to provide activities for their

relative, but were disappointed that befriending service and therapy at home were limited and sometimes non-existent.

Thirdly the concept of *utilising external resources* was developed to include *being a failure*.

Many participants made use of a range of external resources to support their role in terms of engaging their relative in everyday routines activities. These included daycare, personal care services and befriending/sitting services. Carers stated that they felt that they *became a failure* when they decided to accept help, especially against their relative's wishes. Hence many delayed or refused to accept external resources. This can be illustrated in the following discussions below:

- Joan: *You are a failure that you can't do these things and you should be able to do them, or you feel that that is – You are failing him.*
- Janet: *Yes, my husband refused to have outside help.*
- Lorna: *Well you see I didn't with my husband. I pushed and pushed myself until in the end when Dr X came on a home visit one day and this is when he (GP) took my husband into hospital because he said you yourself are on the point of collapse. He said you have pushed yourself too hard...you are now at the point of collapse.*
- Janet: *You sort of feel you are letting your partner down.*
- Lorna: *That is right, you do. You don't feel you can give him up... But he (GP) took it out of my hands. [G5]*

This revealed that, although many carers realised that they required assistance with their caring responsibilities, they also needed reassurance from the outside to help them make critical decisions in the interest of their relative.

Deciding to accept statutory services became even more difficult for carers when appropriate resources were limited and not flexible enough to meet the changing needs of their relative and themselves.

In summary, carers made constant adjustments to their relative's everyday routines in order to enable them to continue to be active in some everyday tasks within the household. Many felt that it was necessary for them to develop a sense of control of their relative's daily routine activities. They saw statutory services as an obstacle for them to develop their preferred structure of routine. Most carers had exhausted a great deal of their personal resources by the time they reached this pattern.

The turning point from the irresponsible activity pattern to the dispossessed activity pattern came when carers felt an increasing need to develop a sense of control of almost all aspects of their relative's daily routine activities.

### 8.3.5 Dispossessed activity pattern

**Table 8.10: The dispossessed activity pattern**

Features	Strategies	Feelings and emotions
<b>1) dependent on carers for almost all aspects of everyday activities</b> <ul style="list-style-type: none"> <li>unable to recognise own home</li> <li>leaving home during night time</li> <li>being a prisoner(carer)</li> <li><u>living the person's life(carer)</u></li> <li><u>total commitment(carer)</u></li> </ul>	<b>1) passive activity for mental stimulation</b> <ul style="list-style-type: none"> <li><u>laughter, happiness</u></li> <li><u>promote calm attitude and comfort</u></li> <li><u>feeling guilty for over-stimulating the brain</u></li> <li>time to pursuit own interest</li> </ul>	<ul style="list-style-type: none"> <li>obliged to take responsibility</li> <li>profound feelings of loss and sadness</li> <li>distanced emotionally and psychologically</li> <li>sense of self being challenged</li> </ul>
<b>2) changing atmosphere at home</b> <ul style="list-style-type: none"> <li>coping with on-going wandering</li> </ul>	<b>2) providing security and comfort</b> <ul style="list-style-type: none"> <li>understand the meaning of the odd behaviour/old self</li> <li><u>keeping the person's old self</u></li> </ul>	
<b>3) distancing from their relative</b> <ul style="list-style-type: none"> <li>not the same person</li> <li>meaning of significant events changed dramatically</li> <li>confused by lucid moment</li> <li><u>soul-destroying</u></li> <li><u>loss of identity</u></li> </ul>	<b>3) emotionally detached</b> <ul style="list-style-type: none"> <li>hiding own emotion</li> <li><u>letting go</u></li> </ul>	

#### 8.3.5.1 Key changes to the features

As can be seen, two categories in Table 8.10 have been modified:

Firstly, the concept, *dependent on carers for almost all aspects of everyday activities*, was refined to include *living the person's life*.

Many participants commented that they had to live their relative's life for them whilst feeling that their relative might not appreciate their input, as shown in the quote below by Ruth:

*'I have to literally guide him through the day the whole time. He wouldn't know if it was morning, noon or night. So you really have to almost, it is awful, almost live his life for him... He is in throw-away-pants, disposable pants; and if there is any sort of wet on the floor or anything. There is no point in me saying anything now – but say a few months ago, you might have said, "oh, you know,*



*you have had an accident, or the floor is a bit wet or something". He would say: "It wasn't me." And with food: there is no point in asking him. I have to make all those decisions for him now; otherwise, he probably would just eat chocolate ice cream all day'. [G3]*

This quote also revealed that many carers had to make decisions for their relative in almost all aspects of their everyday living activities, especially with self-care and basic health needs.

At this point, many participants wanted to keep their relative at home as they viewed that as one way to maintain the dignity of their relative for as long as possible. Some talked about the need to commit wholeheartedly to the care of their relative, as Norman, a 91 year old carer who said:

*'Well it has been going on for about 10 years. She [my wife] is rather an advanced stage. She is walking very slowly at the moment and I would walk behind her with my hands on her back – can't remember a second ago, minutes ago...she is in respite care (name of a day centre), two and a half days. But it is total dedication to – well, if I can give an instance. She had diarrhoea the other day you see, and twice I had to strip her right off and give her a shower... And then at nights, if I get a good night it is a bonus, you see. Perhaps one o'clock in the morning the bed will be soaked, even though she is wearing protective things. I got to force myself to get out of there and then change the sheets and then perhaps two hours later she will want the toilet. But it is not every night'. [G1]*

Despite the fact that Norman received a range of outside resources to support him to care for his wife at home; he felt that he had to devote all his time, day and night, to the care of his wife because the social services care package did not provide sufficient cover for his wife's everyday needs, as Norman explained below :

*'Well the carer (home care assistants) comes in at 8am – 9am. She gets her up, gives her a shower, and gets her dressed. That helps me a lot you see; but from then on, it is all over to me you see and I have to do everything - if I am in the kitchen or anything, every ten minutes to a quarter of an hour just look round the door to see if she is alright you see. Because she is apt to get onto her legs, thinks she can walk and falls'. [G1]*

Carers often experienced high levels of mental and physical exhaustion as their relative became increasingly dependent on them. At this point, many carers often tried to hold onto the caring situation at home until they reached the point of collapse when decision-making would be taken out of their hand.

Secondly, the concept, *distancing from the relative*, was refined to include *soul-destroying* and *loss of own identity*. Many participants talked about how their own mental health had been adversely affected resulting from caring for someone with dementia. This is reflected in a discussion below:

Karen: *I find it drags you down more though than looking after children, because when we have my partners grandchildren come, the oldest one is seven, you can talk to her and you get a lot of feedback, and they lift you; Whereas with mum, you can talk to her but you are not getting anything back, because it has gone.*

Ellen: *It has gone, yes.*

Eric: *Or it is the same topic all the time, going over and over the same thing.*

Karen: *It gets you down; you see children learn.*

Ellen: *Yes they do.*

Karen: *When you tell them two or three times they pick it up, whereas with dementia it goes the other way. Another little cog goes, doesn't it? Every few days... it is quite soul destroying I find. It is very hard not to go with them and not to get depressed, I think. You have to really think to yourself, do I go with, you know, you have got to lift yourself up somehow don't you. That is the only thing I could do on the days when mum went to daycare, was to go and meet friends and do other things.*  
[G4]

This discussion also showed that caregiving was an emotional journey and could not be compared with that of looking after a child who was expected to learn from their experience and so bring hope for the future. Caring for their relative demanded carers' endurance, persistence and patience.

Carers experienced profound feelings of sadness. They spoke of how they gradually lost their previous identity in the partnership as their relative was not involved in the partnership any more, as is reflected in the quote below by Nora:

*'Well the main difference really is : he doesn't really know who I am anymore. I have to do everything for him and he looks at me as if to say well, you are in my space. I am trying to be considerate and sensitive and it is difficult and he looks at me as if he doesn't really know who I am. I tell him all the time; and I tell him that he loves me because I am his wife but he doesn't really ...anymore, which is sad'. [G1]*

Carers felt sad that they had lost the intimacy with their relative and felt being rejected by their relative acted as a trigger for participants to consider alternative long- term care for their relative.

#### 8.3.5.2 *Changes to strategies/ goals of engagement*

The category, *passive activity for mental stimulation*, was refined to include *laughter; happiness; promote calm attitude and comfort*; as well as feeling guilt for *over-stimulating the brain*.

The majority of the participants acknowledged that they became increasingly aware that their relative required some kind of entertainment and amusement. Many tried to look for entertainment to promote laughter and happiness in their relative. As Ruth said:

*'Yes, the stimulation and amusement. That is quite difficult now because he can't follow, say there is television on, he can't follow anything... programmes where people are laughing, I mean some of these very old programmes, Ronnie Barker with the pawn shop or that sort of thing, because people laughing, he will sometimes join in. The things that amuse him most is television commercials with babies in it, with the gurgling and laughing, and he will laugh at that'. [G3]*

Participants often felt that passive activities such as watching television and video tapes, listening to music were beneficial in terms of mental stimulation for their relative.

Some participants were concerned that activity engagement might have pushed the deterioration of their relative forward by over-stimulating their brain as reflected in the quote below by Sandra:

*'There was a christening in the family, the whole family getting together in church in [name of a town] and so... I then said to the drivers; please get my husband in there..., but I had the [paid] carers with me, he came with me, they really went out of the way. We went to the christening. He was smartly dressed, he met all the people. I was happy that he was there. He was so happy, and that was the last time we went out and it was a long day but I had the carers there, he was fine. And what amused me was that he talked about it one more time until he died, practically. So it was a stimulation for him, you know, but it might have pushed the deterioration. It was quite an event for him to be getting into a car, you know. I just pushed and shove [her husband] when crossing the road. It was quite a trauma. It might have pushed the whole thing forward, it wasn't too much for the brain but during that glorious day, that's that stimulation there that kept him for sometime. Is it worth it? And then you have to make that decision'. [G2]*

Many carers lived with a lot of uncertainty and guilt resulting from making decisions to stimulate their relative to take part in activities. Sandra had been questioning herself ever since her husband died. This highlighted that some carers needed regular support and reassurance when they had to constantly make decisions for their relative,

especially for those decisions which had a significant impact on their relative's well-being and on that of their own.

Secondly, the category of *provision of security and comfort* was refined to include *keeping the old self*.

Many carers talked about how the provision of security and comfort for their relative became a priority of their caring responsibilities in this pattern. This also meant that carers needed to understand the meaning of their relative's behaviour and to support them in keeping their 'old self', as Norman said:

*'With my wife, she would sit in her arm chair with a chest of drawers and magazines and newspapers and, she loves, rather than sit forward she loves to take the papers, tear them apart- then, fold and refold, fold and refold, and it keeps her occupied, ...you know, you do study your loved one very intently...they are slumping like that, they really want something to occupy their hands ...Their mind is going back to when they were a wife you know what I mean, putting things away, folding, ironing, and if she is doing something she thinks she is doing the housework'. [G1]*

Implicit in this quote was that some carers tried to find the symbolic meaning of their relative's action as a way to maintain a connection with their old self.

Thirdly, the concept of *emotionally detached* has been revised to include *letting it go*. The majority of the participants tried to look after their relative at home as long as possible. Some participants talked about making the decision to let their relative go into a home as illustrated in a discussion below:

Joan: *Well my husband's whole personality changed. He changed from being a very easy going affectionate person, to a very aggressive and somebody, you know, I didn't like at times when he was threatening me.*

Lorna: *Yes, I know.*

Joan: *And I think that was the final straw, that is what made me accept residential care for him.*

Lorna: *Yes, well this is what happened with me and my husband he actually did hit me.*

Joan: *Well he almost did one Christmas and he got his fist up to me and I said you hit me and I shall walk out and just leave you. And I mean at that stage he couldn't even make himself a cup of tea. He wouldn't have known which door to have gone out of or anything. And I did say – if I had had a gun I would have shot him because he just went berserk.*

Lorna: *Well I was lucky, I had someone, a friend who was visiting me and he actually got me up against the hall wall with his arm against my throat and if she hadn't have been there I might have finished up dead.*

- Joan: *You see, because my husband used to get out of bed at night and two or three times he tried to get out. He got into the porch but he couldn't open the porch and he used to stand there shouting, banging on the doors you know. And one night it must have been five or six times and I did say to him in the end well if you want to bloody well go out, I will unlock the door and you can go.*
- Lorna: *I have had to keep the front and back door locked, all locked, all day...*
- Joan: *It is frightening – well, the day care organiser said to me if you don't do something you are going to end up feeling really ill.*

This quote highlighted some major trigger points for a carer's decision of relinquishing the caring role. Such triggers included difficulty in understanding and managing challenging behaviours (e.g. sleep disturbance, mood-related changes and aggression) of their relative, especially when they had been ongoing problems for a long time.

Despite the difficulties carers encountered throughout the continuum, many carers were motivated to care for their relative resulting from reciprocity, love, companionship and loyalty as reflected in the following quote from Roger:

*'You don't like to be nasty to them but you know, I am very lucky, I can just put it – my wife is crying all day, I honestly don't notice that she is crying sort of. I know she is there but if anything happened, I am there straight away, but they say, all that crying and that, it must get on your nerves, but no, that is, you know, that is what marriage is, I mean what is in there. You know, you get married to look after your partner'. [G3]*

Moreover, many carers often expressed a deep feeling of wanting to reach out to the 'old self' of their relative. They held onto a glimmer of hope that their relative was aware of their presence, especially when they were in their lucid moments.

In the dispossessed activity pattern, carers noticed that their relative was increasingly unaware of the severity of their own problems and its impact on their own and their carers' lives. Many carers had to take control of the caring circumstances and make constant complex decision for their relative's everyday routine activities. The goals of activity engagement focused on promoting moments of happiness, comfort and security. Once carers relinquished their caring role to others, they tended to expect others to carry on with these goals for activity engagement.

To sum up, data from phase two supported the findings of phase one and facilitated the saturation of key categories in phase two, hence the development of the model of

activity engagement. It seemed that the majority of the family carers wanted to look after their relative at home for as long as they could. Against the background of overall decline of their relative, many carers also struggled through a journey of trying to engage their relative in activity, at the same time as becoming more and more emotionally disengaged from them and others during the course of caregiving.

## **Chapter 9: Key findings**

From the two previous chapters on findings, two key aspects emerged that are central to this thesis. The first is: how despite their relative's significant loss of cognitive and functional ability, family carers continue to recognise their relative's agency and their need for engagement in meaningful activities/occupation, and to continually set goals and find strategies to facilitate the person with dementia meeting these goals; and secondly in order to do this carers had to continually negotiate boundaries with their relative. These aspects are highlighted in the model of activity engagement which will be described in terms of its component parts, the relationship of these components to each other, how they change as the phases change and how the patterns merge into one another. Each of these key aspects will be discussed in turn.

### **9.1 Continuing agency and meaningful activity**

From the previous two analysis chapters, it can be seen that, despite their relative's significant loss of cognitive and functional ability, carers continued to recognise their relative's agency and continuing need for engagement in meaningful activities, and so to enhance personhood. The relationships between activity engagement, agency and personhood of those with dementia are intertwined. The term 'agency' refers to the capacity of an agent who makes things happen in their environment and acts according to the agent's will (Kitwood and Bredin 1992). Engagement can be described as 'a sense of involvement, choice and positive meaning and commitment while performing an occupation or activity' (European Network of Occupational Therapy in Higher Education 2010). Through engaging in meaningful activity, an individual can express who he or she is and maintain a sense of agency by choosing the occupation for themselves (Duncan 2006). By supporting those with dementia to meet occupational needs, family carers sustained the personhood of their relatives.

Agency is a very important concept in dementia care (Kitwood 1993; Jennings 2009). A sense of agency can be challenged as those with dementia gradually, with the passage of time, lose the ability to control their environment because of cognitive deterioration. A key aspect which has been highlighted in this thesis is that, although usually in everyday life it is one person who makes things happen and acts according to their own will, in the case of dementia two people are involved; over time the carer takes on responsibility for making things happen and tries to act according to their relative's will. This can be

seen in a quote by Mavis (phase two) who set up the environment for her husband to engage in activity, but was guided by her perceptions of her husband's intention.

*'I am at the stage where my husband needs to be perhaps guided in his everyday routines, you have to just accept that is the way you want to enjoy the life which you have got because you can't deal with it any other way. You have to take on board what your partner wants to do and just guide them, you know, even to make a cup of tea. You know, if I stood in the kitchen and perhaps my husband would like to make us a cup of tea, you would agree that he couldn't find the spoon, to find the tea bag, to find the kettle, to pour the cup. You know, things just get – Even to sweep up a few leaves outside... you just do the things with them ... you need to offer support and guide them through'. [G2]*

Through supporting their relative in carrying out self-initiated daily routine activities, carers provided them with an opportunity to act on their will and to implement their chosen activities with support. This promoted a sense of autonomy in their relative as both past and current wishes of those with dementia are considered to be an expression of a person's autonomy (Koppelman 2002; Nuffield Council on Bioethics 2009). This reflected the view that the promotion of autonomy and a sense of self in these individuals were embedded in relationships (Hughes and Baldwin, 2006; Nuffield Council on Bioethics 2009). Thus, the agency of people with dementia was closely linked with the interaction between those with dementia and others. Family carers promoted the continuity of the agency of their relative through their involvement in the everyday routine activities of their relative.

Family carers did not just 'look after', and 'care' for their relative; they continually set and adapted the goals of activity engagement for their relative in order to enable them to take part in meaningful activities. By encouraging the normal activities and routines of their relative as far as possible, the carers maintained their relative's (and to some extent their own) sense of self and personhood. They created a link to the 'usual' previous life that they had led with their family members (spouses, parents and partners) and created a sense of continuity with the past. This is an important aspect in anyone's life (Sarbin 1986, McAdams 1993), but especially so in the face of unusual events and the life changes brought about by cognitive decline. Routines and meaningful activities were one way of maintaining some stability and continuity, and were of fundamental importance for the carers. In the face of their relative's progressive memory decline, carers considered it very important to maintain stability in their relationship by supporting their relative's sense of control (or agency) in occupations still having some



value or meaning for the relative. The processes that carers went through will be discussed below.

Initially carers often went along with or agreed to something that they were not completely sure of in order to help their relative maintain, as far as possible, their role and responsibility within any usual routine activity. This was often seen as a necessary adjustment, in order to support a family member who was going through some 'bad days'. For example, Eric (Phase two, group four) tried to compensate for his wife's difficulties by assisting her with her paid work. By doing so, he enabled his wife to continue in her role as a teacher, until she finally decided to take early retirement, following the confirmation of diagnosis. By sustaining the role and responsibility of their relative, carers attempted to maintain the stability in the relationship and sense of self-esteem for as long as possible.

Stability was also maintained by controlling the parameters of an activity so that their relative could successfully continue tasks that were usual for them. This was achieved by adjusting the demand of a familiar activity and matching the goal of an activity with their relative's remaining abilities. Through engaging their relative in such a modified activity, carers facilitated a sense of worth and competency in their relative. This could be illustrated in the quote from Jean (phase one):

*'He [my husband] will go down to the shop, the shops that he uses that he knows, but I will give him one thing written on a piece of paper. If I give him more than one he might manage to - but if I give him more than that he will get confused and he certainly can't remember...I have tried not to take away from him anything that he possibly could do'. [C5]*

Thus, carers promoted their relative's sense of success by enabling them to maximize the retained ability which, carers considered, linked with the past self and routine activity of their relative before the onset of dementia. This was felt to enhance a sense of continuity of self and security in their relative.

Often, carers encouraged a sense of stability by developing a strategy to enable their relative to take part in 'risky' activities which their relative initiated. In such a situation, carers felt that the benefit outweighed the risk. Through engaging their relative in activities of their own choice, carers promoted a sense of independence and autonomy in their relative. This could be illustrated by a quote from Lorna (phase two):

*'My husband used to go out with the dog and he would be gone perhaps for three hours, and the dog always brought him home. He always came home. ... I suppose he was just wandering...I used to worry like hell all the time he was out, but I didn't want to take that little bit of independence away from him... I thought it would be good for him because his concentration was such that you couldn't get him to do anything ...' [G5]*

This illustrated that taking risks was an inevitable aspect of carers' daily involvement in their relative's everyday routine activity. When engaging their relative in daily routine activities, carers had to strike a balance between taking calculated risks and facilitating a sense of independence in their relative. This was often at a cost to carers in terms of their own psychological and emotional state.

It seemed evident that carers supported an activity, even if it was not perceived to have been 'successful' in terms of outcome, because they felt it maintained some stability in terms of continuity of identity. It has been suggested that although mood and behaviour of those with dementia may be severely affected by dementia, their 'personal identity' remains the same throughout the course of dementia (Sabat and Harre 1992; Nuffield Council on Bioethics 2009). Moreover, the maintenance of values and beliefs (e.g. a sense of control, respect and dignity) are important factors which define the identity of an individual (Koppelman 2002). Through engaging their relative in activities which aimed at enhancing a sense of identity, carers enabled their relative to express himself/herself in a particular way which reflected the latter's value and interest. This in turn promoted a sense of agency and personhood. This can be illustrated in a quote from Carole (phase one) below:

*'My father is a gardener and I have a patio with pots so...I let him do whatever he likes and then I go round afterwards and sort it out again because he does some weird things now' ... he's still got the mind that he had before - it just doesn't always show'. [C3]*

It is interesting to see how Carole stated, 'my father is a gardener'. This was despite the fact that her father had been experiencing memory loss for many years. By maintaining her father's routine in gardening she was also maintaining her father's identity as a gardener. This would then enable her to support her father to act according to his will and to use his remaining abilities to carry out a familiar activity within a supportive environment. Through taking the action to go round afterwards and sort things out things in the garden for her father, Carole showed an awareness of the need to adapt the environment in order to minimise its demand on her father's performance. This in turn

promoted a sense of safety in her father. There was a sense of wishing to reaffirm a sense of capacity and meaningful purpose in everyday living in the relative.

Carers also helped their relative make a contribution in the relationship through the use of shared activity. By doing so they enabled their relative to express their kindness and gratitude to others, and to achieve a sense of productivity and satisfaction, as illustrated in a quote by Julie (phase one):

*'She [my mother] always say to me "what can I do to help?" ...I try to get her involved as much as I can. You see, she's always done the housework in her own house before she moved in...so I get her to do the washing up...mind you, it does mean that I might have to go along behind and do it again...but it doesn't matter, she likes to think she's helping'. [C6]*

As can be seen, the perceived benefit of activity engagement focused on supporting those with dementia in taking part in the process of meaningful doing, not just producing a tangible end product.

Even when severe cognitive decline was apparent, carers tried to respond to their relative's wishes (or positive choices), and to promote their well-being, by adjusting the environment; thus maintaining feelings of stability, and connection with the past. For some carers, this could mean that despite memory and functional loss, they could enable and share a sense of fun and enjoyment through doing things which were still meaningful to their relative, as illustrated in a quote from Susan (phase one) :

*'He [my partner] liked to watch the television, but erm, he couldn't follow a story, so I wouldn't put on a programme that had a continuous story because he'd be losing the plot...so I wouldn't have that, but something - very old programmes - sort of comedy, you know. He liked that, and it is funny, with University Challenge he would shout out the answer sometimes if it was something to do with his profession that he knew about, he would follow that, but I knew it was no good putting on, you know some murder mystery because he wouldn't know what it was about. So he wouldn't enjoy it – I could leave him there on his own for a while'. [C4]*

It seemed that, in the face of progressive cognitive decline in people with dementia, the need for carers to maintain a sense of happiness and well-being in their relative became increasingly important. This was despite the fact that such feelings were mainly associated with 'moment-to-moment experiences of contentment or pleasure' (Nuffield Council on Bioethics 2009, p28). Hence, carers attempted to identify meaningful activities which prevented their relative from feeling a failure, and being distressed by

demanding experiences. Moreover, such moments of contentment in their relative gave carers a break from their constant supervision and caring responsibility.

Carers faced enormous challenges when their relative was not interested in any activities which kept either their mind or body active. They considered inactivity as an unhealthy state which could lead to rapid deterioration in their relative's well-being. They felt it necessary to find strategies to continuously engage their relative in activities even as dementia progressed, as Ann (phase one) said:

*'I asked him [my husband] if he wanted to do something, or go out, he just said, 'No, I'm all right here'. ... Well he was all right, but you know I felt I ought to stimulate him a bit more, but err, he just sits there all day and doesn't want to be stimulated... If he doesn't sit he will be lying and sleeping... so, I talk with him, we talk together... talk about programmes probably, and events, family events'. [C13f]*

Being inactive was considered by carers in the current study to be a state of stagnation. Carers perceived that, in such a state, the relative ceased to act on own volition or to express who he or she was. This created a barrier for carers, preventing them from connecting with the past self of their relative, and ensuring the continuity of their relative's agency. The link to the past or the person they knew appeared to be lost. Carers felt that this had an adverse impact on the relationship with their relative, and so they made an effort to prevent their relative from sitting idle by encouraging some kind of action as a way of expressing themselves. This in turn enabled carers to support their relative to act on their will and to relate to him/her in a meaningful manner. Lillian said:

*'I try to keep him [my husband] as active as possible, because I believe that if you sit down and let it happen, you stagnate... he's not allowed to stagnate, which I think is helpful to him'. [C12]*

It seemed that recognition of the continuity of the identity and agency of those with dementia could be best understood when a person was engaging in meaningful activities with the support of a carer who endeavoured to connect their relative's past and present unique characteristics. This process, whereby carers sustained continuity of the current self of the person with dementia over time through bringing back the past self when the person was no longer able to do that alone, has been described by Jennings (2009) as 'memorial personhood'.

The fundamental importance of the need to maintain a sense of stability can be seen in that carers continued to support their relative despite facing many difficulties such as having to learn by trial and error; feeling a failure; and often facing a sense of criticism from others. These difficulties will be discussed in detail below.

Because their caring situation changed constantly, carers were often faced with not being sure what to do, but feeling the need to do something. They developed their strategies by trial and error and were not always certain whether they had set the right goal for their relative's activity or had used the right strategy to implement such a goal. This can be illustrated in a quote by Jill (phase one) below:

*'I put things out like to clean his [my husband's] shoes or go and get a box to get that and then it is still standing. I sort of say, 'well are you [husband] going to do your shoes'. He said "Yes I will", and um, but he doesn't. But he doesn't get on and do it – he forgets to do it or he doesn't want to do it. I don't really know. I find it difficult to keep his activities going but I am always looking for ways. I have to arrange it, and it is very difficult but one has to try'. [C11]*

Carers in the study reported that they often lived with a sense of failure. One reason for this was because they realised that their strategies did not always achieve a desirable outcome for their relative and that their relative responded negatively to their action. For example, Nora (Group one, phase two) bought a specialist bed with a view to enabling her husband to get on and off his bed independently. The bed could lift her husband's head and feet up to make it easier for him to get out of bed. To Nora's surprise, her husband reacted to her with anger and hostility when she was operating the bed to help him getting up in bed. As a result, she blamed herself for failing to find ways to help her husband with his bed mobility (see 8.3.4.1). Another reason for feeling a sense of failure arose when carers felt that they could not support their relative with certain daily activities and had to utilise outside resources to help their relative instead (e.g. using day care to provide their relative with activities, or using home care assistants to help their relative with personal care). Carers' sense of failure could be exacerbated if their relative showed resistance to such outside help. Examples of this were illustrated in 6.2.4.1 and 8.3.4.1.

Carers experienced a fear of criticism. One such fear was associated with being judged by their relative. This happened when their relative disagreed with their activity-related

decisions because their relative was not be able to appreciate the potential effect of such a decision and hence was reluctant to cooperate, as Shelia (phase one) said:

*'I think it is important, that he [husband] meets people there [day care], because you're in here and you're cut off... it was to sort of stimulate him. But at the beginning, he was reluctant - I suppose for the first six weeks – "I'm not going. Not again". In the morning, he tended to put on a huge show, but anyway, gradually, gradually... and now he really enjoys it...he likes his paper and pens - I pack them in a bag and he takes them with him'. [C1]*

Fear of criticism was also associated with being judged by others (e.g. other family members and professionals). For example, as Sheila said:

*'It's difficult with my husband's family, normally, we hardly see his family. When his daughter knew that I arranged for him to go to day care. His daughter said to me "well why don't you take dad out and entertain him more? Dad wouldn't want to attend a day care" – you see'. [C1]*

Moreover, some carers felt that they received negative comments from staff. For example, Linda (phase one) felt that she was being criticised by day care staff for allowing her husband to walk home on his own at the end of the day, despite potential risk (see 6.2.4.1).

Even though carers faced a sense of criticism they carried on developing strategies to support their relative, demonstrating how important activity engagement was for them in their lives. Also, engagement in their relative's everyday activities could be a time-consuming and demanding process. However carers had determination and perseverance and devoted the time to facilitate their relative's activity, and highlighting their conviction that there was a fundamental need to maintain everyday routines and connections to the past.

Hence, by recognising the uniqueness of their relative's individual characteristics, carers played a key role in maintaining the personhood and continuity of their relative's identity and agency. This showed that the enhancement of the personhood of those with dementia could be achieved by engaging these individuals in meaningful occupations within a safe and supportive environment. Such occupations reflected not only the current needs but also the past values, beliefs, likes and dislikes of their relative, despite varying degrees of memory loss.

Carers' decision for taking up their caring role was often motivated by love, passion, reciprocity and interdependency, and positive relationship in the past and present. Nevertheless, family carers often faced the challenge of whether they had made the right decisions, with very little support from professional services.

Decision-making about everyday occupation of those with dementia often required carers to renegotiate the boundaries of involvement with their relative. This will be discussed in the next section.

## **9.2 Negotiation of boundary between carers and relative**

From the previous section, it can be seen that carers constantly felt a need to appraise the situation and balance the benefits and harm to their relative, as well as themselves, in terms of maintaining some link with the past.

Over time the ability of their relative to make decisions (i.e. the autonomous ability to make decision for self) reduced, resulting from cognitive decline. This meant that carers had to renegotiate boundaries, through discussions and actions about the changing roles/activities of the relative. This also impacted on the roles/activities of the carers.

Negotiation processes occur in situations in which each individual or group wishes to achieve an outcome that could not be accomplished without the help of the other party (White and Klein 2002). During the process, each party has some influence or power over the other's ability to act (Fowler 1998). In the current study the boundary could be seen as a dividing line between the respective contributions of carers and relative in an established routine. The line was not necessary static and could be negotiable between carers and their relative. Throughout the caring journey, carers had to negotiate the boundaries in many established everyday routine activities, not only: a) in terms of what each person would do; but also b) in the amount of their involvement in their relative's activities. This can be illustrated in a quote below by Ann:

*'Recently I've borrowed a wheelchair from the Red Cross because he's [my husband's] not steady on his feet. I wanted to take him [my husband] out along the back way, down in the lift...along the far end, ...I wanted to take him out on to the seafront...he was rather resistant to that, he didn't want to do it because he said I shouldn't be pushing him it was too much and he wasn't going to sit in a wheelchair and have his wife push him about...but anyway, when my daughter [from the 1<sup>st</sup> marriage] visited from abroad, she said to him, "I'll help Mum do*

*this”, and so on and so, and then he was alright and he really enjoyed going out’. [C13]*

Shifting the usual boundary in the relationship potentially gave rise to conflicts between carers and their relative due to the changes encountered. Therefore carers had to negotiate carefully to try and prevent disagreement or upset. This can be seen in the quotes below by Ellen (phase two):

*‘My husband was diagnosed about 18 months ago with dementia – so it was around last year .... I could see the signs but it took me a year to actually get him to the doctors because you can’t take him to the doctors and sit there. He has got to agree to go to the doctors - well I did eventually get him to the doctors’. [G4]*

This negotiation process became more difficult over time when relatives were less able to make rational decisions. As the relative experienced progressive memory loss and communication difficulty, the negotiation process became more complex for carers; as described by Joy:

*‘In the beginning, when I said to him [my husband], “You are not really able to work out your accounts or anything like that, are you”? He said, “Oh yes, I am”, and he’d get quite annoyed – But I mean, he went into the newspaper shop – because I thought he was capable of going and buying a Radio Times thing, and I said, “Go down and buy this”, and I showed him the picture on the front – and it’s a friend of ours who runs the shop – I said, “Go in and ask for one of those”. He said, “Fine”. Well, one of the girls served him and he gave her £75, just like that. They’re 45p. Luckily they phoned me up and said, “Just check he’s got it still, we made him put it back in his purse”... So I’d to persuade him not to put too much money in his purse – say £10, and then if he wants any more he’ll have to ask me. In the beginning, he was reluctant. Now, he sort of doesn’t mind’. [G 5]*

Despite the difficulties, carers continually negotiated boundaries of involvement with their relative as a strategy to interact with them and to ensure that their relative played some role in the decision-making process and maintained their agency, described in the previous section. This resulted in carers making decisions about their own involvement.

Carers continually negotiated boundaries with the person with dementia by using two key approaches, direct and indirect, as follows.

Prior to the onset of dementia in their relative, carers and their relative often had established a process which enabled usual negotiation concerning the shared activities and the relationship. This was based on some kind of mutual understanding with respect



to the division of responsibilities for the normal running of the household, for example, handling their finance, arranging hospital appointments, developing holiday plans and everyday manual maintenance work in the house. Each individual had an understanding of the other's roles and responsibilities once the agreements were established. The relationship between the individuals reflected interdependency and reciprocity. Hence, each individual in the relationship was considered by the other as an autonomous agent capable of making decisions and aware of own needs.

The direct approach of negotiation required an open style of interaction and discussion between carers and their relative as carers attempted to engage their relative in the decision-making. This involved a series of discussions and an appreciation of the goals, by both the participants and their relative, before a boundary was changed. Often, prior to the negotiation, carers attempted to raise their relative's own awareness of the problem, and so possibly their concern about the problem. The intention was to help their relative appreciate the need for renegotiating the boundaries of involvement. One common strategy which carers employed was to require their relative to do a task perceived as a problem, either by their relative or themselves, or both. This helped carers to gain a fuller picture of changes in their relative's ability to perform a familiar everyday task. An example of this can be illustrated by a quote from Karen below. When she noted that her mother was, on numerous occasions, not able to understand the instruction for the use of a familiar washing machine over the phone, she decided to ask her mother to do the task on one of her visits to her mother's house; as Karen said:

*'She [my mother] didn't use a washing machine, she was washing by hand ....And then time went by and she still hadn't used it despite my instruction and then ...One day when I visited her at home, I said lets put some washing in. So we put it in and I said now you set it, and she couldn't do it. I had to do it ... I then realised that she had forgotten how to do it, and this happened to other things..., it is very difficult to start taking over and saying why can't you do it?'*  
[G4]

Karen was able to confirm her suspicion about her mother's memory difficulty and then raised her concern with her mother about her ability to cope with everyday routine activities. She then supported her mother to accept help in some everyday activities from social services, as she was unable to offer all the necessary support that her mother required due to her own work and family commitments. Consequently, her mother was persuaded to accept outside help. Karen felt reassured that the decision was made with

her mother's agreement rather than solely by herself. The direct approach reflected carers' intention to involve their relative in exploring the problem together, before reaching any critical decisions. This had a potential to enhance a sense of control, empowerment, collaboration, autonomy and independency in their relative.

This direct approach required a commitment from both carers and their relative to work together on a shared problem. Both parties respected one another's decision and were prepared to compromise their own needs if necessary, as illustrated in a quote by Joy below:

*'The doctor asked my husband's opinion, on how he felt about driving. And he said, "Well although I am still capable of driving perfectly alright I am frightened that if there is an accident, because I have got Alzheimer's, I will get the blame even if it is not my fault"... He did in fact change his mind and drive a bit after that when we were out in the country. I said, "Yes go for it", and then we would get to a main road and I would take over again'. [G5]*

As can be seen, after Joy's husband changed his mind about the initial decision to stop driving, both Joy and her husband continued to negotiate concerning the circumstances in which her husband could continue to drive with her support. This reflected that, even after the diagnosis, many carers continued to respect their relative as an agent who was capable of making decision and could negotiate for their own needs. Also, carers recognised that their relative needed time to adjust their occupational goal and to cope with the consequences (both practical and psychological) of related decision-making. In Joy's case, she realised that her husband missed his driving very much because he used to go on holidays with her in his car until he obtained the diagnosis. Hence, she was prepared to compromise her own needs.

As mentioned previously, some carers continued to help their relative carry out certain daily activities even though they may have been considered by others as risky (e.g. unsafe driving, inappropriate use of electrical appliances). They tried hard to get the balance right to enable a sense of agency. For example, Susan (phase one, 6.2.3.2), following the confirmation of a diagnosis of dementia, was reluctant to cooperate with a medical consultant who advised her to stop her partner driving. This was partly because she recognised her partner's wishes to be able to carry on driving and maintain his independence; and partly because she felt that even if she insisted that her partner stopped driving, she believed that her partner would have disagreed with her.

When carers had to negotiate with their relative to stop them from carrying out a risky activity (e.g. driving), whether resulting from their own decision or recommendations from others, they often felt guilty for failing to uphold the relative's independence. Carers were concerned that their relative might perceive the decisions as intruding on their autonomy and so affect their relationship. For example, Joan (phase two, group five) felt hurt that her husband had said that he hated her because she had to tell him to stop driving following the advice from a medical consultant. Since then, her husband refused to go out in a car with her for quite a while. Ongoing usual activity engagement not only had consequences for identity and personhood but also for the nature of the continuing relationship.

The direct approach, however, could present carers with a challenge when their relative refused to discuss a particular issue as illustrated in a quote by Dave below:

*'She [my wife] wouldn't admit that there was anything wrong with her. She wouldn't even admit that she was acting strangely, or not strangely, but strangely, yes, out of character... she was acting completely out of character at that time. She did not give any indication that there was some thing wrong with her mind'. [G2]*

Carers wanted to use the direct approach to negotiate the boundary of involvement with their relative as this approach potentially enabled carers to discuss issues and their concerns with their relative directly, and so build a trusting relationship. However, as the dementia progressed, this approach posed a challenge for many carers due to increasing difficulties in : i) their relative's verbal skills and reduced level of awareness of a particular problem, and ii) their relative's ability to make rational decisions and comprehend the level of information involved. Carers thus found it challenging to find new, effective ways of communicating information to their relative, in order to initiate discussions.

The indirect approach was a more subtle way in which carers interacted with their relative, in order to renegotiate the boundary of involvement. Carers found strategies to compensate for their relative's deficits without raising their awareness of those difficulties. Many wanted to protect their relative from feeling distressed or depressed. This in turn promoted a more relaxed and less confrontational environment for their relative and themselves, as illustrated by a quote from Ruth:

*'I would just sort of say, "I would do the driving, I will drive, you know, if we were going out somewhere – then you can have a drink, then you could have a beer at the pub or something", you know - so I would do the driving'. [G3]*

By not drawing the attention of their relative to their problems, carers focused more on enhancing their relative's retained ability, and offered them an opportunity to make a contribution to the partnership, as illustrated in the following quote below by Brian:

*'I noticed she was getting confused over things like putting out knives forks and spoons. She was putting them in an absurd way ... I was gradually taking over the cooking in the house. But I encouraged her, continued to help ... And I never commented... I just quietly put them right'. [G1]*

Carers were aware of the extent to which their relative wanted to retain control of their decision-making regarding boundary of involvement. They were also aware of the extent to which their relative could influence such a decision even though carers might consider it as no longer appropriate to their changing circumstances. They wanted to maintain a harmonious relationship. Carers carried on negotiating with their relative because they recognised that their relative had a desire to maintain a sense of control over a meaningful activity for as long as possible. They wished to respect their relative's value and their wishes; and they were determined to maintain their relative's dignity as far as they possibly could. This can be illustrated in a quote by Sandra:

*'In the beginning, my husband wanted to sign every cheque, he wouldn't let me do it... But his signed things which were not acceptable to anybody ... I was trying to say to him, its alright, its just the signature, just making little patterns to get the signature in there, I then rang the bank to explain..., and eventually I had to take the financial side over, because he made a lot of silly decisions and people took advantage of it in a little way. You know'. [G2]*

Carers' indirect approach to negotiating the boundary of involvement might take the form of influencing others to enable their relative to achieve a desired goal on their relative's behalf. This was seen as necessary when carers realised that their relative required others to support them to continue with their everyday activity. Carers justified their decisions to shift the boundary of their usual involvement in the established routine activity by ensuring that such decisions were in line with their relative's retained ability, interests, preference, personality and past life. For example, carers helped their relative by negotiating with others in order to maintain their relative's social engagement and enjoyment outside the home environment for as long as possible. This could be seen in a quote below by Lillian:

*'My husband goes out to the local pub with the others. I don't think it ever occurs to him to buy a drink, not out of meanness, ...so one very good friend*

*down there [in the pub] who I know, I will occasionally give him some money and I will say you know, “will you buy my husband’s round for him” but that is the only way you can really do it’. [C12]*

This was necessary when carers realised that there were dramatic changes in their relative’s normal taken-for-granted everyday activities (e.g. performing unsafe tasks, making inappropriate decisions about some critical everyday routine). Carers became aware of the level of vulnerability of their relative and felt obliged to take over some of their relative’s responsibilities. However, they believed that it would be better not to raise their relative’s awareness of the problem before they changed the boundaries and so either took over particular everyday activities, or offered alternate meaningful activities. They made such decisions without an open discussion with their relative. They worried that raising their relative’s awareness of what could be considered to be a weakness in a particular situation might have an adverse effect on their self-esteem, self-worth and confidence, and sometimes, the relationship. Also, some felt that they had great difficulty, using their usual reasoning skill, in helping their relative to understand a particular situation.

An example is Roger’s decision to ‘secretly take over’ the housework from his wife (8.3.2.2). He had noticed that his wife had been having difficulty in doing housework to her own usual standard for a period of time, resulting from recurrent episodes of mini-strokes. His wife was adamant that she would carry on with her duties without any help. When his wife went into a planned hospital admission for investigation of her health problem, he worked out strategies (with the support of her daughter) to take over his wife’s housework. Once his wife returned home, he carried on with some of those responsibilities when she was asleep. This went on for a long time until his wife’s mobility started to deteriorate further. At that point, his wife agreed to receive practical assistance from him.

The process of negotiation could take a long time. It was embedded in the reciprocal, interdependent and historical personal context.

Carers attempted to continue to engage their relative in daily routine activities which enabled them, to as far as practicable, to respect their will, and exercise their sense of

control. This was seen as a means to promote a sense of dignity and trust in their relative, as illustrated in the quote by Lillian (phase one) below:

*'I've got a power of attorney, I could quite easily do all these bank things myself, if I wanted to, but I just thought there's a bit more dignity about writing your own cheque somehow. – erm – I mean, my husband still signs a cheque: I will make it out, and then he'll sign it, and he'll always say to me, 'What do I put? My name? Or what?' and I often have to tell him exactly what to put in'. [C12]*

Despite having a power of attorney, through supporting her husband to continue signing his own cheque, Lillian showed her willingness to maintain a trusting and respectful relationship with her husband. This in turn enhanced a meaningful interaction between her husband and herself through continuing to do something together in the partnership.

As their relative experienced increasing memory and functional loss, and once he or she was no longer able to appreciate dangerous situations, carers employed strategies which involved coercing, persuading and manipulating the environment, to engage their relative in activities which were safer and meaningful for them. This was illustrated by Ellen:

*'He [my husband] does little jobs, he takes the dog out. I have to coax him but that is his job. So that is a routine. He – I know it sounds petty, but he peels the potatoes. He knows about that. He washes up but its – he gets sort of fed up with it really...He might do half and then leave it...you see, he can still do these jobs because that is not a dangerous chore, is it? but using a knife indoors, and cooking, no, I don't think so'. [G4]*

As can be seen, when carers adopted a subtle way of negotiation, they attempted to obtain feedback from their relative through observing clues in their behaviours, e.g. being fed up, being disinterested in the task and showing aggression. This implied that carers often took account their relative's viewpoint in their decision-making even though they did not feel that they could directly discuss their decisions with them. The indirect approach had the potential to enable carers to take over some perceived stressful demand on their relative in a subtle way, in their best interest.

However, as their relative experienced increasing memory and functional loss, carers experienced increasing difficulty in taking over their relative's activity-related decisions. This was particularly because they did not always have the skills and

knowledge to communicate with them effectively. This can be illustrated by the quote below from Jim:

*'It's a job to cater for her [my wife] at times. She will live on ice cream, that's her one weakness, fondness call it what you like. I mean I can get her ice cream every time. If I give her a sort of snack at anytime, she says, "Oh thank you so much". She appreciates it, I think, but you need to have certain amount of iron and stuff. It's a constant battle - I mean - I say to her, "What would you like for dinner"? You know, I said to her last night, "are you hungry?"; "Oh a bit". I said, "Well what would you like? We've got chocolate biscuits, sweet biscuits, KitKats, Wagon Wheels...". I said, "There's bread and cheese, there's ham, tomatoes what would you like"? She said, "Well, I don't know". The shutters come down. There is very little input from her side, I mean she will not turn round and say, "well look can we have fish and chips tonight". The whole thing is a battle, one you will never win. I know what she likes so I tend to be fairly regular in what I produce... She'll have to eat anything I put in front of her'. [C2]*

During the process of negotiation, carers attempted to strike a fine balance between promoting their relative's sense of control and maintaining that of their own. In some circumstances, carers realised that if they made an inappropriate decision which was not in line with that of their relative, they might face the prospect of dealing with undesirable consequences, e.g. resistance from their relative and damaging the relationship.

The indirect approach also required carers to be sensitive to their relative's feelings and emotions because their relative might not be able to give them a coherent verbal response or act in an apparent rational manner. Otherwise, even with the best intentions, they might undervalue the relative and so deprive him/her of an opportunity to take part in a decision-making process. This in turn would lead to a feeling of deception and disempowerment in their relative, and hence might damage the trusting relationship.

This can be reflected in a quote below by Jean:

*'If we[my son and I] have any family problems we have to make sure that we don't mention it in front of him [my husband], because he'll keep saying, 'What are you going to do about it'? - every five minutes, there's a sort of panic, rather than a contribution, and it just adds to your worry. There, you see, that is a case in point, that is the television, this year he's 75 so he only pays half the fee: well, he worries about it being paid. There was a letter about it, and I have actually put that letter up in the clipboard, but he will take that letter off the clipboard and he will put it in with today's post because he wants me to deal with it. He's done that three or four times, and he's knows I've made a note to check it out. So you tend not to mention things in front of him, you just sort things out yourself'. [C5]*

During the process of negotiation, each party attempted to exert their influence over the other's ability to act on a desirable goal. It appeared that as the cognitive ability of the person with dementia deteriorated, the balance of power tended to tip over to the carers' side. Nevertheless, when carers negotiated with their relative in a subtle manner, they took account of various factors. These included their appreciation of not only their relative's past or present wishes but also the relative strength of such wishes. Moreover, carers also considered the degree of importance of the nature of the decision involved, and the amount of distress being caused to their relative and themselves.

In summary, carers' negotiation of the boundary involvement with their relative was a complex and ongoing process, involving the use of a range of skills and knowledge, including communication, a understanding of dementia, goal-setting for meaningful activities at different stages of dementia, and mobilizing available resources. They sometimes involved others (e.g. family members and friends) by negotiating with them on their relative's behalf, so that their decisions were supported by others. Carers, throughout the caregiving journey, continually negotiated boundaries of involvement (open or subtle), with their relative, as a response to their relative's reducing ability to make decisions in order to address his or her occupational needs. They used a different approach at different stages of a negotiation process depending on the issue. This enabled them to find way to involve their relative in decision-making process one way or the other. This in turn promoted a sense of agency in their relative as far as was practical. The need to adopt the right approach at the right time with their relative often presented carers with enormous challenges. They often worked in isolation without getting any helpful feedback from others. Despite the difficulty, carers in the current study showed dedicated commitment and perseverance in supporting their relative, especially in negotiating the boundaries for involvement throughout the caregiving journey. This indicates an urgent need for professionals to understand issues confronting carers during the process of engaging their relative in everyday occupations, so that appropriate training can be provided to address carers' needs in their role. The model of activity engagement, developed in this study, offered insights into carers' experiences in engaging their relative in everyday routine activities. The model will be further explained in the next section.



### 9.3 Key aspects of the model of activity engagement

The two previous chapters discussed how the model of activity engagement emerged in the first phase of the analysis; and how the main categories (that is, the *usual, recognisable, illogical, irresponsible and dispossessed activity patterns*) were refined and saturated in the second phase of the analysis. This section will briefly outline: a) the components of the model; b) an explanation of the components; c) the relationships of these components to each other; d) how activity patterns change successively from one pattern to another; d) how one pattern merges into the next one on a continuum.

#### 9.3.1 The Model and key components

The Model is made up of five activity patterns or systems. Each activity pattern or system is made up of four components (see figure 9.1). These are: i) carers thoughts; ii) carers strategies; iii) carers feelings/emotions; and iv) time. Each activity pattern can be considered as a system which denotes how carers' are thinking, behaving and feeling change at a particular time. These will be discussed in more detail below.

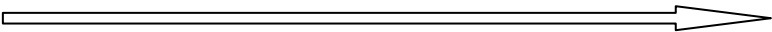
MODEL	FIVE ACTIVITY PATTERNS (OR 'SYSTEMS')				
	Usual activity pattern	Recognisable activity pattern	Illogical activity pattern	Irresponsible activity pattern	Dispossessed activity pattern
COMPONENTS	SUBCOMPONENTS				
Carer's perception	<i>Specific features/ thoughts</i>	<i>Specific features/ thoughts</i>	<i>Specific features/ thoughts</i>	<i>Specific features/ thoughts</i>	<i>Specific features/ thoughts</i>
Carer's actions/behaviours	<i>Specific strategies</i>	<i>Specific strategies</i>	<i>Specific strategies</i>	<i>Specific strategies</i>	<i>Specific strategies</i>
Carers' emotions and feelings	<i>Emotion and feelings</i>	<i>Emotion and feelings</i>	<i>Emotion and feelings</i>	<i>Emotion and feelings</i>	<i>Emotion and feelings</i>
Time					

Figure 9.1: Outline diagram of the Model and its components

##### 9.3.1.1 Key components:

The first component is the family carers' perceptions of the changes in their relative's character and everyday routine activities. Hence, 'features' describe carers' thoughts, at each phase of caregiving, as carers have to develop new strategies in order to engage their relative in meaningful activities. The whole model is developed from their viewpoint. By using the model it is possible to get some insight into how carers make sense of and understand their situations. How carers think about their situation will affect their behaviour, and an understanding of this could be useful for clinicians.

The second component which also goes across all patterns is the specific manner in which the carers feel that they can engage/support their relative in some sort of daily activity, be it self-care, work or leisure - the strategies they use for engagement. It is not a case of just caring for or 'being with' somebody. Rather, it is doing with them, something meaningful, or helping them to meet goals and do things so as to maintain the continuity of their agency, their sense of self and their well-being. This promotes stability in the relationship with their relative. As highlighted previously, the importance of this activity is fundamental in carers' lives.

The third component which goes across all patterns is carers' feelings and emotions which influence carers' thoughts and behaviours. Families are affected in different ways by the progress of this chronic disease. Literature has consistently highlighted the need to recognise the impacts of dementia on family carers' feeling and emotions (Iliffe and Drennan, 2001; Adams and Sanders 2004; Cooney et al 2006).

The fourth component, which goes across all patterns, is time. Carers move through the five activity patterns along a continuum but not at the same linear temporal rate; movement is dependent on many factors including the relationship between carers and their relative but is dominated by the progression of their relative's cognitive decline. As highlighted by the model these changes are not abrupt but emerge gradually so that eventually the overarching system changes and a new set of relationships can be described.

Thus, in summary, the model of activity engagement illustrates how carers' perceptions of the changes in their situations are cumulative and evolve along a continuum. Within each pattern, carers' thoughts influence both their behaviour in terms of how they develop strategies to engage their relative in meaningful activities, and also their emotions and feelings. The carers' experience in each pattern further influences their perception of their situation and thus the development of new strategies in the next phase of activity engagement.

### 9.3.2 *Movement from one activity pattern to the next*

As can be seen in figure 6.4 (model of engagement) on page 107, the patterns overlap. Carers initially begin to perceive how individual instances of activity change from those they have become used to, and gradually the nature and overall way of engaging with their relative changes, and the situation can be considered to be in the next pattern. There are no abrupt triggers from one phase to another. Rather one pattern merges into another over time. This section will describe how one activity pattern merges into the next, on a continuum, with carers' perception of their relative's activity engagement. The term 'turning point' will be used to describe the stage at which two patterns merge because carers' perceptions of their situation are changing and they feel a need to develop a new set of strategies.

The *usual activity pattern* consists of the usual and taken-for-granted assumptions and strategies which carers and their relative employed to negotiate changes in their everyday routine activities. This pattern serves as a starting point for the model of activity patterns because carers' perception of apparent changes in their relative's activity patterns has a root in the past experience with their relative. The turning point from the usual to the recognisable pattern signifies that carers have become aware of some changes in their relative's activity patterns and character, but cannot pinpoint what the problem is. This can be illustrated by the quote from Mavis (phase two) below:

*'My husband drank and the drinking got heavier and heavier and heavier. He liked a drink even when I first met him - we have been married 26 years - but he was clever in the way that he drank. He didn't come home until after he had been to the pub...He finally went to the pub instead of coming home for his dinner and then coming home for a beer. He came home and gave all kinds of excuses because...I noticed that he couldn't remember how many mileages, what day of the week it was, where he had been, who he had met. But I just thought he had been drinking, so he covered it [his memory problem] very well...but in the beginning, you cannot confront someone who is very independent, strong character, wants to do what he wanted to do, when he wants to do it, so you back off, although you think there is something strange'. [G2]*

Within the *recognisable activity pattern*, carers consider that their relative is still able to make decisions for themselves and fulfil their usual responsibilities. Although they notice that their relative occasionally experiences difficulty in achieving their own usual standard of performance and they are not unduly concerned at the time. Carers' activity involvement with their relative is largely based on mutual understanding and sharing within the partnership.

The turning point from the *recognisable activity pattern* to the *illogical activity pattern* comes when carers realise that their relative has started acting in an obviously illogical manner and is frequently making inappropriate decisions. Also, carers become concerned that the apparent changes are just the ‘tip of the iceberg’. They feel that they are no longer able to ignore the problem as this seems to threaten their previous understanding of their relative’s behaviour. This can be seen in a quote by (Phase two): Audrey:

*‘Prior to the diagnosis, my husband lost interest in doing anything with the banking and everything with that sort of thing and I thought well, I thought he was being lazy about it, so I took over, more or less, I mean I knew what I was doing...slowly, he made many silly mistakes, I could not get through to him that what he’s done was wrong...But when he became aggressive toward me, I got frightened so I went to my doctor and that is when he was referred to a psychiatrist because it was quite out of character’. [G 1]*

Within the *illogical activity pattern*, carers frequently notice significant events which are associated with the relative performing an activity in a less recognisable and logical manner (e.g. showing inability to appreciate risk involved in certain activities).

The turning point from the *illogical activity pattern* to the *irresponsible activity pattern* comes when carers realise that they find it extremely difficult to negotiate with their relative because the thinking of their relative has become very irrational. At this point, they start losing confidence in their relative’s ability to manage activities in the household. This change is reflected in a quote below by Janet (phase two).

*‘My husband erm - when his whole world was news, every news. Now he doesn’t always watch the television. Now he can’t turn the television over. He used to be able to flick the telly and go over. Now, he does get up. If I am not there he will either shout or he will walk into the hallway with the remote control – so he has still got enough to know that he wants the television turned over but we might have a week where he doesn’t even want to watch the news and he comes in the kitchen, sits, and I put the radio or a CD on and I think he relates to music that he likes. You know, he is very wide selection of music, from Jazz, to Skim, to whatever. I put on whatever it is makes him move and more cooperative. I mean, I have the radio on with music from the moment we wake up in the morning because he will be more cooperative when I take him to the toilet and then to sit in the room’. [G5]*

Within the *irresponsible activity pattern*, carers have taken over a range of major household duties from their relative who has gradually lost the ability to appreciate the

meaning of those once familiar activities. Carers make constant adjustments to their relative's everyday routines in order to enable them to continue to be active through the use of meaningful activities.

The turning point from the *irresponsible activity pattern* to the *dispossessed activity pattern* comes when carers feel an increasing need to develop a sense of control of almost all aspects of their relative's daily routine activities and feel dispossessed of the relationship they once had. At this point, carers feel that they have to take over almost all decision-making for their relative. Many carers feel that they have to accept outside help for support. This can be reflected in a quote from Margaret (phase one) below:

*'My husband won't let me help him at all.... I mean, I can't get him to wash himself at all... he gets very annoyed. I think there is just something still subconsciously telling him "it is not right that my wife should be doing this. I should be doing this myself, but I can't, so that makes me cross", so then he gets agitated, and aggressive...Now that somebody[care assistant] comes in, she comes in a sort of nurses uniform and everything, no bother at all...It is really strange. I have been worried about it along the way and it has not been a problem at all. You think why on earth I hold back for so long and not getting help sooner....Actually you put your own well-being into the background all the time'. [C8]*

Within the *dispossessed activity pattern*, carers perceive that their relative has become dependent for almost all aspects of everyday activities. Carers notice that their relative is increasingly unaware of the severity of their own problems and the impact on their own and their carers' lives. Many carers have taken control of the caring circumstances and made constant complex decision for their relative's everyday routine activities. At this point, many carers still want to keep their relative at home because they view that as one way to maintain the dignity of their relative for as long as possible. The goals of activity engagement focus on promoting moments of happiness, comfort and security. Once carers relinquish their caring role to others (e.g. residential care), they tend to expect others to carry on with these goals for activity engagement. This can be reflected in a quote from Brian (phase two):

*'My wife is in a home because she fell all the way down the stairs - she now needed full-time care...I'm afraid, inevitably, a lot of time, the person just sits unoccupied because there is only a limited number of staff. But I have encouraged the staff to do certain things with her, for example, taking her out for a walk because my wife loves walking... The other thing they do was with some hints from me, I said she likes feeding the birds, and the staff take her out and feed the bird in the morning...I provide bird seed... When I go in, I try and get my wife on a double seat and I put my arm around her and sometimes she*

*will just put her head on my chest and sit perfectly quietly and we are both enjoying it. I think it is important to encourage a calm attitude and to show affection'. [G 1]*

To summarize, the majority of the family carers wanted to look after their relative at home for as long as they could. Against the background of overall cognitive decline of their relative, carers managed a journey of engaging their relative in meaningful activity. By doing so, they promoted the personhood and the continuity of the agency of their relative. This in turn enabled them to make adjustments as they gradually took over the caring responsibility for their relative as a full-time carer. This had an impact on carer's own sense of identity over time. The process of engaging their relative in everyday routines was both a physical and emotional journey for carers.

## **Chapter 10: Discussion**

With government policy and guidelines emphasising supporting those with dementia at home, and family carers are increasingly advised to involve their relative in meaningful occupation (Department of Health 2005b, NICE 2007; Alzheimer's Society 2007). The concepts of activity and participation are considered to be crucial to functioning and health (World Health Organisation 2001; NICE 2008b). The need for occupation is one of the five main foci of person-centred care (along with attachment, identity, comfort and inclusion) if personhood of those with dementia is to be maintained (Kitwood 1997a). Currently, therapists and healthcare workers are expected to follow a range of guiding principles when working with families and other agencies involved with people with dementia. These principles include, for example: person-centred care (DH 2005c; CSIP 2007); non-pharmacological therapy for challenging behaviours (NICE 2007); home-based care (DH 2000c, 2008b), collaborative partnerships among all agencies (DH 1999b; 2005c; 2006b); and empowering carers in their caring role through support; and systematic information (Audit Commission 2004b; CSIP 2007; DH 2008b). At the heart of good practice in dementia care is the promotion of well-being of both individuals with dementia and their carers in the community. Family carers have a vital role to play in supporting those with dementia to maintain their everyday routine activities within the context of person-centred care. However, a key aspect which has been missing from these ideas is the perspective of family members and how they construct the caregiving situation at home. Previous research has given limited attention to carers' perception of the changes in their engagement as the patterns of activities of those with dementia change through the caregiving trajectory. This has implications for the way in which family carers can be supported to carry out a high quality home-based activity programme. The current study aimed to explore carers' decision making related to their engagement with their relative in everyday activities at home. The findings of this research contribute to the discussion on how support can be offered to enhance carers' confidence and ability in promoting the use of meaningful activities. This in turn could benefit the well-being and personhood of both those with dementia and the carers themselves.

This chapter will: i) examine the link between the findings and Kitwood's work on person-centred care and evaluate of the findings to the relevance of his concepts of well-being, agency, psychosocial needs, positive person work, retained abilities and the

enriched environment; ii) evaluate the implications for current policy, in particular the National Dementia Strategy and the Carers' Strategy; iii) discuss the justifications for the language adopted for the Model of Activity Engagement; iv) outline key messages for family carers of people with dementia, those with dementia, Health Care Practitioners and the Alzheimer Society's public awareness campaign; v) assess the quality of the present research and the findings; the implications/potential for future research in the area including the strengths and limitations of the findings will also be discussed.

### **10.1 The link between the findings and Kitwood's work on person-centred care**

In the early part of the 1990 decade Kitwood developed the dialectic model of dementia (Kitwood 1990). This model later became the Enriched Model of Dementia which is based on the idea that a person with dementia is affected by the interaction of the biological, psychological and social environments (Brooker 2007). The Enriched Model of Dementia stressed the need to recognise that human beings exist in relationships, and that those with dementia need an enriched social environment not only to compensate for their impairment, but also to promote opportunities for potential personal growth (Brooker 2007). Kitwood highlighted that despite severe cognitive loss, individuals with dementia can continue to experience a relative state of well-being when a good quality of care is available (Kitwood and Bredin 1992).

#### **10.1.1 Positive Person-work**

Kitwood (1997a) highlighted key mechanisms of support (or positive person-work) which are fundamental to the maintenance of personhood of the person. This approach is characterised by twelve different types of positive interactions, i.e. *recognition*, *negotiation*, *collaboration*, *play*, *timalation*, *celebration*, *relaxation*, *validation*, *holding*, *facilitation*, *creation and giving* (Kitwood 1997a). The findings of this study showed that, throughout the caregiving journey, family carers' day-to-day interactions with their relative often involved elements such as *recognition* – through valuing them as a unique individual with a past; accepting them without any prejudice; *negotiation* – through consulting them about their preferences; *collaboration* – through engaging and supporting joint activities; *validation* – through appreciating and accepting their subjective experience; *facilitation* – through enabling them to do things which they would not be able to do without support; *relaxation* – through enabling them to let go



of tensions and worry; and *holding* – through providing comfort and support if distressed. All highlighted by Kitwood (1997) as being positive interactions. Without any formal training family members carried out these interactions because they intuitively felt the ‘right’ thing to do. It was evident that carers’ daily interactions with their relative were complex and evolving processes, involving the use of a range of skills and knowledge, including communication skills, their understanding of dementia; of goal-setting for meaningful activities at different stages of dementia; and of mobilizing necessary resources. Carers sometimes worked in collaboration with others (e.g. family members, friends and healthcare professionals) so that they enabled others to interact with their relative in a consistent and person-centred manner.

The data provided insights into the complexity of various types of interactions, and how carers continually modified strategies for their everyday interactions with their relative over time. For example, carers, throughout the caregiving journey, continually negotiated boundaries of involvement (open or subtle). They used differing approaches at different stages of a negotiation process depending on the issue (see 9.2). This in turn promoted a sense of agency in their relative as far as was practical. However as their relative experienced progressive memory loss and communication difficulty, the negotiation process became more complex.

The basis of Kitwood’s person-centred approach is that, when positive interactions have been applied consistently, and over a long period, many psychological needs of the person with dementia are met (Kitwood 1997a & c). However, the findings of current study suggested that family carers often felt uncertain of how to behave or respond over a range of everyday situations, and they were unsure whether the approaches they used were appropriate or not. They found it difficult to work out the appropriate types of interactions with their relative at different points of caregiving. The idea of consistency was challenged on two fronts – firstly the situation facing the carers changed a great deal over time (compared to a ward situation), and so a specific approach which was applied consistently was not appropriate. Also, due to the changing nature of the situation the only constant, paradoxically, was change. This highlighted the need for family members to be supported in learning not only how to behave in a consistent manner, but also how to be able to adapt behaviour, possibly

using underlying principles. The strategies adopted by family members in the current research may form a basis for developing such principles.

Another aspect highlighted in this research was that providing mechanisms of support as a family member was very different from doing so for paid carers (the target audience for Kitwood's original mechanisms of support). The findings suggested that, as dementia of their relative progressed, family carers experienced increasing difficulty in adopting certain aspects of the positive person-work approach. This was especially so as they had had no training in dementia care and received limited support from health and social care professionals. In some circumstances, the notion of positive person-work placed a heavy responsibility on family carers and made them feel guilty when they had to relinquish caring responsibilities. For example: *holding* is a type of positive interaction: family carers usually offered their relative comfort warmth and affection. However, if they found their relative, who used to be very affectionate to them, suddenly threatening either verbally or physically carers found it difficult to 'hold' their relative. The data suggested that when carers themselves did not receive support from others in such difficult situations, they felt that they might decide to give up on their caring role. A case in point is that, several carers in group two (phase two) found it extremely difficult to hold a positive attitude when dealing with aggressive behaviour. This became the 'final straw' for them, and to a decision that residential care for their relatives was necessary. This has an implication for providing carers with training on not only in general positive person-work, but also in specific techniques and approaches when more general principles were not working to support them in their caring role.

It was interesting to note that those carers who were caring for a relative with severe loss of cognition and functioning were often able to give accounts of episodes of positive interactions with their relative, for example, dancing and singing with them and validating their behaviours (see 8.3.4.2; 8.3.5.2). These reflected that the use of *validation, giving, celebration, creation and relaxation* were evident in the later phases of caregiving. Often, carers felt that they developed those skills through trial and error methods and did not receive feedback to confirm whether they were using an appropriate approach or not.

### ***10.1.2 Psychosocial needs***

Kitwood (1997a) pointed out that people with dementia are vulnerable due to not only their neurological condition, but also the psychosocial environment. He suggested that positive interactions (positive person-work) would promote a sense of security, self-esteem, value and social being. Those who provide care for such individuals must offer them love, meeting their key psychological needs including comfort, attachment, occupation, identity and inclusion which, in Kitwood's view, represent a need for love, important to all human beings, in particular, because of the vulnerabilities, for those with dementia. These needs are central to Kitwood's vision of how the well-being of those with dementia can be achieved by others who offer them unconditional acceptance; for example, being generous, forgiving and expecting no reward (Kitwood 1997a & c).

Findings of the current study showed that, through engaging their relative in meaningful activities, carers were able to facilitate a sense of identity, security, bonding and attachment in their relative. The psychosocial needs of their relative were considered by family carers as crucial for their relative, and thus were consistent with Kitwood's person-centred approach.

The current study highlighted that the aim of occupation was not just an end product (a need to be achieved), but was also a process which carers used to meet a range of their relative's psychosocial needs at home. The findings showed that activity engagement consumed a great deal of carers' daily life during the caregiving journey. All the carers did not just look after their relative, but they attempted to encourage their relative to take part in everyday activities which had specific meaning to the person, both in their past and present life situation. The activities with which carers were involved were largely related to self care, household management and entertainment. For example, the types of activities which carers talked about ranged from helping with toileting, going out for a walk, watching television together, listening to music, taking a short holiday break, navigating for their relative when driving and persuading their relative to have a regular bath. The list of activities was endless. In order to ensure that each of these activities was meaningful and appropriate to specific needs of the individual, carers made constant decisions concerning setting goals for activities, identifying changes in their relatives' performance of them; developing subsequent adjustments to

accommodate changes in the relative's ability, and negotiating with their relative. In order to do so, the nature of this decision-making was complex and constantly evolved during the course of caregiving. This was especially so when the family carers felt increasing difficulty in communicating with their relative concerning the latter's wishes and preferences.

The current findings provided an insight into the understanding of how family carers used everyday occupation to promote the psychosocial needs of their relative, highlighting the complexity and evolving nature of decision-making for activity engagement and other psychosocial needs. The findings showed that activity engagement is all pervasive in the lives of carers. Also that it should not be viewed as just doing a variety of tasks per se, and is part of a complex daily decision-making task for carers. This shows the need for supporting carers in making such decisions and providing daily activities for those with dementia.

The findings also showed that trying to meet the continuing activity needs of a relative with dementia on a daily basis can be a demanding task, and carers often did not feel that they had the necessary skills and confidence. Many carers expressed concern that they felt uncertain over a whole range of different everyday activities, and not sure whether the strategies they used were appropriate or not. They found it difficult to work out the right level of challenge for their relative when adjusting an activity to match the changing ability and preferences. This finding was consistent with the studies of Vikstrom et al (2005) and Keller et al (2007). Many carers lost confidence in their ability to conduct constant negotiations, and make subsequent adjustments in order to meet the changing needs of their relative. Moreover, during the process of activity engagement, carers were frequently confronted with a dilemma when they noted signs of frustration, hesitation and insecurity shown by their relative during a task performance. They were uncertain whether they should react to those signs by offering assistance, or ignore them. They were anxious that a wrong decision might hurt their relative's self-esteem. This sometime led to use of inappropriate support for their relative's performance. This finding was consistent with the study of Lewis et al (2000) which highlighted that spousal carers frequently worried about misjudging their elderly relatives' ability and making decisions that unwittingly deprived them of their dignity.

This also applied to the daughters, partner and younger carers who cared for a parent and younger spouses in the current study.

This highlighted that if person-centre care in dementia care is to be adopted fully in a home setting, it is crucial to support family carers in meeting the continuing psychosocial needs of those with dementia. There is a need for practitioners to support carers in choosing from a range of strategies which carers had initiated, and so lead to successful intervention. It is also important to help carers recognise those strategies which might lead to failure or frustration. If support for carers is not provided, it may be possible that carers eventually ignore needs of those with dementia, because they themselves do not have the confidence and skills to do so. This in turn may lead to incidents of ignoring, disempowerment, objectification, banishment and invalidation, or Malignant Social Psychology as described by Kitwood (1990, 1993). Moreover, the personhood of both those with dementia and their carers would be adversely affected.

According to Kitwood's person-centred care approach, care staff are encouraged to show unconditional acceptance; for example, being generous, forgiving and expecting no reward (Kitwood 1997c). In contrast, the current study of carers in the home environment highlighted a key difference: although family carers, in the main, offered unconditional acceptance to a great degree – they found it very hard to behave in this way for 24 hours a day, and seven days a week. Rewards may be gained through the caring itself, but it may also be important to consider other ways of allowing family carers to experience rewards, and meet some of their own personal needs – if not the personhood of the carer could be greatly affected, limiting the support which can be given.

### ***10.1.3 Well-being***

The findings of the current study showed that maintaining well-being of their relative was a key concern for family carers, and were consistent with Kitwood's concept of well-being. There were numerous examples where family carers, through engaging their relative in meaningful daily activity, provided their relative with opportunities to express his/her desire, to initiate social contact, to maintain self-respect and to experience moments of pleasure.

Kitwood identified wellbeing through systematic behavioural observation (Dementia Care Mapping) developed mainly from findings in formal care settings. Hence, some of the indicators (see below) seem to be more applicable for use in an institutional setting rather than a home setting, for example, *acceptance of other dementia sufferers*. The concepts have been criticised as being under-developed and overlooking the views of others (Adams and Gardiner 2005; Dewing 2008). Kitwood's intention was to use the well-being indicators as a mechanism to enable care staff to appreciate what the well-being or capability of a person (as a human being) would look like, and so facilitate care staff to develop their skills for positive person-work.

In order to assess the effectiveness of interactions, Kitwood (1993) developed an assessment to describe relative well-being and ill-being (Dementia Care Mapping). The twelve well-being behavioural indicators give some insight into the nature of wellbeing as described by Kitwood (Kitwood and Bredin 1992, Kitwood 1993). These concepts are used to contrast with signs of ill-being (for example, agitation, apathy, anxiety, withdrawn, unresponsiveness and uncommunicative behaviours) which are often thought to be caused by neurological impairment (Kitwood and Bredin 1992). The findings of the current study showed that family carers, through engaging their relative in meaningful activities, offered opportunities for their relative to show their abilities in: *expressing assertion of desire* – through making choice about what activities they would like to pursue; *experiencing and expressing a range of emotions* – through expressing a sense of satisfaction and happiness; *initiating social contact* – through meeting up with friends and family at home or in a pub; *displaying affection and warmth* – through showing their concern for their family when they felt unwell; *demonstrating sensitivity to others' feelings* – through sharing activities together; *showing self-respect* – through helping their relative to maintain his/her appearance; *using humour* – through showing their usual sense of humour; *demonstrating creativity and self-expression* – through dancing and singing with their relative; *displaying evidence of pleasure* – through showing signs of happiness when engaging enjoyable activities; *showing helpfulness* – through offering help with hoovering and washing up, and *experiencing relaxation* – through enjoying a television programme with their carer.

The findings of the current study showed that when family members were asked to talk about their experiences, both positive and negative, they tended to focus on signs of ill-

being (e.g. apathy, low mood, unresponsive and anger). Almost all carers were more ready to offer examples of negative signs. This may reflect a possibility that carers considered the episodes of well-being of people with dementia to be short lived and fleeting. This may have been partly due to the fact that many carers had been told by the doctors that dementia was an ‘incurable disease’ and that there was ‘not a lot that could be done’ by medical professionals or health and social services staff. Kitwood described the tendency of those with dementia to move from one state of well-being or ill-being to another rather quickly because they are less able to ‘buffer’ themselves against external events (Baldwin and Capstick 2007). Carers may have found this switch from wellbeing to ill-being difficult to manage on a daily basis, leading to more negative overall evaluations. A key aspect is also that carers were not supported or told that it was possible to maintain wellbeing and also supported in learning how to achieve this with their own relative.

Despite the fact that carers did not have any support they enjoyed giving examples of successful interventions. Carers were often highly resilient and resourceful (as found by Murray et al 1999; Searson et al 2008). This suggests that providing carers with information about the nature of dementia, and how psychosocial factors influence the subjective experiences and wellbeing of their relative, could help them in their role. It also highlights how family carers could be an invaluable resource for other family carers in this regard.

#### ***10.1.4 Agency***

Most importantly, Kitwood (1993) stressed that a state of well-being of those with dementia is closely related to the maintenance of agency. He described a person with dementia as an agent, like all of us, as capable of taking control his or her personal life in a meaningful way (Kitwood and Bredin 1992). The person ‘can make things happen in the world, a sentient, relational and historical being’ (Kitwood 1993, p583). Kitwood (1997a) pointed out that nurturing and supporting the retained abilities of these individuals is a moral duty of the others. He was concerned that, in the western culture, when a person is diagnosed with dementia, he/she is often considered to be of lesser value resulting from reduced cognition and functional ability. It seems that Kitwood used well-being indicators to promote care staff understanding of how, despite cognitive

decline, various retained abilities (emotional, social and unique personal being) of the person can be nurtured if care staff recognise them as fellow human beings.

The family carers in the current study provided empirical evidence of this process; through engaging their relative in meaningful everyday activities, they recognised the nature of their relative's past self, history, values, desires, and current ability; and they took actions to develop correspondent strategies which reaffirmed their relative's agency and personhood. They continually set goals to enable their relative to maintain their remaining abilities as far as possible, at different phases of dementia. A difference which was highlighted in this study was that as family carers experienced increasing difficulty in communicating verbally with their relative, they attended more to the bodily source of agency of their relative as a means to help them understand the wishes and preferences of their relative. This has been referred to as 'embodied being' by Kontos (2004 a & b) who built on Kitwood's concept of a person as an agent and developed further the notion that the self in dementia is embodied. Kontos (2005) also suggested that the body was situated in and influenced by a specific social and cultural world, and was engaged in daily habits and usual routines of everyday life. Such a notion challenges Kitwood's theory of agency as overlooking the importance of those bodily sources of agency, which are based on the pre-reflective level of experience. This suggested that, even in the absence of cognitive impairment, the pre-reflective body would still continue to play a significant role in the whole of selfhood (Kontos 2005). Dewing (2008) also agreed that one limitation of Kitwood's theory was the fact that he did not sufficiently develop the concept of embodied self. Nevertheless, it was argued that the notion of an embodied person was a theoretical concept which requires further empirical evidence for development in care practice (Baldwin and Capstick 2007).

Kitwood's dialectic theory of dementia has increasingly been criticised for failing to fully develop his theory to embrace the notion that the person is an embodied being. Despite the ongoing debate on gaps in Kitwood's view of agency, Kitwood's followers support Kitwood's view that the key task in dementia care has always been to maintain the personhood of those with dementia and treat each individual as a whole human being.



The findings of the current study supported Kitwood's view of person-centred care for persons with dementia that care practice takes place in the context of relationships (Kitwood and Bredin 1992). Kitwood (1995) pointed out that central to maintaining a positive relationship with those with dementia is the need that carers develop skills which help them relate positively to others. The starting point is to accept that the interaction with persons with dementia is not between one group 'them', which is damaged, and another 'us' which is whole and perfect. Kitwood suggested that the person with dementia may be more vulnerable in some ways, but the carer is also damaged in at least some areas of capabilities, in particular on an interpersonal level due to their specific fears and uncertainties regarding a progressive illness. Hence, a carer needs support as well as training in order to recognise their own vulnerabilities and to be able to identify the effect on relationships with those with dementia (Kitwood and Bredin 1992; Kitwood 1993). Hence, an enabling care environment would promote a sense of agency, social confidence and hope in those with dementia (Kitwood and Bredin 1992), and thus slow down the rate of neuropathological decline in dementia (Kitwood 1997a).

The current study provided further insight and rich data in the form of the activity engagement model (see 10.3) to support the centrality of the carer-relative relationship in dementia care within the context of family care.

#### ***10.1.5 Enriched Environment***

Kitwood (1997a) pointed out that the personhood of people with dementia would benefit from a positive psychosocial environment. The concept of an enriched environment has also been highlighted in the occupational therapy literature, suggesting that it is crucial to create such an environment in order to enable those with dementia to continue engaging in activities of the right challenge, and so maximise their functional abilities and related skills (Baum 1995; Baum et al 2009). Data from the current study provided deep insight into how family carers, throughout the course of their caregiving journey, offered their relative an enriched environment through engaging their relative in meaningful everyday routine activities. This was evident in numerous examples which demonstrated how carers attempted to meet the need of their relative in respect of special individual needs and perspectives. The findings of this study showed that carers facilitated an enabling environment as far as possible by several means: i) using their

own personal relationships with their relative to continually facilitate and sustain a day-to-day positive interaction; ii) using their own knowledge and skills to continually enable their relative to engage in daily occupations which are meaningful to them and, sometimes, also themselves; and iii) adapting the immediate environment to meet the changing needs of their relative, as dementia progressed. This was achieved through adapting each activity to match the remaining ability of their relative, and initiating external assistance to meet their relative's everyday activities; installing equipment to modify the home environment. This ultimately facilitated a sense of agency, confidence and stability in their relative, and so enhanced the personhood of the person with dementia.

In summary, the findings contribute to the current debate on the possibilities to extend Kitwood's theory to embrace not only the viewpoint of the person, but also their family carers, in particular because family carers play an important role in promoting the well-being of those with dementia at home.

Kitwood's work on person-centred care has been criticised for lacking sufficient evidence, and as based largely on experience from institutional care (see 2.4.4). In comparison, the data of the current study are drawn from family carers' accounts of their experiences of engaging a relative with dementia in daily activities at home, during the course of caregiving. The findings support many of Kitwood's ideas and have provided empirical evidence and illuminated how the personhood of those with dementia could be maintained by family carers within the context of Kitwood's person-centred approach. However this research builds on this work by focusing on a non-institutional setting and so broadens our understanding of the processes involved in personhood in that it is crucial to understand the personhood and self identity of family members who take up a caring role.

The current study showed family carers play an important role in sustaining the agency of their relative through engaging them in daily activities. However, they often experienced a range of psycho-social stresses including loss of sense of self, challenges, failure and criticism. Many felt that they were invisible and were not valued by the society, and hence felt unsupported in their caregiving role. Such negative feelings, coupled with physical demands of their role, may cause carers to become

more vulnerable and less able, from time to time, to maintain positive interactions with their relative with dementia and so engage in Malignant Social Psychology (Kitwood 1990). The findings of this study provided further insight into how this process may occur in a home setting and how carers could be supported to adopt a positive person-work approach through the course of caregiving. This highlighted an urgent need to provide family carers with psychosocial support and on-going training; this would enable them to develop skills and knowledge in managing complex situations at the various stages of the caregiving journey. This suggests carers need support in providing a positive care environment for those with dementia.

## **10.2 Policy implications**

This section will critically evaluate the findings of the present study in relation to current policies, in particularly the National Dementia Strategy (DH 2009) and the Carers' Strategy: Carers at the heart of 21<sup>st</sup> century families and communities (DH 2008b).

### ***10.2.1 National Dementia Strategy***

In 2009, the UK government published the first National Dementia Strategy which set out a vision to transform dementia care services through making significant improvement in three key areas: improved awareness; early diagnosis and intervention; and high quality of care. The present research has confirmed the needs that were raised in the Strategy and highlighted that these were not being met in the participant group. Details of some areas which are relevant to the findings of the current study will be discussed below:

i) The Strategy highlights that the problem of under-diagnosis in dementia is widespread (DH, 2009); this was found in the current study. Carers in the current study often picked up the signs of change in their relative's engagement with everyday activities, but they did not get the early support they needed and acted as best they could, as has been reported by previous researchers. Some carers compensated for their relative's loss of function until it impacted significantly on household operation (as found by Iliffe et al 2002); many raised their concerns with their GP but were dismissed by them (as previously reported by Milne and Wilkinson 2002; Downs et al 2006a). In the current study, many carers acknowledged that they themselves tended to gloss over such

changes, without realising that some of these signs could be the manifestation of dementia. Also, many carers believed that their relative's problems were only part of co-existing illnesses or being old and, although some carers raised a suspicion about their relative's changing behavior, they had difficulty in persuading their relative to seek medical help.

Thus, the findings reinforced the need to raise general awareness of dementia so that timely support for both people with dementia and their carers could be possible. This would facilitate family carers to support their relative in making adjustments during the diagnostic and monitoring processes. These findings were consistent with previous studies (for example, Gitlin et al 2005; Vernooij-Dassen et al 2005; Vernooij-Dassen 2006; Moniz-Cook et al 2006; Cantley and Smith 2007; and Fortinsky 2008).

ii) A key aspect of the National Dementia Strategy is to tackle the existing stigma and misunderstandings associated with dementia (for example, attributing the symptoms to old age) because these problems lead to an environment where both the public and professional groups find it difficult to talk about the positive aspects of dementia, which ultimately creates a barrier to prevent those with dementia and their carers from seeking early diagnosis and accessing appropriate information and treatment (DH 2009). The findings of the current study have highlighted how family carers can maintain many positive aspects of the caring experience. These insights are, however, known and understood mainly by the carers themselves. Carers reported that wider family members and friends were often deterred from visiting by the unusual behaviour and ways of communication of their relatives. It may be that something based on the model of activity engagement could be discussed with other family members, and so help them to understand the meaning of unfamiliar behaviour and as a result still see their relative as the same person they once were.

iii) Another key aspect of the National Dementia Strategy (DH 2009) which links closely to the current research is the recommendation for the need for early good quality diagnosis as a means to promote the access to integrated services. Such a need had already been highlighted in the Standard Seven of the National Service Framework for Older People (DH 2001). The Strategy proposes that a core set of assessment tools should be in place to address 'cognition, behaviour, activity limitation and quality of life in dementia' (DH 2009, p.38). This ultimately would facilitate those with dementia

being cared for in their own home, and would delay admission to residential care. This recommendation is supported by the findings of the current study. This study showed that, if early diagnosis is to benefit those with dementia and their carers, the diagnostic process should include a comprehensive assessment, containing not only the medical diagnosis, but also assessment of functional abilities especially the strengths of individuals, and their psychosocial needs. The present study showed that the actual confirmation of the dementia, and its progressive nature, offered carers and their relative only an initial sense of relief. The majority of the carers commented that the knowledge of diagnosis did not really help them to explain the changes in behaviour and everyday functioning of their relative. This adversely affected carers' ability to support their relative in maintaining their daily functioning and independence. Carers in this study reported that the assessment of such activities was not part of the normal procedure for diagnosis. Although some carers were given the score of a cognitive assessment (i.e. the Mini-Mental State Examination), many were frustrated that they could not use the given score to help them understand the changes in the everyday functioning of their relative. This hindered development of appropriate strategies to promote a positive attitude towards dementia and of therapeutic value of activities, and so the promotion of the notion that there are a lot that people with dementia can still take part in, as indicated by the Strategy (DH 2009). The findings of this study echoed those of a study (Gilliard et al 2005) which stated that 'professional views of the needs of people with dementia demonstrate little about meaningful activities' (p.577). Also, the study reflected the view that the value of everyday activity has been undervalued because of its everyday nature (Wilcock 2003).

The current study supported the recommendation of the Strategy that it is crucial to provide people with dementia effective intervention in the early stage of dementia so that people can benefit more from positive intervention (DH 2009). Hence, carers should be given support and advice to engage their relative in activities in the early stage. This is especially so as research into the needs of people with mild to moderate dementia has stated that those in an early stage tended to emphasize the importance of particular daily activities that were previously taken-for-granted (Menne 2002; Gillard et al 2005). These individuals often experienced difficulty in coping with daily living activities (Farlow and Evans 1998; Gillard et al 2005; Nygard and Starkhammar 2007; Phinney 2008). Nevertheless, many wanted to maintain the continuity of routine

activities (Menne 2002; Nygard 2008), and to make a contribution and feel being useful (Clare et al 2005). Moreover, many actively worked on strategies that enabled them to maintain their self-esteem (Clare 2002) and to preserve their sense of self (Pearce et al 2002; Clare 2003; Clare et al 2005; O'Connor et al 2007). Nevertheless, some individuals acknowledged that their memory difficulty made it hard for them to judge what might be changing in them at times. They were aware that there might be changes which were perceived by others (e.g. their carers), but were not aware by themselves (Phinney 2002; Clare et al 2005). It is crucial that, when working with those with dementia, practitioners understand the perspectives from not only these individuals, but also that of their carers in the caregiving dyad. The findings of the current study offered insight into factors which influenced the decision-making of carers within a dyad. Findings also highlighted areas of diagnostic assessment which should include everyday occupations (e.g. self-management, household-management, recreation and vocation), and necessary support for the promotion of activity immediately after diagnosis, not just when major practical problems arose.

iv) The National Dementia Strategy (DH 2009) recommends that, in order to ensure that a high quality of care will be available, it is crucial that a system be in place to facilitate easy access, for those diagnosed with dementia and their carers, to appropriate care, support and advice. Also, health and social care staff involved should have the knowledge and skills necessary in the roles and settings where they work (DH 2009). The findings of the current study supported such recommendations. Most of the carers in this study were frustrated by the fact that they and their relative did not have access to appropriate care. Moreover, the current study showed that family carers needed accessible, ongoing support, throughout the course of dementia, to develop the skills and knowledge required to engage their relative in meaningful, everyday activities. . Carers felt that it was often taken for granted that carers had already such skills and knowledge, and so no additional help or support was offered unless their circumstances were considered as at risk. It is crucial to support carers before crises occur (Daker-White et al 2002; Audit Commission 2004a).

The current study also showed that it was important that carers had the skills and knowledge needed to enable their relative to maximise their level of functioning and to encourage interdependence in everyday activities within a domestic setting. This is essential if the Strategy is to enable people to 'live well with dementia' in their own

home. Likewise, the current study supported those of a study by Keller et al (2007), which advocated a need to assist carers to develop the best way to adapt a daily activity. Such support should include elements such as how to adapt an activity; modify the environment to accommodate the change; deal with potential crises resulting from behavioural difficulty; and finally, prepare carers to adjust their expectations of the relative's performance. Moreover, the current study suggested that carers often dealt with behavioural problems without support. These episodes sometimes triggered a crisis point at which carers had decided to relinquish their caring role. Carers should have access to carer training which focuses on supporting them to understand the nature of specific behavioural changes in their own relative's circumstances. Carers may be trained to make use of the available behavioural management techniques and assistive technology. Assistive technology, for example detectors of fire, gas and falls, have the potential to support carers to enable their relative to reduce the occurrence of risky activities (Astell 2006). Furthermore, it is crucial to provide carers with ongoing interventions for their own well-being, especially if depression resulting from their relative's behavioural difficulties is to be effectively addressed (Martin-Cook et al 2003).

v) The National Dementia Strategy (DH 2009) points out that current home care practices are problematic for those with dementia and their carers because services are task-oriented. Staff often do not have time to develop relationships with those with dementia and their carers. Hence, the Strategy recommends a need to provide a comprehensive community personal home care support service which is underpinned by a person-centred approach for both people with dementia and their carers. Such a service would include, for example, offering a flexible response to changing needs by trained staff; working alongside those with dementia rather than doing things for them; and supporting access to personalised services (e.g. social activity, short breaks, day services and expert patient and carer programmes).

The findings of the present study reinforced the fact that, currently, there is a tendency for services to 'take over' carers' roles at crisis points, rather than providing individual carers with advice and skills to promote the independence of their relative. In the current study, many carers expressed a concern that home care services tended to focus on doing a task for the person rather than enabling the person to maximise their optimal

functioning, or enabling the family carer to encourage their relative in meaningful activities. Carers felt that such services undermined their relative's strengths and therefore diminished their dignity, especially in the early phase of dementia. Also, such services took away an opportunity for carers to fulfil their duty to their relative through doing something with them. As a result, the acceptance of such outside services could lead to carers' feeling guilt, resentment or embarrassment. For example, some carers felt resentment if their relative with dementia seemed to present themselves in a much better way to strangers when they came to their home. Consequently, carers felt that they were not needed any more. The implementation of personalised care services for those with dementia needs to ensure that both those with dementia and their carers are provided with adequate information and training to understand how the personalised care system could work for them. It is also important to enable family carers to develop strategies to support their relative in making decisions concerning the arrangement of a personalised care package. Moreover, it is crucial that health and social care practitioners, before offering a package of care, identify carers' existing strategies for supporting their relative with everyday activities. This would help to improve the quality of lives of both people with dementia and their carers, and in turn promote carers' positive experience in their caring role.

It was perhaps not surprising that some carers regarded a decision to accept outside support as a failure in their role as a carer and so began to lose confidence in their ability to provide care for their relative. Many carers in this study would like to have learnt related skills so that they could work together with their relative. The implication for health care professionals is to ensure their services are offered in ways that are sensitive to carers' feelings. They must recognise a carer's decision-making journey, and offer support which enables carers to develop a positive relationship with their relative. This will then encourage carers to work collaboratively with them, based on person-centred care approach.

vi) One of the objectives of the National Dementia Strategy (DH 2009) states that family carers are the most important resource available for those with dementia, and advocates the need to ensure that the provisions of the Carers' Strategy (DH 2008b) should be made available to carers of people with dementia. The findings of the current study support this recommendation. Moreover, they have highlighted that, when working with those with dementia, it is crucial that practitioners understand the



perspectives of not only people with dementia but also their carers. This finding was consistent with the study of Braun et al (2009). The current study showed that the support for both people with dementia and their carers should be on-going and provided in people's own home. This is especially the case if the National Dementia Strategy is to improve the quality of life of both people with dementia and their carers. The findings of the current study offered insight into factors which influenced how carers negotiated with their relative in daily decision-making within a dyad.

From the findings of this study, it can be seen that it is the relationship between carer and relative which should be the focus for intervention. This supports the work on relationship-centred care suggested by many researchers (Forbat 2003; Nolan 2002; Keady and Nolan 2003; Adams and Gardiner 2005; Hellstrom et al 2005). It is interesting to note that the Strategy focuses mainly on the person with dementia, rather than on both the person with dementia and their carers at home. The current findings would suggest that this would limit the sort of interventions which are considered. The findings of the present study highlighted the fact that it is crucial that healthcare practitioners recognise the views of both the people with dementia and their carers are equally significant. The consequence of this is that, if the views of carers are not clearly understood and appreciated by the professionals involved, then the relationships between the healthcare practitioners, the people with dementia and their carers may be jeopardized. This in turn would reduce the effectiveness of any interventions for people with dementia in caregiving dyads.

The role of family carers is crucial to the successful implementation of the National Dementia Strategy. It recognises that family carers are the most important resources available for those with dementia, and advocates that implementation should go hand in hand with that of the Carers' Strategy, as stated in objective seven (DH 2009). The next section will discuss the relevance of the findings of the current study to the Carers' Strategy.

### ***10.2.2 Carers' Strategy:***

As discussed earlier, one objective of the National Dementia Strategy advocates that the implementation of it should go hand in hand with that of the Carers' Strategy (DH 2009). The Carers' Strategy (DH 2008b) set out a vision, that by 2018, carers would be respected as an expert care partner who has access to the integrated and personalised

services they need to support them in their caring role. It is envisaged that support will be in place for carers to enable their relative to be ‘a full and equal citizen’ (p.7). This recognises the long-term commitment of family carers in their role. The recommendations which are relevant to the findings will be discussed below:

i) From the current study it is pleasing to see a commitment to recognise the crucial role of carers and to enable them maintain a balance between caring responsibilities and a life outside such a role. This study confirmed the long-term nature of caregiving in dementia care, showing that family carers wished to care for their relative at home, so maintaining their dignity.

ii) A key aspect of the Carers Strategy (DH 2008b) recommends that support will be tailored to meet each individual’s preferences and wants through a personalisation agenda as described in the Putting People First (DH 2007). One component of the personalisation agenda states that those who use social care may choose to have a personal budget to purchase or influence the provision of services to meet their own needs and those of the carer. Hence, the service users (including people with dementia) can be supported to use the budget to support their carers through buying services which carers find it difficult to manage. Such services are expected to empower the users to exercise choice and make decisions for themselves (DH 2008b). A good aspect of the new support system is that it would potentially provide carers with support, care and help with day-to-day tasks, in a more coordinated and flexible manner. Carers, in the current study, felt that the present health and social services systems were often fragmented, did not offer them day-to-day support, leading to the negative feelings about their role.

Another component of the personalisation agenda is to ensure that carers are provided with easily accessible information which is tailored to their needs. It is interesting to note that carers, in the current study, often received neither assessment of their own needs, nor personalised support. In fact, many stated that they were often being ignored within the system of care services. It seemed that the majority of the carers were unaware of their right to request an assessment of their own needs and the opportunity to arrange a personalised care package for their relative. At the time of data collection for the study, when the Carers’ Strategy had not yet been implemented, many carers and

their relative would have welcomed the introduction of the personalisation agenda. This is because many carers, in this study, were disappointed that the existing home-based care services often did not support them to do things together with their relative, for example, facilitating carers to do an activity together with their relative at home, attending a centre, taking holiday together with specialised support. This was especially the case in the early phase of dementia. These aspects need to be considered when implementing the strategy.

A limitation of the Carers Strategy appears to be that it says very little about how, throughout the course of dementia, people with dementia can be supported to make constant decisions to maximise their assessed 'personal budget' to meet the constant changes of their own needs and that of their carers. As can be seen from the current study constant decision making appears to be a key aspect of living with dementia. The findings of the current study highlighted that carers needed support for constant changes and also challenges to sense of self. From the current study, the findings concluded that it was not only deterioration per se, but the need for constant changes in strategy and challenges to the carers' sense of self, that could contribute to a negative experience, creating a sense of isolation. The model of activity engagement can be used by practitioners to frame discussions with carers which help them to develop their skills in decision making and negotiation, and to address their own psychosocial needs.

iii) Carers' Strategy (DH 2008b) advocates a need to recognise the crucial role of carers and to enable them to maintain a balance of caring responsibilities and a life outside such a role. It states that by 2018, the government should create a system for carers which provide them with support, care and help in day-to-day tasks, sustaining existing employment, and access to education and leisure opportunities. The findings of the current study supported the need for a new support system which meet the complex and continuous needs of carers in various areas, throughout the caregiving journey. Many carers in this study were involved in other activities apart from caring for their relative. This included paid employment, volunteering, looking after grandchildren and pursuing leisure hobbies. These activities were felt to be very important by the participants. In the current study, as the dementia progressed carers spent more time focusing on developing strategies relating to the needs of their relative, rather than to their own needs. Many carers often expressed a feeling of guilt for doing things they perceived as

focused mainly on their own needs. They felt that their own sense of self was diminished, which in turn had an effect on the support they could offer their relative. This balance needs to be redressed. The model of activity engagement could be used to explain to the carers the processes they are going through and emphasise the importance of promoting their own activities and mental health, as advocated by the NICE-SCIE Clinical Guideline 42 (National Institute for Health and Clinical Excellence 2007).

iv) The Carers Strategy recommends that carers need to be treated with dignity and supported to maintain their mental well-being (DH 2008b). This is confirmed by the findings of the current study which showed that an important element which underpinned the mental well-being of carers was their perception of a sense of self and confidence derived from maintaining the agency and personhood of their relative. This perception also influences carers' sense of satisfaction in their caring role. The current study found that another source of carer satisfaction could be drawn from their ability to engage their relative in a range of appropriate daily activities, and from the extent to which their relative and others appreciated their effort, as also found by Lundh and Nolan (2003). Such satisfaction included pleasure when observing relative's enjoyment of some activities, and evident feelings of being wanted and needed, or of even helping others in some way. The carer then felt appreciated by the relative and more confident of own ability. The findings of the current study have highlighted that carers' ability to sustain the continuity of their relative was often related to the maintenance of their own personhood and sense of self. It is therefore crucial to support the psycho-social needs of both the carers and their relative.

v) The Carers strategy (DH 2008b) advocates a need to increase the recognition for what carers do for their relative. The current study suggested that such recognition can be enhanced in two ways:

a) Recognition and appreciation of the process carers are going through, and how difficult it is; a non-judgmental and understanding professional approach is essential so as to avoid adding additional challenges to carers' sense of self. It is crucial that carers receive such non-judgmental support especially when they engage in a process of exploring strategies for engaging their relative in everyday routines.

b) Recognition and appreciation that carers have experience and expertise regarding what strategies will work with their relative: this could provide carers with a source of satisfaction which might balance some of the negative consequences of the caring experience. It is crucial to recognise that the carer is a central part of the situation, that is, it is how the carer and relative work together that is important, and hence, carers' own wishes and needs should be taken into account, so that they feel listened to and respected.

In short, the findings of the present study support some key objectives of both the National Dementia Strategy and Carers' Strategy. The findings of the current study in the form of the model of activity engagement could be used to promote a deep understanding, from the carers' viewpoint, of the activity needs of those with dementia. This will then facilitate partnership working and a person-centred care approach to meet the needs of people with dementia. The next section will discuss the development of the model of activity engagement with the focus on the use of language for the various terms within the model.

### **10.3 The language adopted for the Model of Activity Engagement**

Language as a social practice not only describes the world – it creates it (Berger and Luckmann, 1966) – and so the use of language is very important when creating new theoretical models. As Charmaz (2006) noted, in qualitative research, language plays an important part in how researchers code the data and what data they record. Charmaz (2006) stated that 'no researcher is neutral because language confers form and meaning on observed realities...specific use of language reflects views and values, p.46'. Strauss and Corbin (1998) also pointed out that researchers use conceptual names for coding, depending on the focus of their study, their training, and interpretations. They need to ensure that the use of a conceptual name 'should be suggested by the context in which an event is located by "context"...or situation in which the event is embedded' (Strauss and Corbin 1998, p106). The context I explored in this study was the situation in which family carers made activity-related decisions, at different points of their caregiving journey. Thus, the justification for the terms used within the model was related to such a context. Further details will be discussed below.

As an occupational therapist, I am interested in the relationships between meaningful everyday occupations and the well-being of individuals. Occupational therapists have an important function as providers of activity programmes (College of Occupational Therapists/COT, 2007a). They believe that engagement in meaningful activities provides an individual with the following psychosocial needs: a sense of capacity to fulfil one's basic needs (Sifton 2000; Wilcock 2003; Duncan 2006); a structure to achieve meaningful life goals (Blesedell et al 2003); an opportunity to gain pleasurable experiences (Csikszentmihalyi 1993); and a sense of satisfaction and control to pursue one's own values as defined by one's roles and relationships within the socio-cultural context (Duncan 2006). Most important, through participation in activity, an individual can express who he or she is and maintain a sense of agency through choosing the occupation for themselves (Christiansen and Townsend 2004). This contributes to the development of an individual's identity (Christiansen 2004, Hasselkus 2002). Thus the term *activity engagement* adopted for the model, developed in the current study, reflected my professional interest in the use of meaningful activities as a means to promote the personhood of both people with dementia and their carers. These principles of occupational therapy practice are in line with the person-centred care approach, advocated by Kitwood (1990), and current UK government policy.

The language adopted for the successive activity patterns (within the model of activity engagement) reflected the contexts in which co-resident carers made decisions about their engagement in the everyday routine activities of their relative throughout the caregiving journey. As discussed previously (see 9.3.1), the term *activity pattern* aimed to capture the characteristics of family carers' thoughts, behaviour, feelings and emotions when they made activity-related decisions for their relative. In this sense, each pattern can be viewed as a system of thoughts, behaviour and feelings/emotions. A key aspect of the use of terminology is that the name of each pattern reflects the nature of the relationship/interaction/engagement with their relative as perceived by the family carer, it does not relate to how they view the person and personhood of the person with dementia. This is a very important distinction. The terms used were all understood and recognised by the carers who, as has been highlighted, were focused on maintaining the personhood of their family member. On reflection I now feel that this is an aspect which has to be reinforced with readers new to the model to ensure that they do not misunderstand, and assume that the terms relate to the relative with dementia

themselves – as this could severely challenge the family members’ sense of personhood.

The term ‘*usual*’ can be seen as non-contentious in describing the usual activity pattern in which family carers recognised the self of their relative in terms of the life-long habits, daily routine activities, and the usual responsibilities which reflected his or her values, belief and identity.

The term *recognisable* described the activity pattern where carers began to notice that aspects of their relative’s behaviour changed occasionally, but that overall the usual patterns were recognisable and people could apply some logic to their situation to understand what was happening and relate effectively with their relative.

The term *illogical* described the activity pattern where carers were aware that their relative’s behaviour was not only unusual for them but also that they could not use the usual logical discourse shared between the couple, to relate effectively with them. The term ‘*illogical*’ does not mean that carers regard their relative as a non person or a lesser person, far from it. The term *illogical* indicated the fact that carers were facing situations which to them appeared to be illogical. It is in this situation that carers were dismayed that they could no longer rely on their own logical reasoning to understand what experience their relative was going through. This threatened carers’ own sense of self and confidence in their usual shared history.

The term *irresponsible* described the activity pattern wherein carers were aware that their relative could carry out activities perceived to be dangerous or harmful to the relative or others; or that their relatives relied on them to make decisions about their usual activities because of their deterioration in cognitive ability. The term highlighted that they could not use the usual assumption within activity engagement that their relative would take responsibility for aspects of that engagement. Carers then maintained their relatives’ personhood through working intuitively to develop strategies which would help them to maintain their relative’s potential skills, and prevent them from losing their abilities by lack of use.

The term *dispossessed* described the activity pattern wherein carers felt that they had ‘lost contact with’ or were dispossessed of their relative. They tried to maintain the personhood of their relative by continuing to find strategies to meet the activity needs of their relative and to provide some sort of stability and continuity in the relationship. However, in this research, carers did not always know how to support their relative in this phase and they themselves felt ‘lost’. In an ideal world, family carers would be given additional support to help them maintain meaningful links and activities with their relative and this phase would not exist – however at present, for these carers, it does. On reflection it would be important to highlight that this model represents the views of carers in their current situation and that this does not have to be an inevitable phase in caring for a person with dementia at home.

The key aspect to reiterate is that the terms used refer to the person’s activity behaviour and ‘rules of engagement’ as perceived by carers NOT to the person with dementia as perceived by carers.

Thus the model of activity engagement provided insight into the understanding of the personhood of family carers as a key aspect for person-centred care in dementia care, which has been highlighted by Kitwood (1995). The use of the various terms such as, illogical, irresponsible and dispossessed within the model of activity engagement may carry some negative connotations. However, the intention of using those terms is to recognise: a) the difficult situations in which family carers had to make activity decision-making for their relative; and b) the potential challenges (e.g. fears, insecurity, anxiety and uncertainty) which confronted family carers at different points of the caregiving journey – which may lead to carers’ negative feelings about their caring role. If their feelings and emotions are appropriately addressed by supportive services, it would have a positive impact on their ability to continue, within the home, to provide a positive psycho-social environment for their relative.

Moreover, the model may complement the commonly used medical disease model (i.e. mild, moderate and severe stage) as a guide for everyday activity-based intervention. This is because the family carers, in the present study, found that the commonly used three-stage model did not provide appropriate practical help for them in understanding the nature of dementia and its consequences on their everyday management. It is



interesting to note that, in the present study, when the carers were asked how they classified the level of severity of their relative's dementia, many reported that they were unsure of the classification. Many made a guess of the stage of their relative's dementia (in terms of early, middle and late) only following a comparison of the level of functioning of their own relative with that of other carers. This highlighted the fact that, for family carers, the first and foremost of their task is to find out how their relative and themselves would be able to carry on with their everyday life, despite cognitive decline. The focus is on relationship /engagement rather than labelling the individual support. Kitwood (1993) was concerned that those with dementia are considered to be a problem to 'us'. They do not fit comfortably within the structures with which we are familiar. Kitwood contended that such belief should be resisted because it is often founded on our own vulnerabilities (e.g. fears, rigidities) which ultimately lead to a deep division between 'us' and 'them'. In his view, we (professionals, paid carers and family members) are part of the problem too; and so should accept that we are a problem to 'them' (Kitwood and Bredin 1992, Kitwood 1993). The model of activity engagement, developed in the current study, provides a framework to enable health care professionals to work with carers, understanding their strengths, motivation of caring and possible vulnerabilities. This would help to raise their awareness about the day to day consequences of the nature of dementia, and the possible management strategies for addressing some commonly encountered problems.

#### **10.4 Key messages from the current research**

This section will outline five key messages for each of the following groups including family carers of relatives with dementia, people with dementia, Health Care Practitioners (HCPs), the Alzheimer Society's public awareness campaign.

##### ***10.4.1 Five key messages from this research for people with dementia***

- i) Keep doing things which you want to do and enjoy doing, even if you don't feel like it. Because being active helps to improve your health and well-being.
- ii) Work with your family, they can help you to do things you chose to do. Sometimes, they may seem impatient with you – give them time to understand what you are going through.

- iii) It might be hard to talk about your difficult experience with others – it would be useful to share your thoughts, feelings and emotions with someone who cares for you.
- iv) Try to go out with family or friends – it is a good thing to get out of the house and see what's going on.
- v) Try to accept help to maintain your independence, even from people who, at first, seem to be strangers – they may become friends later on.

#### ***10.4.2 Five key messages from this research for carers***

- i) Your help is the most valuable that any person, like your relative, could have. Because you know the person's background such as habits, interests, likes and dislikes. This information will help you to find ways to preserve their individuality and dignity.
- ii) Activity is good for both you and your relative. But don't forget yourself – try to get help, so that you can have time off to do something which has meaning for you.
- iii) It may become hard to cope with the constant change in your relative's health. There will be times when you feel tired and frustrated – don't give up, ask for support, there will be help available.
- iv) It may become very hard when you have to strike a balance between caution and encouraging a risky activity (e.g. driving), even if it would preserve a sense of independence in your relative – get some support to help making those difficult decisions.
- v) A sense of well-being derives from what we do and enjoy doing and supports us in life – you must try to maintain your own interests, and recreation outside your caring role, in order to be most effective in that caring role.

#### ***10.4.3 Five key messages from this research for Health Care Practitioners***

- i) It is important to enable carers to develop skills and knowledge required to engage their relative in meaningful activities – ideally, such activity should be shared by both the person with dementia and their carer.

ii) Find out what strategies family carers have been using in activity engagement and how they understand their situation at that time – this enables you to support carers in a process of exploring more realistic strategies for engaging their relative in everyday routines.

iii) Don't be judgmental when working with carers, respect them and their ways of engaging with their relative – carers need reassurance to enable them to develop achievable goals to enhance the well-being of their relative. This will then provide them with a source of satisfaction.

iv) A key goal for intervention in dementia care should be to support the person with dementia and their carer to maintain a positive relationship during the full course of dementia – a person-centred approach, which is underpinned by relative-carer relationship, is essential in respect of both the person with dementia and their relative.

v) Carers, as well people with dementia, can benefit from a rehabilitation programme – this should include such as promotion for both physical and mental health, provision of psychosocial support, and encouragement to maintain activities which are important to them.

#### ***10.4.4 Five key messages from this research for the Alzheimer's society's campaign***

i) The person with dementia is “still there” – you can reach your relative/friend by spending time and sharing activities together.

ii) The person with dementia is “still there” and able to express their wishes and preferences. This may be in a manner which is not familiar to you – give them time and also take time to understand the new language they are using.

iii) The person with dementia is “still there” – they may be acting in a way that is unfamiliar or worrying for you – accept them as you find them and try and understand what that behaviour means – then you will be able to feel more comfortable.

iv) The person with dementia is “still there” – and so is their carer – don’t forget them. Just spending a short amount of time with them together can make a big difference.

v) The person who is a carer is “still there”. Encourage and support them to focus on themselves now and again. A little support here can go a long way.

### **10.5 An assessment of the quality of the research and the findings**

As discussed in chapters five and seven, I used various criteria to evaluate the rigour and quality of my research. These included credibility, transferability, reflexivity and participants’ validations. Strategies which I used included, for example, member checking and negative case analysis. I also employed criteria for ensuring the grounding of the research data (Strauss and Corbin’s, 1990, 1998; Corbin and Strauss, 2008). Such criteria included fit, applicability, concept generation, contextualisation of concepts, logic, depth, sensitivity, use of memos, and variation, all as described previously (see 5.7; 7.9). I will discuss the strengths and limitations of my research in detail below.

#### ***10.5.1 Strengths of the study***

One of the strengths of this research is that the development of the emerging model of activity engagement was based on the data from family carers’ own stories through in-depth interviews in phase one of the study.

Secondly, the model was then shared with the participants through focus groups in phase two (see 8.2.1). All participants were able to recognise themselves within the different patterns. Carers in the interviews and focus groups were very experienced carers who had been through the prolonged process of engaging their relative in everyday routine activity, and seeking for appropriate and relevant help. They were therefore in a position to talk about what might be the most appropriate strategies for activity engagement. Hence, the strength of the study is the knowledge and insight gained from the carers of this particular group regarding their perception of activity engagement. The transferability of my research is enhanced by using strategies including detailed contextual descriptions of the research and explicit details of the research process (that is, sampling, data collection and analysis). This will enable the reader to have a clear picture of the research process (Lincoln and Guba 1985; Holloway 1997). This in turn will facilitate the reader to make judgements as to whether

the findings of the present study could be transferred to relevant contexts or similar participants (Kvale and Brinkmann, 2009).

Thirdly, this study made it easy for carers to talk about positive aspects of their experiences. It has been suggested that research on the positive aspects of caring is limited (Cohen et al 2002; Nolan et al 2003; Searson et al 2008). The advantages of exploring the positive experiences of caregiving are threefold: firstly, carers wanted to talk about such experiences as it led to a feeling of pride in their ability to meet challenges in their new role, and hence to a feeling of self-worth. Secondly, such knowledge helps practitioners to work more effectively with carers by identifying positive outcomes. Thirdly, this line of inquiry in caregiving research has the potential to provide information to contribute to the development of theories of carers' adaptation and psychological well-being (Kramer 1997).

#### ***10.5.2 Limitations of the study***

There are a number of possible methodological limitations to this study.

First, as mentioned in the methodological chapter, I have been an occupational therapist who worked with people with dementia and their carers in their own home for many years, and I am currently working as a lecturer in occupational therapy. My clinical practice had been influenced by the principles of person-centered practice, collaborative working and occupational based therapy as a means to promote the autonomy and well-being of service users and their carers. This research was inspired by my clinical practice and professional background. Such background had shaped how the methodology and methods had been chosen for this research, as discussed in the methodology and method chapters. My background will have influenced the way in which I interpreted the data. In qualitative research, like other researchers, I was inevitably affected by my socio-cultural background. Nevertheless, in order to maintain the rigour of the research, I adopted the grounded theory approach and made the procedures explicit, described the context in detail and reflected on how I created the data with the participants. By doing so, the readers can judge how the findings of the present research may have brought insight into an alternative approach of understanding carers' needs in dementia care.

Secondly, the participants were aware of my background. It could be that participants told me what they thought I would like to hear during the interviews. Nevertheless, I felt that it was important to inform the potential participants of my background so that they could make an informed choice about their decisions for taking part in the research. It was interesting to note that many carers stated that they wanted to contribute to this study. This was because they realised that engaging their relative with activities was crucial to the maintenance of the health and well-being of their relative, and yet they had received very little support from mainstream services. It was possible that by sharing my professional background with the participants, I was able to encourage participants to focus their discussion on the research topics, rather than their general experience in caregiving.

Thirdly, participants in phase two were recruited from carers' support groups. Some of the participants seemed to have known one another quite well. This might have hindered some group members in sharing their viewpoint, and they might have found it easier to talk to strangers. Despite that, participants' previous experience of joining in groups and their pre-existing friendships enabled the group to develop cohesiveness quickly at the beginning and they seemed to be able to share some very personal stories with each other.

Four, selection biases might have occurred in both stages of the study. In phase one, recruitment was conducted through the medical consultants who were the gatekeepers of the community mental health teams. In phase two, recruitment was conducted through the carers support groups' managers. It was possible that the gatekeepers identified only salient and memorable carers, and so those who took part might have more positive experiences of, and attitude to the use of activity engagement. This needs to be taken into account when reading the analysis.

Five, the transferability of the current study is limited by the fact that the development of the continuum of activity patterns had focused on co-resident carers' decision-making in their engagement of people with dementia, at home, from the onset of dementia to the point when they relinquished their caregiving responsibility, either to hospital admission or residential care. Hence, the results may not be relevant for non-resident carers and relationships within residential care due to the different contexts

involved. Despite that, the findings concerning the characteristics of the co-resident carers add to the understanding of the diversity of carers' needs.

Six, due to sample size, this was only the experience of one group of co-resident carers. Those carers might not represent the type of support provided by co-resident carers who had same sex partners, or those who came from a differing ethnic background and those whose relatives with dementia are still in employment. Thus the findings may or may not be relevant to this wider population. Nevertheless, it is hoped that the findings will contribute to a deeper understanding of carers' experience with respect to their engagement of their relative in activities at home.

Seven, data from the current research were collected from the participants, through both in-depth interviews and focus groups, by asking them to recall their past experiences of engaging their relative in activities since the onset of dementia in their relative. Thus, data were retrospectively collected. It has been suggested that there are some inherent limitations to retrospective study designs (Cox and Hassard 2007). In these designs, data do not cover actual behaviour of the participants, rather their perceptions of events. Moreover, the participants may have difficulty in remembering details of events accurately, or they may selectively remember particularly unfavourable or favourable incidents over other experiences (Elliott 2005). Immediate responses to events will be lost. People will also forget a great deal of the detail of what has happened in the past (Cox and Hassard 2007). Nevertheless, in qualitative research, researchers generally focus on exploring the meaning of events for participants rather than the accuracy of descriptions of the past in order to gain a deep understanding of the participants' experiences (Elliott 2005; Flick 2009). They emphasise how participants' present an interpretation of their past reality (Cox and Hassard 2007). Thus, this kind of research will always be from the present looking back. In the current study, the participants were encouraged to reflect on their thoughts, actions and feelings about their involvement in their everyday routines activities of their relative with dementia. There will always be a balance to be struck between accessing an immediate response to a situation which may give access to current emotions and embodied experiences as in prospective designs. However, even with this retrospective study, people recounted stories full of emotion and seemed to be reliving their experiences as well as being able to put their experiences into a wider context which was extremely helpful. A key benefit of a

prospective study would be to follow the same people over a specified period of time to capture immediate changes, as they happen to those groups of people (Flick 2009). The length of the process I was exploring (potentially up to 20 years) made this impossible in the time available to me and so I decided to use a cross-sectional approach for this study.

Eight, the aim of the present study focused on gaining deep insight into family carers' perspective of their engagement in the everyday routine activities of their relative. This would serve as a first step for service providers to develop realistic strategies to support family carers throughout the course of dementia in a home setting. Thus, the place for the voice of the person with dementia is limited. It would be useful to carry out research in the future to gain an understanding of the perceptions of people with dementia relating to their activity engagement. This would enhance and complement the current model. Although the voice of the person with dementia was not present, it could be seen that family carers, throughout the caregiving journey, were intimately concerned with the personhood of their relative by highlighting his or her individualised physical, psychosocial and activity needs. This was particularly so by the case of those whose relative experienced severe level of cognitive impairment and communication difficulty. By doing so, carers raised issues concerning how their relative's needs were marginalised by the mainstream services. It is crucial to exercise caution concerning the ethical aspects of using proxy information to obtain a view of people with dementia due to the fact that the interests of both the carer and those with dementia may conflict, as highlighted by many researchers (e.g. Clarke 1999; Vass et al 2003; Cotrell and Schulz 1993, Hughes et al 2002, Cantley and Smith 2007) (see 3.4.2). The model was initially developed to gain a deep understanding of family carers' activity-related decision-making for their relative during the care-giving journey, it is envisaged that it would be used in practice with family carers and professional carers in its initial implementation with a view to enabling both formal and informal carers to work collaboratively towards a person-centred approach. Further research will be needed to develop a model which may be used by both people with dementia and their carers together (see 10.6).

Having discussed the strengths and limitations of the study I will now move on to discuss the potential for future research.



## **10.6 The potential for future research**

This section will discuss some possible directions which the current research may take. Currently, the model has been developed with a group of co-resident carers as described above.

Firstly, the model could be developed further by carrying out further research with other groups of carers such as younger carers, those in same sex relationships, or from other ethnic backgrounds to explore the transferability of the model.

Secondly, ideally it would be useful to carry out a longitudinal design to follow participants over a much longer duration during the caregiving journey to capture life as it is lived and explore behavioural responses in activity engagement.

Thirdly, a key aspect of this research is that it has focused on one perspective – that of the family carers. It would be important to explore the processes involved in activity engagement from the perspective of the person with the dementia themselves. For instance, a study could be developed to follow, over time, co-resident carers and their relative dyads and compare how specific strategies change at various activity patterns, from the perspective of both the person with dementia and their carer.

Fourthly, it could be useful to carry out a study using a case study approach – looking at both the behaviour and perceptions of both relative and person with dementia, in order to explore how social ‘systems’ involved in activity engagement work together.

Fifthly, in order for the ideas from the current research to influence practice, it will be useful to carry out action research projects with:

a) health care professionals where the ideas are shared with practitioners and, with support, they then work out what the model means for them, and their practice, and how they may want to incorporate such meanings into their own practice (for example through developing an alternative assessment, or using the model when talking with families). During this study, the model of activity engagement had been presented to occupational therapists at national and international conferences, to nursing colleagues at a research seminar, and to care managers who worked within the area where the research was implemented. There had been positive feedback from these audiences,

which indicated that the emerging model could be a potential useful guide for clinical practice. For example, at a recent international occupational therapy conference, an experienced occupational therapy researcher suggested that she would be interested in incorporating the model into an existing community occupational therapy programme in the Netherlands, as part of a training programme for practitioners who work with both people with dementia and their carers.

b) commissioners /service providers: the model may help them think through how services could be developed to meet both the needs of people with dementia and their carers. For example a young and newly qualified care manager offered comments at the end of one of my presentations, stating that she suddenly realised that social services often offered services for people with dementia and their carers only at the crisis point and that preventative work was limited.

c) family members themselves: to see how they may find it helpful. For example, one of them, a nursing professional informed me that she was able to make use of the model to empower her to discuss with the consultant her feelings and thoughts when attending a case conference for her mother with dementia. Or it may be that people may want to develop a resource database of strategies for carers on an internet online system. For example, they could be invited to contribute their own strategies to the different activity patterns. Ultimately, this could become an on-line data resource for strategies concerning the use of activities. Another way the model could be used is as an aid to promote understanding for other family members, and the public, to enhance their awareness of the challenges faced by carers in their activity engagement with their relative.

## **10.7 Conclusions**

During the course of caregiving family carers make many complex decisions about the potential benefits of daily activities on the identity and well-being of their relative and of themselves. They go on a practical journey and often develop a range of resources and an understanding of their own circumstances. However, they can become isolated and lose confidence in their own abilities. The model of activity engagement, developed by the current study, sheds light into some of the ambiguous and complex circumstances which confront carers' everyday decision-making. It provides an alternative

understanding of carers' perceptions of how the taken-for-granted everyday activity patterns of those with dementia are adversely affected by dementia over time. It is interesting to note that, despite recent government effort to emphasise the needs for supporting informal carers in their caring role through stated policies (e.g. Department of Health 1999a; 2000a & c; 2001b; 2005a; 2006 a & b), many participants in this study expressed the concern that their needs were often marginalised and that their voices were frequently unheard. Hence, when health and social care providers give support to carers, in order for that support to be appropriate, they need to recognise and acknowledge this journey, see the carer-relative relationship as central to intervention, and gain insight into carers' experiences in a non-judgmental way and so that they can develop a realistic and effective approach in supporting carers at all the different points along the continuum. Through working sensitively and collaboratively with carers, health and social care providers may enable carers to feel a shared understanding with others. This will also promote their confidence in their own abilities, which will have an impact not only on their own wellbeing but also the wellbeing of their relative.